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AGEING WELL WITH CHRONIC PAIN IN RURAL ENVIRONMENTS: A MIXED METHODS EXPLORATORY STUDY

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A thesis submitted for the degree of
Doctor of Philosophy

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Abstract

Over half of the United Kingdom (UK) population, aged 75 or over, experience chronic pain. Chronic pain can negatively affect activities of daily living, quality of life and an individual's ability to maintain an independent lifestyle. UK rural populations comprise a disproportionate number of older adults; however, a paucity of research exists on the experiences of older adults living with chronic pain in these environments. The aim of this thesis is to explore and understand experiences of older adults with chronic pain living in rural environments to inform healthcare policy and service provision.

The study is framed by an interpretivist paradigm informed by narrative and ethnographic inquiry to capture storied representations and situated natures of lived experience. A mixed-methods exploratory design supported data generation and analysis through narrative interviews, life-grids, a quality of life measure, photo-elicitation, and 'go-alongs'. Participants were recruited using snowball and spectrum sampling through third sector organisations.

Eight participants (four females; 67-90 years) contributed to 14 interviews (spouses were present during four interviews). Findings focus on the multi-dimensionality of chronic pain, explicitly the relational nature of the rural environmental dimension, and factors that support the maintenance of quality of life domains and ageing well. Quality of life and common beliefs were critically examined: chronic pain as a normal part of ageing, "carrying on", community spirit, and rurality. Implications for methodology and policy and service provision are described.

Table of contents

Declaration.....	i
Abstract.....	ii
Table of contents.....	iii
List of appendices.....	vi
List of tables.....	vii
List of figures.....	viii
List of abbreviations.....	ix
Acknowledgements.....	x
Chapter One: Introduction.....	1
Introduction.....	1
1.1 Rationale for the study.....	1
1.1.1 Ageing.....	1
1.1.2 Chronic pain.....	3
1.1.3 Rural environments and ageing with chronic pain.....	5
1.2 The aim and objectives of the study.....	7
1.3 Personal reasons for undertaking this thesis.....	8
1.4 The role of public and patient involvement and engagement.....	9
1.5 The structure of the thesis.....	11
1.6 The style of the thesis.....	12
Summary.....	13
Chapter Two: Literature review.....	14
Introduction.....	14
2.1 Approach to the literature review.....	14
2.2 Gerontological theories.....	15
2.2.1 Social gerontology.....	19
2.2.2 Critical gerontology.....	26
2.2.3 Ageing well.....	30
2.3 Ageing with chronic pain.....	33
2.3.1 Population studies on chronic pain.....	33
2.3.2 Qualitative studies exploring peoples' perspectives on chronic pain.....	37
2.3.2.1 Taking a multi-dimensional perspective on chronic pain.....	38
2.3.2.2 Using narratives to make sense of chronic pain.....	39
2.3.2.3 Attitudes and beliefs about chronic pain.....	45
2.4 Ageing in rural environments.....	51
2.4.1 Environmental gerontology.....	52

2.4.2 The relationship between ageing and place.....	55
2.4.3 The role of place in health and well-being.....	60
2.4.4 Ageing in a rural environment.....	65
2.5 Ageing with chronic pain in rural environments.....	73
Summary.....	78
Chapter Three: Methodological approach.....	80
Introduction.....	80
3.1 Research aim and objectives.....	80
3.2 Ontology and epistemology.....	81
3.3 Methodology.....	89
3.3.1 Narrative inquiry.....	90
3.3.2 Ethnographic inquiry.....	92
3.4 Mixed methods.....	94
3.4.1 One-to-one in-depth interviews.....	98
3.4.2 Photo-elicitation interviews.....	104
3.4.3 Go-along interviews.....	107
3.4.4 Recording fieldnotes.....	109
3.5 To make sense of the data.....	110
3.6 Sampling strategy.....	112
Summary.....	116
Chapter Four: Conducting the fieldwork.....	117
Introduction.....	117
4.1 Ethical frameworks.....	117
4.1.1 Procedural ethics.....	118
4.1.2 Situational ethics.....	125
4.1.3 Relational ethics	126
4.1.4 Exiting ethics.....	127
4.2 Recruiting participants.....	128
4.3 Management of data.....	131
4.4 Data analysis.....	133
4.5 Assuring the quality of findings.....	140
Summary.....	141
Chapter Five: The lived experience of ageing with chronic pain.....	142
Introduction.....	142
5.1 Description of rural environments.....	143
5.1.1 Village A.....	143
5.1.2 Village B.....	144
5.1.3 Village C.....	145

5.1.4 Village D.....	146
5.1.5 Village E.....	146
5.2 Participants.....	147
5.3 Rating quality of life.....	150
5.4 Case studies.....	152
5.4.1 Frances.....	153
5.4.2 David and Diane.....	158
5.4.3 Catherine.....	163
5.4.4 Henry and Helen.....	168
5.4.5 Anne.....	173
5.4.6 Barbara.....	178
5.4.7 Edward and Ethel.....	183
5.4.8 George and Gail.....	188
Summary.....	193
Chapter Six: Maintaining control and autonomy.....	195
Introduction.....	195
6.1 Maintaining control in later life.....	196
6.2 Autonomy in later life.....	203
6.3 Carrying on with chronic pain.....	212
6.3.1 Self-management, maintaining control, accessing healthcare.....	213
6.3.2 Psycho-social responses, attitudes and beliefs to maintain control.....	223
6.3.3 Environmental interaction adapting self and environment.....	231
Summary.....	242
Chapter Seven: Maintaining self-realisation and pleasure.....	244
Introduction.....	244
7.1 Maintaining pleasure in later life.....	245
7.2 Self-realisation.....	252
7.3 “Starting to come inwards”: the meaning of activity restriction.....	261
7.4 Maintaining sense of self and self-esteem through activity: “It’s up to me to try and get it more outward”	271
7.5 Developing networks to support activity maintenance.....	281
7.6 Constructing a sense of rurality and belonging.....	289
Summary.....	299
Chapter Eight: Discussion and implications.....	302
Introduction.....	302
8.1 Responding to the research objectives.....	302
8.1.1 Dimensions of chronic pain for rural older adults.....	304
8.1.2 The meaning of chronic pain for rural older adults.....	308

8.1.3 The influence of life-course factors on chronic pain experiences.....	313
8.1.4 Coping, self-management strategies and the nature of resilience.....	317
8.1.5 Policy and service needs of rural older adults with chronic pain.....	322
8.2 Strengths, challenges and limitations.....	325
8.2.1 Strengths.....	325
8.2.2 Challenges.....	329
8.2.3 Limitations.....	331
8.3 Reflections on the thesis.....	333
8.4 Implications of my research.....	335
8.4.1 Future research.....	337
References.....	339
Appendices.....	374

List of appendices

- Appendix 1:** Research User Group (RUG) workshop (April 2013)
- Appendix 2:** Project Advisory Group (PAG) member's backgrounds and key contributions
- Appendix 3:** Summary of PAG meeting
- Appendix 4:** PAG newsletter example
- Appendix 5:** Interview materials (topic guide, life-grid, CASP-19)
- Appendix 6:** Recording fieldnotes
 - a. Blank version of post-interview summary sheet
 - b. Photocopied pages from fieldnotes journal
- Appendix 7:** Ethical approval letters from Keele University
 - a. Original ethics approval letter
 - b. Approval following amendment
- Appendix 8:** Participant information pack
 - a. Participant invitation letter
 - b. Participant information sheet with consent to contact slip
- Appendix 9:** Additional participant information sheets
 - a. One-to-one interview
 - b. Photo-elicitation
 - c. Go-along
- Appendix 10:** Consent forms
 - a. One-to-one interview consent form
 - b. Photo-elicitation interview consent form
 - c. Go-along interview consent form
 - d. Photograph sharing consent form
 - e. Post-interview consent form
- Appendix 11:** List of photographs collected during fieldwork

Appendix 12:	Examples of analysis	
	a. Identifying narratives	
	b. Initial coding	
	c. Annotations of transcripts	
	d. Memos	
	e. Coding frame	
Appendix 13:	Coding mind maps for each participant	
	a. Anne	
	b. Barbara	
	c. Catherine	
	d. David	
	e. Edward	
	f. Frances	
	g. George	
	h. Henry	
Appendix 14:	Redacted version of a completed life-grid	
Appendix 15:	Full table of CASP-19 responses	
Appendix 16:	Summary of go-along interviews	
	a. Henry	
	b. Anne	
Appendix 17:	Summary report from stakeholder event	
Appendix 18:	Thesis outputs: presentations and plan for publications	

List of Tables

Table 4.1	Table of data recording times.....	131
Table 5.1	Demographic information from sample.....	148
Table 5.2	Data gathering completed with participants.....	149
Table 5.3	CASP-19 domain and total scores arranged in descending order (n=8).....	150
Table 5.4	Abbreviations for data sources.....	152
Table 5.5	Summary of chronic pain descriptors and impact on activity.....	194
Table 6.1	CASP-19 Item 1: 'Age prevents me from doing the things that I would like to do'	197
Table 6.2	CASP-19 Item 2: 'I feel that what happens to me is out of my control'	198
Table 6.3	CASP-19 Item 3: 'I feel free to plan for the future'	200
Table 6.4	CASP-19 Item 4: 'I feel left out of things'	202
Table 6.5	CASP-19 Item 5: 'I can do the things that I want to do'	204
Table 6.6	CASP-19 Item 6: 'Family responsibilities prevent me from doing what I want to'	205
Table 6.7	CASP-19 Item 7: 'I feel that I can please myself what I do'	206
Table 6.8	CASP-19 Item 8: 'My health stops me from doing things I want to do'	208

Table 6.9 CASP-19 Item 9: 'Shortage of money stops me from doing things I want to do'	210
Table 7.1 CASP-19 Item 10: 'I look forward to each day'	246
Table 7.2 CASP-19 Item 11: 'I feel that my life has meaning'	247
Table 7.3 CASP-19 Item 12: 'I enjoy the things that I do'	249
Table 7.4 CASP-19 Item 13: 'I enjoy being in the company of others'	250
Table 7.5 CASP-19 Item 14: 'On balance, I look back on my life with a sense of happiness'	251
Table 7.6 CASP-19 Item 15: 'I feel full of energy these days'	253
Table 7.7 CASP-19 Item 16: 'I choose to do things that I have never done before'	255
Table 7.8 CASP-19 Item 17: 'I feel satisfied with the way my life has turned out'	256
Table 7.9 CASP-19 Item 18: 'I feel that life is full of opportunities'	257
Table 7.10 CASP-19 Item 19: 'I feel that the future looks good for me'	259

List of Figures

Figure 1 Critical human ecology perspective.....	66
Figure 2 Sequential mixing of methods	97
Figure 3 Photographic image of 'Rural'	104
Figure 4 Rural-Urban spectrum.....	114
Figure 5 Recruitment process flowchart.....	130
Figure 6 Step-by-step guide to analysis.....	137
Figure 7 CASP-19 scores for fully completed measures: stacked column (n=5).....	151
Figure 8 Timeline for Frances constructed from life-grid.....	153
Figure 9 Timeline for David constructed from life-grid.....	158
Figure 10 Timeline for Catherine constructed from life-grid.....	163
Figure 11 Timeline for Henry constructed from life-grid.....	169
Figure 12 Timeline for Anne constructed from life-grid.....	173
Figure 13 Timeline for Barbara constructed from life-grid.....	179
Figure 14 Timeline for Edward constructed from life-grid.....	184
Figure 15 Timeline for George constructed from life-grid.....	189
Figure 16 Radar plot of responses on domain for control in rank order (n=8).....	196
Figure 17 Radar plot of responses on domain for autonomy (n=8).....	203
Figure 18 Photographing adaptation of walking frame to suit needs on the move.....	233
Figure 19 Control and autonomy supported by complex pain management.....	243
Figure 20 Radar plot of CASP-19 scores for domain of pleasure in rank order (n=7).....	245
Figure 21 Radar plot of CASP-19 scores for domain of self-realisation in rank order (n=6).....	253

Figure 22 Mixed data referring to George’s outlook from his house.....	266
Figure 23 Mixed data referring to Barbara’s dog walk.....	269
Figure 24 Photograph #34 and data extract from elicited interview data with Frances.....	278
Figure 25 Photograph #33 and data extract from elicited interview data with Frances.....	290
Figure 26 Photograph #36 from go-along with Henry: “Favourite beauty spot”	292
Figure 27 Video-stills recorded during go-along with Henry.....	296
Figure 28 Maintaining pleasure if not self-realisation through chronic pain experience.....	300
Figure 29 Model of ageing well with chronic pain in rural environments.....	303

List of abbreviations

DoH	Department of Health
Defra	Departments for environment, food and rural affairs
CAM	Complementary and alternative medicine
CASP	Control, Autonomy, Self-realisation, Pleasure
ELSA	English Longitudinal Survey of Ageing
ESRC	Economic and Social Research Council
LTC	Long term conditions
ONS	Office for National Statistics
PAG	Project Advisory Group
PPIE	Patient and public involvement and engagement
RI	Research Institute for Primary Care and Health Sciences
RUG	Research User Group
SHARE	Survey of Health, Ageing and Retirement in Europe
UK	United Kingdom
WHO	World Health Organisation
TOPS	Technology for Older adults maximising Personal and Social interaction
IRAP	International Rural Ageing Project

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Chapter One: Introduction

Introduction

This thesis is an exploration of what it means to age well with chronic pain in rural environments. Chapter by chapter I reveal a journey; I share my reasons for why I have chosen to take this journey, how I have chosen to approach it, and what I have uncovered along the way. In this chapter I provide the rationale for this thesis and introduce the central topics, as a pre-cursor to a review of the literature, and map out the structure of the chapters that follow.

1.1 Rationale for the study

This thesis draws on three broad research fields: gerontology, chronic health conditions, and human ecology. In what follows I provide the rationale for the inclusion of each of these perspectives and how they interrelate.

1.1.1 Ageing

The UK population is an ageing one, those aged 65 years or more equate to 11.1 million people, representing just over 17% of the population. The term ‘older adults’ is typically defined as people aged 65 years or more (Office for National Statistics [ONS], 2013a; Age UK, 2016) although this term may reflect societies in developed countries (World Health Organisation [WHO]: www.who.int/healthinfo/survey/ageingdefnolder/en/). This age group has increased by 17% since 2003; an increase of over 1.5 million people (ONS, 2013b). By 2034, 23% of the UK population is projected to be aged 65 years or over (ONS, 2012). The ageing population results from three interrelated trends: a declining mortality

rate, a declining fertility rate, and patterns of (im)migration (Moody, 2010). The latter is considered by some to have a lower level impact than the other two (Gee, 2002; Bernard & Scharf, 2007). In the UK, declining mortality has occurred most prominently among people aged over 85 years, commonly referred to as the 'oldest old' (Baylis & Sly, 2010: p1). An ageing population represents achievement, for example, in the prevention and treatment of disease and improved nutrition, but also poses challenges, not least to the provision of health and social care services (Kirkwood, 2008). A House of Lords report entitled 'Ready for Ageing?' examined the UK's capacity to respond to this demographic shift and concluded that:

'[T]he Government and our society are woefully underprepared. Longer lives can be a great benefit, but there has been a collective failure to address the implications and without urgent action this great boon could turn into a series of miserable crises.'

(House of Lords, 2013: p7)

Older people remain the group in most need of care, and whose needs continue to go unmet (Age UK, 2015). Men and women in the UK are expected to spend 14 and 17 years, respectively, with a limiting illness or disability (ONS, 2011). Chronic longstanding health problems present a challenge due to the need for long term management and prolonged access to healthcare services. Fifteen million people in the UK have a long-term condition (LTC) (e.g. arthritis, chronic obstructive pulmonary disease, cancer) (Department of Health [DoH], 2012), 60% of people aged 60 years and over in England have an LTC, with 25% reporting two or more. Despite this, chronological age remains a questionable predictor of health status (Lloyd-Sherlock, 2002) and to assume older people represent a homogeneous group defined by health problems and frailty would be misleading. Frailty

is argued to include three or more of the following: shrinking (weight loss), weakness, slowness, poor endurance and energy, and low physical activity (Fried, Tangen, Walston et al., 2001); however, frailty remains a contested term with no agreed definition (Conroy, 2009). Indeed, many older adults continue to be active for longer in later life (Gee, 2002).

1.1.2 Chronic pain

Chronic pain is a long-term health problem that causes disability. The International Association for the Study of Pain (IASP) defines pain as: ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (<http://www.iasp-pain.org/Taxonomy>). Chronic pain is distinguishable from acute pain in terms of duration (acute has a shorter duration), but also cause of onset (Roberto & Gold, 2001). However, there is variation in the literature on the reporting of this pain duration, with chronic pain definitions ranging from two weeks to six months. Rief, Kassa, and Jensen et al. (2010) argued for a revision to the International Classification of Diseases and Related Health Problems (ICD) in anticipation of the forthcoming version, ICD-11 (due 2018). Treede, Rief and Barke et al. suggest that chronic pain be defined as:

‘...persistent or recurrent pain lasting longer than 3 months. This definition according to pain duration has the advantage that it is clear and operationalized.’

(Treede et al., 2015: p1003)

A clear definition of chronic pain is useful; however, Ong (2006) argues that time is only one dimension of chronic pain, and argues for a more nuanced understanding that takes

account of the physical, psychological, social and spiritual dimensions in addition to duration.

Almost half of people with an LTC experience moderate to extreme levels of pain. Where three or more LTCs are present the proportion reporting pain increases to 80%:

‘Having a long term condition usually reduces people’s quality of life, particularly through having chronic pain.’

(DoH, 2012: 13)

Severe pain and suboptimal pain management may negatively affect quality of life (Horgas, Yoon, Nichols & Marsiske, 2008; Ndao-Brumblay & Green, 2010). Chronic pain is reported to have deleterious effects on health, employment and daily life (Smith, Elliott, Chambers et al., 2001) and is also associated with poorer mental well-being, lower levels of happiness and higher prevalence of anxiety/depression (Bridges, 2011).

The experience of chronic pain is reported by people of all ages; however, the prevalence of chronic pain increases with age (ibid). The most common reported cause of chronic pain is osteoarthritis, which accounts for around one third of cases, according to findings from a large-scale survey of 15 European countries and Israel (Breivik, Collett, Ventafridda et al., 2006). Understanding lived experiences of older people with chronic pain, as well as their attitudes towards it, is crucial to inform health service planning (Currie, Phillip & Roberts, 2015).

1.1.3 Rural environments and ageing with chronic pain

In this thesis, I consider environments to be relational and holistic constituting composition (objective), context (subjective) and collective (inter-subjective) aspects (Wakefield, Elliot, Eyles & Cole, 2006), i.e. the milieu in its entirety. Rural is typically described in dichotomous terms as not urban, as the dictionary definition states: 'In, relating to, or characteristic of the countryside rather than the town' (<http://www.oxforddictionaries.com/definition/english/rural>). However, what 'rural' is and means remains contested. I revisit considerations of rural in the literature review (Section 2.4.4: p65) and define rural for the purposes of sampling in Section 3.6 (p112). Two important issues link rural environments with ageing and chronic conditions, specifically chronic pain. Firstly, the ageing profile of the UK differs between urban and rural populations. As of 2011, 10.3 million (or 19%) of the total population live in rural areas of the UK; the median age of this population (45 years) is higher than that of the urban population (37 years). Furthermore, the rate at which the two populations are ageing (in terms of an increase in median age) is higher in rural areas than in urban areas (ONS, 2013c). Secondly, age-related health problems are projected to increase more rapidly in rural areas than in urban areas. For example, a report from the UK Government Cabinet Office suggests in the years between 2009 and 2025 incidence of depression, stroke, falls and dementia will increase by 50 to 60% in rural areas compared with 34 to 42% in urban areas (Cabinet Office, 2009).

Rural environments remain under-researched, despite the challenges and issues that they present (Keating, 2008). Rural environments are represented as positive, serene, idyllic environments in which to age; although this representation continues to receive

academic criticism (Newby, 1979; Wenger, 2001; Keating, 2008; Hennessy, Means & Burholt, 2014) it remains culturally relevant (e.g. television lifestyle programmes such as BBC's *Escape to the Country*). However, living in a rural environment can bring particular issues for people living with long term chronic health conditions. Higher pain grades have been reported among rural residents in comparison with urban residents; in contrast, healthcare utilisation has been reported to be lower (Tripp, Van den Kerkhof & McAlister, 2006). Also, the onset of disabling pain is influenced by the area in which one lives (Jordan, Thomas, Peat et al., 2008). For example, hip osteoarthritis has been associated with rural occupations, such as farming, due to the repeated tasks of heavy lifting that are involved in the job (Croft, Coggon, Cruddas & Cooper, 1992). The lower reported utilisation of healthcare services by rural residents is not confined to pain-related experiences; this has been observed in general practices within a rural/urban comparison study (Farmer, Iversen, Campbell et al., 2006). The lower consultation rates in rural areas may be attributable to socio-cultural factors such as self-identifying as stoical and self-reliant (Deaville, 2001). Moreover, inequalities in health service provision, uptake, and problems with access are reported to persist among remote rural populations (Crocker & Campbell, 2006).

Family support is important in providing instrumental and emotional support to people with chronic pain (Roberto & Gold, 1997); however, in rural environments the dispersed structure of settlements, challenges to accessibility and migration trends (i.e. family moving out of rural areas) may have implications for ageing with chronic pain in rural environments (Philip, Roberts, Currie & Mort 2013). Formal support may also be lacking as Tollefson et al. suggest:

‘...the lack of specialist services and support in rural areas means people with chronic illnesses and conditions such as chronic pain are placed in vulnerable situations.’

(Tollefson, Usher & Foster, 2011: p484).

The literature review, in the next chapter, indicates a dearth of research on the experiences of older adults living with chronic pain in rural environments in the UK. The lack of research means that we do not know how chronic pain is experienced and managed by older adults in rural environments. We do not know the extent to which vulnerabilities are real, concealed, or non-existent. This has important implications for critical gerontology, as an under-researched topic of ageing, and for health and social care services and policy in terms of provision and guidance on pain management in rural environments.

1.2 The aim and objectives of the study

The aim of this study is to understand older adults’ experiences of ageing well with chronic pain in rural environments. To construct an understanding of these experiences, the following objectives are the focus of the study:

1. To explore the dimensions of chronic pain experienced by older people in rural environments
2. To explore the meaning of chronic pain for the day-to-day lives of older people in rural environments
3. To explore the influence of life-course factors on the experiences of ageing with chronic pain within rural environments.

4. To explore coping and self-management strategies, and the nature of resilience, among older people with chronic pain in rural environments
5. To consider policy and service needs of rural older people with chronic pain.

The research objectives are intentionally broad to reflect the current paucity of existing research on this topic; furthermore, this obliges an exploratory approach for the purposes of advancing knowledge. The exploratory approach focuses on human experience at the interface between ageing, living with chronic pain within a rural environment. Thus context is premised; the context of a life lived with chronic pain, the context of place (in this case the interaction with and between older adults with chronic pain and within a rural environment), and also the wider dimensions of context as discussed in terms of the multidimensionality of pain. I have chosen to focus on ageing well (examined further in Section 2.2.3: p30), as this considers a gerontological perspective on processes of adaptation to changes in circumstances in later life.

1.3 Personal reasons for undertaking this thesis

Whilst working as a Research Assistant I attended a conference in 2010 about Public and Patient Involvement. During a discussion session on future research directions a fellow conference attendee, having just passed her Viva Voce remarked: “Well if you want to go anywhere in research then you need to do a Ph.D”. It is strange how some words stick with you, as these did with me. I expect this was because they reignited an ambition I had put to one side following the completion of my Masters in 2007.

I identified a Ph.D studentship at Keele University in early 2012; the timing seemed right, so I applied and was successful. The proposal (‘Ageing with Chronic Pain: the experiences

of rural older people') spoke to me personally, to my interests and experiences, and also to my future ambitions. My background in social science and health research was where I had come from and where I intended to go in the future. The proposal described the use of novel qualitative methods. I appreciate quantitative methods for the questions that they can be used to answer but I have an affinity for qualitative methods and the opportunity to explore at an in-depth level. The opportunity to apply a novel mix of methods was particularly attractive. I had developed an interest in chronic pain through qualitative research with people experiencing chronic health problems (e.g. Multiple Sclerosis, Cancer, Irritable Bowel Syndrome, and Inflammatory Bowel Disease). Older adults in rural environments speaks to my own family background of grandparents and looking ahead to the anticipated futures for both of my parents; I immediately recognised this population as one with specific needs which may go overlooked were it not for exploratory research.

1.4 The role of public and patient involvement and engagement

An introduction to this thesis would not be complete without a description of how public and patient involvement and engagement (PPIE) has informed this research. The Research Institute for Primary Care and Health Sciences (RI) values PPIE and has established a Research User Group (RUG) to support long-term sustainability of PPIE (Jinks, Carter, Rhodes et al., 2016). Members of the RUG work with researchers on the design, coordination and dissemination of research. I attended the annual meeting of the RUG in March 2013 and conducted a 30-minute workshop with a group of eight attendees; the resulting discussion informed development of a Project Advisory Group,

research methods (e.g. interview topic guides), and participant recruitment (for an overview of the workshop see Appendix 1).

I developed a Project Advisory Group (PAG) to facilitate sustained PPIE input and to provide a resource for support and advice throughout the study. I accessed resources produced by the Joseph Rowntree Foundation (JRF) to guide development of the PAG (<http://www.jrf.org.uk/sites/files/jrf/PAG-guidelines-members.doc>). The JRF identify the role of PAGs as contributing a spread of knowledge and experience, which reflected my intention for the group. I discussed the composition of the proposed PAG with my supervisors and colleagues responsible for PPIE in the RI. In terms of expertise I sought to achieve a diverse spread of the following knowledge and experience:

1. Chronic pain: older adults currently experiencing chronic pain or providing care to someone with chronic pain;
2. Rural areas: living in local rural settlements;
3. Health and social care service provision and policy in and around rural areas: GP services, community hospitals, third sector organisations, and community groups

I established a PAG comprising nine people, recruited through the PPIE team within the RI, other Keele University staff, social contacts, people with previous research project involvement, and local third sector organisations (identified through an internet search).

Details of the PAG member's backgrounds and key contributions are provided in Appendix 2 and a summary of the opening meeting with the PAG is provided in Appendix

3. In the chapters that follow I identify where the PAG had input during the study. Over the course of the research I have kept the PAG updated via quarterly newsletter (for

example, see Appendix 4). The members of the PAG also attended a stakeholder engagement workshop at which I disseminated findings of the study (see Chapter Eight for discussion).

1.5 The structure of the thesis

This thesis is organised into eight chapters including this one. In the next chapter, Chapter Two, the existing literature that encompasses the topic of this thesis is reviewed. The literature is broad as it relates to three aspects: ageing, chronic pain, and rural environments each of which combine to guide the keywords for literature searches. Through the process of outlining the work of others, I highlight the gaps within which my research study fits. I commence the literature review by covering understandings of ageing leading to contemporary perspectives and conceptualisations of quality of life in later life. I then present literature organised thematically under broad headings of 'ageing with chronic pain' and 'ageing in rural environments' before rounding the chapter off with a review of a small body of literature that intersects topics of ageing, chronic pain, and rural environments.

Chapter Three outlines the methodological approach taken towards this research to achieve the research aim proposed; this includes discussion of ontological and epistemological positions, methodology, methods, and sampling. Chapter Four talks to the fieldwork and the application of methods outlined in the preceding chapter. I reflect on ethical challenges and decisions, participant recruitment, and managing the data. The process of analysis is also described.

The findings are presented in Chapters Five, Six, and Seven. In Chapter Five I describe the people and places that constitute the participants and the research settings. In Chapter Six and Seven I use the four domains of the CASP-19 questionnaire (Hyde, Wiggins, Higgs & Blane, 2003) to frame the presentation of findings. By doing this I integrate the different data types and also drill down into the meaning of quality of life for older adults experiencing chronic pain in rural environments.

Chapter Eight completes the thesis with a summary of findings and a discussion of these in the context of the research objectives and existing literature. I end the thesis by setting out the implications that this research has for current healthcare policy and provision of services and for future research endeavour.

1.6 The style of the thesis

‘Voice echoes the researcher’s involvement with the studies phenomena; it does not reproduce the phenomena. Yet through struggling with representing our research participants’ experience we may find the collective in the subjective.’

(Charmaz, 2014: p318)

The widely accepted traditional style of reporting scientific research is in a formal third person style, which has come to be associated with positivism, report writing, detachment, passivity. Gillett, Hammond and Martala-Lockett (2009) argue that academic language is generally objective rather than personal with emphasis on the arguments made rather than the author. However, there is a growing trend to move away from this style. Tang and John (1999) argue that ‘academic writing need not be totally devoid of the writer’s presence.’ (pS24). Freshwater (2007), argued against the objective third-person

style of writing, referring to the flatness of this language and how it acted to close the door on the coexistence of competing interpretations. As Charmaz states in the quote above, voice echoes the researcher's involvement in the research process and in the phenomena under study. To write in a detached and objective style would be to present the research processes, analyses, findings and conclusions as facts in which I played no part – when in reality they are my interpretations for which I am responsible. Thus, to leave out my role in the interpretation would be a misrepresentation of the construction of this work and the many decisions that have taken place throughout. I have decided to take a balanced approach between third and first person; to be transparently present as a researcher whilst keeping the focus on the research.

Summary

This chapter has provided a rationale for the research study reported in this thesis. The structure of the thesis has been provided to give a sense of the flow of the chapters. The chapter that follows examines the broad field of literature that constitutes the background context of this study.

Chapter Two: Literature review

Introduction

In this chapter I provide a critical review of the literature to examine the state of current knowledge of ageing with chronic pain in rural environments. The topic of this thesis intersects gerontology, chronic health conditions, and human ecology and spans an extensive body of literature. There remains however a scarcity of research that considers in-depth the combination of ageing, chronic pain and rural environments. I begin this chapter by describing the approach taken towards the literature in this review before presenting that which I have identified to inform this thesis theoretically and methodologically.

2.1 Approach to the literature review

The aim of this literature review is to provide a critical examination of the state of current knowledge to establish a context for this thesis. In this review, I identify the key issues, debates, concepts and theories on ageing well with chronic pain in rural environments. This literature review is not a systematic review (Moher, Shamseer, Clarke et al., 2015) nonetheless it has been undertaken systematically. To conduct this review, I utilised the process described by Hart (2011). I began by mapping the topic through library catalogue searches for monographs, textbooks and periodicals to identify key sources, authors and concepts. My search strategy then progressed to detailed searches of electronic databases (EBSCO [including: Cinahl, medline, psycinfo, ageline], Web of Science, and PubMed) for abstracts and full-text articles. I scanned indexes and reference lists to supplement these sources and ensure important texts were not overlooked.

I position the thesis within the discipline of critical gerontology and, in Section 2.2, review theory underpinning the development of this discipline leading to the development of a concept of ageing well. In the subsequent sections, I present literature relating to firstly ageing and chronic pain then, secondly, ageing and rural environments to establish key issues, debates and concepts within each body of literature (although not entirely mutually exclusive). This division of the literature reflects a stepped search strategy and supports readability; the search criteria are described at the head of each section (2.3 and 2.4). Finally, I provide a summary of the small number of studies that consider ageing, chronic pain and rural environments (Section 2.5). Literature arising from the UK and elsewhere including developed and developing countries is considered; the selection of literature is premised on that which can inform this thesis. The review represents the final version; one revisited pre-, during, and post- data analysis and, as suggested by Charmaz (2014), has also been adapted to illuminate the areas under exploration in this thesis. I begin by presenting some of the key theories to have emerged from gerontology as these provide the context in which a study on ageing is embedded.

2.2 Gerontological theories

‘Ageing is a natural, inevitable phenomenon that can be studied in vivo and in vitro.’

(Chondrogianni, Kapeta, Chinou et al., 2010: p763)

In this section I provide a summary of the key theories generated within the field of gerontology. This is a broad and multi-disciplinary field. In relation to research on ageing, Chondrogianni et al. (ibid) refer to in vitro (Latin translation: *within the glass*) and in vivo (Latin translation: *within the living*) thus identifying ageing as a topic for experimental research and experiential. A sociological perspective on ageing argues that ageing can,

'only be understood within the context of social environments' (Phillipson & Baars, 2007: p69) thus constructing ageing as a topic appropriate for the social sciences to explore. An abundance of literature has been produced through the sociological consideration of ageing. From this literature, I consider three sociological theories of ageing: disengagement theory (Cumming & Henry, 1961); activity theory (Havighurst, 1961); and continuity theory (Atchley, 1993) to present what this perspective has added to gerontology and how the discipline has since developed.

The theory of disengagement argues that:

'...aging is an inevitable, mutual withdrawal or disengagement, resulting in decreased interaction between the aging person and others in the social system he belongs to.'

(Cumming & Henry, 1961: p27)

The mutual process of withdrawal between the ageing individual and society assumes a functionalist view of ageing. Indeed, Rose (1964) describes Cumming and Henry's book, 'Growing old' (1961) as 'a landmark in sociological functionalism' (p46). The basic principle of functionalism is that society and individuals operate to accommodate themselves in equilibrium and avoid disruption. For instance, the death of an older adult is not considered disruptive for society as it is to be expected; in contrast, the death of a younger person would be considered disruptive (unexpected) and therefore disharmonising. Cumming and Henry argue that society and individuals prepare, in advance, for the ultimate disengagement of incurable, incapacitating disease and death by an inevitable, gradual and mutually satisfying process of disengagement.

Disengagement theory is criticised for the symbolism that it perpetuates, as the theory:

‘provides the rationalization for a purely symbolic policy because both society and the individual are seen as better off as a consequence of the exclusion of the aged.’

(Estes, Swan & Gerard, 1982: p152-3)

This criticism is supported by Baars, Dannefer, Phillipson and Walker (2006) who argue against the assumption disengagement theory holds about older adults:

‘It is a curious logic that discovers that individuals post-65 are socially disengaged and decides that this is indicative of human nature, while ignoring the fact that their study population lived under a social regime in which age-graded retirement was a social institution’

(Baars et al., 2006: p3).

In developing disengagement theory, Henry and Cumming purposively excluded perspectives of older adults in poor physical or mental health; the rationale for which was to ensure that the concept of disengagement did not rely on factors of ill-health. Also excluded were people deemed not to have a minimum amount of money necessary for independence. Thus, limiting the scope and applicability of the theory.

In contrast, Havighurst’s activity theory focuses upon the maintenance of activity and attitudes across the life-course. Rather than disengage and withdraw, activity theory argues that:

‘Successful ageing means the maintenance as far and as long as possible of the activities and attitudes of middle age.’

(Havighurst, 1961: p8)

Activity theory argues that when activities or attitudes can no longer be maintained (e.g. employment lost due to retirement, friends and loved ones who pass away) substitutes can be found. Havighurst accepts that disengagement may occur but that it goes, 'against the will and desire of the person' (1961: p9). Activity theory has been criticised for supporting political agendas that focus on recreation and social activity amongst older age groups; however, again this confers with functionalism (Estes et al., 1982). Walker argued that despite providing a response to the 'depressing picture of old age' (2002: p122) (as suggested by disengagement theory) activity theory is considered too idealistic, overlooking biological, economic, societal and political barriers (e.g. social class, economic factors, deterioration in health, and social inequality). Bowling (2005) perceives activity theory to over-simplify the availability of activities and social networks as if these emerge for individuals from an endless conveyor belt.

Both disengagement and activity theory assume that older adults are homogeneous (Jamieson, 2002). More recently, Atchley's (1993) continuity theory, on the other hand, challenges this. Atchley argues that older adults engage in leisure time activities that are familiar to maintain stable patterns; leisure time is important in the performance of ageing and enacting a sense of self. Whilst continuity theory acknowledges the influence of individual life-course factors on activity in later life, it does not address these challenges. The theory fails to address the impact of individual life circumstances and inequalities among older adults such as disability, mobility, financial means and health (Bowling, 2005). Moreover, having the personal desire to continue activities from earlier life may not necessarily lead to the fulfilment of such desires (Liang & Luo, 2012).

Of the three theories described, none capture ageing fully as each overlooks the importance of health (particularly declines in health) and other individual and social factors – each theory emanated from a North American context. Reflecting on this phase of gerontology, Riley and Riley (1999) identify the 1960s as a period in which two key fallacies emerged. First, the ‘life-course fallacy’, which assumed interpretations of cross-sectional age differences corresponded with ageing as a process. Second, the fallacy of ‘cohort-centrism’, which assumed members of all cohorts aged the same. Atchley’s (1993) continuity theory does little to challenge these fallacies. Ageing is a complex phenomenon and the life-course is defined by variability not homogeneity. Thus, a mode of inquiry that appreciates different perspectives in combination is required to ‘respect the nature’ of the subject matter of ageing (Blumer, 1969: p44).

2.2.1 Social gerontology

Social gerontology incorporates psychological, social theoretical and cultural perspectives on ageing (Jamieson, 2002). Three perspectives have nurtured the emergence of social gerontology that build on the foundational work of those early theorists: first, are those that focus on individual adaptation (psychological and sociological perspectives). Second, is the political economy perspective and life-course approach. The third, is critical gerontology. Theorists working from a structuralist paradigm emerged in the late-1970s and early-1980s, led by eminent scholars such as Alan Walker and Peter Townsend in Europe and Carol Estes in North America. Up until this point, theories of ageing (as described in Section 2.1 above) had focused upon individual adjustment to old age but typically functionalist in approach (Walker, 1981). The assumptions about access to, and

availability of, activities and opportunities (upon which previous theories had been based) had not been challenged (Townsend, 1981). A structural view of ageing:

‘Starts with the proposition that the status and resources of the elderly, and even the trajectory of the ageing process itself, are conditioned by one’s location in the social structure and the economic and political factors that affect it.’

(Estes et al., 1982: p155)

Two key theories emerged from this period of social gerontology. First, the political economy of ageing theory (Walker, 1981) which describes the implications of economic life for older adults and the consequences of this on societal treatment. Walker raised the issue of class status as a determining factor in later life experiences. Second, the structural dependency theory (Townsend, 1981), which considers old age as a social construction determined by the dominant economic and political interests in capitalist society. Considering this, older adults were constructed as dependents, with conditions of retirement and role imposed on them from the state (as reflected in Baars et al. [*op cit*] to social regime and institutions). In these terms, older adults were again recognised as a homogenous group defined collectively as in need of welfare and requiring greater access to health and social care. Wilson (1997) reconsidered structural dependency theory from a postmodernist perspective reflecting on the theory as an attempt to act on the structural factors that work against older adults; stating that this effort instead reinforced ageist practice. Critics of Walker and Townsend’s theories argue against the overly pessimistic view of older adults as unable to break from the imposed social construct. Johnson (1989) argues that this deflects away from progressive and optimistic views of the economic social status of older adults.

Successful ageing, a notion referred to earlier in the work of Havighurst, was brought from social gerontology into political prominence through Rowe and Kahn (1987) in North America. Rowe and Kahn compared 'usual ageing' (i.e. average mortality, morbidity, risk rates) with 'successful ageing', which they conceptualised as having three inter-related, albeit hierarchical, components:

'Low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life. All three terms are relative and the relationship among them is to some extent hierarchical.'

(Rowe & Kahn, 1997: p433)

Rowe and Kahn take a positivist stance and focus on the biomedical model (i.e. biological factors only) to identify the reduction of risk of disease, disability, and decline in functioning in combination with active engagement as indicative of successful ageing. Active engagement is considered primarily to involve interpersonal relationships and activity that is productive at a societal level (e.g. volunteer work). Rowe and Kahn identify resilience as a key component of successful ageing, which they define as recovery from crises:

'Rapidity and completeness with which people recover from such episodes and return to meeting the criteria of success.'

(Rowe & Kahn, 1997: p439)

Rowe and Kahn's formulation of successful ageing focused upon outcome; whether an older adult aged usually or successfully without accounting for individual circumstance (e.g. individual and social opportunities and/or barriers).

Working concurrently in a European context, Baltes and Baltes (1990) examined the constituents of successful ageing from a psychological perspective, viewing ageing as a process of development across the lifespan:

‘Rather than deny the inevitable losses that all old people experience in advanced age, the selective optimisation with compensation model implies that old age holds the potential to be a time when the accumulated knowledge and expertise of a life-time is invested in the realisation of a distilled set of highly meaningful domains and goals. In this view, even losses may lead to gains in some highly valued areas of life.’

(Baltes & Carstensen, 1996: p414)

In contrast to Rowe and Kahn’s (1987) notion of successful ageing, the selective optimisation with compensation model is process-oriented not outcome focused (although goals remain important). Selection, optimisation and compensation interact as an individualised process; accepting the heterogeneity of life circumstances (e.g. constraints, opportunities, history, resources, health).

Within the model, selection is described as a process of adaptation to the consequences of increasing restriction experienced through changes in personal and environmental resources. This process involves adjustment of individual goals in response to demands of the environment and personal capacity (i.e. skill, motivation, and biology) and can be reactive, proactive, encompass environmental change, passive adjustment or active behavioural changes. Compensation is described as a process of change at personal or environmental levels in which the means no longer achieve the same ends; alternative means become necessary (e.g. behaviours, skills, or other resources already available or

that have been newly acquired). For Baltes (1991) compensation is prominent in circumstances of physical illness. Finally, optimisation is described as:

‘The enrichment and augmentation of reserves or resources and, thus, the enhancement of functioning and adaptive fitness in selected life domains.’

(Baltes & Carstensen, 1996: p413)

Optimisation means to seek to build on existing opportunities and activities in later life; early and middle life is recognised as a time in which capacity (e.g. reserves and resources) is enriched for later life optimisation. Bowling (2005) supports the view of ageing that this lifespan model encompasses; this fits with the life-course perspective (explained further in Section 2.2.2: p26).

Through applying the model of selective optimisation with compensation, it is argued older adults can maximise positive outcomes whilst minimising negatives (Freund & Baltes, 1998; Freund & Riediger, 2001); maintaining a positive balance. This is not to deny the role of factors that occur beyond the individual:

‘...like many other facets of the human condition, ageing is to a significant degree the product of individual and societal conditions.’

(Baltes, 1991: p851)

Thus, successful ageing should not be premised on normative outcomes of ageing; instead multiple outcomes are possible with variable markers of success (Baltes & Carstensen, 1996). Villar (2012) argues that an ‘ageing paradox’ presents a challenge to the model. The paradox identifies that subjective well-being can be present despite objective difficulties, this is argued to be due to the capacity of the human mind to rate

well-being in surprisingly positive terms, despite objective indications that might suggest otherwise. Thus, the subjectivity of ageing challenges notions of successful ageing, particularly when they are outcome focused. Baltes and Baltes were criticised for being overly subjective; however, their model signalled a shift towards a view of ageing as a natural component of the life span, free from structured social roles, able to explore areas of personal fulfilment and social activity and in good health (World Health Organisation [WHO], 2002; Huber & Skidmore, 2003).

Walker (2002) criticised notions of successful ageing as to achieve 'success' implied denying the onset of old age (i.e. continue mid-life activities and attitudes), which itself represents an ageist discourse (Andrews, 1999). Much of the successful ageing rhetoric has been argued to reflect notions of agelessness and the view of self as an 'ageless self', as described in the work of Kaufman (1986: 7). An ageless self pertains to a sense of self that is maintained despite physical or social changes that are associated with old age. The continuation of 'self' through the maintenance of behaviours reflects a state of agelessness; where 'old' and 'young' do not hold intrinsic meaning – there is only 'self'. Liang and Luo (2012) support the view that ageism underpins successful ageing; furthermore, they argue whether mid-life values can simply be prolonged into later-life and whether successful ageing is Western-centric, with roots based in cultures of consumerism and capitalism. Katz (2000) argues older adults may prefer to be contemplative in later life, which may not project mid-life values. Successful ageing draws further criticism for positioning presence or absence of disease above engagement in activities that are meaningful at an individual level (Villar, 2012). Baltes and Smith (2003) contrast notions of the third age (young-old, positive, active, achievement) and the fourth

age (oldest-old, frailty, vulnerability) which problematises the extent to which successful ageing is achievable in a definitive sense – life circumstances, goals and therefore terms of ‘success’ will differ if remain relevant at all from one age to the next. Notions of phases of ageing are problematic when applied to the context of an ageing population living with increasing long terms health conditions (reported in Section 1.1.2, p3). Methodologically, it will be important for this thesis to recruit participants with a diverse age range to compare the views of those categorised as the young-old and oldest-old.

Successful ageing has been important in shifting discourses from negative pathological assumptions of ageing (i.e. inevitable decline and disability in old age) to more positive views of extended development opportunities linking activity and well-being (Walker, 2002, Villar, 2012). Successful ageing has been highly influential in directing social policy and the research agenda in the UK and globally. The New Dynamics of Ageing [NDA] Preparatory Network is a UK-based research initiative funded by five Research Councils to support an eight-year multi-disciplinary programme aimed at improving quality of life for older people (<http://newdynamics.group.shef.ac.uk/>). The WHO’s global ageing strategy focuses on healthy and active ageing; which the WHO define as a process that:

‘...allows people to realize their potential for physical, social, and mental well-being throughout the life-course and to participate in society, while providing them with adequate protection, security and care when they require assistance.’

(WHO, 2002: p12)

In the ‘Strategy and Action Plan for Healthy Ageing in Europe 2012-2020’ the WHO (2012) outline four priority areas:

- Healthy ageing across the life-course

- Supportive environments
- Health and long term care systems fit for ageing populations
- Strengthening the evidence base and research

With non-communicable disease (NCD) (e.g. arthritis, diabetes, cancer, dementia) becoming the leading cause of morbidity, disability and mortality in old age the WHO utilises policy to target risk factors for NCDs (e.g. smoking, lack of physical activity, poor diet) to prevent or postpone onset (WHO, 2002; WHO, 2012). Walker (2002) utilises the concept of active ageing as a strategy to connect otherwise disparate policy issues of employment, pensions, retirement, health and citizenship, arguing that active ageing should be ageless and non-coercive, but if targeted correctly has potential.

2.2.2 Critical gerontology

For Estes, Biggs and Phillipson (2003), social gerontology came up short in terms of confronting issues such as race, ethnicity, gender and class in understanding ageing. Building on the existing theories, but arguing for a more critical perspective in gerontology they argue researchers and the conceptual tools they used did not keep pace with new sets of influences affecting older adults, or uncritically accepted them as unproblematic. Although social gerontology displaced the negative pathological view of ageing, it remained imperfect:

‘The biomedical model has been offset somewhat by the contribution of social gerontology in studying the relationship between the elderly and society, particularly such structures as the family, community, and economy. Social gerontological

theories, however, have focused largely on individual and their role loss, economic dependence, adjustment, and isolation in old age.'

(Estes et al., 1982: p153)

For some, social gerontology was argued to represent a 'new form of ageism' resultant from superficial views on health disparity and power distribution (Holstein & Minkler 2007: p17). The need for a turning point in the discipline was identified in the UK:

'In any discipline, or sub-discipline, a mainstream or orthodoxy develops which is often conservative and rarely self-critical. There is a need [...] for a constant reappraisal of concepts, ideas and approaches in order to prevent the orthodox approach becoming stultifying.'

(Phillipson & Walker, 1987: p1)

Phillipson and Walker refer to the orthodoxy in which the biomedical model and positivism were dominant, detached empiricism foregrounded, and scientific facts unchallenged. The absence of critical analysis weakened gerontology:

'The neglect of critical analysis has weakened attempts to understand the social processes involved in shaping age and the life-course.'

(Baars et al., 2006: p1)

Phillipson and Walker (1987) criticise, what they viewed as, the liberal-pluralist social gerontology for overlooking the differential impact of ageing and for not attending to the social construction of ageing. They argued for a more value-laden social gerontology to understand ageing and to reconstruct it. Thus, a critical approach was required to

strengthen gerontology and challenge the hegemony of the biomedical perspective: critical gerontology emerged.

The key principles of critical gerontology are informed by fields of sociology, anthropology, and political economy of ageing (Baars et al., 2006) and the humanities (Moody, 1988). These fields perceive ageing as an interpretive phenomenon; a human experience laden with meaning. The shift towards value-laden, rather than detached, empiricism makes for a richer, reflexive, gerontology in which:

‘Perspective is morally relevant because what we notice, and how we notice it, becomes the grounding for what we choose (or do not choose) to act on.’

(Holstein & Minkler, 2007: p20).

To ‘notice’, and therefore act, Holstein and Minkler argue for research that adopts methodological bricolage wherein methods and modes of inquiry matter less than ‘getting the story right’ (2007: p22). By which, the authors mean to attend to understanding personal experiences of ageing as opposed to seeking to make generalisations. The term ‘bricolage’ was used by Denzin and Lincoln (1999) to mean a multi-faceted approach to research connected by a critical thread. Individual experiences are derived from interrelated levels of social structure, such as social stratification, social institutions and interpersonal relationships, together with individual personality and psychological influences (Bowling, 2005). Thus, models of ageing should be broad and multi-disciplinary to capture the complex interactions.

Further building on social gerontology, the life-course perspective is taken as essential in critical gerontology (Bengtson, Putney & Johnson, 2005) and is defined by five key principles:

- Lives are interconnected; people, places and institutions link people together;
- Social and historical context is important in shaping the lives of individuals;
- Life transitions should be viewed in wider social contexts in which choices are made;
- Recognition that people make choices in their lives based on opportunities and constraints; and,
- Ageing and human development are life-long processes.

Giele and Elder (1998) advocate the life-course perspective:

‘Is a useful device for tracing the interplay of person and setting and of dynamic change by the individual in a context of structural leads and lags’

(1998: p9)

The life-course perspective reflects a current contention that the stages of life may no longer be perceived as an ordered process; instead, life is a course open to deviation rather than a series of standardised stages (Daly & Grant, 2008). Giele and Elder (1998) argue that a life-course perspective considers notions of time, agency, social structures, place, space and intersectionality. Critical gerontology provides a theoretical context in which to explore diversity in ageing and it is crucial to the approach taken in this thesis.

2.2.3 Ageing well

Successful ageing, active ageing, healthy ageing all broadly relate to the notion of ageing well albeit taking slightly different approaches (Villar, 2012). Bowling (2005) conducted a study as part of the Growing Older Programme in the UK; focusing on ageing well and quality of life in old age. Bowling (ibid) contextualised her research as occurring amidst a paradigmatic shift in which negative biomedical, functional and pathology-driven views of ageing have altered to more positive health, active ageing focused views. Bowling does not provide a definition of ageing well; instead she refers to ageing well in terms of the work from the behavioural sciences perspective of Baltes and Baltes (1990) on successful ageing (as described in Section 2.2.1: p19). Bowling (2005) combines quantitative and qualitative data, including lay models, to identify as the main building blocks of quality of life in older age:

- An optimistic outlook and psychological well-being, specifically in making downward rather than upward social comparisons;
- Good health and physical functioning;
- Good social relationships, preventing loneliness, and feeling helped and supported;
- Living in a neighbourhood with good community facilities and services, including access to affordable transport, and feeling safe in one's neighbourhood;
- Having an adequate income;
- Maintaining sense of independence and control over life.

Bowling argues that health and money were most often identified as the most important areas of quality of life. She argues that ageing well sits within the framework of quality of

life in which quality of life includes broader considerations of making meaning in later life; such as, drawing social comparisons, sharing in relationships with others, maintaining a sense of independence.

Chapman (2005), a Canadian gerontologist, suggests one way of conceptualising ageing well is as, 'an ongoing process in which individuals make sense of their ageing amid later-life change' (p27). This reflects the developmental life span perspective of social and behavioural sciences. Moreover, Chapman outlines the importance of the environment in the process of ageing well:

'To understand ageing well, we need to study not only those who are ageing and how they are ageing but also the places within and with which people are ageing.'

(Chapman, 2009: p27).

See Section 2.4.1 (p52) for further examination of environmental gerontology, through which ageing is studied as situated; this is important for this thesis.

Ageing well, as a concept, has resonance in public health policy initiatives within the UK. In the 'Healthy lives, healthy people' strategy document (UK Government, 2010) communities and environments were acknowledged as having key roles in supporting older adults to age well. In the report, research from the behavioural sciences was pinpointed as a key resource to identify how environments and communities could be designed to enable older adults to do this. The UK Government also recognised the challenge facing rural environments: 'Sparse older rural populations can present challenges in terms of more limited social networks, transport issues and restricted access

to services.’ (2010: p48). However, there is little acknowledgement of chronic conditions and the impact of such health factors in this strategic document.

As a response to the ‘Ready for Ageing?’ report (House of Lords, 2013, quoted in Chapter One: p2) the UK Government Office for Science produced a report entitled: ‘Future of an Ageing Population’ (2016). In the report, resilience was utilised as a core concept, defined as: ‘an individual’s successful adaptation and functioning in the face of stress or trauma’ (2016: p107). However, the word resilience was used throughout the report in different contexts and often as a colloquial term (e.g. socio-economic resilience, resilience of UK care policy, resilience of the UK); perhaps reinforcing views of resilience as a political buzz word. Furthermore, in the report the adaptation of services and resources was identified as an important health and care systems priority to generate: ‘interventions which prevent and manage chronic conditions, and provide individuals with the tools to take more responsibility for their health’ (2016: p11). Thus, ‘self-responsibility’ and ‘self-management’ are likely to be core components of ageing well. The report failed to report on specific challenges facing older people in rural environments.

Earlier discussion of the development of successful ageing identifies important elements of ageing well: independence, control, activity, and meaning making in later life. In this first section of the review I have focused on the development of gerontology to ground the thesis and identify ageing as a phenomenon for social scientific exploration. In the following sections I review literature relating to ageing in the context of (1) chronic pain and (2) rural environments to continue this scene setting and examination of current knowledge.

2.3 Ageing with chronic pain

In this section I review the literature on ageing with chronic pain to examine the current state of knowledge. As described in Section 2.1, I identified literature by first mapping key sources through library catalogues before progressing to detailed electronic searches using EBSCO, Web of Science, PubMed and scanning reference lists. The search criteria used for electronic searches include: 'chronic or persistent or long term pain' and 'older adults or elderly or seniors or geriatrics or aging or ageing'. The chronic pain literature is voluminous (Thomas & Johnson, 2000), for example, EBSCO returned over 5,000 results using the criteria described. For the purposes of this thesis, articles that reported qualitative research are prioritised – adding 'qualitative' to the search criteria reduced results substantially. Literature was selected to inform the thesis theoretically, empirically and methodologically. Study titles and abstracts were scanned and discarded where the focus was not related to the thesis, for example, children and adolescents, palliative care, recreational drug use, qualitative studies nested in trials that reflected on trial processes only.

I begin by providing an overview of epidemiological studies of chronic pain in later life to scope the issue and associated factors. I then focus on the qualitative research, which I have organised into themes of: chronic pain as multi-dimensional, chronic pain narratives, attitudes and beliefs about chronic pain, and self-management.

2.3.1 Population studies on chronic pain

Chronic pain may affect people of all ages and is considered to present a global problem (Breivik et al., 2006; Tsang, Von Korff, Lee et al., 2008; Goldberg & McGee, 2011). The

Health Survey of England (survey of >7,000 people; age range = 16-75+ years) indicated 31% of men and 37% of women report chronic pain (Bridges, 2011). A survey (n = 2,500; age range = 18-102 years) conducted in the Southeast of England with a UK representative sample indicated chronic pain prevalence of 45% (Carnes, Parsons, Ashby et al., 2007), a survey in Scotland reported similar (46.5%) (Elliott, Smith, Penny et al., [1999]; n = 3,605; age range = 25-75+ years). The definitions of chronic pain used in these surveys were consistent: pain or discomfort persistent or recurrent for more than three months. To my knowledge there are no UK-based studies that report rural chronic pain prevalence. North American studies indicate that chronic pain reporting is higher in rural areas (Hoffman, Meier & Council, 2002; Tripp et al., 2006). A European study (n= 23,712) also reported higher prevalence of chronic pain with neuropathic characteristics to be associated with rural living; one of many factors (Bouhassira, Lanteri-Minet, Attal et al., 2008). Employment has been reported to explain this trend e.g. farmers being exposed to vibrating machinery (see Solecki, 2014). However, this association may not be reliable, as contradictory studies exist (e.g. Varma et al., 1986; Andersson, 1999).

Chronic pain prevalence is reported to increase with age, but is not caused by it, and is more often reported by women (Bridges 2012; Carnes et al., 2007; Elliott et al., 1999). For example, Bridges (2012) report: 14% of men and 18% of women aged 16-34 years reported chronic pain compared to 53% and 59% respectively in the over 75 age group. Chronic pain causes may vary; in some cases, a direct cause may not be identifiable. Most often chronic pain is associated with an underlying chronic illness or musculoskeletal condition. Breivik et al. (2006) reported osteoarthritis as the most common cause (34%); a further 8% reported rheumatoid arthritis. Osteoarthritis-related chronic pain increases

with age (Elliott et al., 1999; Rustøen, Wahl, Hanestan et al., 2005) as does the reporting of chronic pain severity (Elliott et al., 1999), assessed by the chronic pain grade questionnaire (von Korff, Dworkin & Le Resche, 1990). A Scandinavian study reported adults aged 80–85 years had higher pain severity than those aged 86 and over, although the sample size was small ($n = 225$) (Willman, Petzall, Ostberg, & Hall-Lord, 2013). Carnes et al. (2007) reported 75% of those with chronic pain experienced pain in multiple sites (two or more); concluding that multi-site pain is more common than single site pain. Furthermore, Carnes et al. argue that the occurrence of multi-site chronic pain may also be age-related. Bridges (2011) reported 61% of women and 67% of men to experience pain in one site; however, older adults were more likely to report pain occurring in multiple sites, particularly women.

Chronic pain can have widespread impacts that are functional, social, emotional and socioeconomic (Turk, Wilson, & Cahana, 2011). Deleterious effects have been reported to include: reduced quality of life, increased mortality risk in older adults (Harkins, 1996), reduced well-being and happiness (Bridges, 2011), interference with everyday life (Gibson & Helme, 2001), reduced concentration and sense of control (Breivik et al., 2006), employment problems (Smith, Elliott, Chambers et al., 2001), and reduced sleep quality (Herr, Mobily, Wallace & Chung, 1990). Pain interference in everyday life has been reported to increase with age, regardless of the site of pain (Thomas, Peat, Harris et al., 2004). Older adults are also more likely to experience co-morbidities that lead to complex health experiences (Rustøen et al., 2005). Chronic pain has implications for mental well-being; the link between chronic pain and depression is well established (Bair, Robinson, Katon & Kroenke, 2003). A study of rural patients in Alabama (USA) associated co-morbid

depression with pain interference and life satisfaction (Day & Thorn, 2010). Treatment of co-morbid depression has been associated with improved pain ratings, functional status and quality of life (Lin, Katon, Von Korff et al., 2003). There is a link between chronic pain and suicide (Hitchcock, Ferrell & McCaffery, 1994; Fishbain, Cutler, Rosomoff & Rosomoff, 1997; Taverner, Closs & Briggs, 2014). Poor adjustment or maladjustment to chronic pain is associated with psychological morbidity such as depression, anxiety, distress and behaviour problems (Sharpe & Curran, 2006). Thus, targeting the reduction of chronic pain interference in everyday life seems pivotal for the well-being of older adults and for use and targeting of healthcare services.

A review of chronic pain management identifies pharmacological treatments (i.e. opioids, non-steroidal anti-inflammatory drugs [NSAIDs], opioids, antidepressant drugs, anticonvulsant drugs, skeletal muscle relaxants, and topical agents), interventional treatments (i.e. injection therapy, surgery), physical, rehabilitation and psychological approaches, and complementary therapies (Turk et al., 2011). Barry et al. (2005) reported chronic pain management to consist of, on average, 2.7 concurrent strategies per individual, with analgesic medications the most common. The use of analgesics has been found to increase with age (Rustøen et al., 2005). A rural study in Canada indicated that multidisciplinary chronic pain management significantly reduced pain intensity and interference (Burnham, Day & Dudley, 2010). However, the authors recognise the financial cost of providing such services. The financial burden of chronic pain within the UK has been estimated to be more than £12 billion, although such estimates should be treated with caution (Bridges, 2011). Elliott et al. (1999) reported older adults with

chronic pain as extensive users of health services; yet, their experience of pain management is suboptimal. Such experiences are reported in the third (voluntary) sector:

‘Older adults are more at risk of pain than other sections of the population but less likely than younger people to experience good pain management’

(Help the Aged, 2008)

This pattern of apparent health inequality echoes the ‘inverse care law’ hypothesised by Hart (1971); inverse care law asserts that people in society in most need of care are least likely to receive it. This inequality arises from variation in access to and quality of services. Tripp et al. (2006) report lower rates of healthcare utilisation in rural areas specifically by people reporting high pain interference. The authors suggest resource location and access to transport may impact service access and delivery; the study was conducted in Canada in which the scale of ‘rural’ (i.e. distance, remoteness) and therefore access may not be directly comparable to a UK context. Social support has also been identified as important; however, it is the quality of the social support not the quantity that seems to matter in rural chronic pain studies (Hoffman et al., 2002). These are important factors to be explored in the following review of qualitative literature on the experiences of ageing with chronic pain, and then subsequently in the rural literature (Section 2.4.3: p60).

2.3.2 Qualitative studies exploring peoples’ perspectives on chronic pain

‘It is important for health professionals and researchers to gain insights into experiences of chronic pain sufferers, so that they may understand the patient’s perspective and instigate appropriate treatments.’

(Sofaer-Bennett, Holloway, Moore et al., 2007: p271)

Here I review the qualitative literature on chronic pain, focusing on papers relating to older adults (or ageing). As Sofaer-Bennett et al. (ibid) argue, understanding chronic pain experiences has implications for pain management; the importance and variability of which was outlined in the previous section. Qualitative research remains in the minority of literature on chronic pain in later life (Roberto, Perkins & Holland, 2007). I have identified the following through systematic searches (as described above) and have compiled these into four themes to identify key issues and debates and support readability.

2.3.2.1 Taking a multi-dimensional perspective on chronic pain

The IASP definition of pain identifies sensory and emotional dimensions, chronic pain definitions add temporal dimensions. Researchers also describe physiological, physical, psychological, social and spiritual (Ong & Jinks, 2006); existential and cultural (Raheim & Haland, 2006) and environmental dimensions (Fordyce, 1995a; 1995b). Chronic pain theorists have attempted to package multiple dimensions into single explanatory frameworks. For instance, the gate control theory (Melzack & Wall, 1965; 1996) combined physiological and psychological-emotional dimensions to explain how physiological processes were influenced by individual emotional and psychological factors (e.g. past experiences, emotions, expectations of later life, and culture). However, chronic pain is dynamic (Fordyce, 1995a; 1995b), individualistic (Huet, Innes & Whiteford, 2009) and subjective (Blomqvist & Edberg, 2002).

Despite the limitations of chronic pain theories, the gate control theory represented a radical shift away from a biomedical perspective, in which the biological and physical

dimensions had been prioritised through the medicalisation of pain (Ong & Forbes, 2005). The shift emphasised a connection between an individual's mind and body to move beyond objectivity and the Cartesian dualism (the view argued by Rene Descartes, [1641], of mind and body as distinct entities) towards multi-dimensionality (Bendelow & Williams, 1995). Bendelow and Williams (1995) argue that the biomedical model had pathologised ageing, generating a (socially) negative relationship between pain and age. The narrow perspective of the biomedical model does not appreciate the reality of chronic pain:

‘The biomedical approach, with its focus on pathophysiology, does not address the complexity of chronic pain and does not provide adequate guidance for successfully living with it.’

(Thomas & Johnson, 2000: p683)

In contemporary thinking, it is widely accepted that to address the problem, management and measurement of chronic pain in the community, a multi-dimensional approach is essential (Smith et al., 2001; Bridges, 2011; Clarke, Anthony, Gray et al., 2012). This thinking supports the first research objective to explore the dimensions of chronic pain experienced by older adults in rural environments. The environment as a dimension within chronic pain experience has been under-theorised in the literature. In Section 2.5 (p73) I examine ageing in rural environments in the context of health.

2.3.2.2 Using narratives to make sense of chronic pain

Narratives (storied accounts) are commonly used by individuals to contextualise and make sense of their chronic pain experiences (Clarke et al., 2012). Several key authors

have studied chronic pain (and chronic illness) narratives; although their work did not focus on older adults, it remains important in the context of this thesis. In his seminal work, *The Wounded Storyteller*, Frank (1995) identifies three narrative types, or storylines, used by individuals to construct account of chronic illness: restitution (i.e. transition from being healthy to being sick and expectation of becoming healthy again), chaos (i.e. imagining life as never getting better - narrative has little structure), and quest (i.e. believing something can be gained from illness). Frank's storylines have been applied in chronic pain studies. For example, Vroman et al. (2009) categorised the narratives of study participants with low chronic back pain as exclusively chaotic; lower back pain was revealed as a moral event in which authenticity was challenged - akin to Parsons' (1951) concept of the sick role in which illness behaviour was considered deviant unless certified by a medical professional. Another UK study described participants as being unable to establish legitimacy having not felt believed about the existence of their pain (Osborn & Smith, 1998). The way people tell their story of chronic pain therefore has implications for subsequent clinical judgment, treatment, and sense of self. Neither group of participants included by Vroman et al. (2009) or Osborn and Smith (1998) were older adults; the extent to which older adults may share these views is considered further in Section 2.3.2.3 (p45).

The work of Michael Bury and his concept of 'biographical disruption' (1982) and the 'narrative reconstruction' of Gareth Williams (1984; 1993; 1997) have also been influential in work on chronic pain and illness narratives. Bury (1982) argues that chronic illness acts as a trigger in an individual's biography at which point taken-for-granted assumptions become disrupted. The meaning of past events and systems of explanation

become disrupted by such experiences and a shift occurs in the life trajectory otherwise expected. Williams (1984) described narrative reconstruction as functioning to:

‘Repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self and society.’

(Williams, 1984: p197)

Richardson, Ong and Sim (2006) examined chronic widespread pain as biographically disruptive with eight participants (age range 40-60 years); although the age range falls below the anticipated sample in this thesis the findings have important implications. Two explanatory frameworks were identified for the cause and meaning of pain: (1) identification of a key event or trigger for their pain; and, (2) suggestions of a predisposition to developing pain (genetic or environmental). The authors described triggers as turning points in participant narratives. In contrast, predisposition supported beliefs of pain experience as a normal part of life. However, Richardson et al. (ibid) state that pain may not be associated with chronological age but perceived age and lifestage in relation to life expectancy. To draw this distinction, Richardson et al. underline the importance of exploring contextual factors in biographical disruption. For Sanders, Donovan and Dieppe (2002) narratives of disruption and normality may co-exist. Similarly, Kathy Charmaz (1983) argued that narratives are constantly being negotiated and modified over time and course of illness as sense of self is constructed and reconstructed.

The subjective experience of illness has the potential to alter the concept of self and how a person's lived space and time including relationships with others is organised (Bendelow & Williams, 1995). According to Thwaite:

‘The fear of losing one’s identity is very strong [...] When pain takes over, one’s ability to control both oneself and the immediate environment deteriorates.’

(Thwaite, 1998: p10)

Kelly and Field (1996) identify the utility of focusing on self and identity in illness descriptions:

‘One of the virtues attached to using the concepts of self and identity as a means of describing the physical and social reality of illness lies in their usefulness in describing change.’

(Kelly & Field, 1996: p247)

The authors describe how people with chronic illness maintain a sense of coherence; self and identity have an enduring quality. Thus, through chronic pain experience a balance is struck between continuity, to connect past, present with future, and change. A sense of self seems to endure throughout these renegotiations although descriptions and details may change and shift. The studies reported thus far have important methodological implications highlighting the role of narratives.

In a study of 14 participants in the USA (two of which were 65+ years), Thomas and Johnson (2000) described the emotional states participants experienced when living with chronic pain as: anger, helplessness, frustration, depression, despair and exhaustion. Carson and Mitchell (1998) explored narratives of Canadian older adults (aged 54-93 years) living with persistent pain (6 months’ duration). A theme of ‘forbearance’ was described that shaped the lives of participants. Pain was expressed as a persistent anguish; however, all participants expressed a need to endure and to tolerate their pain,

‘to carry on in spite of it’ (1998: p1244). Descriptions of endurance and tolerance of chronic pain reoccur throughout the chronic pain literature; perhaps captured best as efforts to ‘carry on’ or ‘keep going’ (see Busby 2000; Paterson, 2001, 2003; Sofaer-Bennett et al., 2007; Richardson et al., 2014). I return to this literature below within the context of resilience. A second theme Carson and Mitchell (1998) described revealed behaviour patterns of engagement and retreat. Participants engaged in activities, some with others, to achieve pain relief (e.g. taking medications, using non-medical therapies, diversionary activities, spending time with family) but retreated in terms of restricting activities and social interactions, as pain persisted. Restriction of activities may have negative implications for self-worth (Maly & Krupa, 2007), reduced sense of daily functioning, and social withdrawal (Roberto & Reynolds, 2002), which may function as a protective behaviour against stigma and sense of vulnerability (Osborn & Smith, 1998).

Older adults with chronic pain are reported to commonly present a stoic attitude towards their pain, a desire not to be seen to complain (Yates, Dewar & Fentiman, 1995; Blomqvist & Edberg, 2002; Jones, Fink, Clark et al., 2005; Schofield, O’Mahony, Collett & Potter, 2006; Hunhammar, Nilsson-Wikmar & Lofgren, 2009). Stoicism may provide a source of control, as Gammons and Caswell state:

‘Stoicism can be a means of exerting emotional control over pain, allowing the individual to maintain their dignity [but] unvoiced pain not only demonstrates the act of stoicism, it also signifies poor-quality care and the full extent of the problem may remain unknown’

(Gammons & Caswell, 2014: p276-277)

Stoicism may result in inappropriate care, or may keep poor-quality care hidden. An Icelandic study of twelve nursing home residents (mean age= 86 years) Gudmannsdotir and Halldorsdottir (2009) identified the importance of focusing on individuals that displayed stoicism as these residents presented experiences of suffering (e.g. abandonment, neglect, disconnectedness, hiding extent of pain); suffering occurred in silence and without complaint. In this context, stoicism may sustain the invisibility of vulnerability and suffering (Gudmannsdotir & Halldorsdottir, 2009). However, the study context is both physically and culturally different to that considered in this thesis; Gudmannsdotir and Halldorsdottir's findings may reflect the nursing home environment as much as older adult experiences. A Swedish study identified stoicism as a positive way of responding to chronic pain and was perceived by health care professional as symbolising endurance (Blomqvist, 2003). A tendency among healthcare professionals to support and reinforce stoicism is also reported in the UK (Gammons & Caswell, 2014). A critique of the concept of stoicism in contemporary society suggests this phrase may mask underlying sociological factors in health behaviours and requires further questioning (Moore, Grime, Campbell & Richardson, 2012). This has implications for this thesis and unpicking stoicism, if present in the data, will be important; exploring chronic pain narratives presents a possible way of achieving this. In the context of this thesis, it will be important to elicit narratives of older people with chronic pain in rural environments, as narratives provide a means through which to explore meaning that is made of such experiences.

2.3.2.3 Attitudes and beliefs about chronic pain

The literature suggests older adults share a tendency to perceive chronic pain as normal (Harkins, 1988; Davis & Magilvy, 2000; Sanders et al., 2002; Sale, Gignac & Hawker, 2006; Grime, Richardson & Ong, 2010; Gammons & Caswell, 2014; Richardson, Grime, Ong, 2014). Gammons and Caswell (2014) identify the normalisation of pain as a consequence of ageing; presenting a barrier to effective pain management. A Canadian study of older adults with disabling hip/knee osteoarthritis found that perceptions and attitudes toward pain have an important role in pain management and adherence (Sale et al., 2006). Participants in the study were reported to downplay experience of pain and consumed pain medications in lower doses than were prescribed. This behaviour was supported by the following beliefs: fear of addiction, taking one less pill per day, prioritising other conditions above pain (hierarchically organising priority of health problems based on threat to life), and an acceptance of pain as a normal part of ageing. Thielke, Sale and Reid (2012) suggested that the belief that pain was a normal part of ageing to be one of a group of myths held by older people about chronic pain that were unsupported in the literature, these included: pain worsens over time, stoicism leads to tolerance, and prescription analgesics are highly addictive. The identification of causes of pain provide an opportunity to gain legitimacy and be believed, and therefore less likely to accept pain as a normal part of ageing (Bunzli, Watkins, Smith et al., 2012). Knowing a cause also facilitated acceptance of chronic illness and supported planning for the future (Thorne, Paterson & Russell, 2003; Persson & Rydén, 2006) however, causes may infer personal significance in terms of apportioning blame, responsibility, and impacts on sense of self (Eccleston, Williams & Rogers, 1997). Thus, challenging the sense of pain as normal may also have negative implications for the experiencer and their coping.

There is a prominent discourse of self-management in UK healthcare policy and agendas for chronic illness (Morden, Jinks & Ong, 2012). Several qualitative studies have examined perceptions about chronic pain management strategies and coping among older adults (e.g. Blomqvist & Edberg, 2002; Kemp, Ersek & Turner, 2005; Sofaer et al., 2005; Maly & Krupa, 2007; Sofaer-Bennett et al., 2007). Self-management is central to pain management; how well people manage chronic pain depends more on what they do for themselves rather than what is done for them (Jensen, Nielsen & Kerns, 2003). Self-management can be studied in everyday life:

‘Examining how people maintain acceptable social roles, remain competent moral actors and preserve a sense of self is central to understanding self-managing in chronic illness.’

(Morden et al., 2012: p10)

Everyday self-management is described in terms of illness work (Corbin & Stauss, 1988) suggesting a regular routine, often termed ‘hard work’ in the context of chronic pain (Duggleby, 2000; May, 2006; May, Montori & Mair, 2009). In a UK study, Ong, Jinks and Morden (2011) explored the hard work of a group of older adults (age: 50+) with knee pain in a longitudinal study. Ong et al. described living with chronic knee pain as an ongoing adaptation in which strategies were continually devised and revised to maintain activities. They identified that the hard work of self-management may go unnoticed, again through processes of normalisation. The authors raise an important clinical problem: to challenge the belief of ageing and pain as normal may disrupt this everyday coping mechanism; yet, not doing so acts to ignore the hard work that is being exerted.

They argue that the hard work of self-management should be acknowledged so that healthcare provision and advice can be contextualised in every day experience.

In a UK study of 63 older adults (age range: 60-87 years) Sofaer et al. (2005; Sofaer-Bennett et al., 2007) identified four themes of self-management using grounded theory: the desire for independence and control; adaptation to a life with chronic pain; perseverance; and communication and health. They describe participants as living in fear of losing their independence to which they respond by incorporating assistive aids into daily living and by making adaptations to their home environment. Adaptation was important for meaning in life:

‘Substitution and adaptation of activities plus a focus on socialising formed the basis of maintaining a meaningful life. Selective reduction of activities in everyday life has been noted as one way of meeting the challenge of ageing.’

(Sofaer-Bennett et al., 2007: p275)

Learning to accept pain and to compromise on control over the environment may facilitate older adult's adaptation to pain (Sofaer et al., 2005). Another UK study of activity levels among 31 older adults (age range: 67-92 years) experiencing chronic pain found an overarching theme of: 'living within your limits' (Mackichan, Adamson & Goberman-Hill, 2013). Mackichan et al. found all participants had reduced or altered activity levels (social and physical) in a negotiated fashion. Activity restriction was sometimes used to maintain autonomy; however, such restriction had negative implications for physical conditioning, further disability and social isolation. Acceptance of pain has been framed as acceptance of an altered life requiring change in terms of redirecting efforts; and is important in coping in terms of freeing up cognitive and

affective resources by restricting worry (McCracken, 1998; McCracken, Carson, Eccleston, & Keefe, 2004; McCracken & Eccleston, 2005). Weiner et al. (2004) reported that the longer older adults had experienced low back pain the less disability they perceived; the authors pinpointed the role of acceptance.

Sofaer-Bennett et al. (2007) identified “perseverance” as important in supporting maintenance of social activities. Perseverance overlaps with research relating to the concept of resilience, which is commonly identified in studies with older adults experiencing chronic pain and/or illness. A systematic review of resilience was conducted by Windle (2012) who proposes the following definition:

‘Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life-course, the experience of resilience will vary.’

(Windle, 2012: p163)

The author identifies resilience as being supported by protective factors, also termed assets, resources, and strengths. In the systematic review, Windle identified protective factors to have been less effective for 70-90 year olds than for younger older adults (Windle, *ibid*). Thus, resilience is not fixed but is instead dynamic varying across the life-course and across different areas of life. It is not a case of being resilient or not, instead resilience is a concept that can be used to frame ageing well as a process not as an end point (Wiles, Wild, Kerse & Allen, 2012; Richardson et al., 2014).

The concept of resilience shares commonalities with the concept of salutogenesis (Antonovsky, 1979). Salutogenesis places emphasis on health development and maintenance (i.e. how to live well) and originally developed as a point of contrast to a biomedical preoccupation with pathogenic causes of disease. Central to salutogenesis is the sense of coherence (SOC) theory that explains how individuals make sense of the world and their capacity to respond to stress, part of the human condition. The SOC theory positions salutogenesis in health research (Antonovsky, 1996). Comprehension, management, and meaning are important components in maintaining a sense of coherence. Salutogenesis is typically used as an umbrella term to capture similar health promoting concepts (e.g. thriving, self-efficacy, hardiness, inner-strength) (Lundman, Alex, Jonsen et al., 2010; Mittlemark, Bull & Bouwman, 2017; Stock, 2017). Similarly, resilience has been argued to closely resemble SOC (Lindstrom & Eriksson, 2006; Windle, 2011). There has been a surge in interest in the concept of resilience; to the point where it has become a buzz-word in gerontology (Luthar, Cicchetti & Becker, 2000; Wild, Wiles & Allen, 2013) and in wider society (Warner & Grunevald, 2012; www.theguardian.com/global-development-professionals-network/2013/mar/05/resilience-development-buzzwords). Sturgeon and Zautra (2010) argue for a new paradigm of resilience to acknowledge the important role it plays in supporting: adaptation, beliefs about effective pain control, greater emotional knowledge directing more attention within, greater optimism, expressing life as meaningful, accepting pain and its consequences, and experiencing less negative emotion. In this thesis, I have chosen to focus on the concept of resilience, acknowledging the proximity and arguable overarching nature of salutogenesis, to provide a critical gerontological and rural perspective on this popular concept.

Resilience is a multi-levelled concept in which the environment forms an important aspect (Windle, 2011). Researchers have examined the role of the environment in the context of resilience in later life (Staudinger, Marsiske & Baltes 1993; Grenier, 2005; Sapountzaki, 2007; Smith & Hayslip, 2012; Wiles et al., 2012). Environmental perspectives on resilience are also multi-levelled; social resilience, for example, considers the ability of communities to cope with environmental change (Adger, 2000). Community resilience is beyond the scope of this thesis; instead, I focus on the interactions between individuals and their physical and social environments to understand resilience at this level. People do not live in isolation from their immediate and surrounding environment; daily interactions occur with physical, social and environmental contexts and are influenced by these contexts (Windle, 2011). The environment may include resources and assets to support resilience but may also present risks and challenges that resist an individual's resilience (ibid). The focus on rural environments supports inclusion of resilience as an important sub-focus for this thesis to explore the role rural environments have in the context of resilience in the face of chronic pain in later life. Resilience fits with the notion of ageing well and critical gerontology:

‘The potential of resilience as a concept is that it allows people living with age-related disability or challenging social and spatial circumstances to be understood as ‘ageing well’.’

(Wiles et al., 2012: p423)

Areas for future research have been recommended: resilience in later life (Windle, 2012), resilience in the context of pain management (Sturgeon & Zautra, 2010), the role of family and community resources in supporting resilience, and there is also no gold

standard for measuring resilience (Windle, Bennett & Noyes, 2011). Thus, it is important in the context of this thesis to explore resilience among older adults to understand this concept better. The literature indicates that resilience, along with attitudes such as perseverance, are intuitively bound together with self-management (in the context of chronic illness in later life). It is within this debate that the third research objective of this thesis is embedded (Section 1.2: p7). Qualitative methods will facilitate exploration and the identification of factors (psychological, social, environmental, community) that support resilience for older people with chronic pain in rural environments.

2.4 Ageing in rural environments

In this section I review literature that crosses the boundaries of health, place (specifically rural) and ageing. As described in Section 2.1, I identified literature by first mapping key sources through library catalogues before progressing to detailed electronic searches using EBSCO, Web of Science, PubMed and scanning reference lists. The search criteria used for electronic searches included: 'older adults or elderly or seniors or geriatrics or aging' and 'rural or rurality'. I supplemented these articles by scanning reference lists. The retrieved literature reveals a rich and complex source of concepts and theory around ageing and the role of the environment. Thus, in this section I have selected literature to identify the key concepts and theories that inform this thesis. I begin with a summary of environmental gerontology, a sub-field of gerontology, as discussion of this helps to bridge the discussion of gerontological literature (Section 2.2) to this section and considerations of environments and health. In Section 2.5 I pull the threads all together to review research specifically on ageing with chronic pain in rural environments.

2.4.1 Environmental gerontology

The study of health and place has developed into a multi- and inter-disciplinary endeavour incorporating geography, sociology, psychology, and health sciences. Environmental gerontology has emerged as a sub-field of gerontology (Wahl & Weisman, 2003; Wiles, 2005) and remains prominent (for example, Rowles & Bernard, 2013). Environmental gerontology attempts to capture the relationship between older adults and their socio-spatial surroundings (Wahl & Weisman, 2003) or 'ageing in place' (Gitlin, 2003). The importance of the environment in which ageing occurs is acknowledged by the WHO and its policy on age-friendly environments, although the focus is on cities (WHO, 2007). More broadly, age-friendly environments 'promote capacity-enhancing behaviours' and 'remove barriers to participation, compensate for loss of capacity' (WHO, 2015: p15). Age-friendliness also fits with the European Commission's Partnership on Active and Healthy Ageing, established in 2010:

'Physical and social environments are key determinants of whether people can remain healthy, independent and autonomous long into their old age.'

(European Commission Report, 2015: p4)

The fit between the individual and their environment for the promotion of independence and well-being in later life is imperative (Wahl & Weissman, 2003). On the one hand, older adults are required to make decisions on how to live in their communities in terms of what services and opportunities are available to them. On the other hand, age-friendly environments are not fixed but part of an ongoing process to provide the optimal environment for later life (Liddle, Scharf, Bartlam & Sim, 2014). The age-friendly approach

is being contextualised to rural environments through such initiatives as the Age Friendly Communities Initiative in Manitoba, Canada (Menec, Means, Keating et al., 2011).

Human ecology theory seeks to explain the connection between people and places acknowledging that the quality of human life and the quality of the environment are interdependent (Rettig & Leichtentritt, 1999). Durkheim (1895; 1982 reprint) recognised that well-being is influenced by society as a whole – therefore to understand individuals we must study them in multi-levelled contexts of external and societal as well as internal and personal. Social cohesion and social capital are two important concepts here and may help in understanding how rural environments can support or restrict aspects of health in every day interactions. Social cohesion refers to the sense of connectiveness to a group based on level of supportiveness, shared values, shared identities, sense of belonging, and solidarity between group members (Kawachi & Berkman, 2000). Dimensions of social cohesion have been identified as: common values and civic culture, social order and social control, social solidarity and reduction in wealth disparity, social networks and social capital, and place attachment and identity (Forrest & Kearns, 2001). A sense of community spirit in rural environments is typically underpinned by the expectation that individual needs will be responded to by people in the surrounding community (Forrest & Kearns, 2001; Winterton & Warburton, 2011; 2012) this symbolises social cohesion.

Social capital is centred upon social interactions and the extent to which a community or neighbourhood provides opportunities and resources to increase an individual's personal resources – it is the connections among individuals, social networks and the norms, reciprocity, trust, and values that they create (Putnam, 1995). Bourdieu (1986) argues that social capital is unevenly distributed and that 'community' is not an objective entity;

social capital may therefore be best understood as a metaphor for the quality of social relationships (Lee, Arnason, Nightingale & Shucksmith, 2005). Ferlander (2007) summarises different types of social capital by form and strength of a network and of relationships. In form, social capital can be either: vertical (hierarchically organised relationships) or horizontal (relationships based on equivalent status) and formal (relationships between citizens and civil servants – civic society) or informal (friends, family, neighbourhoods). In strength, social capital may be based on: bonding (homogeneity of members – synonymous with strong networks) and bridging (heterogeneity of members – synonymous with weak networks). Social capital has been shown to improve health, reduce mortality and support individuals during ill-health (e.g. Kawachi, Kennedy, Lochner & Prothrow-Smith, 1997; Lindstrom, 2004). However, the opportunity to develop social capital and maintain strong social networks is likely to be dependent on personal characteristics (shared characteristics in relation to others), experiences (physical or mental health problems), and the environment in which individuals live (facilitates or impedes social relationships).

Kearns and Moon (2002) argue that a shift has occurred in thinking about health and place; since the 1970s a move has been made away from medical geography and disease towards the emergence of health geography and well-being. The notion of 'ageing well' helps to bring in the role of the environment as a place (physical) alongside environment as a shared system of values and identity within a health and well-being context. Unpicking the complex relationality of ageing in place highlights the need for interdisciplinary research and mixed methods approaches (Hennessy, Means & Burholt, 2014); and acts to position this thesis. In the next section I present literature that

considers ageing and place to drill down into the role of environment before considering interactions with health.

2.4.2 The relationship between ageing and place

The understanding of 'place' has shifted to coincide with the disciplinary transitions. In early medical geography place was considered as an objective, bounded and 'unproblematised activity container' (Kearns & Moon, 2002: p609). More recently, the objectivity of place has been superseded by place as subjective, complex (Andrews, 2002) processual (not static), (re)negotiated, interrelated, simultaneously material/physical and symbolic and social (Wiles, 2005). The shift in understanding place has been described as a 'relational turn' in how place is conceptualised (see also Graham and Healey, 1999; Massey, 1999; Watts, 1999; 2000; Castree, 2004). To understand the relationship between people, place and health, Cummins et al. (2007) argue that:

'To operationalise 'relational' conceptions of place it will be necessary to move away from empirical research designed to distinguish between contextual and compositional effects and instead concentrate on the processes and interactions occurring between people and places over time which may be important for health.'

(Cummins, Macintyre, Davidson & Ellaway, 2007: p1828)

A relational perspective is also important to understand health inequalities, as place both: 'constitutes as well as contains social relationship and physical resources' (ibid: p1825). The relational concept views place as a fluid arrangement that occurs over time (life-course) and space and involves a mutual and reciprocal interrelationship between people. The change in concept of place has led to a change in modes of inquiry; Andrews (2002)

identifies the expansion in qualitative methodologies, specifically ethnography and a range of analytical derivatives. This change in perspective has emerged in debates around the concept of community also; extending understanding of community from place-oriented notions to social interactions and shared identities (see Means & Evans, 2012).

Places are important for what they represent but also for what can be drawn from them. Day and Hitchings (2011) argue in terms of identity formation and maintenance; identity is both constituted and performed in place. Similarly, Bartlam, Bernard, Liddle et al. (2013) describe the creation of home-like places in a UK retirement village environment. Evans (2009), also from within the context of retirement homes and villages in the UK, identifies housing quality as an important factor in health and well-being and home as intersecting the relationship between place and personal identity, social interaction and sense of control: 'the opportunity to shape their environment in a way that affirms histories and identities' (2009: p126-7). For, Williams (2002), place is a sense of connectedness and rootedness (a phenomenological notion developed by Relph, 1976), through which belonging and meaning of life is drawn. Place is important in identity formation:

'Place is deeply woven into human experience, and place identity is understood to be the construction of self in the world and its connectedness to place and the environment.'

(Williams, 2002: p145)

Relph (1976) emphasises the differential between place and space: 'Emotional attachments not only provide places with special meaning, they also differentiate them from surrounding space' (p179). For Relph home is 'the central reference point of human

existence' (1976: 20); a place in the world. Home is symbolically important to identity as Townsend describes:

'Home was the old armchair by the hearth, the creaky bedstead, the polished lino with its faded pattern, the sideboard with its picture gallery and the lavatory with its broken latch reached through the rain. It embodied a thousand memories and held promise of a thousand contentments. It was an extension of personality.'

(Townsend, 1963: p38)

Home remains a powerful symbol for autonomy and independence, particularly for many older adults (Wiles, 2005). However, the interpretation of home may not always be as a tranquil haven (Wiles et al., 2011). The influx of home healthcare has arguably destabilised interpretations of home as at times it may resemble a clinical area, in which an 'outsider' contests for space and power in this domain (Twigg, 1999). Thus, if places are treated as objective containers and older adults as homogenous groups their needs are likely to go unmet (Wiles et al, 2011).

Mapping the literature on ageing and place reveals two prominent and closely related concepts: 'ageing in place' and 'attachment to place' (Andrews, 2002). Andrews argues that the concept of 'ageing in place' has been popular with policy makers. Ageing in place is described as enabling older adults to maintain independence, autonomy, and connection to social support (e.g. friends, family) and avoids costly institutional care (Wiles et al., 2011). Critical analysis from Minkler (1996) identifies a lack of choice for older adults as policy is driven by idealised notions of community care and the role of family in providing support in later life; this has financial implications in terms of cutting public health and social service costs. In the context of the objectives of this thesis, the

experiences of older adults ageing in place with chronic pain, their use and access to health and social care services, and support networks will be explored and discussed in the context of coping but also policy recommendations.

The concept of attachment to place is used and developed by theorists such as Rowles (1980; 1981; 1983; 1990), Kaplan and Kaplan (1989), Swenson (1998), Rosel (2003), and Burholt (2006, 2012, 2016), among others. Attachment to place refers commonly to the positioning of home both in relation to its physical setting and its emotional meaning and the association with identity or place identity – as dimensions of self (Williams & Vaske, 2003). Through attachment to place a person develops a sense of belonging – a sense of unity and integration through human social interdependence (Marshall, 2002) – that provides meaning to life; a sense of being at home and of having a place in the world (Taylor, 2001). Place attachment provides a stable factor in a person's life. A sense of belonging (or place in the world among others) is considered to help maintain a sense of identity (to draw meaning, security) and well-being, and to facilitate successful adjustment in old age (Andrews & Phillips, 2005). A sense of attachment to place is argued to increase with age; increasing investment of meaning in objects and places over time (Chapman, 2006). Long-term emotional attachment to environmental surroundings has been shown to contribute to well-being in old age (Rubinstein, 1990; Taylor 2001).

Rowles (1981) explored attachment to place and identified three dimensions of “insideness”, a notion that differentiates community members from the world outside:

- Physical insideness (i.e. intimate familiarity with place)
- Social insideness (i.e. sense of integration within social fabric of community)

- Autobiographical insideness (i.e. temporal depth of meaning constructed across the life-course)

Rowles argues that autobiographical insideness is more pervasive than the other types and provides a basis for attachment and identity, which can be preserved in later life. The powerful memories associated with a specific place enable an individual to maintain a positive self-image despite changes associated with later life. Burholt (2006) argues that: 'attachment to place is a social product, even when older people refer to the physical attributes of the environment' (p1108). Burholt (2006, 2012) conceptualised attachment to place based on statements from older adults living in rural environments of North Wales; she identified four overlapping themes: social (social support and social integration), psychological (life satisfaction), physical (appropriateness of the environment and aesthetic quality) and temporal (historical perspective). A specific locality may infer a different sense of identity depending on personal biography and divergence in 'imag(in)ery' (public and private representations of identity); as studied by Burholt, Scharf and Walsh (2013) among island dwelling older adults. In the context of retirement villages, Evans (2009) identifies the importance of social interaction as sustaining a sense of community and belonging. The author also acknowledges the role the environment plays (the built environment in the case of retirement villages) in both supporting patterns of social interactions (i.e. routines) and facilitating older adults to overcome restrictions (e.g. frailty, impaired mobility). Thus, ageing and place are intricately woven together. The nature of this relationship and role of the environment contextualises each of the research objectives in this thesis. Therefore, to unpick such

intricacy an in-depth approach is necessary. In the next section I focus more on the role of place in terms of health and well-being.

2.4.3 The role of place in health and well-being

The effect place has on health has been under-conceptualised and remains a, 'black box of somewhat mystical influences on health' (Macintyre, Ellaway & Cummins, 2002: p125). Macintyre et al. examined health promoting and/or damaging features of environments in Scotland. The authors do not specify rural or urban environments as their focus but talk in general terms. Material resources, defined as 'opportunity structures', were identified as important to healthy living:

- Shared physical features (e.g. air quality, climate, drinking water);
- Availability of healthy environments at home, work and play (e.g. housing, safety, may not affect everyone in the same way); and,
- Services (public or private) to support people in their daily lives (e.g. transport, street cleaning, lighting).

Collective features included: socio-cultural features of a neighbourhood (political, economic, ethnic and religious history of community, norms, values, integration, support networks); and reputation of an area (perception of area by residents and others, self-esteem and morale). Macintyre et al. draw on Maslow's (1943; 1968) hierarchy of human needs to identify a list of influences of place on health: air, water, food, shelter, security, hygiene, education, healing, housekeeping, work, means of exchange, information, transport, personal relationships, religious, involvement in group activities, and play. Maslow's hierarchy has important implications for this thesis in the context of breaking

down factors that support, or not, older adults to age well with chronic pain in rural environments.

Attachment to place has an important role to play in ageing and the maintenance of health, well-being and meaning in life:

‘There is general agreement... that there is a strong reciprocal relationship between older adults, their social and physical environments, and their health and well-being, most obviously manifest through a strong sense of attachment to place.’

(Wiles et al., 2009: p666)

Similarly, Andrews and Phillips (2005) identify ageing and place as important for quality of life and suggest that they may support successful ageing. However, this relationship would seem to be dynamic and individualistic. Gillear et al. (2007), using data from the first wave of the English Longitudinal Study of Ageing (ELSA), reported ageing in place to be ambiguous, ‘as people grow older they may be grounded by their area of residence or they may be trapped by it’ (Gillear, Hyde & Higgs, 2007: p591). Greater well-being was associated with attachment to place, younger age, and degree of deprivation of an area (lower deprivation linked to higher CASP-19); but ageing in place had a modest impact on well-being. Gillear et al. (ibid) argue that feelings of well-being may contribute to a sense of belonging and connectedness (rather than other way around); this may be linked to feelings of pleasure and sense of self-realisation.

The relationship between place and health has been considered using the concept of landscapes, as a theoretical framework to understand healing (Gesler, 1993; 1996; 2005):

‘A therapeutic landscape arises when physical and built environments, social conditions and human perceptions combine to produce an atmosphere which is conducive to healing. The term healing is used here in a broad manner to include cures in the biomedical sense (physical healing), a sense of psychological well-being (mental healing) and feelings of spiritual renewal (spiritual healing).’

(Gesler, 1996: p96)

The ‘therapeutic landscape’ assumes a holistic perspective on healing and includes traditional hospital care settings and non-traditional care settings such as home. Several studies have noted the power of environments to be restorative and ease stress and negative emotions (Ulrich, Simons, Losito et al., 1991; Parsons, Tassinary, Ulrich et al., 1998; Korpela & Ylén, 2007). Peace et al. (2011) argue that attachment to place may be compromised by a decline in health leading to decline in competence within these environments or change in environments. Thus, environments can support healing or they may challenge or reinforce disability; the fit between individual and environment (person-environment fit) can vary between individuals and across the life-course as health and environments change (Putnam, 2002). The role of the environment in the context of ageing with chronic pain, whether positive or negative, will be of fundamental interest in this thesis.

The aesthetic features and qualities of an environment are acknowledged as important to support health and wellbeing (Ogunseitan, 2005). Pleasant environments may help to restore health in post-retirement years (Burholt & Naylor, 2005). Lothian (1999) argues that the aesthetic quality of an environment is a subjective judgment. The concept of biophilia describes the ‘deep-seated need of humans to connect with nature’ (Ryan,

Browning, Clancy et al., 2014) therefore indicating aesthetics are part of a deeper sense of connection and attachment. Objective measures have been developed to capture aesthetic qualities as a dimension of place attachment. Burholt (2012) distinguishes aesthetic attachment (scenery, space, peacefulness) as one of three dimensions of place attachment with social attachment to place and appropriateness of resources and the environment the other dimensions – more recently identified as amenity/environment oriented physical attachment (Burholt, Curry, Keating & Eales, 2014). Burholt (2012) argues that the aesthetic qualities of rural environments may be more important than urban environments to develop place attachment. Similarly, Raymond, Brown and Weber (2010) refer to the attachment to nature as a dimension of nature bonding (implicit or explicit connection to the natural environment), which sits alongside social bonding (belongingness), place identity (dimensions of self) and place dependence (functional aspects of place). Exploring the extent to which nature bonding and aesthetic attachment is maintained in the context of living with chronic pain will be an important aspect of this thesis.

Day (2008) explored how physical environments supported or challenged older people's health and subjective quality of life through three urban case studies in Scotland. Day identified dimensions of healthy outdoor environments, as:

- Clean and free from pollution;
- Peaceful and quiet;
- Facilitates exercise;
- Supports social interaction; and,
- Emotionally uplifting

Many of the features identified in this urban study are synonymous with rural environments. Finlay, Franke, McKay and Sims-Gould (2015) studied the impact of green (i.e. park, trees, forest) and blue (i.e. water, waterfronts, lakes) spaces on the health and well-being for low-income older adults (aged 65-86 years) in Canada. They found that nature played an influential role in everyday life; although the relationship was nuanced reflecting the individualised interactions of people and place over time. Finlay et al. describe these relationships in terms of embodied biographies (meaning developed across the life-course) as mediating relationships with 'potentially therapeutic landscapes' (2015: p103). Participants in Finlay et al. described embodied struggles due to chronic illness, disability, and overall progressing older age; natural space may pose barriers. The aesthetic features of an environment seem insufficient to support health; biographical factors are also important.

A study that highlights the significance of personal biography in the context of space is the 'Older People's use of Unfamiliar Spaces' (OPUS) project, conducted in the UK and which formed part of the NDA research initiative, explored older adults use of outdoor spaces (<http://www.newdynamics.group.shef.ac.uk/nda-findings-4.html>). The authors report that older adults are increasingly encountering previously familiar spaces as unfamiliar (due to a variety of reasons including: cognitive decline, tourism, land redevelopment); this lack of familiarity can present risks to physical safety (Phillips, Walford, Foreman et al., 2010). This may also have implications for Rowles's notion of physical insideness (described above). Outside spaces may therefore present challenges or provide comfort in later life; this relationship is dependent on the person-environment context. To unpick the relationship between people, place and health a relational

perspective on environment (as context, composition, and collective) is necessary to inform understanding and reveal the role that environments have in older people's health (Macintyre, Ellaway & Cummins, 2002; Conradson, 2005; Cummins, Curtis, Diez-Roux & Macintyre, 2007). In the context of this thesis, rural environments provide the context and assume the focus for exploration in terms of how such environments support and or challenge older people to age well with chronic pain. In the next section I focus more on the experiences of ageing in rural environments.

2.4.4 Ageing in a rural environment

Rural ageing has emerged from gerontology as a sub-discipline to counter an urban-centric agenda (Keating & Phillips, 2008). However, literature on rural ageing remains sparse despite most older adults living in rural environments worldwide (Wenger, 2001). Keating and Phillips (2008) argue for a critical human ecology perspective on rural ageing to combine critical gerontology and human ecology, summarised in Figure 1 (on the next page). Keating and Phillips argue for this perspective, in order: '...to understand rural adults in the environments in which they live and to critically evaluate their interactions with these environments.' (Keating & Phillips, 2008: p3). The critical human ecology perspective has influenced the view taken in this thesis and facilitates a critical exploration of the environment; the individualistic and relational environment.

Figure 1: Critical human ecology perspective

Critical Gerontology

- Older people are not a homogeneous group (people's lifestyles are more varied)
- There is no singular experience of ageing
- Challenges the assumptions around ageing – deconstructs traditional concepts
- Challenges policy and practice
- Takes seriously that older adults have agency (older people can change and adapt)

Human Ecology

- People do not live in isolation but in interaction with physical and social contexts
- Boundaries between environments are permeable (e.g. physical character of an environment can influence local service provision)
- Older people are not passive recipients of the environments in which they live (agency is alive)
- Agency is influenced by personal and environmental resources (person-environment fit)
- Environments are multileveled (i.e. micro-environments, macro-environments, also interpersonal, community, policy and services)
- Physical environments include built (infrastructure) and natural (topography)

Synthesised from Keating and Phillips (2008)

A prominent point of contention in rural ageing is the understanding of 'rural'; this is a contested term. Typically, rural it is defined as non-urban (as described in Section 1.1.3, p5) but it is more complex:

'Rural places are seen as dynamic and multi-layered communities, as having their own general physical, economic and political attributes as well as being further characterised by the local institutions, social practices, social structures and human agents that influence daily lives.'

(Joseph & Cloutier-Fisher, 2005: p135)

Within the context of the relational turn, rural environments are not a fixed, stable construct, or an objective entity (Woods, 2006). Rural is socially constructed, individualised and localised, it is also a performance, and embodied experience. Halfacree

(2004) supports the view of rural as performed through everyday representation, practice and experiences; a performance of rurality. Watkins and Jacoby (2007) argue that although dynamic rurality retains an essence (essential quality); the essence is contextualised through social relations and places. Similarly, Bourke, Taylor, Humphreys and Wakerman (2013) recognise the relationality of rurality; experienced through lived experience and relationship between people and place.

The rural idyll is an important social construct in rural studies and is described as:

‘Pictured as a less-hurried lifestyle where people follow the seasons rather than the stock market, where they have more time for one another and exist in more organic community where people have a place and an authentic role. The countryside has become the refuge from modernity.’

(Short, 1991: p34)

These idyllic places invoke specific lifestyles and culture; one that contrasts sharply with urban life. The rural idyll may act to define those who belong and those who do not (Watkins & Jacobs, 2007). Cloke (1997) conceptualises rurality as ‘rich tapestry of myth and symbolism capable of hiding or excluding othered identities’ (p369-70). Cloke argues that such constructions of rurality, such as the rural idyll, are virtual or hyper-real; such is the detachment of this symbolism from physical reality. However, Jones (1995) argues that the reason rurality and the rural idyll remain is because of surface phenomenon, aesthetic characteristics on which these cultural constructs are based. If unchallenged, the rural idyll can hide aspects of life that are not characteristic of the popular image: health disparity, poverty, deprivation, crime (Cloke, Goodwin, Milbourne & Thomas, 1995; Scharf & Bartlam, 2006).

From the construct of the rural idyll and rurality, cultural myths about rural places have emerged in the UK. Wenger (2001) challenged four myths of rurality associated with older adults in the UK:

- Rural older adults spend retirement happy and contented in pretty villages and small towns with few concerns;
- Rural older adults have strong family support networks;
- Rural older adults live in well-integrated communities that take special pains to ensure that the needs of older adults are met; and,
- Rural older adults have better health and life satisfaction than people in urban areas and so have fewer service needs.

Wenger finds some support for all four myths but also challenges them. Wenger argues against the homogenised view of rural environments, which risks overlooking rural disadvantages and challenges (e.g. reduced mobility in later life leading to giving up driving and walking shorter distances, lack of pavements, sparsely distributed amenities that are also in decline, transport problems). In terms of health care provision, Wenger argues that a rural dimension is typically absent from service planning; yet, the cost of service provision to rural areas is high (per person) and specialist healthcare services are often great distances from rural areas. The assumption of community spirit in rural areas supports expectations of self-care and self-sufficiency; rural older adults are expected to present stoicism and be independent. An Australian study conducted by Bourke et al. (2013) reported that distance, isolation, and access to health services act to reproduce discourses of deficit and disadvantage among rural stakeholders. They argue for a more critical understanding of this pluralistic discourse to uncover myths and assumptions.

A systematic review with qualitative meta-synthesis conducted by Brundisini et al. (2013) examined chronic disease experiences and access to rural health care; the authors focused on experiences of vulnerability. The review considers 12 qualitative articles from North America, Europe, Australia and New Zealand; inclusion of chronic diseases may not necessarily be chronic pain conditions. Themes emerged on three different aspects of rural health care access: (1) geography (distance, access, isolation, weather); (2) availability of health care professionals; and, (3) rural culture, which Brundisini et al. described in the following terms:

‘Rural culture can nourish feelings of marginalization from the health care system and foster reticence to seek care. However, community belonging, personalization of relationships with health care professionals, and self-reliance may be useful means of coping with deficiencies and gaps in the rural health care system.’

(Brundisini et al., 2013: p23)

Thus, the authors argue that rural culture can support living with deficiencies in service provision – this seems to reflect earlier discussion of social capital. Effective rural community care is reliant upon the goodwill of the community (McCann, Ryan & McKenna, 2005). An Australian study by Fitzgerald, Pearson and McCutcheon (2001) identified a lack of choice of healthcare services in rural areas, solved only by travelling long distances at great expense in terms of finances and time. Although travel within a rural environment is an aspect of rural life, when illness affected ability to drive this became a barrier to access to care; this is likely to be as true in the UK as it is reported in Australia, although the scale of distance may be significantly reduced.

Considering studies conducted in the UK, Scharf and Bartlam (2006) reported hidden and uneven distribution of disadvantages for older adults in rural areas including financial hardship, loss of services and facilities, and impact on social relationships (e.g. loneliness). Older adults attempted to downplay such disadvantages and still reported good quality of life. The authors also reported how older adults living in rural environments adapted to hardship; resilience in the face of limited material resources was of crucial importance. Manthorpe, Malin and Stubbs (2004) argue 'rural communities are often attractive for the very reasons that give rise to their problems' (p98). Manthorpe et al. explored a paradox of rurality in which discourses of decline and disadvantage contrast with reports of higher quality of life. Challenges included a lack of transport, fear of isolation, extra traffic on the roads due to tourism, and services being in decline were accepted as part of village life and lives were managed and adapted. Burholt and Scharf (2014) demonstrated the role environment has as a moderator for feelings of loneliness drawing on cognitive discrepancy theory (discrepancy between desires in social relations against achievements, a mismatch gives rise to loneliness) to makes sense of this:

'...rurality does not exacerbate the interaction between poor health and social participation. However, the interaction between health and location does have a significant negative effect on social resources.'

(2014: p319)

Wenger and Burholt (2004) argue that loneliness can exist in the absence of objective social isolation, and isolation can exist independently of loneliness. Thus, it is important to distinguish between objective and subjective isolation.

Looking again at research outside of the UK, Goins, Spencer and Williams (2011) explored the meaning of health among 101 rural older adults (aged 60+ years) in Canada. The authors identified a key theme of health as a valuable commodity; health enables an individual to fulfil a social role. In studies in the USA, rural older adults defined health in terms of functional ability; health provided a means to maintain productivity and engage in the community (Arcury, Quandt & Bell, 2001; Davis & Magilvy, 2000). In studies from Australia, Kingston, Judd and Gray (2014) explored experiences of living with a traumatic hand injury among rural and remote participants. The authors described how loss of occupations and activities meant loss of role and independence; this was felt strongly in a rural area as productivity was perceived as important. Tollefson and User (2006) argue that the concept of health in rural areas is gender-specific. For men, health is the ability to work, for women, it is the ability to adapt and cope. The importance of occupation, productivity and health as a commodity will be explored in this thesis as a biographical factor to consider this from a UK perspective.

The Grey and Pleasant Land (GaPL) project, funded through the New Dynamics of Ageing (NDA) programme explored older adult's experiences of rural environments and engagement with civic society in England and Wales (Hennessy, Means & Burholt, 2014). Specifically, the authors explored the concept of connectivity, a heuristic metaphor that cuts across different disciplines (e.g. technology, social science, geography) and therefore supports an inter-disciplinary methodology. The GaPL project comprised distinct studies with specific focus; however, findings reported in several of these indicated common transport and mobility challenges in rural environments. For instance, access to transport was important in rural areas for older people to participate in leisure activities (Hennessy,

Staelens, Phippen, & Lankshear, 2013) and getting around was identified as important in supporting social and environmental interaction and inclusion (Parkhurst, Galvin, Musselwhite, et al., 2013). A survey of 920 older adults (over 60 years of age) reported health as limiting older people from participating in community activities; with one-in-ten experiencing such limitation (Curry, Burholt, Fisher & Evans, 2013). It is important to note that 'connectivity' also included remembered journeys and so went beyond physical transport issues, as a means of maintaining environmental and biographical connections.

The existing research on rural ageing identifies important factors to be taken forward in this thesis that look beneath and beyond the standard challenges of transport and access. The need for additional research on rural ageing and justification for this thesis is supported further by recommendations by the International Rural Ageing Project (IRAP). IRAP identified seven themes in need of research: demography, health, intergenerational relationships, life-course perspective, participation and the role of rural older adults, impact of technology, evidence of policies working in rural settings. Burholt and Dobbs (2012) suggest that these themes have not been addressed equally and that research on ageing remains dominated by the biomedical perspective. They argue that, although health of older adults in rural areas has received significant attention in the literature, there remains 'little evidence of a focus on epidemiological health and ageing in the rural areas of the EU' (2012: p435) and that research on health behaviour tends to overlook environmental or social factors. Woods (2010) identifies mixed methods or multi-methods studies as missing from the rural literature. Research such as the GaPL project highlight the value of mixed methods and interdisciplinary research to exploring the gaps in rural ageing research (Hennessy, Means & Burholt, 2014). In the following section I

review the literature that considers specifically rural older adults with chronic pain, pulling the three threads together.

2.5 Ageing with chronic pain in rural environments

In this section I take a narrow focus to consider research on older adults, with chronic pain, in rural environments. I identified literature for this section through a detailed electronic search of academic databases: EBSCO, Web of Science, and PubMed. I also used Google Scholar to supplement the academic databases; although searches are limited to titles and full texts only. I used the following search terms: 'older adults' or 'older adults' or 'ageing' or 'aging' (or similar derivatives identified by the search engine); and 'chronic pain' or 'persistent pain' or 'long term pain'; and 'rural' in combination to search titles, abstracts, and full texts. The following articles were returned in searches (July 2015): 24 (EBSCO), 3 (PubMed) and 106 (Web of Science). Duplicates were removed as were articles deemed not relevant to the thesis based on scanning titles and abstracts. Articles that were excluded described studies about, for example: legal services, surgical procedures, pharmacology, psychiatry, insurance, drug misuse, children, nurse management, and sexual health. Seven articles are described below that report qualitative research.

Davis and Magilvy (2000) explored experiences of chronic illness (where chronic pain is assumed) in a sample of 42 rural older adults (60-94 years of age) in Colorado, USA. The authors identified chronic illness as an ongoing negotiation of treatments, roles, and responsibilities in which living one day at a time reflected a sense of control and hope. Self-care was identified as a key component of health maintenance; not visiting the doctor was also perceived as a symbol of good health and independence. A sense of

belonging within the surrounding community was important, as was finding meaning in life:

‘As interdependent members of community networks, older participants in this study exhibited quiet pride as they engaged in creating meaning despite illness.’

(Davis & Magilvy, 2000: p390).

Quiet pride relates to ways in which participants in the study lived with chronic illness yet maintained connection with cultural heritage. A limitation of the study is the lack of detail regarding the types of chronic illness and disability that the participants experienced; this makes contextualising the experience of actualisation of quiet pride difficult. Pride is also identified in other research. Goodridge, Hutchinson, Wilson and Ross (2011) explored the experiences of seven older adults (57-88 years) in rural Canada living with advanced chronic respiratory illness; not chronic pain. The authors identified a sense of pride (and appreciation) towards the support received from members of the local community; this sense of support balanced the negative experiences of distance, and lack of health literacy. Similarly, Bushy (2008) identified characteristics of rural older adults as valuing a stoic, self-reliant attitude which places emphasis on self-responsibility for health (stoicism was identified as important in ageing with chronic pain, see Section 2.3.2.3: p45).

Tollefson, Usher and Foster (2011) explored the lived experiences of seven people (23-55 years of age) living with chronic pain (6+ months duration) in rural Australia. Although this was not a study of older adults per se, the findings reveal much about rural culture that I anticipate will influence later life experiences. The authors identified four themes about relationships, which were important in supporting well-being: pain as silence, privacy as a

way of protection, no place out here to get support, and dealing with health-care professional who do not understand. The authors comment:

‘Stoicism, privacy, autonomy and dignity were intimately bound together to protect the individual from the outside world... the quiet endurance of adversity and setbacks with courage and grace is a rural cultural expectation... It can keep outsiders from seeing what goes on in our undisclosed lives and from browsing in our souls.’

(Tollefson, Usher & Foster, 2011: p481)

Privacy was utilised as a resource to control the intimate experience of pain. In relationships with healthcare providers the authors identified participants as feeling their personal integrity threatened by disclosing health problems in small communities; they worried about becoming the topic for local gossip.

Roberto and Reynolds (2002) explored experiences of 20 rural older women (mean age 71 years) with chronic pain in the USA. The authors explored chronic pain experiences in relation to coping and self-management strategies, perceptions of self, and social contexts. The authors identified that pain had personal and shared meanings; personal experiences varied in location, intensity, and consistency. The subjectivity of pain experience meant only people in similar pain situations could share understanding. Participants shared beliefs about aches and pains, those experiencing pain: ‘...often viewed themselves as stoic bearers of normal declining health processes.’ (Roberto & Reynolds, 2002: p20). Participants expressed reluctance to dwell on conversations about pain with others and attempted to maintain self-reliance and autonomy; participants received praise for coping in this way reinforcing a stereotype of coping. A mix of coping strategies were described including: prescription medication, over the counter (OTC)

medications, and, where these were insufficient, psychological and social strategies were used to keep their mind off pain or adjust lifestyles. Where activities were prevented by pain participants experienced a sense of loss. Notions of self were impacted by pain experience; participants described variations in acceptance of pain as part of self. The authors recommend further research into self-help strategies, interpersonal relationships, and of the complex associations between older adults and pain as central to broader health and social care in ageing research.

Currie, Mort, Phillip and Roberts contributed four papers to the literature search, all based on a three-year (2012-2015) study referred to by the abbreviation TOPS: 'technology for older adults: maximising personal and social interaction'. Briefly, TOPS explores social isolation, chronic pain, health and social care and new eHealth technology. The TOPS study is set in rural locations in Scotland and Wales. Mort and Phillips (2014) conducted a narrative review of the literature that focuses on the intersections of social isolation, chronic pain, health and social care and technology. The authors suggest an emerging research agenda; however, the body of literature on which the review and therefore the recommendations are based is limited and not systematically selected. The suggested agenda includes:

1. Older adults have diminishing social networks
2. Rural older adults are further isolated by their geography
3. Suffering from chronic pain in a rural area could exacerbate feelings of social isolation amongst older adults with chronic conditions

4. Personal interaction with health and social care staff is a crucial component to maintaining older adult well-being, when this interaction may be the only personal communication they have on a daily basis
5. The introduction of healthcare technology into rural older adult's homes could disrupt this social interaction and potentially result in a reduction in health and well-being, the very opposite of what is intended.

The authors argue that an 'extitution' model of care is apparent; a UK policy shift that promotes community-based delivery of care outside of institutions (e.g. hospitals). Furthermore, discourse around ageing in place frames and provides support for this shift, in combination with economic drivers for such change. The argument links back to the critical analysis of Minkler (1996) and an idealised notion of community care, which assumes the existence of a 'community'.

Philip, Roberts, Currie and Mort (2013) argue that information technology may support resilience among older adults experiencing chronic pain; however, they identify that use of such technology among this group is low in the context of pain management due to cost, physical impairment, and unfamiliarity. The authors argue that technology, if used in place of nurse home visits, may undermine quality of life (e.g. loss of social interaction). Philip, Roberts, Currie and Mort (2015) describe the impact of nursing home visits:

'Professionals bring news of the outside world and allow older adults to retain feelings of connection with and belonging to their community as well as monitoring the older adult's condition and being able to spot deterioration or improvements in health and adapt the care provided accordingly.'

(Philip et al., 2015: p8)

Activities observed included professional or clinical activities but also good will gestures in which carers conducted household chores (e.g. taking the post in, washing up). In the context of this thesis healthcare technology is not a primary focus; however, I will be mindful of this in my observations and look for examples of self-management and extitution, particularly in how such technology may support resilience. The impact of geographical isolation will be important for this thesis and will be explored; this will also be considered from the point of view of policy recommendations around healthcare services in rural environments.

Research that considers ageing, chronic pain, and rural environments is scant; what is available is limited in terms of the scope of this thesis. Studies reviewed here are primarily North American or Australian in origin and, given the landscape and scale of rurality, may not be wholly generalizable to UK contexts. The growing body of research emanating from the TOPS study is promising but narrowly focused on health technology; likely to be only a small component in this thesis.

Summary

The literature review has assisted in the framing of the objectives of the research. The relative scarcity of research literature that considers older adults with chronic pain in rural environments suggests a need for further exploration. The lack of consistent definitions presents a challenge to comparability: 'older adults' (over 60 or 65 years of age), 'chronic pain' (time, disease specific, process of healing), and 'rural' varied across the studies; the definition of rural was often not stated. The existing literature indicates that areas for further exploration include: pain management, self-management and self-care, relationships with individuals and the community, and the role of rural values and

whether these support pain management (e.g. stoicism, privacy, being self-sufficient). The role of activities was also identified, which may also have implications for maintaining a sense of belonging, productivity, and meaning in life. Isolation, solitude and loneliness are also like to be important but have not been explored with older adults in the context of chronic pain.

A key concept that is missing and which may draw together rural values is resilience, which seems intuitively relevant but seemingly unexplored in the context of older adults, chronic pain and rural environments. Also, the positioning of rural in existing research was often maintained at a surface level treating rural as the research setting (objective) as a more-or-less silent partner in chronic pain experience, when a relational perspective facilitates a critical approach. The existing literature also lacked a gender-balanced perspective; older female perspectives on chronic pain in rural settings are dominant. In Chapter Three I describe the methodological approach I have taken towards this research. This draws upon the lessons learnt from the literature review.

Chapter Three: Methodological approach

Introduction

In the previous chapter I presented a review of the literature that supported development of the research objectives. In this chapter I discuss the methodological approach that I have taken in this thesis. I include discussion of my philosophical considerations – including my ontology and epistemology – and outline the research design as well as describing the selected data gathering methods, which are mixed. I begin this chapter with a recap on the aim and objectives.

3.1 Research aim and objectives

The aim of the study is to understand older adults' experiences of ageing well with chronic pain in rural environments.

1. To explore the dimensions of chronic pain experienced by older people in rural environments
2. To explore the meaning of chronic pain for the day-to-day lives of older people in rural environments
3. To explore the influence of life-course factors on the experiences of ageing with chronic pain within rural environments.
4. To explore coping and self-management strategies, and the nature of resilience, among older people with chronic pain in rural environments
5. To consider policy and service needs of rural older people with chronic pain.

The research objectives are exploratory and therefore intentionally broad to reflect the current scarcity of existing research and an effort to advance current understanding.

As a precursor to the sections that follow, briefly the approach taken in this thesis is underpinned by constructivism and interpretivist epistemology that recognises the multiplicity of realities and a human world that combines the natural and social as a lived world. I draw upon theoretical perspectives developed in the literature review of critical human ecology (Keating & Phillips, 2008) and the life-course paradigm (Giele & Elder, 1998) as a way of accessing these lived worlds incorporating time and space in a critical way. In terms of methodology, I am guided by two forms of inquiry: narrative (the reconstructing of experience and identity through stories) and ethnographic (encapsulating the cultural situatedness of the research). I use a mixed methods approach to data gathering; the selection of methods is described. To make sense of the complex set of phenomena and mixed data, analytic techniques informed by constructivist grounded theory were implemented.

3.2 Ontology and epistemology

In this section I state my philosophical position and the influences that have informed this. The focus of this thesis is exploring human experience; thus, to generate knowledge about human experience it is essential to understand what it means to be human (human existence) and therefore how human experiences are constituted. My ontology or understanding of 'what is' is a world in which objects exist but that this existence becomes meaningful in the minds – subjective minds – of human beings through interactions with the world and with other human beings. To understand what it means to know, my epistemological stance, I consider that we do not experience the world

independent of the world itself. Instead we each interact, interpret, take a perspective, and construct meanings so that multiple truths are apparent. To further our own understanding of social phenomena (e.g. ageing, chronic pain, rural living) it is necessary to explore the understanding of those who have experienced such phenomena, not to 'know the truth of their experiences' but to understand their experiences through their interpretations.

My ontology has been influenced by phenomenologists such as Edmund Husserl (1859-1938) and Maurice Merleau-Ponty (1908-1961), for whom the notions of the life-world and the lived body are important. My epistemology has been further influenced by the writings of Paul Ricoeur (1913-2005) and Hans-Georg Gadamer (1900-2002) on narrative theory and language. However, my philosophical deliberations began with Rene Descartes who provided a useful starting point for considering the constituents of human experience and existence. In *Meditations on First Philosophy* (1641) Descartes describes the relationship between the human mind and body:

'On the one hand, I have a clear and distinct idea of myself, in so far as I am a thinking and not an extended thing, and, on the other, a distinct idea of the body, in so far as it is only an extended and not a thinking thing, it is certain that I am really distinct from my body, and can exist without it.'

(Descartes, 1641; translated by Moriarty, 2008: p57)

The distinction that Descartes makes, later termed the *Cartesian Dualism*, argues that human beings have a mind and a body each functioning in different realities; the thinking and unbounded mind (no physical form) and the non-thinking bounded body. Thus, the

body occurs as an object in a world of other objects. Descartes argues that the body and mind, although distinct, are linked by causality (cause and effect):

‘For otherwise, when the body is injured, I, who am nothing other than a thinking thing, would not feel pain as a result, but would perceive the injury purely intellectually, as the pilot perceives by sight any damage occurring to his ship.’

(Descartes, 1641; translated by Moriarty 2008: p57)

Causality between object and subject explains a rationalist perspective on human experience; as subject to stable laws logically governing human action. That Descartes considered the mind and body to belong to different realities, the immaterial and material, a connection by causality is problematic as the mind is conceived ultimately as not being part of the world at all.

Franz Brentano (1838-1917) argued that physical and mental phenomena belong to two distinct classes of a *single* world; this formed the basis of phenomenology. Physical things belong to a physical class. Mental phenomena exist as ‘intentional in-existence’ a notion that infers a conscious reference or direction towards an object (an object of thought not of a physical class or realm). Edmund Husserl, a student of Brentano (and influenced by him), developed his own view of phenomenology in his *Cartesian Meditations* (1931). Husserl argued that the relationship between objects and experience was essential, neither object nor experience can be described in isolation from the other. Subjects and objects, as interdependent, belong to a life-world; a world in which the lived body (subjective and objective body), objects in the world, subjectivities of others are part of a whole system: ‘a universal unity of synthesis’ (Husserl, 1970 [reprint]: p168). The concept of intentionality was crucial for Husserl’s development of phenomenology as

intentionality (active), not causality (passive), explains the relationship between the object and subject.

Maurice Merleau-Ponty (1908-1961), a student of Husserl, developed a concept of existential embodiment to elevate the role of the body in the life-world perspective. In contrast to Descartes's cogito 'I think therefore I exist' Merleau-Ponty supposed 'Je suis donc mon corps' (I am therefore my body) (Merleau-Ponty, 1945). Merleau-Ponty stated:

'My body is the fabric into which all objects are woven and it is, at least in relation to the perceived world, the general instrument of my "comprehension".'

(Merleau-Ponty, 1945 [translated by Smith, 1995]: p235)

Merleau-Ponty centres upon a notion of the lived body, the unity of body (material, object) and mind (self-conscious, subject). Thus, experience is formed at the interaction of body-mind-world; the life-world, each as inter-dependent, harmonious and always constant. Through the concept of intentionality, Merleau-Ponty discerns that human beings are always oriented towards the outside world and that situations encountered in the outside world move along a continuum from object (material) to subject (self-conscious). The outside world is always already there; human beings do not experience it anew each day but instead through sedimented structures, which can be altered as meaning is made in an ongoing process. Merleau-Ponty argues that perception is a process of active engagement with a world of interrelated objects. Through active engagement we take a point of view on things; however, this view may change thus things and objects remain ambiguous, not determinate. Subjectivity is embodied as we experience the world through the lived body, thus we are always part of the world. Furthermore, the view that we take on things is also driven by needs (subjective and

biological) that motivate actions and in relation to which elements in the surrounding environment are meaningful.

The phenomenology of Brentano, Husserl and Merleau-Ponty stands in contrast to the scientific rationality of empiricism and positivism. Scientific rationality emphasises a realist and objectivist view in which meaning is considered held within objects awaiting discovery by observers and that definitive objective truth exists. Empiricism assumes that objects are perceived using sense organs (e.g. eyes, ears) which *cause* a representation of an object in the mind of the perceiver. The causal process is passive and the perceiver is detached from the world; this provides true beliefs about an object as a determinate object in the world. Positivism argues that the social world may be made knowable through the methods of the natural sciences as features of the social world are fixed and determinate. Phenomenology takes a more active contingent view of truth and meaning.

For Merleau-Ponty, the world that we encounter is a human world shared with others who may also hold similar meanings of objects as we do. Language provides a means through which meanings are shared; the human world is a social world. Merleau-Ponty conceives of language as a set of tools that we learn to apply through experience of others using them in specific contexts. However, the notion of language as a set of tools is problematic in the sharing of embodied experiences. Hans-Georg Gadamer (1900-2002), a hermeneutic phenomenologist, confers a unity between language and thought. Gadamer argues:

‘The interpreter does not use words and concepts like a craftsman who picks up his tools and then puts them away.’

(Gadamer, 1975: p404)

Furthermore, that:

‘All understanding is interpretation, and all interpretation takes place in the medium of a language that allows the object to come into words and yet is at the same time the interpreters own language.’

(ibid: p390)

Thus, interpretation is the cornerstone of hermeneutics and always ‘enters into the content of what is understood’ already (ibid: p399). An interpretation is just that; it does not contend to be correct or absolute. Gadamer asserts that all interpretation takes place through language; the world is experienced as read whether linguistic in nature (a book or text) or otherwise (body language, nature). Language is a cultural system of signs and symbols that are not fixed objects; words have polysemy and concepts are continually formed. As human beings we think in terms of these symbols. However, each individual has their own interpretation of these symbols and how to use them. The notion of truth therefore takes multiple forms. In objectivism truth is determined; but through interpretation truth is relative and subjective.

Paul Ricoeur (1913-2005), also a hermeneutic phenomenologist and student of Husserl, argues that human beings are linguistic beings that express themselves through language; this is how they relate with others. Ricoeur argues that meanings are not given to us directly or passively; instead a view is taken and a situated interpretation is made. In the absence of passive meanings, hermeneutic ambiguity occurs, which Ricoeur describes as a split between suspicion and faith. Interpretation is required to decipher meaning. The hermeneutics of faith (or belief) require that there is a real meaning to the symbol and that after criticism that stems from suspicion the meaning can be restored. Ricoeur

identifies the function of narratives in language through art, literature and as a means of interpreting human existence:

‘Between the activity of narrating a story and the temporal character of human experience there exists a correlation that is not merely accidental but that presents a transcultural form of necessity.’

(Ricoeur, 1984 (translated): p52)

An individual cannot transcend beliefs, as thought and language are inexplicitly linked; language is value-laden and cultural. Narrative is also conditioned by time. Ricoeur conceives of narrative as a way of structuring human experience that brings unity to human action and time; narratives provide a means to understand human existence. This cultural view of language and creation of meaning echoes much of social constructionism (Berger & Luckman, 1967); which conceives of meaning as contingent on social interaction. Thus, human beings are meaning-makers; interpreting and (re)constructing the world around them as they come into contact (directly/indirectly) with it and with others.

In narratives about oneself, the self assumes the position of subject (as creator) and object (as focus for narrative). The self is represented through narratives:

‘All forms of representation of experience are limited portraits. Simply stated, we are interpreting and creating texts at every juncture, letting symbols stand for or take the place of the primary experience, to which we have no direct access. Meaning is ambiguous because it arises out of a process of interaction between people: self, teller, listener and recorder, analyst and reader.’

(Riessman, 1993: p15)

Riessman (1993) reflects on the different levels at which representation occur during the typical research process, five levels are considered: *attending* (constructions in thought process - accepting that there is choice in what features of senses are noticed), *telling* (the narrative performance, re-presenting events through language), *transcribing* (tape recording only records the verbal part of the narrative performance, in converting audio to textual transcribes are representations based on set conventions), *analysing* (the presentation of a narrative is shaped by what the researcher focuses on and chooses to include), and *reading* (a text is open to interpretation, the researcher does not have ultimate authority). As constructions, narratives tell us something about human existence. Salmon and Riessman (2008) argue that all narratives are co-constructions between the speaker and listener (real or imagined), and so do not comprise a single subjectivity but rather an inter-subjective construction. This echoes the insights of Mead (1934) and Goffman (1978). Goffman holds the view that narratives act as expressions of self, not self as a single entity but as one of multiple selves, a desired self that is performed to specific audiences. Thus, narratives act as representations of what people want to reveal; a person can have multiple identities depending on who they are talking to and what details of a story they include, omit, or emphasise. For Lieblich, Tuval-Mashiacha & Ziiber (1998) narratives:

‘...present an inner reality to the outside world, whilst at the same time they shape and (re)construct the narrator’s personality and reality. We know or discover ourselves and reveal ourselves to others through the stories that we tell’

(Lieblich et al., 1998: p7)

Moreover, stories can be a way of remembering the past, they can act as a tool for persuading others, and they can be used to engage the audience in the experiences of the individual. Ultimately, stories reveal truths about human experience (Riessman, 2008).

Thus, narratives provide a representation – a construction – of lived experience. The representation may tell us something about an individual; however, such representations should be treated with a critical eye so that one does not become seduced by a good story. The critical approach that I have taken is informed by the work of Keating and Phillips (2008) who argue for a critical human ecology perspective (blending critical gerontology and human ecology, refer to Figure 1, Section 2.4.4: p66) to be taken in rural ageing research. This approach supports an exploration of the life-course and a critical examination of older adults' interactions with, and within, their environment.

3.3 Methodology

Methodology refers to the principles underlying the approach to fieldwork and selection of methods. The methodology here is exploratory and informed by narrative and ethnographic inquiry. A mixed methods approach has been incorporated to maximise the potential for exploration. The qualitative and quantitative data are brought together through the analysis phases and techniques of constructivist grounded theory. There is a growing body of work that argues that merging distinct approaches does not compromise methodological purity, but can enhance rigour (e.g. Johnson & Onwuegbuzie, 2004; Tashakkori & Creswell, 2007; Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012; Bartlam, Waterfield, Bishop et al., 2016). I now seek to justify the choice of each approach before concluding on the way in which these will be integrated.

3.3.1 Narrative inquiry

In Section 3.2 (p82) I described how narrative theory frames human experience to create meaning and provide a means for construction of self. Through narrative inquiry narratives are taken as objects for study. Narrative inquiry is now commonplace in the study of personal experiences of illness, as supported by an expansive body of literature that centres upon chronic illness (Bury, 1982; Kleinman, 1988; Riessman, 1993; Frank, 1995; Hyden, 1997, Charmaz, 1999). Stories are further recognised for the role that they have in developing understanding of health and healing (Green & Thorogood, 2009).

To study narratives one needs, first, to be able to identify narratives. Greenhalgh and Hurwitz (1998) outline the common features of narratives: a time sequence (e.g. beginning, middle and an end), the presumption of a listener and a teller (each of which bring different points of view to the story), a focus on individuals (e.g. recounting of emotion and feeling rather than pure action), discretion (on the part of the teller in terms of what is included or omitted), and finally narratives are engaging (they can bring the listener into the experience being replayed through narration). Labov (1972) provides a structured framework for identifying narrative in conversation, which considers narratives to be comprised of common characteristics: 1) provide an abstract for what follows; 2) orientate the listener; 3) carry out the complicating action; 4) evaluate its meaning; 5) resolve the action; and 6) return to present time (coda). For Riessman the fourth structure - the evaluation, provides the “soul” of the narrative and the final coda brings the narrative back into present time and space; a reflection on what the narrative has all meant in the context of the life-course. Thus, as Riessman argues (1993, 2008), this framework provides a useful starting point. From here she suggests following the broad

research question(s) to guide interpretation to look beyond mere content but consider the structure of narratives also; ultimately, to fine-tune the analytical process to suit the nature and aims of the specific study.

Polkinghorne (2007) identifies the threat to validity that narratives, as constructed through language, pose:

‘The validity threats arise in narrative research because the language descriptions given by participants of their experienced meaning is not a mirrored reflection of this meaning.’

(ibid: p480)

As stated previously, I would not expect narratives to correspond with an objective reality. I will not be seeking a clinical explanation of chronic pain in a rural environment. Instead, narratives are interpretations of experiences. I will not subject narratives to judgements regarding the accuracy with which they reflect the reality, how could I when no single reality exists? I will instead attend more to coherentism and consider the plausibility and internal coherence of narratives (Nicolson, 2013). In taking this view I recognise that the stories that participants share will only be partial impressions of their experiences, relayed to me as best they can with the skills and resources available.

By focusing upon narratives I am prioritising lay perspectives in this research as opposed to clinical explanations. Although I use the term ‘lay’ I consider that having actual experience of ageing with chronic pain in a rural environment my participants will have developed a corpus of knowledge, rather than mere beliefs (Bendelow & Williams, 1995), about these phenomena. Therefore, the lay perspective is to all intents and purposes an

expert perspective (Williams & Popay, 2001) as experts by experience. Lay perspectives will no doubt be rich in variation of experiences and interpretations of experience; such variation will help generate understanding of this complex set of phenomena. Therefore, such stories and the language used to construct them will remain revealing in terms of what is said (and what is not said), and how it is structured and organised.

This thesis considers the role the environment has in constructing experiences; I anticipate that narratives will include a relation to the environment in which participants live and tell something of their place in the world. However, research led by narrative inquiry alone may limit the extent to which environments are disclosed and described. Thus, to narrative inquiry I have also blended an ethnographic appreciation of lived experiences to support data gathering that reflects a more naturalistic view.

3.3.2 Ethnographic inquiry

Ethnography can be understood as:

“[T]he study of people in naturally occurring settings or ‘fields’ by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also in the activities, in order to collect data in a systematic manner, but without meaning being imposed on them externally”

(Brewer, 2000: p.11)

Ethnography is a methodology in its own right that seeks to place the researcher within the setting among the people in which cultures are enacted and social realities are constructed. People are typically embedded within multiple cultures and sub-cultures, which (re)occur over time and space (Crang & Cook, 2007). Ethnographic studies typically

value the use of mixed methods and a prolonged period spent 'in the field'; to develop a holistic impression of the 'cultures' under study.

Ethnographic inquiry incorporates the following strengths: reflexivity, flexibility, developing relationships with the researched, analytic induction, interpreting meanings of human action, and valuing the context (immediate socio-cultural and broader socio-economic and political) (Lambert, Glacken & McCarron, 2011). By adopting these tenets, I will be better adept at reflecting on my role in the construction of meaning, in the relationship between researcher and researched and making effective use of field notes and observational methods. Situated relationships are important in exploratory research, specifically in terms of relationships that participants have with space and place in relation to chronic pain and ageing (Hinck, 2004). In addition, ethnographic inquiry supports the inclusion of visual data and the capturing of everyday, taken-for-granted aspects of life. Within the unremarkable there may be details of profound importance that may otherwise go unnoticed (Spencer, 2011).

Ethnography and narrative inquiry sit together as they share an affinity for one another (Riessman, 2008). Madden (2010) argues that the aim of ethnographers is to produce a 'storied reality' by way of their representation of the research environment; this is supported by qualitative data and an authorial presence. Moreover, through ethnography the tenets of critical human ecology come into focus, specifically the notion of multi-layered environments and of individual-level interactions with the environment. Ethnographic inquiry also permits the exploration of situated agency and will add richness to my interpretations of participants' narratives.

3.4 Mixed methods

The types of inquiry adopted for this research support a mixed methods approach to data gathering; and prioritise methods that facilitate narrative elicitation. It has been argued that mixed methods research has emerged as the third major paradigm, beside qualitative and quantitative research (Johnson, Onwuegbuzie & Turner, 2007). A keystone of mixed methods is the integration of qualitative and quantitative forms of data (Creswell & Plano Clarke, 2011). In this study several exploratory methods were adopted; the major focus was upon qualitative data gathering. Quantitative data was collected in the form of demographic information and a quality of life measure (CASP-19, described in Section 3.4.1.3: p101). The justification for the use of mixed methods stems from the exploratory approach to study phenomenon that have thus far been under researched (in combination with one another) (Sim & Wright, 2000).

The objective in this research is to gather rich data as: ‘rich data get beneath the surface of social and subjective life’ (Charmaz, 2014: p23). By adopting mixed methods (and mixed data) these combine to provide different perspectives on the central phenomena. The term ‘triangulation’ is often noted in mixed methods research, this term originated in navigation to signify the use of different methods to measure a single point (Foss & Ellefsen, 2002). The take up of the term has been operationalized to varying degrees and for different purposes in research and often centre on validation (Mason, 2006a). The version of triangulation that I employ is one that ‘gets away from the idea of convergence on a fixed point and accepts a view of research as revealing multiple constructed realities’ (Seale, 1999: p474).

As argued by Hammersley (1992), I consider that particular methods and types of data (i.e. qualitative and quantitative) are not automatically wedded to particular paradigms (e.g. positivist and interpretivist) or ways of seeing the world (realist and anti-realist). The logic I use to justify the mix of qualitative and quantitative methods fits with the multi-dimensional logic explained by Mason (2006a). The premise of which is that:

‘...different methods and approaches have distinctive strengths and potential which, *if allowed to flourish*, can help us to understand multi-dimensionality and social complexity... instead of ultimately producing one integrated account or explanation... or a series of parallel accounts, one imagines instead ‘multi-nodal’ and ‘dialogic’ explanations which are based on the dynamic relation of more than one way of seeing and researching.’

(Mason, 2006a: p9-10, emphasis in original)

For Mason (2006b), ‘lived experience is about connections between multi-dimensional domains’ (p12) lived simultaneously at micro (subjective, individual) and macro (cultural, public) levels. Thus, to take a simplistic one-dimensional view of such lived experiences would be to impoverish the understanding that could be generated. Life is multi-dimensional and so it should be researched as such. This logic therefore focuses upon the strengths of different approaches to explore different dimensions – this includes the mixing of qualitative and quantitative methods but also those which focus on different senses: oral and visual.

To get the mix right, I also incorporate the typologies as defined by Greene, Caracelli and Graham (1989) into my thinking on the research design. Greene et al. identify *complementarity*: seeking elaboration, enhancement, illustration and clarification of the

results from one method with the results of another; and *Initiation*: seeking to encounter paradox and contradiction to facilitate recasting of questions. Bryman's (2006) typology of *completeness*, which enables the researcher to bring together a more comprehensive account of the area of inquiry is also useful. Thinking in terms of these typologies emphasises the utility of the multidimensional approach; to engage with the lived experiences of older adults in this research from different angles to work towards comprehensive and holistic interpretations.

As with any research paradigm there are critics of the mixed method approach. Giddings (2006) considers that 'ideologically mixed-methods continue the privileging and dominance of the positivist scientific tradition' (ibid: p202). Howe (2004) criticised mixed methods for constraining qualitative methods to an auxiliary role, and failing to use qualitative research in an interpretive way. However, a more qualitative approach is possible, even preferred (Mason, 2006b). Sim and Wright (2000) argue that qualitative methods are suited to exploratory research, the aim of which is to generate new knowledge about phenomena that have 'not yet been described in detail and likely to be poorly understood' (p45). Furthermore, that mixed methods facilitate a holistic understanding of the phenomena under study (ibid). Ultimately, the balance of methods must be driven by the research question, supported in turn by the philosophical underpinnings. Therefore, it is my intention in this research to prioritise qualitative methods to support exploration and lead with the interpretive paradigm.

The mixed methods design that I have utilised in this doctoral research study includes a sequential mix of methods across two stages; depicted in Figure 2 (next page). The mix of methods that I selected reflects the priority that I have given to eliciting narratives and is

framed by the research objectives. I have selected three types of interview to gather data: in-depth one-to-one interview, photo-elicitation and go-alongs (a mobile interview). A life-grid, topic guide and quality of life measure (CASP-19) are included in the one-to-one in-depth interview (described in turn below) (see Appendix 5 for interview materials). To reflect ethnographic inquiry, I have also chosen to record participant observations in fieldnotes. The different types of interview have been selected to provide flexibility and opportunity to respond as situations as they arise during fieldwork (e.g. interests, activities, hobbies). Prior to follow-up data gathering in Stage Two participants will be consulted, to confirm continued participation and their preferred method.

Figure 2: Sequential mixing of methods

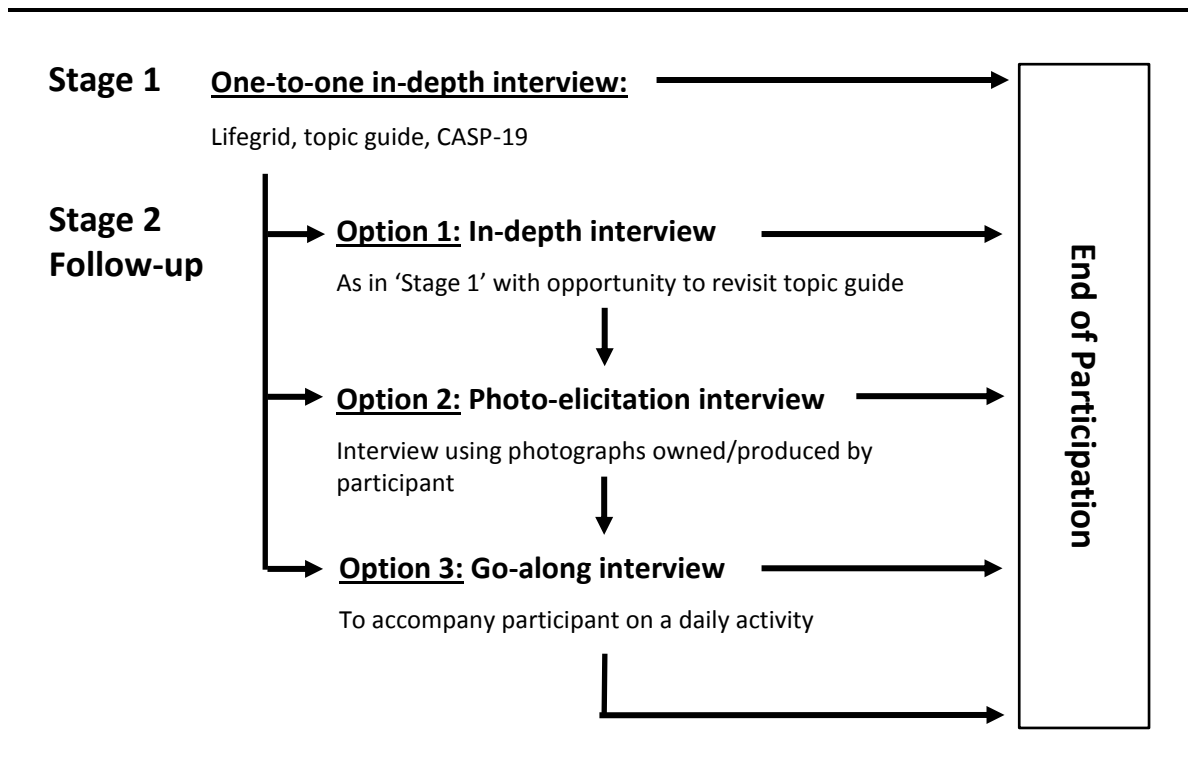


Figure notes: At 'Stage 2' participants had the opportunity to take part in follow-up data gathering activities (choice of none, one, two or three).

In the sections that follow, I describe the different interview types and data gathering techniques in more detail and provided reasons for including these.

3.4.1 One-to-one in-depth interviews

Interviews are a widely-used method for gathering qualitative data and provide a way of exploring experiences of health and illness and as a means of eliciting narratives (Green & Thorogood, 2009; Andrews, Squire, & Tamboukou, 2013). In-depth interviews provide access to realities, contexts, situations and cultures that ‘people use to make sense of these experiences and their social worlds’ (Miller & Glassner, 2011: p131). In-depth one-to-one interviews are included in stage one; these are intended to be conducted face-to-face. The purpose of the in-depth interview will be to elicit narratives about lived experiences of ageing with chronic pain in rural environments, but also to explore broader biographical information. The setting for the interview will be a familiar place to the participant (e.g. their home) for convenience and to put them at ease, but more than this, meaningful places such as home represent a social context in which every day lived experience is situated (Herzog, 2005). To elicit narratives three resources are integrated into the in-depth interviews: a topic guide, a life-grid, and the CASP-19. I describe each in the following sub-sections and reflect on how they will support the research objectives.

3.4.1.1 Topic guide

The in-depth one-to-one interview has been designed to be semi-structured directed by a topic guide. The semi-structured approach provides scope for individual participants to determine the flow of the interview; however, topics for conversation will be guided to fulfil the research objectives. The topic guide includes a mixture of open and closed questions about: demographics, family, work, social life, health, pain, coping, home and environment. The guide includes open questions to enable the lived experiences of chronic pain to be explored; reflecting a narrative approach (Riessman, 1993) and to elicit

story telling through which detailed accounts of the participant's understandings, concerns and experiences can be shared. For instance, to begin each in-depth interview an open question of: "tell me about yourself" will be posed. From here, I will use participants' responses to inform the direction of questions and prompts from the topic guide; selecting topics in the context of the conversation to prevent talk from becoming stilted. Closed questions are included to construct a profile for each participant (e.g. demographics, site of pain, length of time with pain). The questions and prompts have been created through engagement with the literature, discussion with supervisory team, members of the Research User Group (RUG), and Project Advisory Group (PAG).

The topic guide for follow-up one-to-one interviews will be constructed after preliminary analysis of stage one interviews and based on gaps in understanding and opportunities for further exploration and elaboration. Where necessary, the literature will be revisited to identify concepts that emerge from the preliminary analysis; this will help me to focus my questions and prompts to explore these concepts in the context of participant experiences (I describe an instance of this in Section 4.4: p133).

The implementation of the topic guides will facilitate data gathering to support the fulfilment of the research objectives. The open questions will facilitate the exploration of the multiple dimensions of chronic pain (Objective 1), the sharing of narratives that will provide access to meanings about chronic pain in everyday life and in the context of place and life-course (Objective 2 and 3), and ways in which individuals cope with pain and extent to which they engage in self-management (Objective 4).

3.4.1.2 The life-grid

A life-grid has been included in the in-depth one-to-one interviews in addition to, and to complement, the topic guide. A life-grid is typically set out as a set of timelines; each of which refers to a different aspect of life (e.g. employment, residence, health) set against the same time scale (e.g. list of years). Blane, Berney, Smith et al. (1999) developed the life-grid method as a way of improving the accuracy of participant information recall. Subsequently life-grids have been adapted to suit exploratory research and life story approaches, rather than factual data recall. Life-grids encourage: 'interviewees to address the issue of change over time explicitly in their narratives' (Bell, 2005: p64). Completing life-grids in an interview setting can be a shared activity between researcher and participant. Sharing in this task can facilitate development of rapport and acting as an aide memoir for aspects of biography. This also provides the participant with a sense of control over the interview situation (Parry, Thomson, & Fowkes, 1999). Richardson et al. (2009) also suggest that life-grids can be used to reconstruct life stories and to tell the story of pain throughout the life-course. The life-grid has been used in studies of chronic pain previously (Richardson et al., 2007; Grime et al., 2010; Mackichan et al., 2013).

The life-grid developed for this study includes seven columns, or timelines. Column headings were adapted from those used by Richardson (2005) and include: 'years', 'family/personal', 'work/leisure', 'health/illness', and specifically 'pain'. In addition, columns for 'interference/coping', 'home/environment', and 'other' are included. A list of years provides the timeline against which other events and details can be plotted. The additional column interference/coping was included to record details relating to the interference of pain on activities and ways of coping; home/environment means to

include house moves, maintenance, and adaptation of home environments. The 'other' column provides additional space should any important information be shared that does not fit the column themes. I omitted the use of 'external events' as a prompt for years as Richardson (2005) reports this column as a source of distraction.

The life-grid has been selected to facilitate conversation about life-course factors that influenced and had been influenced by ageing, chronic pain and geographical context (Objective 3); data generated by the life-grid should also support the construction of participant profiles (e.g. length of time with chronic pain).

3.4.1.3 CASP-19

A quantitative measure of quality of life was identified as an important inclusion in this doctoral research study. Such a measure provides a means of comparing between participants in the study and with findings from existing research; to enable drivers of quality of life in older adults to be identified. The CASP-19 (Hyde et al., 2003) was selected as it has been validated for use with older adults in the UK and is widely used; for instance, the measure has been included in the English Longitudinal Study of Ageing (ELSA) and the Survey of Health, Ageing and Retirement in Europe (SHARE). CASP-19 has been used widely in research on ageing (see 10-year review: Hyde, Higgs, Wiggins & Blane, 2015). CASP-19 was selected because quality of life is an important component of the concept of ageing well. Alternative quality of life measures were considered, including: EQ-5D (Oppe, Devlin & Szende, 2007), Older People's Quality of Life (OPQOL) (Bowling, 2009), World Health Organisation Quality of Life – brief version (Saxena, Orley & WHOQOL group, 1997). The CASP-19 was selected above others as the domains provide a

useful source of comparison, both quantitatively and qualitatively, in terms of analysing diverse components in an individual's capacity to 'age well'.

CASP-19 is a measure of needs-based quality of life, as opposed to health-related quality of life, and draws upon Maslow's Hierarchy of Needs (1943; 1968). The measure comprises 19 statements organised into four domains: control, autonomy, self-realisation and pleasure. For each statement participants are required to respond on a 4-point frequency scale (with ratings from 'often' to 'never'). The control domain is scored out of 12 (4 items), all other domains are scored out of 15 (5 items). The total CASP-19 score is out of 57 where a high score denotes high quality of life. The domains of control (i.e. the freedom to intervene in the surrounding environment) and autonomy (i.e. the freedom to act without unwanted interference from others) represent basic human needs, or the base of Maslow's hierarchical pyramid. The four items in the control domain are: 'My age prevents me from doing the things I would like to', 'I feel that what happens to me is out of my control', 'I feel free to plan for the future', and 'I feel left out of things'. The autonomy domain includes five items: 'I can do the things that I want to do', 'Family responsibilities prevent me from doing what I want to do', 'I feel that I can please myself what I do', 'My health stops me from doing things I want to do', and 'Shortage of money stops me from doing things I want to do'.

The domains of pleasure and self-realisation are not defined but: 'capture the active and reflexive processes of being human' (Hyde et al., 2003: p187). Pleasure relates to higher order needs in Maslow's Hierarchy; for example, belonging – satisfaction from attaining 'a place in the world' and 'giving *and* receiving love' (Maslow, 1943: p381) – and self-esteem, the satisfaction from: 'self-confidence, worth, strength, capability and adequacy

of being useful and necessary in the world' (*ibid*: p382). The pleasure domain includes five items: 'I look forward to each day', 'I feel that my life has meaning', 'I enjoy the things that I do', 'I enjoy being in the company of others', and 'on balance, I look back on my life with a sense of happiness'. Self-realisation maps onto Maslow's higher order need of self-actualisation (morality, creativity). The domain includes five items: 'I feel full of energy these days', 'I choose to do things that I have never done before', 'I feel satisfied with the way my life has turned out', 'I feel that life is full of opportunities', and 'I feel that the future looks good for me'.

The CASP-19 has been incorporated in the in-depth interview to enable participants to reflect qualitatively on their responses to statements, in addition to providing quantitative responses on the scale. This approach enables participants to raise concerns related to quality of life, which can then be discussed further. Integrating CASP-19 in this way also provides a means of assessing the validity of statement on the measure against the personal experiences of participants and their sense of quality of life, as lived. This provides a means of 'interrogating the social world represented' by each participant (Mason, 2006a: p9).

It is anticipated the CASP-19 will facilitate exploration of coping and self-management (Objective 4). In combination, the integrated methods used in the stage one interview will generate data on lived experiences that will contextualise and inform considerations of health and social care policy and service recommendations (Objective 5).

3.4.2 Photo-elicitation interviews

In the second stage of the mixed methods the option of a photo-elicitation interview method has been included. Photo-elicitation interviews involve the use of photographs to act as prompts for discussion. Photographs are useful as prompts because images are polysemic, meanings are not fixed and instead represent a view of the world. Thus, conversation with participants about specific images elicits interpretations and constructions of meaning (Prosser, 2006).

As with the world around us, photographs are open to interpretation; Figure 3 acts to illustrate this point.

Figure 3: Photographic image of 'Rural'



Source: Google Images using search criteria: 'rural' and filtered by 'labelled for reuse' (search conducted: 18.03.2016)

The image comprises many objects and features; each of which holds meaning depending on who is viewing the image. Therefore, one may assume (based on prior experience) that a farmer would typically perceive labour, crops, pasture for livestock. In contrast, a rambler may perceive a hill terrain for walking. Personally, the image represents a place similar to home, a comforting and relaxing landscape, but simultaneously this image presents a barren and remote wilderness, albeit a managed one. To an older adult experiencing chronic pain this image may represent something else entirely (challenge, mobility problems, isolation); go back to a time in this person's life when they were free of pain and again meaning is reconstructed based on experiences up to that point. For each individual these objects and representations constitute the total world, the lived world, comprising natural and social aspects. In the absence of a human consciousness, the objects in the scene still exist only they do not have meaning. Meaning is constructed and reconstructed by humans over time and informed by experience.

In this study I have chosen an auto-photography approach; thus, photographs used in interviews will be constructed by the research participants (Dodman, 2003). Hinck (2004) utilised photo-elicitation in this way to explore the lived experiences of older people in rural areas. Hinck describes auto-photography as useful for participants to:

‘...reflect on what was meaningful to them when they made decisions about what to photograph and provided insight into how participants were situated within their past and present relationships and the rural setting.’

(Hinck, 2004: p782)

Participants will be directed to use their own camera or provided with a disposable camera. A set of guidelines will prompt participants to photograph places that have

meaning for them (positive/negative) in the context of their health, past and present, e.g. the road where they walk the dog, the fields they walk in, their favourite chair to sit in. The guidelines stipulate that the participant take a minimum of six photographs no maximum was set; however, the disposable camera (if using) has capacity for 25. Photographs will be collected from participants with permission, printed, and used as prompts in an interview to be held in a convenient location (i.e. participants home). In the event that participants are not able to use camera equipment due to health impairment they will be provided with the opportunity to participate using existing photographs (e.g. in photograph frames or albums). For each photograph used in the photo-elicitation interviews the following questions are to be asked to gather contextual data:

1. Can you describe this photograph to me?
2. Where is this photograph taken?
3. Why have you taken this photograph?
4. Who else was with you?
5. What did you want the photograph to represent?
6. Did the photograph show what you wanted it to?

The photo-elicitation interviews are intended to elicit narratives about place and relationships with rural environments as dimensions of chronic pain (Objective 1), chronic pain meanings (Objective 2), life-course factors (Objective 3) and also coping and self-management strategies (Objective 4).

3.4.3 Go-along interviews

The go-along interview is a method of interviewing that takes place whilst interviewer and participant are mobile. This is a naturalistic form of interviewing that blends participant observation with interviewing-on-the-move; and so therefore fits with ethnographic inquiry. Mobile interviewing has received increasing interest within the social sciences; particularly over the last decade or so (Kusenbach, 2003; Jones, Bunce, Evans et al., 2008; Brown & Durrheim, 2009). During mobile interviews the environment can act as a prompt for conversation and are suited to eliciting rich narratives about place and facilitate spatial specificity (Evans & Jones, 2011). The go-along method has been used in studies on health and place (Carpiano, 2009).

Kusenbach (2003) suggests that the go-along method may take the form of a “walk-along” or “ride-along” (e.g. undertaken whilst driving) and can be described in the following terms:

‘go-alongs provide independent, empirical evidence of a phenomenon which is difficult to access and substantiate by other means’

(Kusenbach, 2003: p469)

The language that Kusenbach uses suggests a realist-objectivist perspective. In contrast, I consider the go along to facilitate access, through observation, to the *interaction* between participant and environment. Through talk about environments as participants interact with these environments the perceptions of participants can be explored. Kusenbach argues that go-alongs are suitable for exploring five key themes: environmental perception, spatial practices, biographies, social architecture (i.e. implicit meanings

between individuals and specific spaces), and social realms (i.e. interactions and social patterns in neighbourhoods). Carpiano (2009) argues that a strength of this method is to empower the participant (to take control of the route walked) and that the method facilitates building of rapport. Mobile interviews may not be suitable for everyone; particularly, older adults living with chronic pain and as this method occurs on the move in an external environment, safety is an important issue. Rural environments may also present specific challenges and hazards (e.g. poorly maintained pavements, narrow lanes, lack of benches to rest).

In this study, go-alongs will include accompanying participants during a routine activity. Routine activities provide an opportunity to interact and observe participants as they experience chronic pain in everyday situations. The route, activities, and amount of time that I spent with participants will be determined by the participants; although guided by the research aim and objectives. Activities will be selected according to their routineness taking into account the appropriateness of my presence during such activities (e.g. sensitive situation, safety) and the burden my presence may have upon the participant (e.g. time, inability to take part in activities as they normally would have done). During the go-along participants will be asked to comment on their experiences, thoughts and memories; the environment and activity provided prompts for conversation. Visual, audio and written descriptions in fieldnotes will be recorded from the go-alongs. Visual data will be recorded by a digital video camera (Panasonic NV-GS320) and through photographs. Fieldnotes will be used to record descriptions of activities and settings (see sub-section 3.4.4, next page). The method was selected to provide the opportunity to explore: relationships between participants and their surrounding environment (Objective 1),

chronic pain meanings in everyday life (Objective 2), life-course and biographical factors (Objective 3) and coping and self-management strategies (Objective 4).

3.4.4 Recording fieldnotes

Fieldnotes will be maintained to record my observations, descriptions of activities, personal reflections on research activity and involvement, and to document decisions taken with and by participants for transparency and audit purposes. Conversations during activities will be recorded digitally and transcribed, with permission. Handwritten fieldnotes will be recorded as soon as possible after the research activity has finished (i.e. whilst sitting in the car prior to driving back to Keele University). The handwritten fieldnotes will be typed up on the same day where possible. The accompanying audio and visual data will then be checked through to aid the recall of additional details. Inevitably, fieldnotes are the researcher's own representation of events and as such are limited accounts open to subjectivity, attention and recall biases (Fetterman, 2010) – the techniques described (above and below) will help overcome some of these challenges. The fieldnotes will be included in the data analysis to facilitate my interpretations and to provide an alternative point of comparison. Fieldnotes will further support a thick descriptive account in the construction of case studies (of people and places). Recording observations can act to generate data on situated aspects, visual information, and participant behaviours and activities not otherwise recorded during interviews; this could be important and facilitate inter-subjective understandings.

I will record fieldnotes in two ways. First, I have created a two-sided A4 form to summarise my thoughts after each interview (see Appendix 6a for blank version) (Fetterman, 2010); routinely completing this will ensure that I reflect on each interview

directly after it has occurred. Second, I will maintain a research journal and record my reflections on interviews, research settings, and my representation of the environment. On the opening page of the journal I will include a bullet-point prompt note taking to maintain a systematic approach. The list has been adapted from Crang and Cook (2007) and includes: locating an ethnographic setting, describing the physical space, describing interactions within the setting, describing your participation in interactions, reflecting on the research process, and self-reflections. Fieldnotes will be typed up and included as data for analysis. Furthermore, I will supplement the journal with photographs and sketches (for example, see Appendix 6b for photocopied pages of journal).

3.5 To make sense of the data

To make sense of, and to integrate, the different data and modes of inquiry I utilise techniques synonymous with constructivist grounded theory (Charmaz, 2014). This version of grounded theory differs from its origins. The original form of grounded theory, see *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss, 1967), emerged from the systematic strategies that Glaser and Strauss applied to their study of death and dying in hospital settings. At the time of their work, positivism and quantitative research were dominant. Denzin and Lincoln (1994) argue that Glaser and Strauss launched a 'qualitative revolution' (1994; p ix), challenging assumptions around qualitative research as impressionistic and unsystematic; thus, moving qualitative analysis beyond descriptive levels and into the realms of theory development. Since the publication of their book, however, Glaser and Strauss diverged in their considerations and application of grounded theory each publishing separately their re-workings (Glaser, 1978; Strauss & Corbin, 1990). Thus, the foundations of grounded theory were criticised

in light of a revisiting of *The Structure of Scientific Revolutions* (Kuhn, 1962). As Charmaz and Bryant (2011) argue, the failure to reconcile the epistemological foundation of grounded theory left many of its exponents 'open to attack' in the intervening period. Both quantitative researcher and interpretivists alike found cause for criticism, as grounded theory straddled juxtaposed positions.

As part of the development of grounded theory it moved into the social constructionist paradigm (Charmaz & Bryant, 2011). The redefined constructivist grounded theory perceives the existence of multiple realities, inter-subjectivity, the situated nature of knowledge (i.e. it does not occur in a vacuum) and that data is constructed and as such should be viewed as problematic and partial reflecting the messiness of the social interactions in which it has been gathered. Charmaz chooses the term 'constructivism' to acknowledge subjectivity and the researcher's involvement in the construction and interpretation of data; aligning this with contemporary considerations of social constructionism (Charmaz, 2014). Glaser and Strauss originally argued the literature review stage be avoided until post-analysis, so as to ensure that resultant theory was grounded solely in the data and not influenced by existing literature. On the contrary, constructivist grounded theory is pragmatic in this regard arguing for engagement with the literature as part of the iterative data collection and analysis process; the literature acts as another voice for comparison (Mills, Bonner & Francis, 2006).

Grounded theory has received criticism. For instance, the over-reliance on coding has been criticized for leading data to be fragmented and decontextualized losing a sense of an individual's narratives (Coffey & Atkinson, 1996). Furthermore, Charmaz's work has typically included in-depth longitudinal interviews, over several years (e.g. Charmaz,

2002). Constructivist grounded theory is suitable for working with various types of data (e.g. interviews, narratives, ethnographic materials) (Charmaz, 2014) which makes it a good match for this doctoral research study. I describe how I applied techniques of constructivist grounded theory, to overcome the criticisms, in Chapter Four as a precursor to the chapters on findings.

3.6 Sampling strategy

In this section I define the parameters for the interview sample; in Section 4.2 (p128) I describe the process of recruitment. A sample size of 20 rural older adults with lived experience of chronic pain was set as the target at the outset. It was anticipated that this number of participants would be an *adequate* and *appropriate* sample (Morse, 2015) and would generate sufficient data to support analysis. Thus, the inclusion criteria were stipulated:

- Aged 65 years and over at the start of participation
- Self-report as having chronic pain (3 or more months)
- Living in their own homes (i.e. not in institutional settings)
- Live in a rural settlement (population of fewer than 10,000 people)

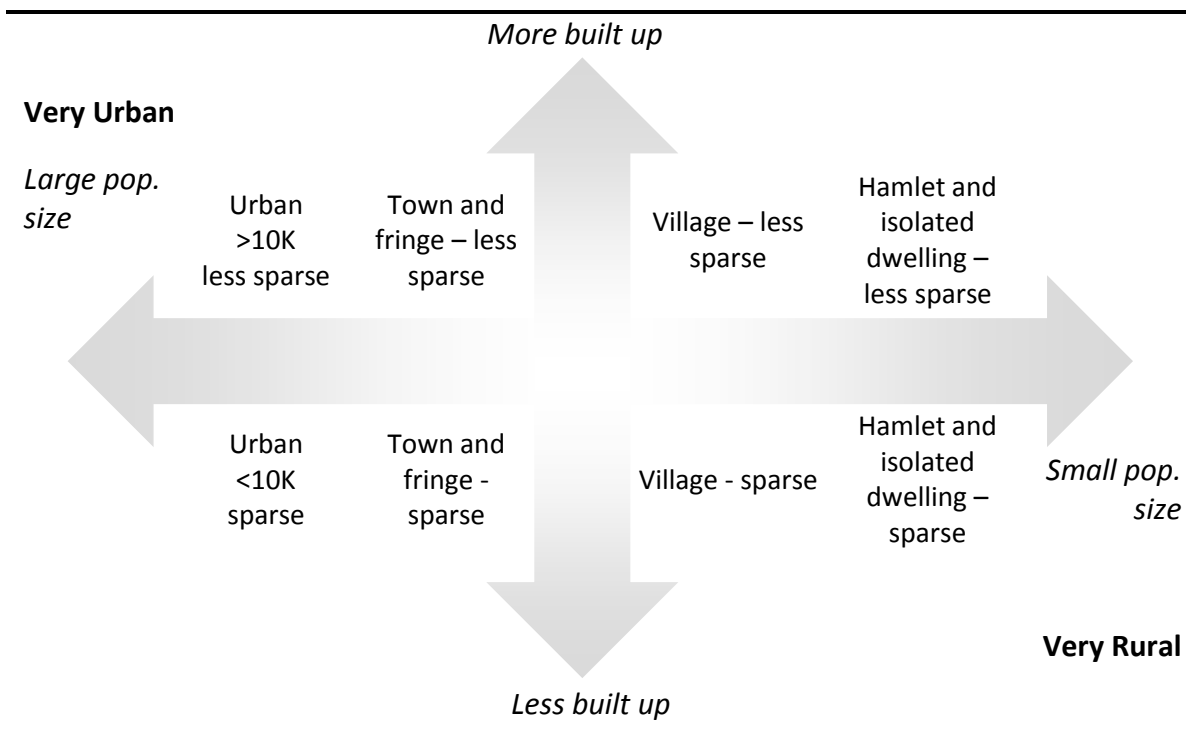
Individuals will be excluded if they have a cognitive impairment (i.e. problem with concentration, memory) which compromises their decision-making and ability to freely provide informed consent. Cognitive capacity will be presumed in accordance with the Mental Health Act (2005) and the rights of individuals. I will confirm participant's understanding of the study by asking them to briefly describe the study back to me (to check information had been retained and communication). The choice of definitions used

for inclusion criteria reflect an effort to be clear, concise and understood by potential participants, clinicians and researchers alike.

In Chapter Two, I identified the importance of defining terms such as chronic pain, rural and older adults; highlighting this through the frequent lack of such definitions in the existing literature. The definition of 'chronic pain' that I have chosen to use is pain that has persisted for three or more months, as described in Section 1.1.2 (p3). Based on the literature, I have selected to include people aged 65 years of age and over; by stipulating this age I am seeking to recruit those with experience of ageing in later life, not to define a homogeneous group.

The definition of rural used in this study reflects the complexity with which it is viewed in academic research; often considered to be a problematic concept (Watkins & Jacoby, 2007; Mills, 1988; Cloke, 1997). Mills (1988) suggests that rural should be positioned on a continuum against urban; suggesting shades of ruralness or urbaness as opposed to a fixed dichotomy. The definition used by the Department for Environment, Food and Rural Affairs (Defra, 2011) takes into account two broad characteristics: population size and sparsity. I depict these in Figure 4 as a two-dimensional continuum (on next page). For the definition I use for this study, I specify a 'rural settlement' by which I mean to focus on settlements to the right hand side of Figure 4. I consider a population of 10,000 people to represent the central point on the continuum between small and large populations. This population size has been used in previous research to define rural populations (e.g. Barlow, Williams & Wright, 2001).

Figure 4: Rural-Urban spectrum



The definition of 'rural' that I suggest enables comparison with views taken in existing literature and in policy (important for Objective 5). I have focused participant recruitment on settlements within the Staffordshire Moorlands. I have done this for two key reasons: 1) The Moorlands area has been classified as 89% rural (defined as above); and, 2) The Moorlands has the oldest demographic profile of the eight districts in Staffordshire (Staffordshire County Council, 2012). Furthermore, Keele University is located within Staffordshire and so the Moorlands are convenient in terms of travel.

A purposive sample is required to purposefully identify prospective participants who match the inclusion criteria and will share experiences of the central phenomena (Green & Thorogood, 2011). The intention is to recruit through community groups therefore to identify a purposive sample a mixed sampling strategy has been applied comprising: snowball and spectrum sampling. Snowball sampling refers to a process of making

contacts through existing contacts, or through a series of referrals between people who know one another (Vogt, 2005). Snowball sampling may be effective in overcoming challenges of recruiting hard-to-reach populations (e.g. older men) (Faugier & Sargeant, 1997). Spectrum sampling is an active search for heterogeneity among research participants based on 'experiences and circumstances' that differ from those encountered with the explicit aim of challenging the emerging 'ideal types' (Rosenfeld, 2003: p185). An iterative approach to analysis and therefore recruitment is necessary to identify criteria to guide the search for heterogeneity (e.g. identify sex, age, social network, living arrangements); these will emerge during the fieldwork. The two sampling techniques are driven by the purposive frame as set by the inclusion criteria. Snowball sampling will guide decisions on *how* to recruit a purposive sample based on opportunities arising during fieldwork (i.e. establishing networks and contacts); spectrum sampling will guide decisions on *who* to recruit to achieve heterogeneity within the purposive sampling frame to support the credibility of the analysis (i.e. by including contrasting experiences).

The challenges of recruiting older adults for research are widely reported (Mody, Miller, McGloin et al., 2008; Ridda, MacIntyre, Lindley & Tan, 2010; McMurdo, Roberts, Parker et al., 2011). However, Dibartolo and McCrone (2003) identified specific challenges to recruiting rural dwelling older adults into research. Dibartolo and McCrone described the following barriers to recruitment: physical and mental health impairments (e.g. vision, hearing, reduced mobility, stigma), socio-economic disadvantage, lack of transport, a misperception about availability of time, lack of access to remote dwellings, and a lack of trust towards research. The authors provide a useful list of potential solutions to

overcome these challenges (e.g. obtain support from the community to enable access, address transportation issues during consent). I attended to these in the set-up of the project, design of the participant information documents, and during the conduct of fieldwork. This is described in the next chapter.

Summary

In this chapter, I have outlined the combination of methods that I have chosen to gather rich data and fulfil the research objectives. The justification for the use of mixed methods stems from the explorative approach to study phenomenon that have thus far been under researched (in combination with one another). Through the combination of methods that I plan on using I hope to gain as full a perspective as possible. In the chapter that follows I talk about my fieldwork and data gathering, the evolution of the research, and my reflections on the process, before describing my findings.

Chapter Four: Conducting the fieldwork

Introduction

In the previous chapter I set out the methodological approach I have taken in this thesis and the selection of methods I have chosen. In this chapter, I describe how the fieldwork was conducted. The chapter describes the ethical review and the processes comprising the fieldwork including participant recruitment, management of data and data analysis. I describe these to set up the presentation of findings in Chapters Five, Six and Seven.

4.1 Ethical frameworks

‘We must consider the rightness or wrongness of our actions as qualitative researchers in relation to the people whose lives we are studying, to our colleagues, and to those who sponsor our work... Naiveté itself is unethical.’

(Miles & Huberman, 1994: p288)

Ethical research is a hallmark of good research (Tracy, 2010; Stige, Malterud & Midtgarden, 2009). Typically, a principalist approach to research ethics guides the conduct of such ‘good research’. For example, Beauchamp (2003) argues that ethical research acts in accordance with four moral principles: respect for autonomy (protection of human rights, specifically the choice to participate or not), non-maleficence (avoidance of harm), beneficence (provide benefits), and justice (observing fairness through avoiding exploitation and benefit-risk balance). Similarly, the Economic and Social Research Council (ESRC) adopt six principles: voluntary participation (autonomy); value outweighs harm or risk; informing researchers and participants; respect right to anonymity and confidentiality; quality assured; and, conflicts of interests made explicit.

Ethical principles are, of course, important. Where qualitative research is potentially challenging is that it takes place in the real world, which can be messy and within which ethical dilemmas are emergent (Wiles et al., 2008). Kvale (1996) argues that skilled researchers can respond to situations in which ethical dilemmas emerge in the context of research. The emphasis in qualitative research is therefore placed on the skill of the researcher to apply, rather than learn, ethical principles: ‘learning ethical principles is not sufficient to become an ethically responsible researcher’ (Brinkmann & Kvale, 2005: 178). Bryman and Bell (2011) observe how problems occur when researchers are assumed to inherently know right from wrong in research situations; particularly in cases of novice researchers and the sheer breadth of ethical situations that may arise in social research. Thus, Tracy (2010) constructs a list of eight criteria for excellent qualitative research that relies upon the skill of the researcher: (1) a worthy topic, (2) rich in rigor, (3) sincere, (4) credible, (5) resonant, (6) significant contribution, (7) ethical (comprising procedural, situational, relational, and exiting ethics), and (8) coherent. The four components reflect ethics as process in the conduct of real-world research; I adopt these components of ethics as an ethical framework for this study. In the following sub-sections I describe my approach to ethical review and the application of this principles. I also utilize Brinkmann and Kvale’s (2005) notion of ‘thick ethical description’ to describe and account for decision making in the field.

4.1.1 Procedural ethics

I submitted an application to the Keele University Ethical Review Panel (ERP) and obtained ethical approval on 13th September 2013 (see Appendix 7a for letter of approval and 7b for approval of a subsequent amendment). The application form for ethical review

included sections on: informed consent, avoiding harm, anonymity, confidentiality, and health and safety. In preparing the application for ethical review I created study documents that constituted the basis of communication with participants. The documents included: letters to participants, information sheets, and consent forms (see Appendix 8-10). During the course of the research the PAG assisted with preparation of participant letters and information sheets, provided insight into personal experiences of chronic pain which provided the foundation for the topic guide, and provided advice on recruitment strategies. Study documents went through a quality assurance process, to be consistent with standard operating procedures within the RI, prior to submission to the ERP. This involved producing a paper-based folder containing all study documents and arranging for members of the supervisory team, a Research Programme Manager, and an administrator to provide critique on drafts. The quality assurance process benefitted the application for ethical review as only one change was suggested and the panel remarked on an excellent submission.

4.1.1.1 Informed consent

With input from the supervisory team and members of the Project Advisory Group (PAG), I created a study information pack. The purpose of the pack was to ensure that (prospective) research participants were informed about the nature of the study prior to agreeing to provide consent to take part. The study information packs contained: a letter of invitation, a study information sheet, a consent form for further contact, and a freepost return envelope (see Appendix 8-10). The information packs were distributed through third sector organisations and community groups. Having an information pack gave prospective participants the opportunity to take information away with them, to

read it in the privacy of their own homes and to discuss with friends and relatives. Once prospective participants had returned the consent to contact form I contacted them by whichever means they had stated as a preferred option on the form (i.e. telephone or email). During this conversation I checked that individuals had read through the information and invited questions; after this I agreed an appointment for the stage one one-to-one interview. I sent confirmation letters for interview appointments by post and enclosed additional information about forthcoming interviews (one-to-one and follow-up methods) to prepare participants for what to expect.

Consent was recorded on non-carbon-copy paper comprising two sheets: a white top sheet to be retained by the researcher and yellow under sheet to be retained by the participant. To account for the mixed methods of data gathering five different consent forms were designed (see Appendix 10a-e). Consent was recorded: prior to the one-to-one interview, prior to the go-along, prior to photo-elicitation, and then post-interview (for all types) to allow the use of quotes and audio clips. The photo-elicitation consent form included a photograph release form in which participants were asked to share the copyright of photographs that they had produced as part of the research with Keele University. A separate photograph release consent form was also created to reciprocate the sharing of photograph copyright for photographs that I produced during data gathering (e.g. go-alongs, fieldnotes).

I used the task of completing consent forms with participants as an opportunity to build rapport and trust and gauge participant communication and understanding of the research (see eligibility criteria p.104). At the beginning of interviews completion of the consent forms provided opportunities to reassure participants about what they could

expect and to remind them that should they feel uncomfortable during an interview they retain the right to stop at any time. The post-interview consent form continued the process of informed consent as the timing meant participants were aware of what they had said during interviews and were in a position of knowing the content of that which they were consenting to be used.

4.1.1.2 Avoiding harm to participants

The study did not involve an intervention so risk of harm stemmed from emotional responses and consequences of disclosing personal information. The research methods, specifically the go-along, presented a risk in terms of conducting research in an uncontrolled environment (i.e. public space) within which potential hazards are likely to occur. I anticipated from the outset of the study that the prospective participants could potentially present characteristics of vulnerability both physical (e.g. frail and living alone) and emotional (e.g. low mood, loneliness). To safeguard participants, I obtained a Disclosure and Barring Service check. I recruited participants through “gatekeepers” who were known to participants and who could be trusted. I invited participants to share information about the study with a relative or friend before deciding whether or not to participate and to have a chaperone (a friend or relative) to accompany participants during interview should they prefer. I included a photograph of myself on the invitation letter and wore my Keele University identification card during home visits. I made it clear that individuals could ask for the recording to be stopped should they feel unable to continue. In the case of participants becoming distressed during interviews I was prepared to stop an interview and explore with participant’s possible avenues of support (e.g. to contact a friend, relative, their GP). Avoiding harm also includes harm to the

researcher. I observed Keele University's Lone Working Policy and was insured by Keele University. Furthermore, an opportunity to debrief following data gathering activity was put in place between me and the supervisory team; this provided me with opportunity to receive support should data gathering become personally distressing or emotional.

One participant exhibited signs of distress describing a parent who had died; this occurred after the interview when the recording had stopped whilst we shared a cup of tea. I provided the participant time and space and reassured them; I delayed my exit from their home to ensure they were safe. One participant asked for a specific topic not to be recorded as it was potentially sensitive; but, the participant wanted to explain their reasons for this after the recording had finished. We agreed to continue with the interview and directed conversation away from the topic. The participant offered an explanation after the recording had stopped (I did not record details of this conversation).

4.1.1.3 Maintaining confidentiality

The RI's Data Security Policy and procedures therein, have been incorporated into the process of data management within this research study. In terms of data storage, the paper-based field notes, interview transcripts, photographs were stored in a locked filing cabinet and all electronic data stored in password protected folders on secure drives on the RI's networked server. Fieldnotes, audio recordings and photographs from data gathering activities were transported securely to the RI as soon as possible after collection, where possible using electronic encryption, and stored in a locked filing cabinet. Electronic files were transferred to a password protected folder on a secure drive on the RI's networked server and deleted from the audio recorder. When the data were transferred to the qualitative analysis software package NVivo (Version 10) for analysis

purposes, project and personal details were removed. The NVivo file was password protected and held on a secure drive on the RI's networked server.

Snowball sampling presented risks to maintaining confidentiality where individuals (community members or participants) identified prospective participants whom they knew from their social network and where a disclosure of chronic pain was made. This risk was discussed with gatekeepers. It was also discussed with participants as part of the informed consent procedure. Rural settings posed a risk to the maintenance of confidentiality. Participants described a sense of close knit communities; however, one participant spoke of this in terms of feeling stigmatised and under scrutiny by neighbours. I observed on visiting a participant's home that other residents were interested in my car, perhaps because it was unfamiliar, my presence in the setting may have been a talking point. Some participants also described knowing other participants in the study (they had been informed directly by these individuals) and asked me questions about them. I did not disclose any information about the other participants and directed conversation back to the participant. This was unavoidable as some participants were recruited from the same groups (i.e. luncheon club) on the same day. It was made clear in the information to participants that confidentiality would be breached should they participant disclose a threat of abuse or harm to themselves or another.

4.1.1.4 Anonymity

Interview transcripts were anonymised using pseudonyms and/or altered to protect the identity of participants and others present during data collection or mentioned in interview conversations. For the purposes of transcription participant names were replaced with a code e.g. CP001F to denote the project (CP = chronic pain) the participant

number in chronological order of initial interview (001-008) and whether male or female. Interview data were filed under these codes for each participant. For the purposes of the presentation of analysis the codes have been replaced by pseudonyms; the chronological order was maintained by selecting names alphabetically so 001 was exchanged for a name beginning with A (e.g. Anne) and 002 exchanged for a name beginning B and so on. Pseudonyms were selected through discussion with academic supervisors and consultation with a name database that includes names by year and popularity (<http://www.babynames.co.uk> – references source of UK national statistical data). Pseudonyms were chosen to achieve cultural credibility. The rural communities in which participants lived were also pseudonymized by replacing the name of the village, for example, with 'Village A'.

The use of visual data in this research presented risks to the maintenance of anonymity of people and places (Crow & Wiles, 2008). The inclusion of visual data is justified as a way of presenting, albeit in a partial sense, the environments in which participants live; steps were taken to anonymize visual data. To protect the anonymity of individuals, photographs created as part of the research were adapted in the presentation of this visual data: facial features were either distorted (i.e. blurred) or removed (i.e. cropped) from the image as were potentially recognizable objects (e.g. cars, houses) and people that could be directly associated with the participant. The anonymity of place is complicated as even apparently insignificant environmental features may be significant and recognizable to someone (e.g. a road, a hedgerow). The visual data presented in the findings chapters has been selected to be sensitive to the risk of breaching anonymity.

I provided participants with the option of being named if they so wish in interview data and/or photographs rather than assume a preference from anonymization (excludes personal information which will not be disclosed e.g. address, post code etc.). The consent forms include options for this. Where participants indicated that they would like to be named or recognizable in photographs I would discuss the implications of this decision with the participant to ensure the decision was an informed one, and how the participant would wish this to be done (e.g. overtly such as named as the creator of a photograph or real name used in interview transcripts, or less obviously by inclusion as a name in the acknowledgements, or some combination).

4.1.2 Situational ethics

Situational ethics repositions research from the institution (as formulated within an academic institution) to out into the real world. According to Ellis (2007) situational ethics refers to: 'the unpredictable, often subtle, yet ethically important moments that come up in the field' (p4). Situational ethics relies upon the self-reflective skill of the researcher to react to events that present ethical challenges as they occur. I described above situations in which participants either experienced distress or requested that the interview recording equipment be turned off. The go-along raised ethically important moments. For example, in the case of one participant (Anne), I was aware from the first in-depth interview that over-exertion caused their pain to worsen. Thus, I was aware prior to the go-along that participation in the method (e.g. being mobile) may lead to the onset of pain. My approach was not to be paternalistic but to provide options and an environment in which participants felt that they could do as much as they felt comfortable. In the case of Anne, I attempted to balance my awareness of activity as a potential cause of pain

against potentially undermining her agency to make decisions for herself. Anne informed me during the day of when pain had increased and so we stopped for a rest. Anne requested that we continue shopping after having rested.

4.1.3 Relational ethics

Relational ethics:

‘...recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work’

(Ellis, 2007: p4).

I described above the procedural ways in which the rights of participants were protected (e.g. through consent procedures, confidentiality and anonymity). The in-depth nature of the interviews facilitated the sharing of life stories and personal information; the conversational style of the interviews provided scope for participants to ask their own questions about the research and about my personal life. I considered it important for me to share information about myself to encourage trust, build rapport and develop reciprocity in the research relationship. Instances occurred in which the nature of the relationship between researcher and researched changed. For example, one participant offered a bottle of wine to me after our first interview as a gesture of appreciation. The gesture altered the research relationship and presented an issue of situational ethics. I responded to the participant by stating they did not have to give me a gift; however, the participant insisted so to maintain the research relationship and not to cause offence I accepted the bottle of wine. During a go-along a participant described how her relative

would usually have taken her shopping as I had done; thus, I had assumed the role of relative and carer albeit for a small fraction of the participant's life.

4.1.4 Exiting ethics

Exiting ethics refers to the process of drawing the research relationship to an end and of the use of the research data that has been gathered. In this doctoral research study the in-depth nature of the methods and the development of research relationships with participants made exiting from the research field particularly important. I made participants aware in study documentation of the expectations on time and the number of visits that I would make to talk with them. I did this to prepare participants for my exit from their lives. Of course, in all research ethical considerations continue beyond the data collection phase to how researchers leave the scene and share the results (Tracy, 2010). Brewer (2000) states that: 'informed consent does not prevent informants from feeling angry once results are published' (p101). The post-interview consent form was important as it allowed me to check that participants were happy for interview data to be used and in what format. I submitted an application to the ERP for an amendment to enable contact to be made with participants to invite them to attend a dissemination event in July 2015. I shared a summary report of the dissemination event with participants and thanked them for participating in the research; this signaled my exit from their lives. In this section I have described the ethical considerations that I made in the study set up and fieldwork through to dissemination.

4.2 Recruiting participants

I obtained ethical clearance from the Keele University Ethics Panel in September 2013 (as described above). I commenced recruitment in October 2013. To support my fieldwork, I was successful with a funding application to the Postgraduate Research Committee in the RI at Keele University to support my fieldwork travel costs and interview transcription costs (October 2013). I specified in my ethics application to recruit participants via non-clinical sites and opportunities (i.e. not through NHS services); this meant that NHS research ethics committee approval was not necessary. The rationale for this was so that I did not limit recruitment to only those people who had sought or were currently receiving medical intervention. I recruited through third sector organisations and local community groups to access populations anticipated to include people that matched the inclusion criteria. The approach to recruitment involved an iterative cycle of data collection and analysis that then informed recruitment. The strategies of spectrum sampling and snowball sampling overlapped throughout and even blended. I describe the approach to recruitment below accompanied by a flow diagram in Figure 5 (p130).

Recruitment commenced in October 2013 and continued for seven months to May 2014. To commence recruitment, I identified a charity organization that supported older adults in the Staffordshire Moorlands area (Moorlands Homelink). The charity provides luncheon clubs, social gatherings for older adults, in rural areas facilitated by a single coordinator whom I utilized as a gatekeeper. The location of the luncheon clubs tended to be village halls; attendances varied from 6-20 older adults and were typically attended by women. I attended six different luncheon club venues over two months (some on more than one occasion) I distributed 24 packs to people attending these clubs who expressed an

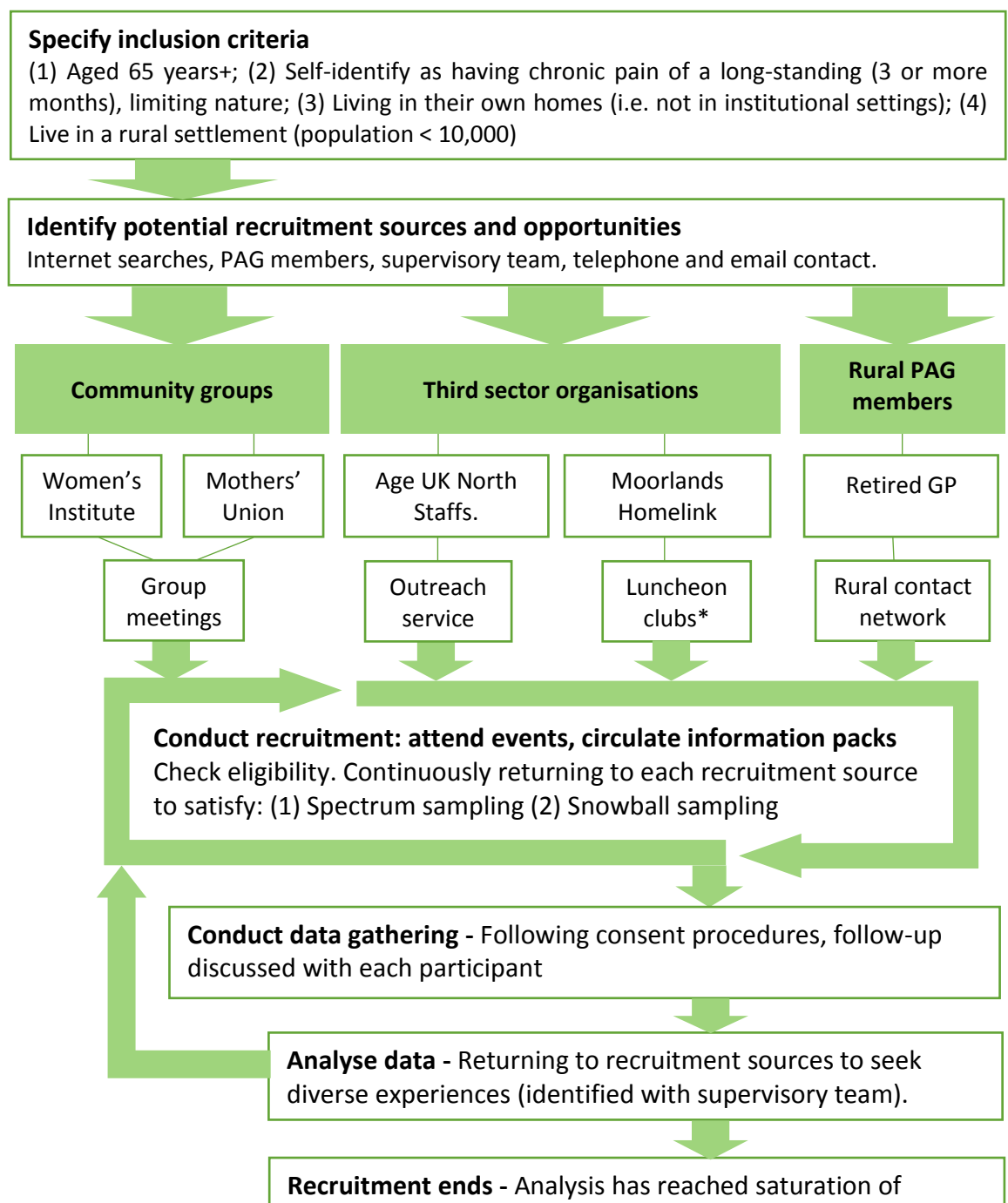
interest following discussion. Three individuals (females) were recruited; a further three returned consent to contact forms but lived in towns with a population of more than 10,000 people. To identify potentially housebound older adults (to contrast with the experiences of those attending group activities) Age UK North Staffordshire agreed to distribute the study information pack to service users during home visits, if appropriate. I provided the outreach service coordinator with 20 participant information packs; but no participants were recruited through this method.

The three participants recruited to this point were homogeneous in terms of: sex, age, lived alone and time spent with chronic pain. Informed by spectrum sampling, in December, I sought to establish contact with community groups in the Staffordshire Moorlands as an alternative source of recruitment. I contacted leaders of the rural Women's Institute and Mothers' Union groups; this was facilitated by PAG members. I attended meetings held by both groups in January 2014. I distributed six information packs to attendees at the Women's Institute meeting and four to attendees at the Mothers' Union meeting. This method yielded one participant directly from the meeting; two attendees took information for their respective spouses (both of whom returned consent to contact forms and were recruited); and the leader of the Mothers' Union group recommended two potential participants in the local community and distributed information to them, both completed consent to contact forms and were recruited.

By April 2014, eight participants had been recruited; heterogeneous on several criteria (e.g. sex, age, village location, marital status, time with chronic pain, and cause of chronic pain). Recruitment through the identified sources seemed to have been exhausted; I used PAG members and participants to identify potential participants who could add further

diversity to the sample. A PAG member distributed an information pack to a neighbour (a single male living alone); who returned consent to contact but declined to participate. One participant identified a friend (married and living with a spouse) as a potential participant and distributed an information pack; but the friend declined to participate.

Figure 5: Recruitment process flowchart



Alternative techniques were considered to support recruitment, for example, advertising in the local media (e.g. newspapers, posters); however, through discussion with my supervisory team this was considered unsuitable for the small study sample required and prohibitive due to high cost. A pragmatic decision was made to cease recruitment following discussion with my supervisory team. The data that I had gathered to this point represented a rich and substantial body of data. From the data that were gathered, my analysis reached a level of “category saturation” (no new codes or categories emerged); however, the inclusion of additional participants with different experiences and circumstances (spectrum sampling) to those included may have held alternative perspectives and therefore contributed different data (for further discussion see Section 8.2.3 Limitations).

4.3 Management of data

The data gathered from the mixed methods used were copious. I present the recorded interview data in Table 4.1.

Table 4.1 Record of data gathering

Method of data gathering	Number completed (n)	Recorded data (time)
Stage 1		
1-to-1 in-depth interviews	8	16hr 43m
Stage 2		
1-to-1 in-depth interviews	2	4hr 33m
Photo-elicitation	2	2hr 30m
Go-along	2	5hr 12m
Total	14	28hr 58m

In addition to data reported above I gathered visual data and recorded observations in fieldnotes. A (partial) video recording of the go-along amounted to 1hr 30m. 101 photographs were compiled taken either by myself to supplement fieldnotes or by participants for photo-elicitation interviews (full list provided in Appendix 11). The participants are described in case study format in Chapter Five together with a record of participation.

All interviews and conversations during go-alongs were recorded with permission using a digital voice recorder and then transcribed. I transcribed nine interview recordings using the transcription facility in NVivo 10 (QSR International), which allowed digital recordings to be played back at slower rates, typing could be performed simultaneously, and keyboard shortcut keys worked similarly to foot pedals. I included non-verbal information such as pauses and inflections (e.g. raised tones, emphasis) in transcripts. Transcribing provided an effective method for reviewing the content of interviews, which facilitated analysis. To support transcription, I used an external transcription service; one used frequently by Keele University. The service permitted digital audio recordings to be transferred online; this is a secure system provided by SendThisFile®. The external company transcribed five interviews (amounting to 10hrs 59m). I proof-read and anonymised transcripts as they were returned against the original digital recordings.

The photographs that participants created were done so using a disposable camera, I collected these and developed the film into printed images and onto compact disc (CD). I also created photographs to supplement fieldnotes; I used a mobile phone camera – this was a password protected device.

As per ethical approvals all data were stored securely in the RI at Keele University. To prepare the different types of data for analysis I converted all data into electronic formats. This enabled me to use NVivo 10 to organise the research data into files for each participant; this provided an effective means of storing and accessing the range of data to facilitate analysis. Due to the amount of data that I was handling it was essential for me to have a platform on which to make comparisons across different documents relating to one participant as well as others. The NVivo file was password-protected and saved in a folder with strict permissions on access.

4.4 Data analysis

The process of analysis was driven by the data and represented an inductive and iterative process; however, deductive reasoning was also inculcated to integrate quantitative data. The quantitative data derived from responses to CASP-19 were analysed at a descriptive level; this is due to the small sample size. Scores for each participant were calculated for each of the four domains and for total scores. The results were tabulated and are presented in Chapter Five. The numerical data provided a point of comparison with narrative data. To guard against mixed methods research becoming presented as ‘disjointed and unfocussed’ (Mason, 2006a) the CASP-19 measure was integrated into the one-to-one interview. Thus, participants’ responses to statements in the measure were included in the qualitative analysis also. Conversations around items in the CASP-19 provided points of contrast and coherence in the development of understanding of individual participants, as well as across participants.

The approach to analysis of the qualitative data (interview transcripts, photographs, video, fieldnotes) combined narrative analysis (Riessman, 1993, 2008) and techniques of

constructivist grounded theory (Charmaz, 2014) (In Section 3.5 [p110] I described the role of constructivist grounded theory as influencing my methodology). Riessman (2008) identified narrative analysis as lacking a recognized set of procedures; she describes, confidently and positively, a process of progressive fine-tuning in an unstructured way leading to understanding. The lack of guidance was suggested by Riessman to be a source of potential enjoyment. However, the lack of a systematic process generated feelings of anxiety and uncertainty in me over whether everything would simply fall into place. I was also concerned about data that may “fall between the cracks” of narratives, the utterances, the factual statements, the random thoughts verbalized by participants that form part of conversation but not necessarily go on to constitute narratives. I was also concerned about how to incorporate the different types of data (e.g. photographs, video) into analysis and later in the presentation of findings. The version of grounded theory described by Charmaz (2014) made sense to me as an inductive process of analysis into which deductive reasoning could also fit, and provided a systematic framework, her research on chronic illness narratives was also influential. Furthermore, combining grounded theory and narrative inquiry has been argued for previously (Lal, Suto & Ungar, 2012) as both have strengths that may overcome the pitfalls of the other.

Key strengths of constructivist grounded theory are contained within the techniques of coding, memo writing, constant comparison, and theoretical sampling (Charmaz & Bryant, 2011). I describe each of these key techniques in turn to evidence my understanding before then providing a step-by-step guide to my analysis. The first technique is coding; codes are applied to data and take the form of:

‘...a researcher-generated word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data.’

(Saldana, 2013: p262).

Charmaz (2014) argues for codes that prioritise actions and processes as opposed to structures of what has been said; coding for actions, ‘helps to keep that life in the foreground’ (Mills, Bonner & Francis, 2006: p7) and maintain a sense of such action. The second technique is constant comparison, which begins at a data level, comparing and contrasting segments of data with one another to formalise codes, progressing to comparing different codes, then to compare to identify properties of conceptual categories and so on. Constant comparison acts to increase internal validity as the researcher searches for differences within the data from the same participant, and then across a range of participants, to check against the conceptual categories that the researcher has constructed. The third technique is memo writing; memos provide an ‘interactive space’ in which to convene with thoughts, hunches, questions, assumptions, and to be reflexive (Charmaz, 2014: p164). Including raw data in researcher’s memo writing maintains the participant’s voice and their meaning through to the theoretical outcome (Mills, Bonner and Francis 2006).

Sampling of participants, data gathering, and analysis occurred in an iterative cycle. In theoretical sampling, the researcher conducts fieldwork to collect further data to formalise the properties of constructed categories, which are being pulled together into a theoretical explanation. Charmaz (2014) argues theoretical saturation occurs at a point when cases fail to reveal any new properties beyond those included in the developed

categories. Charmaz (*ibid*) describes an initial stage of sampling; this is premised upon establishing criteria prior to data collection for people, situations, or settings (i.e. phenomenon that have been identified in research formulation and questions). This strategy mirrors the purposive, data driven, sampling approach taken in this thesis based on the stated inclusion criteria. Similarly, sampling in constructivist grounded theory targets variation and heterogeneity. Thus, theoretical sampling is similar to spectrum or maximum variation sampling.

In Figure 6 (see next page) I present a step-by-step guide to my analysis. The step-wise approach is presented for clarity; however, the application was iterative; early steps were retraced to progress understanding and develop conceptual categories. I describe each of the steps below Figure 6.

Figure 6: Step-by-step guide to analysis

<p>Step One: Stage one in-depth interviews</p> <ul style="list-style-type: none"> • Single participant at a time • Close (re)reading of data for: narratives followed by coding, incorporating narrative structure labels and in vivo coding where suitable • Construct coding framework for each case • Write memos as reflections on wider meaning, potential categorizations, narratives and wider reading, building theory, typologies, criteria for comparison, identify gaps in data <p>Step Two: Comparison with mixed methods</p> <ul style="list-style-type: none"> • Single participant at a time • Incorporate different type of data (CASP, photo-elicitation, go-along, fieldnotes) • Refine coding • Write memos to reflect on wider meaning, potential categorizations, narratives and wider reading, building theory, typologies, criteria for comparison, identify gaps 	<p>Construct participant-specific coding</p> <ol style="list-style-type: none"> 1. Maintains sensitivity to participant 2. Triangulation of different methods/data 3. Enhancing internal validation 	<p>A. Constant comparison (includes engagement with literature)</p> <p>B. Sampling based on heterogeneity (based on properties of conceptual categories)</p>
<p>Step Three: Comparison with similar participants</p> <ul style="list-style-type: none"> • Confirm comparable experiences/typologies/criteria • Compare and contrast coding frameworks within similar cases • Develop overall categories for codes for groups of cases • Write memos to reflect on wider meaning, potential categorizations, narratives and wider reading, building theory, typologies, criteria for comparison, identify gaps <p>Step Four: Comparison with different participants</p> <ul style="list-style-type: none"> • Compare categories across different participants • Building on comparisons and memos to develop concepts and theory • External validation (against existing research of central phenomena) • Write memos to reflect on wider meaning, potential categories, narratives and wider reading, building theory, typologies, criteria for comparison, identify gaps 	<p>Construct framework of understanding</p> <ol style="list-style-type: none"> 1. Categorization of codes (properties) 2. Concept and theory building 3. Collect further data 	
<p>Step Five: Concept/Theory building and reflection on narratives</p> <ul style="list-style-type: none"> • Finalize conceptualizations and theory • Reflection back on narratives identified in Step One and Two to ensure coherence/correspondence with context of participant experience 		

Step one and two are driven by an effort to understand participants at an individual level. I read and re-read the interview transcripts to achieve a sense of familiarity. I adopted a Labovian approach to identify narrative structures (as described in Section 3.3.1: p90). By applying this structure as a cognitive framework helped me to gain an understanding of the way in which specific participants constructed meaning and identify the central themes of their interviews (e.g. topics, people, places, events). See Appendix 12a for an example of this part of the analysis.

Following an initial reading for narratives I conducted an intensive line-by-line coding of stage one interviews (for example, see Appendix 12b). The narrative structures helped to inform this coding process. I then constructed models of codes to develop categories of codes by grouping and linking codes together to identify potential characteristics of experiences. The models were also useful for looking beyond transcript content to identify processes that linked codes and helped to develop categories (see models for all participants in Appendix 13a-h). In step two, I continued to code and refine existing codes only this time through comparison with participant follow-up data (if completed). Moving from step one to step two I refined initial codes into focused codes (Charmaz, 2014). In this step, the visual data from the photo-elicitation and go-along interviews were incorporated. Photographs (photo-elicitation interviews and fieldnotes) and video stills (freeze-frames) were coded to correspond with coded interview transcript or fieldnote segment. I recorded memos and annotations to evidence my reflections on this data and my interpretations of it (for example, see Appendix 12c and d). The memos provided the building blocks for sections of the findings chapters. I revisited the literature to compare concepts with ideas I had formulated through my interpretations and to develop

interview questions for follow-up interviews. For example, I revisited the literature on place attachment and belonging and consulted qualitative and quantitative research; the measure of place attachment used by Raymond et al. (2010) was useful for framing the interview prompts to explore participant's connections with place.

In step three and four the emphasis on analysis changed and progressed from an individual level to an inter-individual level; thus, increasing the level of abstraction of codes and categories. This progression extended constant comparison beyond individual participants; this required further refinement of codes and categorization to map shared experiences and to begin to develop an overall model of understanding. In step three I focused upon participants who shared similar experiences identified through demographic information, narratives, and coding. In step four I focused upon participants who had contrasting experiences, again as evidenced by demographic information, narratives, and coding; this step relied upon implementing the sampling strategy to identify a diverse range of participants.

Step five represents the final process in the analysis and takes place when no new properties of developed categories emerge. I organized the categories and contributing codes into a coding frame (see Appendix 12e). At this point I returned to the initial narratives to confirm relevance and credibility of conceptual analysis with narratives and thus experiences. In the three chapters that follow, I present a selection of the conceptual categories developed through the analytical process described. I have been selective in the presentation of findings to tell a story of the analysis and to maintain a sense of coherence; it simply would not be possible to present all my analysis. Prior to presenting the findings I explain why and how the quality of the findings can be assured.

4.5 Assuring the quality of findings

The quality of exploratory research is often described in concepts such as reliability, validity (Silverman, 2011), and trustworthiness (Bryman, 2010). Silverman (2011) refers to reliability in terms of credibility. Charmaz and Bryant (2011) consider the credibility of constructivist grounded theory against three distinct levels: credible data, analytic credibility and theoretical credibility. Firstly, the credibility of data is described where 'the quality and sufficiency of the data for accomplishing the research goals matter' (2011: p299). Credibility at this level requires revisiting the research questions to assess whether the methods selected will generate data sufficient to answer these questions. In previous iterations of grounded theory, the data were taken as an unproblematic entity. In constructivist grounded theory data collection is considered to be located in temporal, spatial, social and situational conditions (*ibid*, 2011: p298). These considerations can be reflected upon in a reflexive manner through the strategy of memo writing. The iterative process of grounded theory helps the researcher to formulate codes and the properties of conceptual categories, reflecting on these enables the researcher to then ask appropriate follow-up questions. This process acts to ensure the credibility of the data. Entwined within this process is analytic credibility, which builds as coding processes progress from initial coding to focused coding.

A way in which reliability can be assured is through processes of cross coding; comparing views between different researchers. Hammersley describes this as inter-coder reliability:

'...reliability refers to the degree of consistency with which instances are assigned to the same category by different observers'

(Hammersley, 1992: p67)

In the context of grounded theory, Charmaz and Bryant (2011) claim that ‘inter-coder reliability does not make sense’ in the construction of codes and conceptual categories as each researcher will approach the data with their own different sensitivities and interests. However, in the context of a thesis, discussion and sharing of a PhD candidate’s analysis with their supervisory team is vital. To do this I selected narrative segments and provided contextual information for one participant and asked the members of my supervisory team to construct their own codes for these data segments. We then compared our coding and discussed contrasting interpretations. I found the cross-coder checking informative as it provided an open platform for discussion of my interpretations with others during which I could verify coding frames. The process supported interpretations but also provided new directions in which to take the analytic inquiry. The inter-coder reliability process provided another aspect of constant comparison to check interpretations made sense. For theoretical credibility the process of sampling is important; based on saturating properties of conceptual categories that the researcher has constructed. The premise of this sampling strategy is to seek variation in experiences. To saturate conceptual categories in-depth, rich data can also be ‘sampled’ through constant comparison in the development of analysis.

Summary

In this chapter I have described the ethical review process, application of the data gathering methods, and data management and analysis processes. The data that I gathered were rich, diverse and copious and required (in my mind) a systematic approach to analysis. In the following three chapters I present the findings of this process of analysis.

Chapter Five: The lived experience of ageing with chronic pain



Photograph #58: This photograph is overlooking Village A (beyond the line of trees). I took this image from a nearby hilltop. Village A was a central area during the fieldwork. Four of the participants recruited for this study live here. A General Practice accessed by all but one of the participants is also located in this village. I present this photograph to help situate the findings that I am about to reveal.

Introduction

The aim of this chapter is to introduce the study participants and their lived experiences of chronic pain. I begin by presenting an overview of the sample including: demographic information, a record of participation and data gathered. Following this, I integrate the mixed data to construct detailed case studies for each recruitment site and each participant; this sets the context for the two chapters that follow. In Chapters Six and Seven, I use the CASP-19 domains to frame presentation of data; this enables an in-depth exploration of quality of life in the context of chronic pain.

5.1 Description of rural environments

The sites of data gathering included five villages located within the Staffordshire Moorlands. In the sections that follow I describe the key features of the villages. Data from national statistics are not available at a village level so data to compare in terms of population size, demography, turnover, or area deprivation is not included (discussed in section 8.2.3 Limitations). The size of villages and population size are instead estimated from aerial images from Google Maps (www.google.co.uk/maps) based on scale and housing density, geographical features of the villages are described. The images are not included as villages would be potentially identifiable. The villages are presented in descending order by approximate area and population size where Village A is likely to be the largest and Village E the smallest.

5.1.1 Village A

Village A is the largest of the five villages in terms of estimated population size based on the density of housing and the size of the area. An A-road runs through the centre of the village that provides the main route between two large urban centres, both around 12 kilometres in either direction. At the centre of the village a lane branches off from the main road; this passes through built-up housing areas and continues up a hill and out of Village A (and leads to Village E). Houses are distributed either side of the lane, although some are also dispersed along the main road. Side roads leading from the lane act as tributaries connecting housing estates on each side. There are pavements throughout the village; these are generally in a good state of repair. There is street lighting throughout the village and within housing areas. Housing types and ages vary ranging from standalone farm houses, cottages, bungalows along the main road, semi-detached houses

along the lane, to modern housing estates (circa post-1990) comprising large family homes. The housing areas are surrounded by fields leading up to, and beyond, the village boundary.

Services that can be accessed within the village include: a General Practice with pharmacy, a primary school, church, shop (newsagents), Post Office (this closed during the time of the study), public house (pub), petrol station, community centre, café, and a take away restaurant. There is a bus stop along the main road that has a designated shelter on one side of the road but not the other, neither has a bench. The closest hospital is 11km from Village A; a small community hospital. The nearest supermarket is 12km.

5.1.2 Village B

Village B is a similar size to Village A covering a similar sized area; Village B is also comprised of several housing estates. The centre of the village is situated on the crest of a steep sloping hill; this rises by approximately 50 metres from the village edge (bottom of Figure 8) to the central road junction. There is a main road (a B-road) that runs through the village; this has pavements on either side that run up to the top of the hill. There is street lighting throughout the village. Housing types and ages vary, as in Village A they include standalone farm houses, cottages, bungalows, semi-detached and detached houses. There are several housing estates that represent an expansion of the village. Farm houses are located on the outskirts of the village and the accompanying fields surround the village; one farm is situated in the heart of the village. There is also a business park within the village with industrial units.

Services that can be accessed within the village include: a shop (newsagent), a butchers and a Post Office all of which are located at the centre of the village at the crest of the hill. Three pubs are located within the village boundary in addition to a Methodist church, a fire station, a village hall, a primary school and a nursery. The nearest General Practice is in Village A (8km away) and nearest supermarket and hospital are in a town (8km away).

5.1.3 Village C

Village C is smaller than Village A and B and has lower density of buildings and observations housing confirm no housing estates are present. Dwellings are typically detached or semi-detached properties; these are predominantly stone built cottages. Several farm houses are located within the village boundary with adjoining farmland surrounding the village. Fields are demarcated by rows of drystone walling that run across rolling valleys. The village is accessible by a network of lanes that lead to an intersection at the heart of the village. A long straight road leads downwards into the centre of the village where there are two pubs, one of which provides rooms to stay. A single pavement runs parallel with this road but ends at the centre of the village; there is no street lighting. The village is served by the parish church located on the outskirts. There is also a community centre in the village but there are no shops or newsagents in the village. There are several car parks in Village C one of which has a public toilet; there are several signposts for walkers, which this area is popular for. The nearest newsagent is approximately 5km away, General Practice 7.6km away, urban centre 12km away a small rural town.

5.1.4 Village D

Village D is slightly smaller than Village C; there is a lower density of buildings. There is no discernible centre to the village. Instead, houses, which are low in number (approximately fewer than 100), tend to be either attached or occur in small groups dispersed along the edge of the main road. There is a row of red-brick terraced houses located along one of the main access lanes. The village mainly comprises farm buildings and open land divided by hedgerows and dry stone walls, there is also a large industrial site within the village boundary. The road network in this village consists of two lanes one leading east to west and the second north to south. The lanes are used by large vehicles (e.g. buses, tractors with trailers, and other heavy goods vehicles) to access main transport links. Tributaries of narrow lanes lead off from the roads to connect remote farms and provide routes to neighbouring settlements. The terraced houses are serviced by a bus stop, telephone box and local information board that are approximately 25 metres beyond the final house in the row. A pavement runs the length of the terraced houses to the front. However, there is no pavement on the opposite side of the road where the telephone box and information board are located, only a grass verge (this was overgrown on each of my visits). There is no designated bus shelter or bench. The village is served by a church and a pub but has no village hall. The nearest General Practice, shop (a newsagent) and Post Office are located in the neighbouring village, Village A, two kilometres (by road). The nearest urban centre is 12.8km by road.

5.1.5 Village E

Village E is situated on a hilltop above Village A; this is the smallest of the five villages. The hill slopes gently down into Village A declining by approximately 20 metres; the road is a

narrow lane with a tight bend at the steepest part of the decline/incline. The village comprises farm buildings with working fields distinguished by drystone walls some of which are in a poor state of repair. Properties in this area are stone-built semi- or detached cottages and also barn conversions. The parish church is situated within the boundary of the village and there is also a community hall, which was formerly a school. A network of narrow lanes and tracks connect Village E with neighbouring villages. There are few amenities except for a pub, a public telephone box and two information boards in the village. Services are available in nearby Village A, 1 km down the hill. There are no pavements within the village or to connect Village E and Village A; there is no street lighting either. There are two information boards in the village one outside of the village hall and one at a road junction.

Having now described the rural environments in which the participants are situated I will now present the participants as individual case studies. As a precursor to the case studies I also present data from the CASP-19 to establish a sense of the current life circumstance for each participant.

5.2 Participants

A total of eight participants took part in this study. Table 5.1 presents important demographic information and data related to health and dwelling type for these participants.

Table 5.1 Demographic information from sample

Pseudonym	Gender (F = female)	Age (yrs)	Ethnicity	Education level	Employment status	Relationship status	Children (n)	Grandchildren (n)	Contributing factor to CP	CP location	Estimated time with CP (yrs)	Additional health problems	Rural location*	Property type	Time in current property (yrs)
Anne ¹	F	82	White British	Secondary schooling	Retired	Widow	2	7	Osteoarthritis	Low back, shoulder, hip, hands	10-12	Diabetes, macular degeneration, leaking heart valve	D	Mid-terrace	>50
Barbara ¹	F	78	White British	Secondary schooling	Retired	Widow	5	5	Arthritis (unspec.)	Shoulder, hands, feet	4-5	None reported.	A	Bungalow (estate)	12
Catherine ¹	F	90	White British	Professional training	Retired	Single	0	0	Muscular pain	Hip, right buttock	3	Bunion, macular degeneration.	C	Detached cottage	10
David ²	M	70	White British	Secondary schooling	Retired	Married	3	2	Osteoarthritis and other	Low back, elbow, hands	40	Sleep apnoea, diabetes.	A	Detached house (estate)	12
Edward ²	M	81	White British	Degree level	Retired	Married	2	6	Osteoarthritis	Lower back, right hip	4	Barretts Oesophagus, 'Parkinsonism'	A	Detached house (estate)	10
Frances ³	F	67	White British	Professional training	Retired	Single	1	2	Sciatica	Hip, lower back	20	None reported.	A	Semi-detached roadside	4
George ²	M	74	White British	Secondary schooling	Retired	Married	4	2	Arthritis (unspec.)	Feet, ankles	25	Stroke, Diabetes, Cellulitis, Lymphedema, Osteomyelitis	E	Bungalow on hill	1.5
Henry ²	M	78	White British	Secondary schooling	F/T (30 hrs)	Co-habiting	0	0	Post-shingles	Abdomen, lower back	3	Prostate cancer (remission), COPD.	B	Detached house (estate)	14

Table notes: All years (e.g. age) are calculated at time of participation. Recruited via: [1] Moorlands Homelink [2] Mothers Union [3] Women's Institute

*Rural locations are described in Section 5.1

Data were also contributed by spouses of three participants during data collection; consent forms were completed but demographic information was not obtained for spouses. In Table 5.2 I present a record of completed data gathering activities for each of the study participants

Table 5.2 Data gathering completed with participants

Pseudonym	1-to-1 interview	CASP-19	Life-grid	Follow-up	In-depth interview	Photo-elicitation	Go-along
Anne	23.10.13	Yes	Yes	Yes			14.11.13
Barbara	29.10.13	Yes	Yes	Yes		15.11.13	
Catherine	13.11.13	Yes	Yes	Yes	16.04.14		
David*	06.03.14	Yes	Yes	Yes	23.04.14		
Edward**	12.03.14	Yes	Yes	No			
Frances	13.03.14	Yes	Yes	Yes		28.05.14	
George***	18.03.14	Yes	Yes	No			
Henry	03.04.14	Yes	Yes	Yes			20.05.14

**David's wife Diane was also present for the interviews*

***Edward's wife Ethel was also present for the interview*

****George's wife Gail was present for the interview*

All participants completed the stage one interviews, including the life-grid and CASP-19. A redacted version of a completed life-grid is provided in Appendix 14. Although the sample size was eight participants, fourteen interviews were completed and the data collected were in-depth equating to almost 29hrs of recorded conversation (see Table 4.1 for breakdown; p131). In addition, photographs, fieldnotes, CASP-19 measures and life-grids made for a rich and complex set of data. Data gathering stopped when there was considered sufficient data to achieve saturation of conceptual categories (i.e. sufficient to describe connections between codes and categories) (Charmaz, 2014). In the next section I present the results from the CASP-19 measures before presenting the participants as individual case studies.

5.3 Rating quality of life

All participants completed the quality of life measure, CASP-19, during the first stage interview. All items for control and autonomy domains were completed but missing values were recorded for self-realisation and pleasure domains: item 11: 'I feel that life has meaning' and item 19: 'I feel that the future looks good for me'. The small sample size meant that imputing missing values (e.g. using a mean score derived from other participant's scores) was not statistically appropriate. The missing values limit quantitative comparability but are explored further in Chapter Seven as qualitatively the missing values had far greater significance by being missing. The responses from participants for CASP-19 have been calculated to produce scores for individual domains and overall quality of life (Table 5.3) where domain scores are reported missing values are clearly stated. For a full table of CASP-19 responses see Appendix 15.

Table 5.3 CASP-19 domain and total scores arranged in descending order (n=8)

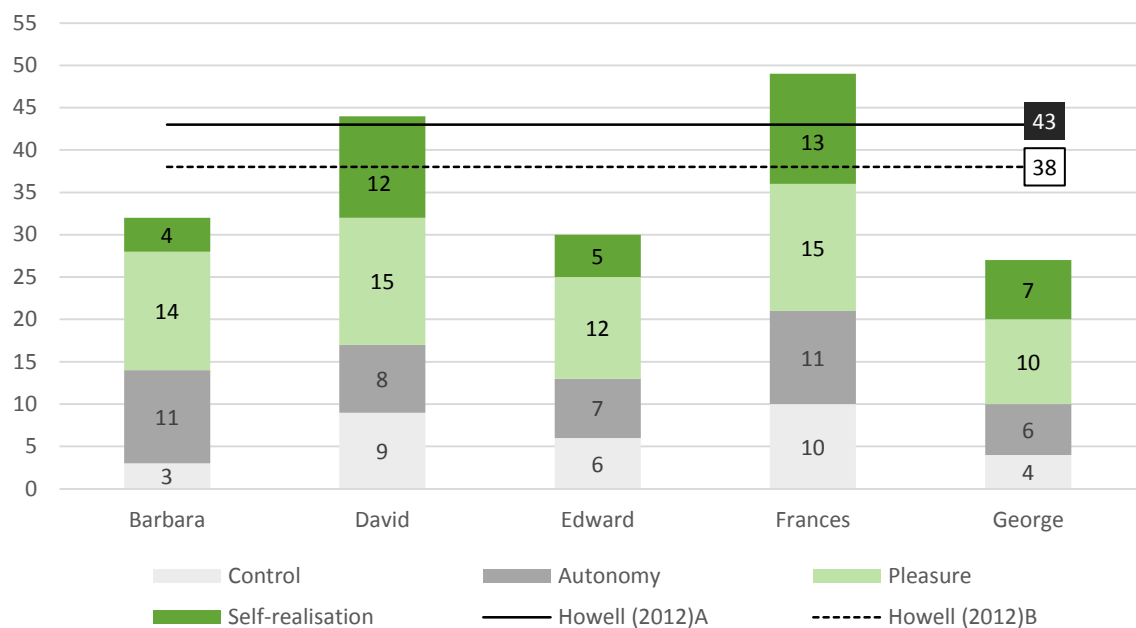
Participant	Control	Autonomy	Pleasure	Self-realisation	Total
Frances	10	11	15	13	49
David	9	8	15	12	44
Catherine	8	10	15	8	41
Henry	7	10	15	7	39
Anne	3	9	12	11	35
Barbara	3	11	14	4	32
Edward	6	7	12	5	30
George	4	6	10	7	27

Table notes: Highlighted figures indicate where participants did not provide an answer on one item within this domain.

Of all the study participants, Frances reported the highest quality of life score, whilst George reported the lowest. This would not have altered even had no data been missing. All participants scored high on the pleasure domain. However, the scores for the three remaining domains are consistently lower for all participants and vary greatly between

participants. Figure 7 presents the CASP-19 responses from participants who completed all items: the two horizontal lines represent statistics from Howel (2012) who reported average (mean) CASP-19 scores from Wave 1 of the English Longitudinal Study of Ageing (ELSA). The scores provide a useful point of comparison for the eight participants in this study.

Figure 7: CASP-19 scores for fully completed measures: stacked column (n=5)



Howel (2012) study used data from English Longitudinal Study of Ageing (ELSA). Sample: n=6,128; aged 50 years and above (25% over 70 years). A: denotes average quality of life score (=43). B: denotes average quality of life score for survey participants with chronic illness (a broad category that subsumes a variety of long term conditions) (=38).

Frances and David scored above the average reported by Howel (2012). The total scores for Catherine (41; with one missing value) and Henry (39; with one missing value) place these participants above this line also. In contrast, Barbara, Edward, and George provided scores that place them below the line. The total score for Anne (35 with one missing value) suggests that she would at best fall on the lower line. The CASP-19 responses indicate differences in the overall quality of life reported between participants and

contextualise their responses within the national picture. In the section that follows I present a series of participant case studies; I present these in descending order of their CASP-19 scores to facilitate comparison.

5.4 Case studies

For each case study, I construct a summary of health, social relationships and environment to reflect the broad themes from analysis and points of comparison. I use the different data to illustrate these findings; integrating data from the interview methods – biographical, photo-elicitation, and go-along – and the life-grids. Where data are reported, and to avoid repetition, data sources are identified using the following system presented in Table 5.4:

Table 5.4 Abbreviations for data sources

Participant	Context of data gathering	
	Stage One	Stage Two (follow-up)
Anne	A01	A02
Barbara	B01	B02
Catherine	C01	C02
David	D01	D02
Edward	E01	E02
Frances	F01	F02
George	G01	G02
Henry	H01	H02

Where conversation extracts are included the interviewer is denoted as 'Int' In some cases, I have edited data extracts for readability in relation to the analytical point being made. Edits were conducted post-analysis and were undertaken sensitively with care not to alter the meaning of the data. During some interviews participants were accompanied by their partners whom I include in the following descriptions. I present the case studies in the order of the CASP-19 scores, beginning with the highest scorer: Frances.

5.4.1 Frances

Figure 8: Timeline for Frances constructed from life-grid

<u>Year</u>	<u>Details of life event</u>	<u>Location</u>
1947	Frances is born: a twin with four other siblings Childhood spent in urban city	Living with family (urban)
1952	Birth: brother is born described as a “ <i>change of life baby</i> ”	
1953	Family relocate to UK coastal town to open a hotel <i>“My mother had poor health... the air... is supposed to be extremely good for bronchial problems”</i>	Living with family (coastal)
1958	Education: Begins secondary school	Moves around UK for work (urban and coastal environments)
1963	Education: Attends catering college Employment: Gains first employment role outside of family business Employment: Frances successfully progresses career through promotions	
1967	Health: Frances experiences low back pain (becomes chronic)	
1969	Marriage: Frances gets married and works alongside husband	
1970	Birth: Frances has a child	Moves back to family home
1973	Loss: Frances and husband separate Employment: Frances leaves job and experiences regression down career ladder Health: Frances has a car crash Health: Frances diagnosed with sciatica	
1981	Loss: Frances’s mother dies Employment: Frances successfully progresses career with promotions	Moves around UK as Frances progresses with career again (urban and rural environments)
1998	Employment: Frances changes job to reduce responsibilities	
2002	Employment: Frances retires	
2010	Relocates to rural environment in retirement – moves with sister	Moves to Village A during retirement
2011	Birth: first grandchild is born	
2012	Birth: second grandchild is born	
2014	Frances agrees to take part in research study	

Living, learning, working within tourist and leisure industry

Figure 8 provides a summary of Frances's life history. Frances is 67 years of age she lives alone in a semi-detached house in Village A. Frances was born in a city in the Midlands (England) and has five other siblings including a twin. Her parents relocated the family when Frances was aged six. The family moved to a coastal town to start a hotel business and also for the benefit of Frances' mother who had respiratory health problems. Frances and her siblings provided support to their parents with the hotel business; she attended catering college and later left the family business to pursue her own career in the leisure and tourism industry. Frances has worked at various locations across England in urban, rural and coastal settings including in the Staffordshire Moorlands; she progressed up to a managerial level role. Frances married in her twenties and had a son; however, her marriage ended shortly after the birth of their son and she has not since remarried. Frances first experienced lower back pain in her late teenage years but continued to work in what can at times be a physically demanding job; she retired at 55 years of age. In retirement Frances and one of her sisters relocated together to Village A; they currently live across the road from one another. Frances maintains an active lifestyle through voluntary activities and roles; she also enjoys several hobbies including gardening and crafts.

"I'm a sciatica sufferer" (F01: Frances, stage one interview) Frances says in the opening line of our interview together. Sciatica is the cause that Frances attributes to her pain: "this has been on and off for 20 years" (F01) although as noted Frances experienced low back pain as a teenager. Frances identifies a trigger point when her sciatica-pain started:

"I know exactly how it started, I'd turned over in bed one night, and that was it. And the pain was excruciating. It was so simple. I couldn't believe it, and I had three years

of it at The Hotel, which was quite a physical job, but I kept thinking it would get better and it didn't." (F01)

Other reasons may have contributed to the onset of her pain but Frances does not explicitly include these in her explanatory framework, for example: the physically demanding nature of the work itself, or a car crash Frances had in her twenties that caused a back injury. In describing her chronic pain Frances identifies its invisibility as challenging:

"You can't actually see anything, because I don't look any different. Erm... I just think... if you had a physical disability, that people could see, it's a given isn't it?" (F01)

However, Frances is physically disabled by her pain; referring to chronic pain as "debilitating" (F01) and through this disability her struggle provides visible signs of pain:

"[T]he sciatica situation, you know, some days you can go in [to work] and it's fine, some days you're just dragging yourself around and it's not pleasant, it's not pleasant for people to see you" (F01).

Frances' pain and related disability fluctuates between a "dull ache [...] I don't let that worry me too much" to a "sharp pain" which can be "breath-taking" meaning that: "I'll be walking and suddenly it'll be there and I can't complete the step" (F01). This type of pain experience has interfered with social events and family trips (e.g. days out on nature walks). To cope with her fluctuating pain Frances is bodily-aware: "I'm more mindful and I sit carefully and do jobs with more thought and more care" (F01). Frances experiences her pain as fluctuating and describes it as occurring in episodic cycles that may last for a

period of months or even years. Frances experienced the ending of a cycle across the two interview times (March 2014 and May 2014). During the stage one interview Frances had been experiencing: “a really bad bout of sciatica this last month” (F01). Frances referred to a 0-10 pain scale (where 0 is no pain; 10 is high pain), describing her pain as numbers:

“On a scale, one to ten, this bout of sciatica has been ten (laughs). Today I would say, I mean it's still there but I'm coping, so I would say it's about maybe four or five. [...] Some days there is no pain at all, but generally I would put in the sort of three to four category.” (F01)

Pain continues to fluctuate within a cycle. By May 2014 the “bout” or cycle had ended enabling Frances to be retrospective about this cycle. Looking back Frances scored her pain between January and March as ranging from 7 to 10/10 this had decreased by May-time to 1 or 2/10. The numerical scale helps Frances to make sense of her pain experience. In terms of her wider health Frances was the only participant not to disclose any existing health problems in addition to chronic pain. Frances acknowledges the fortune of her situation: “I've been extremely lucky really” (F01).

Frances lives alone in a two-storey semi-detached house in Village A. Her sister lives across the road; they support one another in attending social clubs and activities: “I think having two of you is easier” (F01). Frances’ son and family, including Frances’ two grandchildren, live within 55 kilometres of her house and they visit one another monthly. Frances sees the rest of her family infrequently as the majority continue to live in and around the coastal town where her parents had been; both parents have passed away. Beyond the family, Frances attends several activity groups, often with her sister; these take place in surrounding towns (within a 14km radius) and include learning arts and craft

skills. Frances and her sister have befriended members of the activity groups and they arrange social events outside of the groups. Social isolation is a concern for Frances: “I don’t mind living on my own [...] but I’m not an isolated person, I do like to have contact” (F01). During these social activities Frances is reluctant to talk about her pain: “I don’t like to talk about it [...] I don’t think people are not sympathetic, it’s just that you don’t - I don’t feel as if I want to constantly talk about it” (F01). Attending these groups provides Frances with an opportunity for distraction from pain. Frances also uses her art and craft skills to build relationships with others in Village A; she has created a piece of embroidery for the local primary school and made curtains for two of her neighbours. The neighbours have in turn provided help with her garden.

Frances still drives her car, which enables her to access the social groups that she and her sister attend. For long journeys Frances has started to use public transport as this provides her with the opportunity to stand up periodically and stretch her legs. However, Frances drives to the train station (around 35km distance) to use it. Although Village A has good amenities: “we’ve got pretty much everything we need” (F01) it does lack a supermarket, Frances drives to the nearest town (12km) for this, although she has started to do her shopping online.

In terms of quality of life, Frances scored high on the CASP-19 overall (49/57). She scored high on all domains, her score for pleasure (15/15) is her highest and autonomy (11/15) her lowest but this is the highest score of the other participants. That Frances does not experience co-morbid health problems may contribute to this high score; she has also learned to adapt to her pain having experienced it for many years. As Frances also retains the ability to drive she is autonomous in completing tasks that require transport.

5.4.2 David and Diane

Figure 9: Timeline for David

Year	Details of life events	Location
1943	David is born: shares name with 3 previous generations Health: David is injured playing rugby (broken knee cap) "Smashed my kneecap playing rugby" Health: David is injured playing rugby (kidney removed) Employment: misses out on opportunity to sign professional rugby contract due to injury	Living with family on family farm (situated on urban fringe)
1958	Education: Leaves school at 15 ½ years of age Employment: Works with father on family farm	
1962	Loss: David's mother dies	
1965	Marriage: David gets married to Diane	
1972	Have own family house built adjacent to family farm Birth: First daughter born Birth: Second daughter born Birth: Third daughter born (no male heir) Father remarries, David and his father had: "done everything together until he got remarried" David experiences challenging relationship with step-mother, to the point that his father tells him: "There's nothing here for you" Employment: David, Diane and children relocate to Staffordshire Moorlands – starts own farm Health: David experiences knee pain (becomes chronic) Health: David diagnosed with arthritis in knees Employment: farm is struggling and they sell business	Move to own home with new family (situated on urban fringe)
1975	Employment: David becomes a salesman (reconstructs role as "training" for future job) Employment: Becomes a farm advisor travels nationwide	Move to The Moorlands
1985	Employment: Company is purchased, retains job	Purchases and renovates houses in The Moorlands
1992	Employment: Company sells business, David changes job (to work in a warehouse)	
1998	Birth: first grandchild is born	
2000	Employment: David takes compulsory retirement due to knee problems (mobility impaired) Health: David undergoes knee replacement: one of three Health: David experience back pain (becomes chronic)	
2000	Health: David experiences elbow pain (becomes chronic) Health: David experiences hand pain (becomes chronic)	
2008	Moves house to downsize garden	
2011	Health: David diagnosed with diabetes Birth: Second grandchild is born	Downsizes garden in Village A
2013	Health: diagnoses with sleep apnoea	
2014	David agrees to take part in research study	

Figure 9 provides a summary of David's life history. David is 70 years of age he lives with his wife, Diane, in a detached house in Village A. David was born on a farm on the outskirts of an expanding urban town and has lived in rural environments his entire life. David attended school until he was 15 and a half years of age his intention had been to sign a professional sport's contract. However, he was severely injured whilst playing sport resulting in the removal of a kidney; he could not compete professionally and instead worked on his father's farm. David experienced the loss of his mother before the age of 20. In his early twenties he and Diane married. She is of a similar age to David; they have three daughters together. At age 30 David, Diane and their children relocated to the Staffordshire Moorlands and started their own farm business. They struggled to make the business profitable and sold the farm land seeking work opportunities in other industries. David worked as a salesman, a farm advisor, and latterly a factory manager prior to retirement, David had previously volunteered as a member on the local board of governors but he is no longer involved in this role. David was forced to take early retirement due to chronic knee pain. David and Diane have remained in the Moorlands during this time and have profited from property development whilst the value in the area has increased. Six years ago, David and Diane moved to a four-bedroomed house on a quiet estate in Village A; they did so to downsize the garden as David had struggled to maintain the garden at the previous house. Diane attended both interviews with David; they shared in the leading of conversation and so Diane feeds into the telling of David's lived experience of chronic pain. Diane completed the same process of consent as David, as she contributed data.

David experienced the start of chronic pain in his thirties. He has arthritis, which was initially localised to his knee joints; he has undergone three knee replacements: “can’t be any arthritis in me knees. It’s tin. I’ve got rust!” (D01: David, stage one interview). David has developed multi-site chronic pain he experiences pain in his lower back, his elbows and also his hands not all attributable to arthritis. David is undergoing medical investigations to identify the cause of his hand/elbow pain; the initial diagnosis was carpal tunnel but David has since been referred to a neurologist. His multi-sited pain is unpredictable; he rates his pain as fluctuating from a 5/10 up to 10/10 in terms of severity. For example: “at odd times in my legs I get a surging pain [...] when it comes [...] it fetches tears to your eyes” (D01). To make sense of some of his chronic pain he compares it to more common pain sensations describing his hand pain as similar to “toothache” (D01). In everyday experience of pain David is restricted in terms of completing domestic activities from opening a jam jar to mowing the lawn and cleaning out the chicken coop; he still drives his car but he can no longer drive for more than an hour without taking a rest. The combination of pain sites that David experiences prevent him from sleeping in a bed, instead he sleeps in an adjustable chair. He understands his restrictions as a process of “slowing down” (D01); a part of ageing.

The complex experience of chronic multi-sited pain has implications for David’s attempt to understand reasons to explain the onset of such pain. His narratives explore explanations of trigger points: slipping whilst playing racket sports, lifting a heavy door, “smashing” or breaking his knee cap when playing rugby at a young age, and/or a trapped nerve resulting from the removal of his kidney. David also considers whether pain is hereditary and therefore genetic as his grandmother experienced severe pain as a result

of arthritis: “Unfortunately... it’s a bit in-bred” (D01). He also constructs the environment as having a role in the development of his chronic pain:

“And then [I would] spend a lot of time, I suppose, when you were farming [...] you got wet through, and you didn’t bother changing your clothes [...] you let it dry on you. [...] A big brave man. [...] It told in the finish.” (D01)

Within this explanation is the maintenance of a socio-cultural identity as a farmer and a “big brave man”. His wife Diane supports this: “a lot of farmers suffer from that, I think” (D01).

David also experiences additional health problems: diabetes and sleep apnoea. David usually walks with a stick to provide stability; at the time of the follow-up interview David had experienced a fall resulting in bruising around a rib and acute pain. Diane also experiences health problems she has had a knee replacement and her mobility is impaired; she experiences dizziness meaning that she can no longer, for example, complete the supermarket shopping alone. David takes responsibility for this.

Diane is David’s main source of social contact and support. Their three daughters also provide support; the closest of whom lives 12km away. They see each other frequently. The furthest is 50km away, whom they see once a month. Support includes, for example, a daughter will help to hang curtains whilst the son-in-law will mow the lawn. Although David and Diane have downsized, David struggles to control the petrol lawnmower that they have and so cannot complete the task himself. David and Diane provide regular child care for their grandchildren, of which they have three; this is a source of great pleasure for both of them. Outside of the family network, David and Diane regularly attend a local

church as part of a small congregation; although David does this more for Diane than himself, as Diane suggests: “I wouldn’t say we were religious [...] I want to go and he, but I think you support me” (D01). Diane also attends other social groups (e.g. Mother’s Union) but David does not have any other regular social network and his closest friend died recently.

David still drives a car; he is comfortable driving on journeys lasting for one hour but at this point he requires a rest and opportunity to stretch his back. Although Village A has good services David is also able to access services beyond the village under his own autonomy. For example, David travels to the nearest urban centre to do the shopping and has the choice of which supermarket to use. Moreover, he may choose the time of day that he attends the supermarket; he chooses to shop early in the morning to avoid queuing at the checkouts as this can aggravate his back resulting in increased pain.

David scored high on the CASP-19 overall (44/57). He scored high for pleasure (15/15) and self-realisation (12/15) and control (9/12) but low for autonomy (8/15) compared to the other participants. David maintains high quality of life except he experiences diminished autonomy due to chronic pain and related disability that impact upon specific activities (e.g. mowing the lawn, cleaning out the chickens). These activities may have important life-course connections; yet, as he accepts his limitations as part of a process of slowing down this may act to protect his sense of the other CASP-19 domains.

5.4.3 Catherine

Figure 10: Timeline for Catherine

Year	Details of life events	Location
1923	Father serves in trenches in World War I (1914-1918) Catherine is born: oldest of three children Father works finance sector, mother as homemaker Living in “nice family home” in urban city Childhood included 2-week family holidays each year	Living with family in family home (urban city)
1934	Education: attends grammar school	
1939	Education: attends 6 th form college “We were evacuated to different people’s houses” “We’d sooner got back (home) for the summer holiday then the bombs started to fall... We just sat the bombs out”	
1941	Education: attends teacher training college Education: evacuated to a shared room with 7 others “I’m still in touch with two of the eight of us”	
1948	Moves abroad to undertake voluntary work (Africa)	South African township
1963	Employment: returns to home city and starts teaching Loss: father dies Purchases cottage in the Moorlands (visits cottage at weekends)	Lives with family in family home (urban city)
1968	Headmistress at new school in home city	
1980	Employment: City Council restructuring of schools – leads to relocation to 3 different schools in 12 months	
1981	Employment: Accepts early retirement	
1989	Loss: mother dies	Living in Village C cottage
1993	Loss: sibling dies	
1999	Health: experiences heart attack hospitalised “I’ve been getting older ever since”	Downsizes but remains in Village C
2004	Sells cottage to move next door	
2011	Stops taking nature walks “I used to go up the road every morning before breakfast” Health: hospitalised to have hip replaced following “excruciating” pain Health: reports muscular pain (becomes chronic)	
2012	Health: diagnosed with macular degeneration	
2013	Health: develops bunion experiences soreness Catherine agrees to participate in the research study	

Figure 10 provides a summary of Catherine's life history. Catherine is 90 years of age and lives alone in a cottage in Village C. Of her age she says: "there's something about real old age, you don't have to try and hide it" (C01: Catherine stage one interview). Catherine was born in a city in the Midlands (England); she has two younger siblings, one of which is still alive. Catherine's school years were interrupted by World War II; she describes having been evacuated on more than one occasion from secondary school and again from college. She shared stories of sitting out bombing raids and inspecting the damage the following morning. Catherine attended teacher training college and worked as a teacher for almost 40 years within the city of her birth progressing up to headmistress. During this time Catherine purchased a cottage in Village C, she spent time at the cottage on weekends gardening and walking among nature and hosted visitors including church youth clubs. Catherine is a Christian and she values her religious faith. Catherine was removed from her post as headmistress during the merging of two schools and relocated to three other schools within a 12-month period; after which Catherine accepted early retirement. Throughout her life-course Catherine has committed her spare time to charitable work with local youth clubs, church groups and Christian missionary work. Post-retirement and following the death of her mother, with whom Catherine had been living with, Catherine relocated permanently to her cottage in Village C. Catherine continued to provide accommodation to visitors and developed a large contact network through doing this. Ten years ago Catherine downsized to a smaller cottage in the same village.

Catherine has a complex history of chronic pain which minimises the impact of current pain experiences. In her seventies Catherine experienced hip pain that was "excruciating

[...] like [like] a saw-edged bread knife" (C01) she had a hip replacement; she has also experienced polymyalgia in which "everything aches" but this has since ceased. The current experience of chronic pain started three years ago and is a muscular pain she feels in her bottom; Catherine recalls a Medical Practitioner describe to her: "[the] muscles in your bottom try and compensate for the fact that there's something wrong at the bottom of the spine" (C01). Catherine understands the cause as resulting from wear and tear and is aware of the potential damage caused by everyday use of her joints: "presumably you're using that bit of your spine so much [...] every time you sit down, aren't you?" (C01). Putting this process into her own terms she refers to her spine as: "I should think it's crumbling" (C02). However, she acknowledges that an explanation of pain: "doesn't interest me. When I say it doesn't interest me, I mean I can't be bothered somehow" (C01); perhaps Catherine accepts her pain.

Catherine does not recognise the word 'chronic' as it is medically defined but in a colloquial sense: "I thought chronic equalled excruciating." (C01). Catherine is familiar with excruciating pain; this is not how she would describe her current pain which is an "aching" sensation. Catherine also associates her pain with a specific room in her house; the kitchen. This is because standing for long periods of time causes her pain to increase; during the day she may need to stand in the kitchen to prepare a drink or a meal. This has negative implications for Catherine's capacity to cook for herself and so she eats mainly ready-meals: "I'm sure they're perfectly good food [but] I hate them. I think it's because I resent them" (C01). Catherine uses her religious faith to cope with her pain and put it into perspective:

“I do not escape [...] the aches and pains of humanity. [...] We wouldn't know what it meant to be human if we didn't know what pain or sorrow or whatever else was, would we?” (C01)

Catherine has experienced additional health problems; for example, she had a heart attack at age 70, has been diagnosed with macular degeneration and as a result she had to give up driving, she also has a large bunion, a swelling that rises about one inch, on her right foot which can be a “nuisance” (C01). Catherine is undergoing investigations for fatigue:

“At the moment I've got appointments for blood tests, because there may be something – well, they've told me ages ago my kidneys weren't very good, but they'd last me out” (C01).

Catherine uses age to legitimise her multiple health problems as well as her faith:

“I'm so amazingly fortunate and blessed [...] I've got this far and this is all that's wrong with me [...] There's nothing wrong with my hearing. Well, I mean there's, you know, a little bit of old age, but there's nothing really wrong with it. [...] I don't feel sick. I don't feel poorly. I don't get headaches ever.” (C01)

Healthcare practitioners reinforce fatigue as age-related: “You don't feel full of energy; at least I don't. [...] I did mention it to the doctor and he said, 'You are 90, you know!'" (C01).

Catherine lives alone. She has never married and does not have children; her closest family member is her brother approximately 90km away. An extensive social network provides Catherine with support: members of a church group, a gardening group,

residents in Village D, and also various people that have stayed at her previous cottage. Catherine shares relationships with people who provide her with general services. For household chores: "I don't do any housework. I couldn't. The treasure does that" (C01) she receives help from "the treasure" (a local woman) and has done for over 12 years. For gardening, a man in the village maintains Catherine's garden she has invited him to use her vegetable patch for his own family as she can no longer tend to it. For post, Catherine shares an understanding with the local Postman as she can no longer walk to the post box in the village she leaves her letters in her letterbox for the Postman to collect when he delivers her mail each day. Catherine wears a home assistance buzzer for emergencies. Catherine does feel part of the community in Village D: "Yes I do and I would say that the village would agree" (C01) however that sense of connection has diminished. She only sees her neighbours infrequently: "I really don't have any contact with them" (C01). The centre of Village D is approximately 250 metres from her house; due to physical impairments she can only manage a distance of approximately 50 metres.

Relocating to Village D was driven by Catherine's affection for nature; Village D represented a location for leisure whilst she was working in the city. She moved to the village permanently aged 68 years. However, now in "real old age" Catherine can no longer walk and explore nature as she has given up driving, gardening and no longer takes walks in the countryside. As there are limited services available in Village D Catherine requires transport to access shops. She has come to depend on a Council funded bus service: "it would have been very hard if it hadn't been for the bus" (C01). To attend social groups Catherine relies on others that are attending to provide her with transport.

Catherine scored high on the CASP-19 for overall quality of life (41, with one response missing); she scored high for pleasure (15), and relative to other participants moderately high for control (8) and autonomy (10). However, she scored low for self-realisation (8) and did not answer an item in this domain ('I feel that the future looks good for me'); this will be explored in Chapter Seven. The impact of health impairments on her ability to garden, maintain contact with nature, cook for herself and confronting end of life ("kidneys will last me out") may support this score.

5.4.4 Henry and Helen

Figure 11 (on next page) provides a summary of Henry's life history. Henry is 78 years of age he lives with Helen, his partner (not married) in a detached house in Village B. He was born in a village on the outskirts of an urban centre in a county that neighbours the Moorlands. Henry is an only child; he left school at 16 years of age to work on a local farm. He then worked for local government ploughing and tilling sites using: "tractors on tracks where the farmers couldn't get [to]" (H01: Henry stage one interview). Subsequently, Henry worked in transport and distribution. He did this for 30 years progressing to a managerial role which he enjoyed although: "there was a lot of paperwork" (H01). Henry married in his early twenties; however, after 30 years of marriage they separated Henry was 55 years of age at this time. Henry and his wife did not have children, although Henry did want them. Shortly prior to the divorce Henry's father died; this remains an emotional topic for Henry to talk about. Henry began a new relationship with a childhood friend a year or so later, Helen. The couple purchased a pub in the Moorlands which Helen managed; Henry continued to work in transport.

Figure 11: Timeline for Henry

Year	Details of life events	Location
1936	Henry is born (only child) Childhood spent in village on outskirts of large town	Living at home with parents (rural on urban fringe)
1952	Education: leave school at 16 years of age	
1957	Employment: works on local farms Employment: begins role with local government: "similar to farming... plough the land"	Living with wife in same area as childhood (rural on urban fringe)
1959	Marriage: Henry gets married Employment: Henry works in transport and distribution	
1973	Company wins a European Award Employment: Henry promoted to Transport Manager "I used to have three phones on my desk"	
1990	Loss: Henry's father dies	Living in The Moorlands between Village E and presently Village B
1991	Loss: Henry and his wife separate	
1992	Henry purchases a pub business with new partner (Helen)	
1996	Employment: Henry is made redundant from Transport Manager role	
2002	Henry and Helen sell pub business: "hard work"	
2009	Employment: Henry drives minibuses for local company	
2011	Health: Henry is hospitalised with fluid on the lungs Health: Henry is hospitalised with shingles Health: Henry experiences pain (becomes chronic)	
2013	Health: Henry diagnosed with Prostate Cancer Receives radiotherapy and has 3-monthly injections Health: Henry diagnosed with Chronic Obstructive Pulmonary Disease	
2014	Henry agrees to take part in research study	

Continues to work:
passionate about working with large machinery (passionate about driving, pride in area)

They ran the pub for 10 years during which time Henry was made redundant from his transport job; running the pub was physically demanding: “we was getting worn out” (H01). Henry and Helen sold the business in the early 2000s and moved to a detached four-bedroom house on a housing estate in Village B. Henry now works as a bus driver often working in excess of 30 hours per week. Helen did not attend the interviews and so her voice does not feature in the data for Henry.

Henry experienced the start of his chronic pain three years ago at the age of 75 following “a very, very bad attack of shingles” (H01). The pain is localised in a two-inch band at Henry’s waist, circling from his abdomen around to his back and then leading up his lower back. The site of chronic pain corresponds with the location of the blisters and rash that Henry experienced during his “attack of shingles”. When describing his pain Henry frames his pain experience in the context of more common pain experience:

“I don't get the stabbing pains. It's just [...] like a continual tingle. I think the nearest thing to it, for you to know, it would be sunburn.” (H01)

Later in the interview, Henry elevates the status of the comparison to “bad sunburn” (H01). However, Henry’s chronic pain exhibits different characteristics to sunburn:

“I can touch it. I can mess about with it. But it’s on the inside, you know tingling, and they say you can have it for years.” (H01)

The experience of sunburn corresponds with Henry’s life-course experiences; Henry shares narratives about holidays in hot countries and describes how he is vulnerable to sunburn because of his skin tone. He also talks of his pain as intermittent:

“I'd be sat here watching telly at night and all at once it would kick in and uhh... almost made you want to cry” (H01)

At night it may disturb his sleep: “it'd wake me up in night stabbing, terrible” (H01). At its peak during the shingles episode Henry reached a point of crisis:

“I was in a real mess... I mean they [health services] got me when they [shingles] was at the height, as I didn't know what I was doing” (H02: Henry, stage two go-along)

Henry was hospitalised at this point for shingles. Currently, Henry's pain has eased and he has greater control over his activities: “I've been doing more walking and exercising” (H01). The experience of shingles occurred during a period of deterioration in health. The year 2009 seems to represent a starting point in terms of a downturn in Henry's health: “I never knew what illness was until 2009” (H01). He was hospitalised with fluid on the lungs, and since then he “had erm prostrate [sic] problems, well, cancer actually” (H01) which he was “gutted” (H01) about, and has also been diagnosed with Chronic Obstructive Pulmonary Disease (COPD).

As Henry does not have any family of his own the main source of support he receives is from Helen. During his health crises Helen provided stability and strength:

Int: Was Helen a good help when you were struggling with pain?

Henry: Oh, she was. She's a brick... I think I was a difficult person to live with, anyway, you know, when I'd got so much pain.

Int: How did she handle you?

Henry: Well, it got her down a bit as well you know, which were my fault. (H02)

In addition to this, they both enjoy taking annual holidays abroad sometimes with Helen's family; they also eat at fine-dining restaurants in and around the Moorlands. Henry shares camaraderie with his work colleagues, they run errands for one another; during the go-along Henry parked outside of his place of work and exited the car: "I'm just going to drop my mate's paper off" (H02). He also maintains routines outside of work as he frequents a pub in Village B at the end of his working days, unless he is working again the following day. Helen does not accompany Henry to the pub on these occasions. Henry talks with friends at the pub about his health, specifically his pain:

"Me friends will say, 'how are you going on?' and I'll say, well, I've still got the pains you know, and I mean they can't believe it that it's been going on for so long." (H01)

Henry uses his experience as a lesson for his friends: "I always said to them make sure you go and have an injection [to prevent shingles] 'cause I wouldn't wish it on my worst enemy" (H01).

Henry exhibits immense pride in The Moorlands; as evidenced by his enthusiasm during the go-along (see Appendix 16a for description of the go-along). Both Henry and Helen still drive they also have two cars between them therefore services such as the GP service beyond the village remain easily accessible to them. The nearest supermarket is located in a town 8km away. In terms of quality of life, Henry scored fourth highest of the participants on the CASP-19 (39/57). However, Henry did not answer one of the items ('I feel that the future looks good for me') in the self-realisation domain; this will be explored in Chapter Seven. Relative to the other participants, he scored moderately for control (7/12), low for self-realisation (7/15; one missing value), high for autonomy (10/15) and pleasure (15/15).

5.4.5 Anne

Figure 12: Timeline for Anne

<u>Year</u>	<u>Details of life event</u>	<u>Location</u>
1931	Anne is born: youngest of four children; only child of mother's second marriage Anne describes being a child during World War II: "We had to scrap and scrape"	Living in family home with parents – 3 miles from Village D
1947	Education: Leaves school at 16 years of age Employment: Works locally: "in service" (domestic assistant role)	
1956	Loss: sibling dies	
1957	Marriage: Anne gets married and moves into a house with her husband's parents Employment: Anne gives up work	Living in house in Village D – remains here up to present day
1963	Loss: Both of husband's parent die Birth: Anne has two children Loss: Anne's father dies Health: Anne diagnosed with diabetes	
1993	Loss: Anne's husband dies	
1996	Loss: Anne's mother dies	
2001	Health: Anne reports chronic pain to have started at this point Health: Anne hospitalised to undergo knee replacement Health: Anne diagnosed with arthritis of her spine Health: Anne diagnosed with macular degeneration	
2012	Health: Anne is hospitalised for heart valve replacement Health: Anne experiences an infection of wound whilst in hospital: "all hell broke loose"	
2013	Health: Anne registered partially blind Health: Anne continues to receive home visits for heart wound to be redressed (12 months' post-operation) Loss: Anne's sibling dies Anne agrees to take part in research project	

Figure 12 provides a summary of Anne's life history. Anne is 82 years of age and lives alone in a terraced house in Village D. She was born in a village in the Moorlands and was brought up in a household with three older siblings during war time. The family experienced difficult times having to: "scrap and scrape and do [...] run errands for people, for try and get a penny" (A01: Anne stage one interview). Anne left school at 16 years of age to work in service providing domestic assistance for a local family. In her early twenties Anne married and ceased paid employment to have a family: "I've got two sons and they were both born here" (A01). Her marriage spanned almost 40 years prior to her husband's death, which came only a short time after he had retired. Providing informal care defined much of Anne's life as she provided care for family members: parents-in-law, brother-in-law, her husband and finally her mother, "I looked after them 'till they died" (A01). The last person Anne provided care for was her mother; Anne now lives alone.

Chronic pain started in Anne's left knee at the age of 70: "And then of course I've never been free from it" (A01). She has had two knee replacements but her chronic pain has since developed in other sites of her body: hips, lower back, shoulder and hands. When asked to describe her pain Anne struggled to find the right words:

"It's a funny thing to try and explain pain, sometimes it's worse than others, I can't really tell you, I mean I'm alright when I'm sitting but the moment I get up it starts, you see, and when I come to walk." (A01)

She finds it difficult to articulate pain; this may be due to its fluctuating nature. Anne attributes the cause of her pain to arthritis, which has subsequently led to structural changes: "arthritis in the spine. It's curving at the bottom. I think [...] that's causing all the

pain” (A01). The type of arthritis that Anne has is osteoarthritis although she refers to the disease only as “arthritis” suggesting unfamiliarity with medical language. What is familiar for Anne is a process of wear and tear:

“They [the medical practitioners] say it’s ‘wear and tear’. It’s old age I reckon, when it’s all said and done (laughs) [...] You’ve done so much and it’s wearing your bones out and that, you know they all turn round and say ‘it’s wear and tear when you’re getting old’.” (A02: Anne stage two go-along)

Wear and tear, ageing, and pain form part of the same process and explanatory framework for Anne. Chronic pain represents a source of restriction for Anne her mobility is impaired and she walks with the aid of two sticks. Domestic tasks are difficult: “I can just stand at the sink and wash up [...] and it’s killing me for finish washing up” (A01) she has to sit down to dry the dishes. Experiencing restriction may be a source of agitation, even anger, for Anne: “I do get a bit cross... especially when it’s very bad” (A01). Such experiences may also negatively impact her mood and sense of self:

“It has changed me really, because I can’t do what I want [...] when I get it [pain] I can say “oh God” it gets me down, it gets me down, I sit, I sit and I have a cry [...] I think well what’s good of crying? I’ve got to put up with it...” (A02)

Anne endures her pain and she is resilient as she picks herself up from such low points to carry on. Anne also presents stoicism: “I thought, well why should I bother [moaning]? I’m old. That’s it. I think to me self, well that’s what comes with old age” (A01). Such stoicism (and ageism) may deny her own suffering as she seeks to maintain control of her emotions.

In addition to chronic pain, Anne experiences a complex set of health problems (see Table 5.1; p148) these cause multiple physical impairments (i.e. mobility, finger dexterity, vision). Anne also has a surgical wound that requires redressing three-four times per week; a home care nurse visits Anne to do this and has been doing this for over 12 months. Anne prioritises her heart condition, as revealed here:

“As soon as ever they've finished with me at Hospital A over this heart job I'm going to go back again to Hospital B to see what they've got to say about it. Tell them I can't stick it any longer. But [...] well is it worth it? I'm getting old. But you shouldn't have to suffer pain even if you are getting old, should you?” (A01)

Anne identifies her own suffering and here posed a moral question about it.

Anne lives alone and has experienced significant loss in her life but she has access to a social network comprising mostly of family. One of her son's lives with his two step-children in close proximity: “They live just up the road now” (A01). Her son works night shifts but “he calls every night as he goes to work to see if I want anything and then at weekend” (A01). Anne has seven grandchildren but only sees two of her granddaughters on a regular basis as they live in a nearby town (just over 14 km away) and often visit at weekends. Anne receives support from her extended family too, specifically her nephew and great-niece: “he comes once a week to take me shopping or do me garden or anything like that and his daughter, she comes and does my cleaning once a week” (A01). The contact that Anne has with her neighbours is minimal: “I don't see neighbours,” however she feels sure in times of crisis: “if I wanted them, they'd be there” (A01). The nurse who redresses her wound is also a source of regular contact but she will stay only briefly: “just depends how much writing they do, sometimes they're here perhaps quarter

of an hour and other times they perhaps here only five minutes” (A01). Anne admitted: “I don't have many visitors, but I quite like it that way [...] I like to be independent” (A01). Asked if she feels lonely, Anne replied: “sometimes I feel very lonely. And other times, well why should I be lonely? I can get out, I know it's a struggle [...] but I can get out” (A01). Anne attends local social groups organised by a third sector organisation; these include a weekly luncheon club and a fortnightly friendship group. Both of these groups meet in a hall in Village A (around 4km away) to get there Anne is dependent on transport provided by the organisation as she cannot drive. Anne participated in a go-along; she chose to go shopping to a local town (a description is provided in Appendix 16b).

Ageing in a rural place Anne has lived her entire life within a 5 kilometre radius and resided in her current house in Village D for more than 50 years: “Me husband was born here, it was his house” (A01). Anne is determined to remain in this house such is her attachment to it: “[If] I go out [of] here, I go out feet first” (A01). The house is a two-storey, three-bedroomed terraced house located in Village D (part of the row described in 5.2.4). The combination of Anne's restricted mobility and the lack of services in Village D mean that she is dependent on other people, usually family, to provide her with transport to access routine services such as supermarket (around 14km away) or her GP (around 4km away). The public transport within Village D is limited in terms of times of availability, the destinations that it serves, and also accessibility for Anne: “I don't think I dare venture on the bus now on me own” (A01). The alternative is to pay for a taxi but, since “they've knocked all these subsidies off we've got to pay full fare” (A01), so the cost of such transport can be prohibitive.

Anne's quality of life may have been affected by her health problems. On the CASP-19 Anne scored relatively low for control (3/12), moderately high for autonomy (9/15) and high for self-realisation (11/15) and high pleasure (12/15, one missing value) for the item: 'I feel that my life has meaning') compared to the others. The missing item will be explored further in Chapter Seven. The complexity of her health and consequent impairments may explain Anne's low overall score (35/57) and her low sense of control and diminished autonomy.

5.4.6 Barbara

Figure 13 (on the next page) provides a summary of Barbara's life history. Barbara is 78 years of age and lives alone in a bungalow in Village A. She was born in a village in the Moorlands; she had a brother who died tragically when she was in her late teenage years: "my brother was killed [...] I've been on me own since then" (B01: Barbara, stage one interview). Barbara has lived in the Moorlands throughout her life and identifies herself as a "country girl" (B01) revealing a connection to the rural environment around her. Throughout her life Barbara has worked in various jobs many of which were physically demanding; she retired in her mid-60s and her last job was as a delivery driver on a part time basis. Barbara described how work as a delivery driver kept her in contact with other people: "I knew a lot of people round here, because I used to travel around here every Tuesday every Saturday" (B01). Barbara has been married twice before; both husbands have died. Barbara has three daughters from her first marriage and they all live within a radius of approximately 39km from Barbara's current house.

Figure 13: Timeline for Barbara

Year	Details of life events	Location
1935	Barbara is born: one of two children Experience of war: a relative served in armed forces, camp for allied forces was located nearby and visible	Living in family home with parents in The Moorlands
1951	Education: Barbara leaves school at 16 years of age Loss: Barbara's only sibling dies (under the age of 20) Employment: Barbara worked in local factory	
1956	Marriage: Barbara marries first husband Birth: Barbara has her first daughter Birth: Barbara has her second daughter	Living in own home with new family in The Moorlands
1970	Birth: Barbara has her third daughter Loss: Barbara's first husband dies	
1995	Marriage: Barbara marries her second husband (a farmer) Employment: Barbara works on the farm Loss: Barbara's father dies Loss: Barbara's mother dies Loss: Barbara's second husband dies	Living on a farm in The Moorlands
2000 2002	Employment: part-time delivery driver Sells the farm to late-husband's children Purchases bungalow in Village A	Moves into a bungalow in Village A
2009 2013	Barbara's daughter gets her a pet dog Health: Barbara experiences pain in her hands (becomes chronic) Health: Barbara experiences pain in her shoulder Health: Barbara reports pain in her feet Health: Barbara reports pain in her knee Barbara agrees to take part in the research study	

Barbara started to experience pain at the age of 73-74 years; this first occurred in her hands but has since extended up to her shoulders and she also describes pain in her knees and feet which has become chronic. Barbara has arthritis but she is unsure of the exact diagnosis, when asked to clarify she responds: "I don't know what it is" (B01) but what she does say is "I'm screwed up with rheumatism" (B01) which is used in the colloquial meaning of the term (not rheumatoid arthritis). When describing her pain Barbara uses figurative language: "Oh it's vicious it's [...] a knifey pain. [A] knife what someone's digging into you." (B01). She suggests that she is vulnerable and powerless as she anthropomorphises her pain:

"It's in me feet. It's in here, shoulders... sometimes it gets me [...] here in me knees and everywhere. It's everywhere really, but it's not all of the time, it just gets me when it feels like it." (B01)

Pain is out of Barbara's control and fluctuates, as she suggests: "me hands' (are) hurting me" (B01). I observed Barbara being 'stabbed' by pain as she stretched her hand around her back to point to the location of her pain: "I've got, something, *arrggh* [screams and makes a facial grimace] round me back now, I can't turn" (B01). The pain Barbara experiences is restrictive, for instance: "You get up in morning, and you want to do something, and all of a sudden you can't" (B01), her mobility is limited and she walks using a walking frame for support. The pain and swollenness of her fingers has reduced her finger dexterity as evidenced by her struggle to open the arms of her glasses to put them on: "come on you stupid things" (B02, stage two photo-elicitation). The sense of restriction has had additional impact on Barbara's sense of self: "I've changed because I've always been a person what would help anybody, and I can't now" (B02).

In attempting to understand the onset of her pain Barbara reasons that it may be hereditary and that to believe otherwise would be naive: “My father’s crippled with it, and it runs hereditary in the families and I’m the one what’s got it” (B01). Barbara passively accepts her pain but singles herself out as a case of misfortune realising that she may herself become “crippled” by pain. Previous work roles are also integrated into explanations for pain:

“[It] was heavy work, and this is what’s done my, I’m sure, this is what’s done my hands now... I mean, I’m probably wrong saying that, but lots of people who I’ve worked with, they’re the same as me [...] I don’t know whether it is or not, shall have to put up with it.” (B01)

The experience is corroborated by former work colleagues. Shifting the onset of pain as “heavy work” related provides an opportunity for Barbara to assume a collective identity.

Barbara describes a history of falls but did not disclose any additional health problems these were revealed through the assistive aids I observed: *‘Beneath Barbara on the armchair was an absorbent sheet’* (Fieldnotes). The use of an absorbent sheet indicates incontinence. The experience of chronic pain that limits mobility is likely to exacerbate these difficulties.

Barbara lives alone, although she shares her house with her pet dog: “Oh, she’s wonderful!” and her “best friend, the television” (B01). Barbara can no longer walk her dog; this has physical health implications for her and the dog but also social implications as Barbara would have met people whilst walking locally. Family is important to Barbara: “I like my family around me [...] but [...] they haven’t got the chance” due to their busy

lives. The family member Barbara sees most often is her daughter who owns a food shop; Barbara drives 19km to see her and buy food most days. The other daughters visit and take her out but predominantly keep in contact by telephone; which has become routine: “girls are checking on me” (B01) Barbara says as she lifts the telephone receiver to answer it during the stage one interview. Barbara has five grandchildren; photographs of them are displayed on her living room wall, but she does not seem to see these regularly. Carers visit twice a day to help Barbara wash and dress: “I couldn't manage without them” (B01) she says. Barbara does attend a luncheon club provided by a local third sector organisation; however, she discloses only doing this to satisfy her daughters. Of her neighbours, Barbara indicates a lost sense of connection:

“These [indicating the house to the left] I used to look after are dead and gone, that's empty. This one here [house to the right], I probably see him once a week that's about all. But the one down below again is a very good friend to me” (B01)

Her good friend also experiences pain and Barbara describes commonly sharing a joke with her; this reveals a sense of shared experience and empathy. Barbara indicates: “unless you've got that pain nobody understands” (B01). Barbara expresses difficulty in sharing her experiences of pain with family members, of her daughters she says: “They know I'm in pain” (B01). However, knowledge does not confer understanding: “even my daughter [a nurse] doesn't understand me... she'll say, ‘no, I understand mum’, but she doesn't” (B01). Not being understood is a source of angst: “If there's somebody [who] doesn't understand me, who I'm talking to, that does me worse” (B01).

Barbara moved into her bungalow after retiring; her choice of house was in part driven by the availability of local services in Village A. Barbara depends on her ability to drive, for

example to attend the GP service (less than 1km away) and use the pharmacy. However, her ability to drive is deteriorating: “I only go out in my car if I feel sure (and) have confidence to control my steering” (B01). Pain has reduced Barbara’s mobility inside and outside of her home. As stated, she does drive to visit her daughter in her shop although this is in a neighbouring village it remains 19km in distance and the route comprises narrow winding lanes. There is a supermarket located in a town that is only 13km away. Barbara does not use the bus service as she cannot walk to the bus stop due to pain-related disability.

In terms of quality of life, Barbara scored relatively low on the CASP-19 overall (32/57). She scored low for control (3/12) and self-realisation (4/15) this is likely to be due to the impact of health problems on her control in her environment and the affect pain has had on her sense of self. However, she reported high autonomy (11/15) and pleasure (14/15) compared to the others.

5.4.7 Edward and Ethel

Figure 14 (on the next page) provides a summary of Edward’s life history. Edward is 81 years of age and he lives with his wife, Ethel, in a detached house in Village A. He was brought up in a city in the Midlands (England). Edward is well educated and he attended a Grammar school, studied at university and obtained a professional teaching qualification. He completed two years of national service, referred to in the UK as conscription (1939-1960). After this, Edward worked as a teacher at various schools in locations across southern England progressing to headmaster. He completed two years of national service, referred to in the UK as conscription (1939-1960).

Figure 14: Timeline for Edward

<u>Year</u>	<u>Details of life events</u>	<u>Location</u>
1932	Edward is born	Living at home with family (urban city)
1943	Education: attend a Grammar School	
1951	Education: attends University to study music	Moves between locations as employment changes (urban)
1956	Conducts two years of national service	
1958	Employment: commences first teaching role at a Grammar School	
1960	Marriage: Edward gets married to Ethel Birth: Edward's first child is born Birth: Edward's second child is born	Moves to rural location with family
1962	Employment: Edward moves schools to be appointed Head of Department	
1974	Employment: Edward is appointed Deputy Head at same school	
1987	Loss: Edward's mother dies	Coastal town Relocate to Village A in retirement
1990	Birth: Edward's first grandchild is born (one of six)	
1992	Employment: Edward retires as School Master Edward and Ethel relocate to a new house by the sea	
2000	Edward and Ethel relocate to Village A to be nearer to children Health: Edward is diagnosed with Barratt's Oesophagus Health: Edward is diagnosed with high blood pressure Health: Ethel experiences a bad fall and Edward provides informal care from this point) "lifting the wheelchair out of the car boot has become difficult"	
2010	Health: Edward experiences pain in his hip and lower back (becomes chronic) Health: Edward diagnosed with osteoarthritis	
2011	Health: Edward experiences a fall Health: Edward undergoes medical tests for unexplained symptoms labelled as "Parkinsonism"	
2014	Edward agrees to take part in the research study	

Volunteers as organist at local church

Edward and Ethel have two children and a grandchild. Edward retired at the age of 60 years after which time he and Ethel relocated to a coastal area in Wales. Edward and Ethel subsequently relocated again 10 years later to live where they do now on a housing estate in Village A. Ethel was present in the room for Edward's interview but she had a minimal role in conversation, although Edward often tried to include her.

Edward started to experience pain at the age of 78 years that became chronic; he has been diagnosed with osteoarthritis that affects his lower back and hip. Edward does not automatically associate osteoarthritis with his experience of pain: "I don't know whether it's arthritis that's causing me pain or not..." (E01: Edward, stage one interview) but he recognises that the sites of his arthritis correspond to the location of his pain. Edward describes his pain as a "dull ache" and his experience of pain leads him to question the medication that he receives:

"Yes erm [clears throat] two of the tablets that I'm on are specifically for back spasms. Well I don't really get spasms, I just get this dull ache, you know? I don't get a sudden shot that makes me jump or anything like that, it's just aching." (E01)

He rejects the term 'spasm' as this does not correspond with his interpretation of pain. The dull ache is sufficient to impair Edward's mobility, restricting him when he attempts to stand up:

"There are times when I can get up from here and walk through to the front door, or where ever, perfectly well, slowly perhaps, but not in pain. But there are other times just to get up on my feet can be hard work." (E01)

Chronic pain fluctuates in Edward's experience it may or may not be present at every attempt of the same activity. This experience of impaired mobility can be a source of agitation for Edward, he is stoic in his response to it: "[I] just bite my tongue" (E01). He understands his own limitations as being part of the ageing process: "I know I've got my limitations erm... (sigh) I suppose like anyone else of my sort of age" (E01).

In addition to pain Edward experiences other health problems including Barretts Oesophagus and has had a number of falls in his home; this has subsequently resulted in clinical investigations and referral to a falls intervention programme. A medical practitioner has labelled Edward's symptoms as "ParkinsonISM" (E01, Edward adds emphasis). The label and associated implication of suspected Parkinson's Disease causes Edward distress. Ethel has also experienced deterioration in her health following a fall six years ago; this has severely limited her mobility and capacity to complete household tasks. As a consequence, Edward takes on most of the domestic responsibilities something he may not have been used to previously. For example, Edward provides all of the cooked meals on a daily basis:

"I used to enjoy cooking a meal when it was once a week and [a] Saturday and my turn but when it becomes a virtually daily requirement it wears a bit" (E01)

He also provides assistance to Ethel who uses a wheelchair when outside of the home; this is getting progressively more challenging: "we push it along this long path which is about 100 yards I would say and seems to get longer every time I go" (E01). They pay to receive help in the home from a cleaner and also a former farmer to maintain the garden as for Edward: "slumping along behind a petrol mower is not an option anymore" (E01).

Edward and Ethel provide support to one another on a daily basis; beyond this relationship their two children are their main source of support. Edward and Ethel relocated to Village A to be closer to their two children as previously they lived 350km from their nearest child; currently they live 150km from their nearest child. Edward still drives a car, but it has been a while since he and Ethel drove to visit either of their children. Instead, their children visit Edward and Ethel but this usually takes place in school holidays as their son has a child in school and their daughter is a teacher. During school term time their children keep in touch via telephone and sometimes by email. Outside of the family Edward and Ethel describe a limited social network; they attend the local church, Ethel goes for a coffee morning with a neighbour on a “fairly regular” basis (E01). Edward is not socially active: “I used to be quite good in conversation but I tend to leave it to other people these days” (E01). For much of the interview Edward responds to questions in short, often monosyllabic, responses. Of the gardener Edward describes how: “he just talks [...] aimlessly, pointlessly and boringly” (E01). Edward does not seem to share a sense of connection with the surrounding community: “it’s a funny [...] old community” (E01). Despite these experiences their neighbours provided assistance during an emergency situation. When Ethel fell she cut her head which then bled onto the living room carpet, Edward says “[the] lady over there [indicating neighbouring house] cleaned it all up and made sure the house was all secure” (E01) and the neighbour’s husband also accompanied Edward and Ethel to the hospital.

Village A has good services; however, Edward can only access these through his ability to drive a car. For example, the walk from the house to the GP Service is less than 100 metres but Edward acknowledges that he uses the car to complete this journey: “I feel a

bit, what you might call ashamed about it. I should be able to walk it but I can't, so there you go..." (E01). Edward uses the car to access the supermarket in an urban centre around 12km away. Relocating to Village A brought them closer to their family and they were a manageable distance away; however, as health has deteriorated that distance has become challenging, limiting the support available to them. Edward uses online shopping services but only rarely.

In terms of quality of life, Edward scored low on the CASP-19 overall (30/57). He scored highest for pleasure (12/15) but low for control (6/12) autonomy (7/15) and self-realisation (5/15). In addition to Edward's own disability he also experiences the burden of caring for Ethel; this has a cumulative effect in terms of his sense of restriction, which had negative implications for his quality of life ratings.

5.4.8 George and Gail

Figure 15 (on the next page) provides a summary of George's life history. George is 74 years of age and lives with his wife Gail in a bungalow in Village E. He has got:

"An older brother; then he's got a twin brother, a younger brother and a sister. Born of parents [...] later in life [...] They were married late thirties, which is rather unusual for that era." (Gail, G01: George stage one interview)

The extract is from Gail, who participates in the interview with George and interjects frequently, often controlling the conversation. George's family has a rich farming history that goes back several generations he has lived on (or among as he does now) farms his entire life. He has also stayed within the Moorlands throughout his life.

Figure 15: Timeline for George

<u>Year</u>	<u>Details of life events</u>	<u>Location</u>
1939	George is born: has two other siblings at this point including a twin Birth: sibling born Birth: sibling born Education: attends Grammar School	Living and working on a family farm in The Moorlands (family move between different locations before settling on a farm in Village E)
1955	Employment: Edward leaves school at 16 years of age and works on family farm in The Moorlands	
1967	Marriage: George and Gail get married	
1968	Loss: George's father dies, George takes over running of the family farm	
1970	Birth: George's first child is born	
1972	Birth: George's third child is born	
1977	Birth: George's fourth child is born	George maintains good health Gail: "He never had a milking day off in 20 years" (G01)
1978	Loss: George's mother dies	
1991	Health: George experiences pain in his ankles (becomes chronic) – makes farming difficult Health: George is diagnosed with arthritis in ankles Health: George is hospitalised for an ankle operation he describes as a "clean up" Health: George experiences swelling in his ankles Health: George is diagnosed with cellulitis	Living in a bungalow (Village E)
1997	Employment: George is forced to retire from farming due to health problems – family farm passed on to his son Health: George is diagnosed with diabetes Health: George is diagnosed with Osteo-myelitis	
2010	Health: George experiences a stroke	
2012	George and Gail move to a bungalow – this overlooks the family farm	
2014	George agrees to take part in the research study	

George inherited the family farm from his father; he since relocated to a farm in Village E: “We moved up the road so we got more land then” (G01) George states. George and Gail got married in the late 1960s and had four children. They now have two grandchildren also. George has several health problems, which has meant he has had to give up farming; his son has taken over responsibility for the farm maintaining the family tradition: “And he’s got a son, so that [...] can carry on” (G01) as George acknowledges. In the past 18 months George and Gail have moved from the farm house into an adjacent bungalow that overlooks the farm buildings and fields. The bungalow had previously belonged to Gail’s mother who lived there before she died, referring to the move Gail acknowledges: “it’s history repeating itself” (G01). George’s responses during the interview were limited; at the start he indicated: “I’m not very good at telling stories” (G01) and so Gail takes much of the lead. Gail is of a similar age to George but differs in terms of her health, social network, and social activities. I highlight these counterpoints below.

George experiences chronic pain in his ankle joints. This started when George was about 50 years of age, Gail explained that “he started to limp” (G01). George describes the pain in terms that minimise its impact: “I get a little bit of pain in me ankles. My feet are a bit-very tender” (G01). The pain that George experiences is intermittent and is activity-related:

“If I start doing anything, even like gardening [...] The pain kicks in and it’s a bit er - it’s very uncomfortable.” (G01)

George limits his activity levels and has stopped some activities altogether; for example, he no longer does any gardening. In March 2014 (the time at which the interview took place) George’s pain did not seem to be severe, as Gail describes: “He does seem to be

actually at the moment on [...] better form” (G01). During the interview George discloses how he experienced a recent episode of intense pain that had disrupted his sleep, but George confirmed this episode “disappeared after about three days” (G01). Gail had thought the worst: “I thought we’re starting all over again, but that seemed to go” (G01). The unpredictability of fluctuations in pain can be distressing for those experiencing pain but also for significant others.

Chronic pain forms part of a complex web of health problems for George; he has several chronic conditions (see Table 5.1; p148) Gail describes George in the following way: “He’s got a number of ongoing degenerative conditions, which all together, that’s him” (G01). George experienced a stroke at around 70 years of age. Both George and Gail play down the significance of the stroke, George described it as “a bit of a blow” (G01) and Gail legitimises this by confirming “it wasn’t too bad a stroke” (G01) but he has lost some function of his right arm. A physiotherapist oversaw George’s rehabilitation and provided him with an exercise routine; Gail describes: “I could see him religiously going and lying on the bed with his walking stick and doing this [arm raises] [...] he was very determined” (G01). Gail indicates that George’s health problems interact with one another causing a cumulative impact:

“[B]ecause there’s so many different conditions that he’s got. I think probably the fact that he’s got the arthritis and he’s not very mobile doesn’t help all the other conditions, like the circulation and [...] and the diabetes is circulation and feet. (G01)

Gail describes this interaction as “a vicious circle” (G01) for George. To improve his circulation George needs to be mobile; however, being mobile causes his pain to increase

which leads to a lack of control. In contrast, Gail reports having arthritis but no other health problems:

“I started with it in me hands [...] the pain went up my arm and kept me awake [...] I’ve got the deformity but no pain now. I think it burns itself out” (G01)

Gail refers to the nodules on her hands as her deformity. George shares in Gail’s metaphorical notion of pain burning itself out: “It does sort of burn itself out” (G01) however, George’s pain remains albeit as a tenderness around his ankles.

Gail is George’s main source of social support, the person he has most regular contact with. Gail will accompany George on his general practice or hospital appointments. Their son and daughter live in Village E with their families and so George and Gail have regular face-to-face contact with them. The couple provide child care for their grandchildren and also look after their daughter’s pet dog when the family go away; George takes the dog for a walk, although he cannot go far due to his ankle pain. Beyond the family sphere George’s social network and interactions are limited: “I’m not a social person” (G01) he does not get out much. Instead, he stays abreast of local news through Gail, as she suggests:

“I think George lives through me, because he wants to know who I’ve seen and what they’ve got to tell me.” (G01)

George maintains a connection with farming as he is a member of a “farming partnership” but this mainly involves administration; however, it does provide a weekly opportunity for George to visit other local farms. In contrast to George, Gail is more socially active and participates in community groups.

Village D lacks services other than a pub and the church George and Gail therefore rely on having access to transport to reach services in Village A (1km away) and beyond. George and Gail still drive the car whilst George is restricted in terms of the distance that he can travel he insists: “[I’m] not a road hazard [...] I wouldn’t like to go miles and miles but [...] I’m all right driving” (G01). The location of the bungalow compares favourably with the farm where they previously lived, Gail indicates: “it wasn’t a place for older people [...] it’s much more convenient here” (G01).

In terms of quality of life, George scored lowest of all participants on the CASP-19 (27/57); he scored low on control (4/12), autonomy (6/15; the lowest of all participants on this domain), self-realisation (7/15) and also pleasure (10/15; the lowest score of participants on this domain). The multiple health problems, of which chronic pain is one, that George experiences are likely to contribute to this low score as these restrict George’s activities.

Summary

In this chapter I have introduced the study participants and their lived experiences of chronic pain. Participants experienced chronic pain as complex, pervasive, elusive and dynamic. Participants used a number of techniques to articulate pain experiences including narratives, metaphors, numerical scales, and activity. Fluctuating pain made this process complex and medical language was challenged. The acceptance of medical terminology was complicated by the multiplicity of voices and systems of language that were encountered in seeking mixed forms of therapeutic intervention. In Table 5.5 (on next page) I summarise the descriptors and impacts of chronic pain.

Table 5.5 Summary of chronic pain descriptors and impact on activity

Participant	Pain description	Impairment and impact
Anne	Fluctuating (activity-related); aching; gnawing [gnawing] pain; rising to terrible when active	Walking, climbing stairs, household tasks are limited to one or two jobs, getting on bus
Barbara	Fluctuating (no control); knifey pain; stabbing; it's everywhere; gets me when it feels like it	Walking, washing, cleaning, cooking
Catherine	Fluctuating (activity-related); aching; standing too long; kitchen	Cooking made difficult, walking up to 50 metres, no longer gardening
David	Fluctuating (no control); toothache; intense; multi-sited;	Opening jam jars, household maintenance, standing still for too long, sleeping in a bed
Edward	Fluctuating disability (no control); aching; no spasms	Walking, getting up from chair, standing over cooker, gardening
Frances	Fluctuating (no control); aching to sharp pain	Driving long distances, walking long distances (sometimes), mowing lawn in one attempt
George	Constant; tenderness; aching	Gardening, farming, walking
Henry	Constant; tingling; internal sunburn	Long distance walking

Chronic pain was also a social experience and participants attempted to control who they shared pain with; however, the visibility of their painful bodies gave away their pain. Participants connected experiences of pain with ageing, sometimes reinforced by ageist attitudes; this normalised the experience of pain. This normalisation is reinforced in the experience of multiple health problems in later life. The nature of additional health impairments has consequences for the positioning of chronic pain on a prioritisation hierarchy. There are suggestions of cultural aspects of chronic pain that have connections with rurality, specifically a farming culture. In the chapters that follow the rural place and space are considered further in terms of the domains of the CASP-19.

Chapter Six: Maintaining control and autonomy



Photograph #83: I created this photograph whilst conducting fieldwork in Village C. I present the photograph here as it helps to situate the fieldwork but also it represents, to me, the way in which participants described their lived experiences of chronic pain. The long road represents the long process of living with chronic pain. The undulated tarmac represents fluctuating pain. The incline represents challenges participants face in everyday life.

Introduction

In the previous chapter I presented summaries of the study participant to provide an interpretation of their lived experiences of chronic pain, social relationships and environmental settings. In this chapter, I explore how participants manage their chronic pain and maintain control and autonomy in daily life; framed by the respective CASP-19 domains. In Chapter Seven, I explore self-realisation and pleasure (higher order needs). I present an integration of deductive and inductive analysis and support findings with quantitative and qualitative data: CASP-19 responses, interview data, photographs and fieldnotes.

6.1 Maintaining control in later life

A full table of the CASP-19 responses for all participants is provided in Appendix 15. In Figure 16 I present participant scores for control. The control domain includes four items: 'My age prevents me from doing the things I would like to', 'I feel that what happens to me is out of my control', 'I feel free to plan for the future', and 'I feel left out of things'.

Figure 16: Radar plot of CASP-19 scores for domain of control in rank order (n=8)

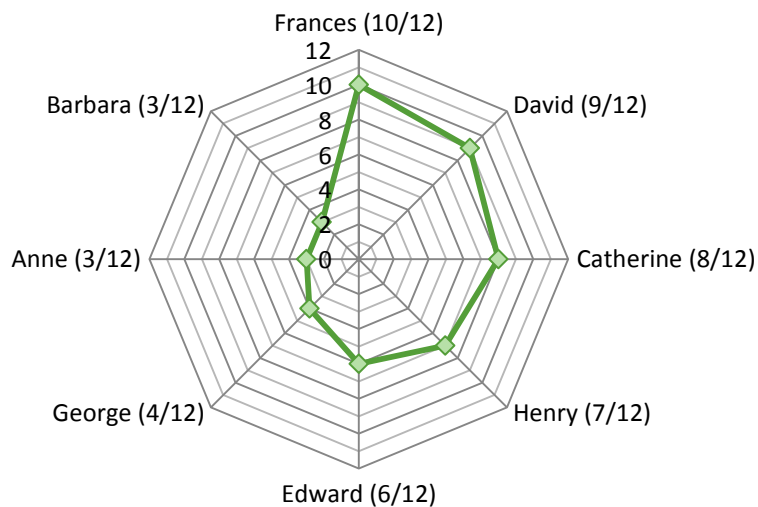


Figure notes: data points closer to the centre of the radar indicate lower scores for this domain.

Frances (10/12) and David (9/12) score highest overall whilst Anne (3/12) and Barbara (3/12) score lowest. I explore specific responses by these high and low scorers to each of the four items, including the qualitative responses they elicited, in a table format for easy comparison. I then draw in responses from other participants to identify commonalities and contrasts.

Frances distinguished clearly between ageing and pain to identify pain as the primary cause of her feeling lowered control; her chronic pain started early in life. David perceived ageing and pain as having a combined impact, describing a reduction in activity through a process of “slowing down” in which ageing is foregrounded (Table 6.1 on next page)

Table 6.1 CASP-19 Item 1: 'Age prevents me from doing the things that I would like to do'

Participant (Response)	Qualitative data extracts from stage one interview
Frances (Not often)	"I don't think my age is a hindrance. I don't feel that it's not an age thing. Erm I think it's more...you know the pain thing, so erm [...] Not often. I mean I'd love to go skiing but I don't think I'll start that now (laughs)."
David (Sometimes)	<p>Diane: Because he used to do everything, you know [...] he built Farm A from a two-up and two-down to a big four-bedroomed house [...] he certainly couldn't even contemplate starting on that, could you?</p> <p>David: I could design it (laughs).</p> <p>Diane: No, that's not what I'm saying, but you did all the work didn't you?</p> <p>David: Yeah.</p> <p>Int: Would you say that was age-related or more pain?</p> <p>David: I suppose it's a bit of both, really [...] I think it's perhaps, we're just slowing down a little bit... I probably think more of what I'm gonna do now than what I used to do, and that must come with age, you know...</p>
Barbara (Often)	"Quite often, because I can't- can't go anywhere, you see."
Anne (Often)	"Well it stops me [...] quite often (chuckles) [...] It's more pain that stops me like, you know, than that."

Barbara focused primarily on age as the cause of her restriction, although pain-related disability is central to her sense of restriction; whereas Anne perceived pain as more prominent in her restriction but did not discount age.

This relationship between age and health is also illustrated in George's response of 'often' to this item, as he explained:

George: I suppose as I get older I think that I can't - I'm not supposed to be doing it, so....

Int: Is it age that makes you feel that way or the health conditions that you have?

George: Er well, health conditions really, I suppose. I certainly can't do- I'd like to do more than I do. (G01, George, stage one interview)

George identified a cultural perception of ageing in terms of what he was “supposed” to be doing working in combination with his health. Catherine’s response to this item was ‘not often’ she shared the same perspective as Frances: “I had to give up gardening this year, but that I don't think is my age. I think it's my pain” (C01). The qualitative data suggest that, for many, ageing legitimises a reduction in activity; participants who associated restriction with pain (not ageing) presented a greater sense of control.

Table 6.2 CASP-19 Item 2: ‘I feel that what happens to me is out of my control’

Participant (Response)	Qualitative data extracts from stage one interview
Frances (Never)	<i>No further discussion in response to this item.</i>
David (Not often)	David: “No, I don’t think I'm out of control.” Diane: “I think your pain’s out of your control.” David: “Yes, probably. Yeah, but, er, you might feel it some days, and if the sun’s shining the following day, it’s a very different story, you know.”*
Barbara (Sometimes)	“Well I can't control anything can I? I can't control pain. It just comes, doesn't it?[...] Sometimes, put sometimes, don't make it so bad [laughs]”
Anne (Sometimes)	“Well, it is out of your control isn’t it, when you can't get about... I don’t know [...] Well, you can put sometimes I think.”

**A long narrative continues for 161 lines of transcript just in response to this item. Topics covered include: companionship, travel and exploration, socialising, passion for natural world, using nature to restore well-being.*

Frances was definitive in her answer about control but David less so (Table 6.2). The item prompted David and Diane to talk at length about how the environment contributes to their sense of well-being. Diane challenged David’s sense of control over his pain; which he admitted was as changeable as the weather. In contrast, Barbara reported feeling incapable of controlling anything including chronic pain. Barbara joked about not wanting to make her response seem too negative and so altered her response which may result from her not wanting to be perceived negatively (i.e. avoiding stigma); this may be a

copied mechanism to reduce any sense of lost control. Anne centralised her lack of mobility in feelings of low control. Comparing across cases in terms of chronic pain-related disability, Anne and Barbara described having significant physical disability as a result of chronic pain, and for Anne additional health problems; neither can walk without the use of an assistive aid. In contrast, Frances and David did not report experiencing such levels of disability.

Of the other participants, Henry's responded 'often' to this item as:

"Well health-wise it's always [out of my control] isn't it because you never know do you? [...] I think the doctor's got the control over your health." (H01)

In contrast, Catherine suggested that she retains a higher level of control; her response to this item is 'not often' but she too sees control as located outside of herself:

"I think I've still got most of my marbles, which a lot of people haven't at my age. [...] I'm a practising Christian therefore yes, I suppose you would say that it's [...] out of my control. I don't think [...] I myself am entirely responsible for what happens to my life. But also, [...] I still think I can put two and two together (laughs)." (C01).

Catherine indicated different dimensions of control referring to control in 'spiritual' and 'mental health' terms. Catherine revisited the importance of maintaining mental health during the course of the interviews, highlighting the demeaning nature of diseases such as dementia. These contextualised responses to these items suggest that participants who identified pain or health as factors reported lower scores.

A sense of mortality or life expectancy underpins the difference between the pairs of participants responding to Item 3 (Table 6.3).

Table 6.3 CASP-19 Item 3: 'I feel free to plan for the future'

Participant (Response)	Qualitative data extracts from stage one interview
Frances (Often)	<i>No further discussion in response to this item.</i>
David (Often)	"All the time, yeah."
Barbara (Sometimes)	"I feel free? Well I've already done everything that I've got to do for the future, I've done that, 'I feel free to plan for the future' [...] Sometimes, because I don't go anywhere..."
Anne (Sometimes)	"Oh, what can you say to that... well... you can't plan for the future too much can you, as you get older [...] Sometimes I should say to that I think."

Frances (age: 67) and David (age: 70) were definitive suggesting they felt in control of their future; both are the youngest of the participants. In contrast, Barbara (age: 78) and Anne's (age: 82) responses suggest an awareness of their own mortality. Barbara was retrospective and described having done all that she needed to have done, although she based these plans on her not being active; whereas Anne was guarded about looking to the future.

Among the other participants, Catherine's (age: 90) responded to the item as 'sometimes', although she had difficulty interpreting the meaning of the item:

"I don't think I know the future and I don't think I know what's going to happen to my health. So I don't know what, what category you call that? [...] Say it again [...] That's a difficult one because I mean on the physical side planning for my future is to where I live and that kind of thing. At the moment I'm capable of doing that. What does that

rank as? [...] I don't think I know what the future is at all. Does anybody? So you can, you can put that under what category you think (laughs).” (C01)

Ultimately, Catherine views the future as out of her control, which relates back to her sense of spirituality referenced on the previous item; this underlines the limited nature of the practicalities of planning. George scored lowest, responding ‘not often’ which he and Gail discussed in depth:

George: Well, we aren't very free [...]

Gail: We're governed by our financial circumstances, health circumstances and family circumstances. We're not really free to do....

George: [...] We don't feel free really [...] We perhaps like to feel as we're restricted [...] We perhaps feel that we don't want to be free.

Gail: Yeah, I think there's a certain security in erm knuckling under and accepting things. I think you're better if you do. I think we've accepted it. I think we've accepted how we are and try to make the best of it [...]

George: [...] We're restricted. We restrict ourselves. (G01)

George and Gail share a sense of multiple restrictions. Gail referred to “knuckling under and accepting things” which indicates prior experience of facing adversity; this may relate to farming and the demanding nature of this work (i.e. a daily, labour-intensive commitment). Restrictions may have become engrained into George and Gail's life-course because of farming; a coping mechanism since borne out in other aspects of their lives.

Frances maintains a close relationship with her sibling who lives near; her son also lives within 20 miles of her which may explain her response to Item 4 (Table 6.4).

Table 6.4 CASP-19 Item 4: 'I feel left out of things'

Participant (Response)	Qualitative data extracts from stage one interview
Frances (Not often)	<i>No further discussion in response to this item.</i>
David (Never)	<i>No further discussion in response to this item.</i>
Barbara (Often)	"I feel left out on things because I can't get there, can I [...] Often..."
Anne (Often)	"Left out? Well, I am left out of things a lot of things because, I mean, I can't go where I want you know, same things as go off I can't go, because I can't get there sort of thing so what can you put, to that... Well, [I'm] let down often [...] when you can't go out and you can't get about ..."

David and Diane presented self-assurance that they are not left out of activities; perhaps due to their relationship they can construct their own activities. David and Frances remain able to drive and so support their own transport needs beyond the home. For Anne and Barbara the opportunity to participate in activities is limited by restricted mobility and access to transport. Anne cannot drive and struggles to board public transport; Barbara still drives her car but is restricted in terms of the distance and route that she is confident to travel. The other participants did not provide any contrasting accounts. The data suggest being mobile (as referred to beneath Table 6.2; p198) and having access to transport are important in maintaining control in later life.

In this sub-section I explored the responses of participants to items within the control domain of the CASP-19. An important finding here is that where participants incorporated pain and/or health into their interpretation of control they reported a lower sense of control. Also, maintaining mobility and having access to transport were identified as important in supporting a sense of control in later life; control of movement, which chronic pain often impairs.

6.2 Autonomy in later life

In Figure 17 participant responses on the items of the autonomy domain are presented in a radar plot. The autonomy domain includes five items: ‘I can do the things that I want to do’, ‘Family responsibilities prevent me from doing what I want to do’, ‘I feel that I can please myself what I do’, ‘My health stops me from doing things I want to do’, and ‘Shortage of money stops me from doing things I want to do’.

Figure 17: Radar plot of CASP-19 scores for domain of autonomy in rank order (n=8)

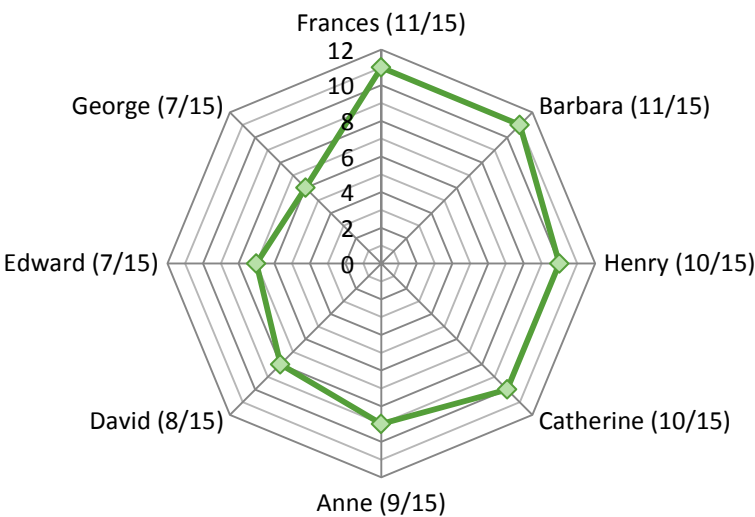


Figure notes: data points closer to the centre of the radar indicate lower scores for this domain.

Frances and Barbara (11/15) scored highest overall whilst George (6/15) and Edward (7/15) scored lowest for autonomy. In what follows I explore specific responses by these high and low scorers to each of the five items, including the qualitative responses elicited, in a table format for easy contrast, before drawing in responses from other participants to identify commonalities and contrasts.

The qualitative data extracts from the high and low scorers is presented in Table 6.5 but it is limited in terms of responses given around this CASP item. More is revealed in data presented in Section 6.3 (p212); activities also relate to data presented in Chapter Seven.

Table 6.5 CASP-19 Item 5: 'I can do the things that I want to do'

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Often)	"In the main. Yes."
Barbara (Often)	"Often really, often, if I answer truthfully."
Edward (Sometimes)	"Sometimes"
George (Not often)	"I can't do everything I want to."

Barbara's response here contrasts with a response in Table 6.3 (p200); she reported high autonomy (can 'often' do what she wants) but low control ("I don't go anywhere"). This implies ambiguity in Barbara's interpretation of a lack of activity; is it through freedom to choose or restriction? Amongst the other participants Anne, Catherine, and David all responded: 'not often'. Catherine provided examples of activities that she could no longer do: "Like my garden, like driving" this is related to her deteriorating eyesight "I'd drive if I could but I can't see" (C01). Similarly, David described:

"I struggle to do some of the things I want to do. [...] Not often but it happens. [...] I tend to work round things rather than- if I can't do it, I'll think of something else- it might not be just what I want, but it's close." (D01)

David expressed a capacity to adapt and be resourceful. The strategy is limited as the completion of something close to the initial task remains something other than the original task. Henry responded to this item as 'often' although he identified a lack of control here: "I mean the only restriction is your health" (H01) not autonomy. David reported higher control (9/12) than Henry (7/12), but lower sense of autonomy; perhaps by compartmentalising health in terms of control enables Henry to maintain autonomy.

The qualitative data suggest that disability due to health problems may cause restriction; this relates to lower control indicating overlap across the domains.

Frances reported high autonomy in the context of family responsibilities; her responsibilities are minimal her son and family do not utilise her for child care and she decides when to visit her Aunt (Table 6.6).

Table 6.6 CASP-19 Item 6: 'Family responsibilities prevent me from doing what I want to do'

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Not often)	<p>Frances: I don't really feel I've got anybody preventing me from doing anything.</p> <p>Int: No? You mentioned your aunt that you have to go and see</p> <p>Frances: Well yes but I work around it if I want to go away or something, yes. [...]</p> <p>Not often, not often, no.</p>
Barbara (Not often)	<p>Barbara: Well perhaps, oh heck, I don't know, how to answer that 'cause I don't go any, I don't do anything, so what would you say to that.</p> <p>Int: Do you baby sit or anything?</p> <p>Barbara: No, not now, I used to, not now, family responsibilities. [...] Yes, well it would be very unfair to say that family responsibilities prevent me from doing what I want to do, now- [...] I mean I do as I can, that's how I am and if I can't do that's fair enough.</p>
Edward (Often)	"Well, of course family means my dear wife and that's often then, isn't it?"
George (Sometimes)	"Well, to a certain extent, don't they?"

Barbara specified the limited nature of her activity participation for which she perceived blaming family responsibilities as unfair; her activity is limited in other ways which she accepted: "I do as I can [...] if I can't do, that's fair enough" (B01). In contrast, Edward suggested that he does not have a choice in family responsibilities; specifically, in the care that he provides his "dear wife". It may be for George that providing child care for his grandchildren, who live in close proximity, underpinned his response. This may link to his response about future planning; he identified family as restrictive (Table 6.3 p200).

Among the other participants, Anne, Catherine and Henry responded ‘never’ to the item. Anne explained: “If I want to do it, I do it and that's it [...] I don't take any notice of them” (A01). Anne insists upon her autonomy. Similarly, David responded as ‘not often’ to the item; perhaps acknowledging the child care role that he and Diane occasionally provide for grandchildren. Catherine described herself as not having any dependent family members and Henry did not disclose any further information. The qualitative data suggest that participants have few if any dependents; those with spouses, particularly ones with health problems, reported the impact on autonomy as high. For those providing grandparent roles the interference of such responsibilities seems marginal; perhaps due to the pleasure that this role brings (see Section 7.1: p245).

The pattern of responses to Item 7 is mixed (Table 6.7).

Table 6.7 CASP-19 Item 7: ‘I feel that I can please myself what I do’

Participant (Responses)	Qualitative data from stage one interview
Frances (Often)	“Most of the time, yeah.”
Barbara (Sometimes)	<p>Barbara: [laughs] I don't, I can't do anything... I don't know what to say.</p> <p>Int: A good example would be that you mentioned somebody coming round to say are you coming to the bonfire and you could decide for yourself that you're not going.</p> <p>Barbara: That's right.</p> <p>Int: The other way, you might not go to the luncheon club unless your daughters were telling you to go.</p> <p>Barbara: No I wouldn't.</p> <p>Int: So sometimes you could do what you like but others you couldn't?</p> <p>Barbara: You answer it love, because you know how I feel, you answer it.*</p>
Edward (Sometimes)	(Sigh) Well, the second one.
George (Often)	<p>George: Quite often.</p> <p>Gail: Not very often in my case (Laughs).</p> <p>George: Oh well, it's not your questionnaire.</p> <p>Gail: [...] Oh dear (Laughs).</p>

**Interviewer comments in extract from Barbara's interview represent participant's responses (as paraphrased) from earlier in the interview; these were reflected back to the participant to support understanding of the item.*

Frances did not provide any further contextual information. Barbara acknowledged her limited participation in activity as a consequence of chronic pain; this is consistent across the domain, Barbara does what she can and accepts what she cannot do although there is ambiguity here in terms of autonomy. Edward limited the information he shared. George presented ambiguity within the autonomy domain; having stated he cannot do everything, which relates to restriction through lower control (4/12), but that he can please himself. Gail expressed that she cannot please herself; this tension may reflect Gail experiencing restriction because of George's health problems, but not vice versa.

Amongst the remaining participants, Catherine and David responded to this item as 'often'. Catherine reflected on this in the following extract:

"Ref. my Christian commitments [...] Yes, but I (laughs) I do feel I can do what I want to do, but, but I am bounden by what I feel is my duty to other people and that kind of thing. So you can make what you like of that (laughs), I don't know. But I yes, I'm free because I'm free to make that decision as well. Yes, I'm free." (C01)

Catherine referred to her spiritual beliefs to support her sense of freedom, although she feels "bounden" by her religious commitment; however, this reflects freedom to choose. The remaining participants did not provide any further contrasting accounts. The qualitative data suggest participants reflected on their commitments and levels of activity when responding to this item. Participants who reported a lack of activities as a result of chronic pain (e.g. Barbara) experienced this item as having low face validity.

The qualitative data from the high and low scorers is limited (Table 6.8). All eight participants reported their respective health to prevent them from doing what they want to do to some extent (reporting either ‘sometimes’ or ‘often’).

Table 6.8 CASP-19 Item 8: ‘My health stops me from doing things I want to do’

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Sometimes)	“Yes, there is a erm.....sometimes I would say.”
Barbara (Sometimes)	“Yes it does [...] sometimes.”
Edward (Often)	“True, yeah, often.”
George (Often)	“Er, often I would say.”

Similarly, poor health was reported to diminish control also. Anne’s response of ‘sometimes’ was contextualised by:

“I still go to luncheon clubs and I should go to my friendship [group] for as long as I can [...] I just have one night out at bingo, but that night I have to get picked up and brought back, but I mean I wouldn't go if I wasn't.” (A01).

Anne’s social participation may represent her contribution to support these community activities; however, her participation is dependent upon provision of transport by others. Anne indicatively lacks agency (i.e. the capacity to act in any given environment) due to health; which may relate to her low sense of control (3/12), but she maintains a sense of autonomy. Anne retains freedom to choose to attend social activities; the transport assistance that she receives is therefore enabling. It is not interfering with her sense of freedom, as captured by the definition of autonomy.

Catherine reflected on her multiple impairments in response to this item:

“Well, I mean it [health] prevents me - we've said gardening. It prevents me driving. It prevents me trotting round the village visiting people. [...] Well, all the time. [...] And the sight too. We mustn't forget the sight because that's a bit of a pig.” (C01)

The disease-related restrictions that Catherine experiences have implications for her maintenance of local social networks and her sense of agency as she no longer drives a car and relies on others for transport. In contrast, David suggested pain makes life harder:

David: No, I don't think it stops me. It makes it harder work, but it doesn't actually stop me.

Diane: It stops you mowing the lawn

David: Oh, yeah, but I mean, that's neither-

Diane: And things like that. So I think you, er, sometimes it stops you.

David: Who's answering these me or thee?

Diane: You. Sorry. (D01)

David perceives his health problems as presenting challenges that cannot be avoided but that he feels he can overcome; representing passive acceptance and supporting earlier assertions of David's sense of adaptation and resourcefulness. David becomes agitated at the end of the excerpt as the positive identity that he attempts to construct was threatened by his wife. Thus health problems may diminish autonomy; but agency is also important to explain this reduction. The provision of assistance from others may not be perceived as interfering or threaten autonomy.

The qualitative data for Item 9 are limited for high and low scorers (Table 6.9). Frances expressed how she felt fortunate not to hold great desires to take part in expensive activities; this protected her from any sense of deprivation.

Table 6.9 CASP-19 Item 9: 'Shortage of money stops me from doing things I want to do'

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Not often)	"Erm...not often. I think it's because I don't have any great desire to do things that are that expensive. So I'm lucky in that way, I'm quite content, so I don't feel deprived..."
Barbara (Never)	"No, that's nothing to do with it... No never, I'm not short of money"
Edward (Never)	"No, never"
George (Sometimes)	"To a certain extent [...] Just sometimes."

Barbara and Edward indicated that they are both financially secure. George admitted a sense of restriction relating to money; this supports an earlier extract in which George and Gail identified multiple restrictions that included health, family and finances (beneath Table 6.5; p204). Amongst the other participants, Henry provided a contrasting perspective as his response to the item is 'often':

Henry: Well money always restricts you, what you want to do, I mean I should like to go to New Zealand, I should like to go to Canada, but money restricts you.

Int: Do you keep working to get money in?

Henry: Yeh.

Int: Is that for the money or is that for the activity?

Henry: Both, it's the activity and to get money. (H01)

Henry identifies a need to maintain employment as he lacks autonomy in terms of money. He contextualises this by referring to foreign holidays; Henry suggests these far and away destinations are prohibitively expensive. For Henry, work is more than a financial means to an end as the activity of work is also important. Anne contextualised her 'sometimes' response by warding against frivolity: "I haven't enough so as I can throw it about sort of thing, I can just manage." (A01). Anne presents herself as being financially prudent. Catherine responded 'never' on his item and describes her financial means as enabling her to maintain independence and autonomy, as she pays for domestic assistance:

"I've got a wonderful treasure [domestic assistant] who comes here every Monday. She's absolutely marvellous and golden and she's come every Monday [...] And I can pay her [...] I'm not worried about paying for fuel and that kind of thing." (C01)

The nickname ('treasure') that Catherine gives her domestic assistant symbolises the value of this person to her in maintaining her lifestyle. It seems that participants' feelings of financial security are contextualised in terms of maintaining independent living, which is central to autonomy.

In this sub-section I explored the responses of participants to items within the autonomy domain of CASP-19. All participants reported health problems to prevent them to some extent. Feelings of autonomy are facilitated by participants continuing to participate in activities despite health restrictions and to adapt where possible. Maintaining the capacity to act within the environment (agency) was also important and was distinguishable from autonomy. The absence of dependents in need of care and support facilitated higher ratings of autonomy; for example, living with a spouse with health problems impacted negatively on autonomy. However, living with a spouse regardless of

health problems continued to provide many positive factors. Feelings of financial security were contextualised in terms of the desires that respective participants hold beyond maintaining independence, which is central to autonomy. In the next section I return to my inductive analysis of the remaining qualitative data to present findings that relate to control and autonomy beyond the items of the CASP-19 but which appear linked.

6.3 Carrying on with chronic pain

Participants described the day-to-day experience of living with chronic pain as a process of “carrying on” a phrase used by both Anne and Barbara but which is semantically similar to phrases used by others. Anne used the phrase in the following terms:

“I know there's sometimes when you can't be independent but that's it, you just carry on as far as you can.” (A01)

“I'm frightened to drop anything, that's why I can't pick anything heavy up, so I don't bother, I just carry on and I think, well I keep living.” (A01)

In contrast, Barbara referred to carrying on as a process of avoidance: “Just carry on, [laughs] sit down and just try and forget it” (B01). Other participants used similar phrases: “pick yourself up and get cracking” (D01) as David describes and Frances:

“I just think try and get on with it and try and keep as fit as you can [...] heal thyself almost. [okay] Erm that's sort of the attitude I tend to take” (F01)

I explored this process further to conceptualise “carrying on” as an individualised process underpinned by mixed strategies of self-management, psycho-social responses driven by attitudes and beliefs, and adaptation and interaction with the environment. ‘Carrying on’

both supports and is supported by a sense of control and autonomy. In the sub-sections that follow, I present findings that appear to be an expression of a concept of 'carrying on' and integrate the deductive perspective captured in the CASP-19 control and autonomy domains. Referring back to Maslow's hierarchy of needs, the foundation for CASP-19, the following sections consider the foundations of Maslow's pyramid through the basic needs of control and autonomy. In Chapter Seven the higher order needs are explored.

6.3.1 Self-management, maintaining control, accessing healthcare

Participants described utilising multiple strategies to regain and/or retain control of chronic pain and limit its impact on everyday life; thus, supporting a sense of carrying on. In this sub-section I focus on self-management strategies including: pharmacological intervention, physiotherapy, complementary and alternative medicine (CAM), and physical (in)activity.

All participants in the study reported accessing healthcare services and thereby engaging in self-management. In the following extract, Henry expressed an attitude towards chronic pain that was shared by others and that supports help seeking behaviours:

"You keep wishing that you could do something about it, like rub cream on it or something like that, to get rid of it." (H01)

All participants in this study reported using oral medications (painkillers or analgesics) whether obtained on prescription or purchased over-the-counter to "get rid" of chronic pain or at the least control it: use of paracetamol (most common), co-codamol, and co-dydramol were reported. The use of painkillers varied; for some painkillers formed part of

a daily routine, as they do for Henry who takes paracetamol: “two in the morning, two at lunchtime, two at night” (H01). However, such generic painkillers may not be seen as an effective strategy for controlling pain:

“[The GP] just shoved me off with the same thing [...] painkillers, but they didn't do nothing. Like I say, they might as well have given me jelly babies, I'd have enjoyed them better (laughs).” (H01)

Henry indicated dissatisfaction with the treatment that he has received, specifically with the ineffectiveness of his pain management strategy highlighted by the persistent tingling pain sensation that he describes. Henry scored moderately for control (7/12) on the CASP-19 and identified Doctors as responsible for control of his symptoms. He experienced a change when a new GP took over the GP Practice he attends:

“Up to this lady doctor come, I were just [...] grinning and bearing it, but thank God, she sorted some tablets out. They have done me good, and she told me today to increase the dosage.” (H02)

Henry describes a new prescription (Gabapentin) as: “these special tablets” (H01) that his GP apparently says are specifically for shingles-related pain. The change in medication has altered Henry's perception of painkillers from “jelly babies” to “special tablets”. Henry recognises that medications are a central component in his health and his coping strategy:

“[The] tablets I have to take, if I had to pay for them I'd be bankrupt (laughs), mind you there's some mileage in them, better than the alternative” (H02).

Henry is grateful for the free access he has to medications through the NHS in terms of adding extra years, or 'miles', to his life. The change in painkillers seems to have enabled Henry to carry on more effectively and positively; this underlines the importance of painkillers for Henry in his self-management strategy.

Participants also described using painkillers strategically as a prophylactic to maintain control, as David described:

"If I know [...] I've got a bit to do, I will probably tank myself up on painkillers [...] I'll have a couple of Paracetamols half an hour before." (D01)

It was not disclosed whether this strategy had been advised by a healthcare practitioner; but David suggests the process is ritualistic and enables him to carry on with certain tasks despite his multi-sited chronic pain. However, this strategy may not be sustainable:

"I was on Co-hydramol [Co-dydramol] and I've cut them down 12 months ago, because I was getting addicted to them. I was on eight a day of the damn things" (D01).

David described fear of addiction and development of dependency. To remain active is the driving force for David. The ritualistic taking of painkillers, as David described, was not supported by all participants, for example Catherine stated the following:

"You can't sort of have a paracetamol when you're going to do the washing up or that kind of thing" (C01).

The perceived need to take painkillers may therefore relate to the availability of support to complete tasks. Catherine accepts that she cannot complete some domestic tasks by

herself (e.g. washing up, laundry, changing the bed sheets) and instead pays for domestic help; therefore, she may not identify a need to use painkillers. David struggles to accept help in this way from family members; indicating a greater need to complete activities himself. Furthermore, Catherine has received a painkilling injection: "I think if I hadn't had that injection, I really would be suffering quite a bit; I really do" (C01). Consider Anne in contrast who would prefer not to use painkillers but recognises a need to do so: "I don't like taking painkillers if I can help it, but there it goes you've got to do something" (A01). Anne is hopeful about receiving a painkilling injection like Catherine has had:

"When I go back [to the consultant], I'm going to see if I can have the injection again. Because he [the consultant] doesn't really want to operate, because if he operates on me then it means that I've got steel pins in my spine. I [...] shalln't be able to bend. And that'll be worse than ever. Or I might be a cripple and be in a wheelchair and not be able to walk at all." (A01)

Anne sees the injection as a last remaining option in her attempts to maintain control over her pain but also her body. Should Anne lose control this would have implications for her sense of independence and autonomy, as her ability to walk may become severely impaired; the wheelchair acts as a symbol for this. In the absence of the injection, Anne's struggles continue and are not relieved:

"I've got co-codamol for pain [...] I could take eight a day of them, but I don't. Well, I had to the other week when it was that bad. I'd been without for three days and it had got that bad 'til, oh, I was, well I was getting desperate." (A01)

On the CASP-19, Catherine reported a higher level of control (8/12) than Anne (3/12); perhaps a combination of acceptance of her limitations, financial security to buy-in domestic help and having received the painkilling injection contribute to these reported differences. David reported a high level of control (9/12); which may support the use of painkillers as a preventative measure to carry on despite the risk of becoming “addicted”. The fast and effective pain relief that participants seek does not seem to exist, specifically for those with multi-site pain. However, many remain hopeful that relief is possible as in the case of Henry’s “special tablets” or the injection that Anne seeks; others have learned to use painkilling medications as part of self-management strategies to carry on with tasks.

Frances scored high for control (10/12) and autonomy (11/15) on the CASP-19, as she did for quality of life overall (49/57); her mixed strategies for self-management relating to pain may act to support these responses. After a recent bout of severe pain Frances attended an appointment with her GP who prescribed her painkillers:

“Very heavy painkillers [...] the painkillers are not suiting me at all, they're putting me on another planet and making me feel nauseas. [...] I'm only taking one if I absolutely need it and just resting [...] that seems to be working.” (F01)

Frances combines painkilling medication with periods of rest to manage her chronic pain, due in part to the side effects of the painkillers. The attitude that Frances expresses towards the management of her chronic pain is: “heal thyself” (F01) and so taking painkillers may not correspond with this attitude. As an adjunct to pharmacological intervention and rest Frances also integrates physiotherapy and complementary and alternative medicine (CAM) into her complex pain management strategy. Physiotherapy is

provided by the NHS through a referral from her GP whereas CAM was accessed through her own initiative; she has trialled different types of therapy, as have other participants.

Types of CAM accessed by all participants included: acupuncture, chiropractic, osteopathy, reflexology and yoga. Frances described the use of physiotherapy and CAM as enabling her to reduce her intake of painkillers as a result of physiotherapy and CAM:

“I've been able to exercise and do what the physio has asked me [...] I've started to do more yoga, and it has eased. I'm not taking so many tablets. [...] Well generally I'm probably in the one or two area [of pain 0-10 scale] now so that is, you know, really good for me, which is great. And I can, you know, do more things so I don't feel as though I am tied to the house. Erm, I can actually go out and walk without being doubled up, which is for me something that I prefer, not to be doubled up.” (F02).

Frances suggests the combination of yoga and physiotherapy had led to a reduction in her pain. The outcome for Frances has been an enhanced sense of control of her body and autonomy to move beyond the immediate vicinity of her home. Frances reported similar positive effects from having received reflexology also: “it seemed to either take the pain away or ease it, so it was much more manageable” (F01). David, Edward, and George also reported using CAM, although they report various levels of effectiveness. For instance, David describes the following experiences of chiropractic therapy:

“I'm always worse for two or three days after. [...] If he's gone in deep, then it's about a week before I start getting any benefit of what he's done, and that's the time that I'll probably have a few painkillers.” (D01)

David describes a delayed treatment effect following a chiropractic therapy session; during the delay he continues to take painkillers. The variability in the effectiveness of chiropractic intervention leads David to conclude: “I might go one session that, it felt as though I’ve been wasting my time [...] it isn’t the be-all and end-all” [D01]; yet he has continued to access CAM for over eight years. Perhaps being active in self-management provides David with a sense of control regardless of treatment effectiveness. In contrast, Edward did not continue with chiropractic treatments as he did not experience an immediate improvement:

“Well maybe we should have gone every week for a year or something like that (chuckles). Don't know what to do. Don't know how to improve our situation... [Pause: 00:06]” (E01).

Edward senses that his situation has become hopeless; this is reflected in his CASP-19 scores as he experiences diminished control (6/12) and autonomy (7/15). A narrative from Edward about a falls intervention that he was referred to helps to make sense of his “situation”:

“I've got the folder [of information] she [the intervention leader] gave me [...] with all of the exercises that I don't do. I was given the option of attending for the six weeks or coming home with the exercises and getting on with it. I haven't carried on with it. I haven't done the exercises, and I can't see what use six weeks of anything is [...] if somebody came here to do something to improve my condition I'd be quite happy with that.” (E01)

Edward identifies a systemic barrier to obtaining information about CAM from NHS sources: “the NHS people, the local surgery, they don't seem willing to recommend anybody” (E01). He also identifies a geographical barrier in terms of accessing such interventions; he prefers home-based provision as his ability to drive is impaired. David has experienced positive effects from the treatments which support continued attendance and he also retains capacity to drive himself to appointment whereas Edward has not received such positive reinforcement and experiences greater physical restriction.

Being physically active seemed to support a greater sense of control over pain. Frances described participating in yoga and David expressed a preference to use physical activity to relieve pain: “the best way is to have a stretch” (D01). In the following extract, David described bodily stretches and postures he has learned:

“When I stand up, I have to be at the right sort of height, and lean on one side, and put one weight on my left leg, then the weight on my right leg, and keep doing that. And [...] nine times out of ten it works.” (D01)

David also described the stretching exercises as adaptable to suit different pain locations: “it’s just a little bit of a different exercise. I just stand in a different position” (D01). David was introduced to stretching exercises by a physiotherapist. David combines physical activity in the form of stretching exercises with the taking of oral analgesics to manage pain; this combination provides David with a sense of control over his chronic pain. However, whilst Diane indicated (about David’s pain) in the contextual data from the CASP-19: “I think your pain’s out of your control” (D01), being active may provide an alternative or combination of options to maintain control of pain.

Catherine has experienced a change in opinion regarding physical activity, which reconnects her with activities of early life:

“The doctor sent me to physiotherapy, in which I may say I have very little faith, but actually it's a very good thing (laughs). I always loathed gym at school (laughs). [...] Unnecessary activity seems a waste of energy to me. But anyway I did go for physiotherapy and they gave me little exercises to do. That's this year. [...] He [my GP] said he's going to send me for some more. Well, I'll try and do the exercises but I do loathe it, really.” (C01)

Catherine associates ‘exercise’ with “gym at school” yet prior to her heart attack at age 70 she would regularly walk in the surrounding area before breakfast. At the time of the stage one interview (Nov-2013) she described having stopped walking around her local community. In her second interview (April-2014) she described a new routine that involved walking up and down the road outside of her home (approximately 50 metres from her house). Catherine identified support for this behaviour change in cultural discourse: “Well, they’re all saying if you’re old you should exercise” (C02). Walking supports an enhanced sense of autonomy for Catherine whilst concomitantly improving her sense of control. Physical activity has significance for Catherine as she used to take long walks around scenic areas; similarly David’s stretching routines may provide a sense of meaning in the context of his rugby-playing days.

It seems there is a balance to be found between activity and over-exertion; Anne described attempts to find this balance:

“Well, I just cope with it, I just keep getting up and walking about a bit, because if I didn't I should never go but you see, I walk about a bit, I do a job or two perhaps, and then it comes on, and then I have to sit down I just take it every day as it comes like that.” (A01)

Anne indicates that being active enables her to maintain her home and therefore maintain her independence. Pain interferes with Anne's sense of autonomy as the number of household tasks that she completes may be limited. Pain also interferes with Anne's sense of control; she lacks choice of whether to sit down or not. For Barbara, immobilisation is an active strategy to control pain, as she described in the following extract:

“I can be in bed by half past five and happy to do that because I know my body's resting, and I'm not interfering with anything.” (B01)

Barbara indicates that to control her pain she goes to bed; as a compromise she limits her interactions with the home environment. The use of the term “interfering” implies risk; she may feel safer in bed. Barbara's described a new threat that may complicate her management strategy:

“Female F [a friend] had fell out of bed, she's got such a bruise [...] now that's what I'm frightened of doing.” (B01)

Barbara's familiar strategy of using bed to provide safety and to support pain management reveals vulnerability to additional risks. Notions of risk and risk management emerged as a potential underlying theme for participants; however, risk was commonly implied but not described in relation to self-management.

In this section I have explored participants' complex self-management strategies that have included pharmacological interventions, physical therapy, complementary and alternative therapies and physical (in)activity. Participants were found to mix different strategies; the exact mix was developed over the illness journey and incorporated recommendations, exercises and responses to their own body (in the case of immobilisation). The first resort for pain relief was suggested to be pharmacological intervention; however, pain management through this alone was reported to be ineffective leading to potential disillusionment. In the next section I present findings related to the management of chronic pain from a psycho-social perspective.

6.3.2 Psycho-social responses, attitudes and beliefs to maintain control

In the previous section I described how participants incorporated sometimes multiple self-management strategies to maintain or restore control of chronic pain. 'Carrying on' was also supported by psycho-social strategies towards pain which were presented as endurance, stoicism, distraction/avoidance and privacy; participants actualised these to maintain a sense of control and autonomy, but also pleasure and self-realisation. I discuss each of these psycho-social strategies in turn.

The ability to endure chronic pain underpinned the process of carrying on. Pain management strategies did bring relief to the experience; however, this was limited in some cases and in all cases pain persisted. In discussing his chronic pain experience David presented a capacity to endure: "At the minute I've got a twinge in my back, but nothing that I can't cope with" (D01). Anne also anticipated a need to endure pain to prepare herself for what comes: "normally I just take it as it comes" (A01). Anne's endurance is recognised by others in her social network:

“I can't get about and do what I want do that's what annoys me more than anything, and then I get cross with myself, and somebody says 'I don't know how you carry on like that' well I say, you've just got carry on with it, you can't just sit and moan about it, that's no good.” (A01)

Anne endures chronic pain; she utilised stoicism to support this in social interaction outside of the interview. In Anne's experience there come times when her capacity to endure becomes overwhelmed by the pain experience: “it gets me down, I sit, I sit and I have a cry” (A02) (see Section 5.4.5 [p173] for full extract). Attitudes of endurance and stoicism may influence help-seeking behaviours. The stoicism that Anne presents may support the maintenance of her sense of autonomy: “I don't want no fuss, I like to be independent” (A01). Stoicism may also indicate avoidance style coping. Anne revealed stoicism to be a central characteristic in her sense of self. Anne indicates that she would go to the doctors when asked to do so but would not choose to attend of her own accord; this is Anne actualising her autonomy.

Anne also provided an indication of when stoicism, used to facilitate continuation of a meaningful activity, presented a risk to health:

“A fortnight ago when I was at friendship [an organised social group] it just - something hit me there (points to chest) and I went (intake of breath) as though it was just going to take my breath a bit, and I thought oh its funny that is, but I didn't say anything, never mentioned it to anybody.” (A01)

Anne prioritises her needs for independence before her needs for safety. Carrying on represents an effort to control the image of self to others and maintain a sense of

autonomy; to reveal suffering would be to invite help, which may undermine her independence and challenge her notion of self.

Avoidance styles of coping may underpin participant perceptions of carrying on. Barbara presents herself as carrying on through hope, which revealed underlying avoidance:

Barbara: [I] just carry on, (laughs) sit down and just try and forget it [...] I don't go pushing [...] tablets down my throat or anything like that. I just sit quietly and hope it'll go... [Pause: 00:04]

Int: Did you have your pain for a while before you went first to the doctor?

Barbara: Oh yeah, I hoped it would go off (laughs). (B01)

The central role of hoping may reflect the low control that Barbara reported on the CASP-19 (3/12 for control). Furthermore, that Barbara indicates enduring her pain rather than to seek medical assistance; this suggests support for her high autonomy score (11/15). Barbara also reported utilising distraction to support taking her mind off her pain, her dog is a positive distraction: "She comes and talks to me, I talk too, and stroke her. [...] It takes your mind off [...] the pain" (B01). Passive avoidance may indicate not having accepted the presence of chronic pain; thus, autonomy is maintained but only through avoidance of reality.

Henry described his employment role as providing a distraction from his chronic pain; furthermore he described using the natural environment as a distraction watching the birds in his back garden. In contrast, George can no longer maintain his role as a farmer; he provided an alternative perspective on carrying on positioning the phrase in an existential sense:

George: I would like to think that I can do more farming, but I can't do and so that's it. The pain, the pain - if I started bending down or whatever it's just hopeless, so...

Gail: ...you can't work, you see.

George: I can't do it.

Gail: Which is a pity - so he gets a bit frustrated.

George: I would do it if I could do it. It's not as I'd like, but I suppose at nearly seventy-five I can't carry on forever, so....

The contrast between George and Henry links with differences in their CASP-19 scores. Henry reported higher scores for control (7/12) and autonomy (10/15) than George (control: 4/12, autonomy: 6/15). Maintaining employment as a distraction from pain may enable Henry to control pain better and provide a greater sense of autonomy; with the absence of work explaining George's scores. George expressed feelings of hopelessness as a result of pain; this was reinforced by George having scored lowest overall on the CASP-19. Maintaining hope was central to Barbara's sense of carrying on; this may explain her higher score on autonomy (10/15) than George. George also attempts to be stoic about his health, as exemplified by his response to having experienced a stroke as: "a bit of a blow" (G01). As a strategy, stoicism seems to be ineffective for George in maintaining either control or autonomy; in contrast at least Anne scored higher for autonomy (9/15) than George.

Maintaining privacy of chronic pain in social relationships outside of the research interview is important to Frances; she utilised this strategy during years of employment:

“I have worked through quite a lot of pain really, but you don’t want your staff to know, and you don’t want your customers to know, so you do the best you can” (F01).

Frances worked for approximately 40 years in the leisure and tourist industry and lived on the premises of her employer and so was “on call” for much of the time. Later in her working life she purchased a house and used this space as an opportunity to maintain privacy:

“I worked in Town J (Northern England) and really I've always had a home since then outside of work, erm- and it's the best thing because you can close your front door and that's - you can truly relax. Whereas with all my, you know, previous things obviously you're on call and you know it's not quite the same as...” (F01)

She continues to utilise privacy as a strategy to maintain control of pain and reduce the opportunity for stigma when among social groups:

“I feel frustrated when I'm not able to do- and I just feel as if you know... people looking askance to you as to, you know, well why aren't you? And as I say apart from constantly saying you're in pain, erm which you know is a sort of a conversation stopper really. I feel you know I want to do the best I can. So that's how it works.” (F01)

Frances described feeling under scrutiny from other people “looking askance” if she is not participating in an activity. Frances also acknowledged a risk of being stigmatised alluding to ageism associated with poor health in later life: “I suppose I have enough vanity to say that I don’t want to be a little old lady with a walking stick” (F01). Thus, Frances supports

privacy as a means of controlling how she is perceived by others. In the following extract, she described an instance the guarded way in which she did talk about her chronic pain with others:

“I don’t generally [talk about pain]. I didn't go [to the social group] one week and of course they sort of asked after you [me] and I did mention the sciatica but [...] quite a number of people round the table were able to empathise because they themselves have sciatica. But we don’t tend to talk about illnesses or that sort of thing, because it's a very light-hearted situation [...] there's a certain amount of privacy for all of us really and so no, it's not a general discussion to be perfectly frank.” (F01)

Frances continues to consider chronic pain as a private topic despite describing how potential opportunities for empathy and shared experiences occur. Keeping chronic pain private may support a sense of stoicism for Frances; this is acknowledged as a socially accepted value, or norm, Frances talks of the collective “we don’t tend to talk about illnesses” not the singular. Alternatively, Frances may also use such social activities as an opportunity for distraction away from thoughts of chronic pain, as Henry uses employment and Barbara her dog. Thus, to talk about pain during these activities would undermine the strategy. As pain management strategies both Henry and Barbara set out to keep the lived experience of chronic pain hidden from others; through stoicism participants seek to maintain a sense of independence and autonomy but also present an identity of endurance through carrying on.

Maintaining the invisibility of pain may act to reduce the opportunity for stigma and the risk of being seen to be “different”, as Frances observed above. Stigma also has cultural significance in rural environments. Anne indicated feeling vulnerable to stigma within her

particular rural setting; this acts to threaten her capability to maintain privacy over her health:

“I don’t want anybody to see me to be down. No, I don’t. [...] This is what makes me think because I know what people say about people up here [Village D]. [...] They think well what’s wrong with her, coz she’s got nurses going. There must be something wrong with her [...] and yet she can go out. [...] But, I mean, nurses say ‘if you can go out, then go out’ because it does you good. They come in, they dress you and then they’re gone again.” (A01)

Anne feels vulnerable to being labelled a hypocrite as a result of receiving care in the home every other day whilst maintaining social activities; she may be conscious of such judgements based on her own observations from her window observatory on to the neighbourhood and of being part of the culture, reinforced by long periods of time spent house bound. I observed this with Barbara who became distracted by a white van parked on the roadside outside of her home during our interview together; the white van was noticeable as it altered the outlook from her window and she automatically started to question why it was there. I also observed this ‘look’ first-hand when I drove through the village housing estate where David’s house is located; I recorded the following in my fieldnotes:

On approaching the participant’s home my first observation was that three local residents – who were outside one of their homes on the lawn talking – took a keen interest in my car as I drove by to get to the participant’s home at the end of the road. Reflecting on this I considered why they might have found my car interesting: not

seen it before, resident's cars are all recognised and well-known, who might this be?

(Fieldnotes)

Despite my observation, David and Diane do not consider themselves to be overlooked which they disclosed as being important to them. Diane and David value the privacy that they feel their rural dwelling provides. Diane identified the potential negative consequences that rural environments impose in which privacy and social isolation converge on one another, of a previous neighbour she described: "The only person who ever saw her was, was Female M, the post mistress, wasn't it?" Diane acknowledges the social role of people, such as the post mistress, have in rural communities. Diane suggests that for some households the post mistress may be the only regular visitor they receive. Catherine maintains the privacy of her pain when interacting with others in her community:

'During the interaction the participant (Catherine) played down her pain to (the postman) even joking that she did not have any pain and instead asked the postman about his problems – deflecting attention.' (Fieldnotes)

Catherine's actions deflect attention away from her chronic pain and support her desire: "I do hope I'm- I'm not someone who goes on about their aches and pains." (C01) but also presenting support to the postman. Stoicism and maintaining privacy of chronic pain seem central to psycho-social strategies of pain management. Rural environments may better support these strategies through relative geographical isolation; however, these environments are socially intimate spaces in which some may feel under scrutiny. In the next section I present data relating to the management of space and place as part of efforts to maintain control of chronic pain and limit impacts on autonomy; this is

important for the consideration of achieving self-realisation and pleasure with implications for ageing well in rural environments.

6.3.3 Environmental interaction adapting self and environment

The interaction between participants experiencing chronic pain and their surrounding environment is a dynamic one. Chronic pain related disability meant that participants adjusted and adapted activities to maintain mastery over their home space; some of these adaptations also extend out into wider spaces. A series of adaptations take place to maintain the fit between the environment and participants, and facilitate the capacity of participants to age well in place with chronic pain. Participants also described utilising the surrounding rural environment to support other forms of pain management. The rural environment also provided participants with a sense of belonging as they (re)constructed place to suit a change in needs and activities; these findings are presented in the next chapter as framed by self-realisation and pleasure. For now, I begin by presenting data relating to adapting the home space.

Participants described integrating assistive devices into their daily lives. I focus here on devices that were primarily used to overcome disability relating to chronic pain; however, this does not exhaust the devices that were used for other impairments due to additional health problems (e.g. magnifying glass for deteriorating eyesight). Assistive devices were used to support mobility and maintain activities that were important in maintaining independent living. Only Frances and Henry did not report using a walking stick or similar device to support their mobility; the other participants described various types from solid wooden walking sticks to metal crutches. The level of dependency each participant has on these walking aids varies. Barbara uses a walking frame to move around her house; the

frame supports her sense of safety in the home, as described: “it’s something you can get hold of” (B01). Barbara has experienced falls in the past: “I’ve done that many, many times, many times, yeah... because when you fall you’ve got no control over anything” (B01). The walking frame has provided greater control but also autonomy to be mobile in her home. Anne also has a walking frame but tends to use her walking sticks to get around her home:

“I’ve got a walking frame and I’ve got a wheelchair if I go far but I don’t want to use that if I can help it much, but erm I use sticks more than anything but err I mean there’s, there’s days that I have to use them about the house which I don’t, I don’t like.” (A01)

The use of walking aids may seem unfamiliar to Anne in a familiar place resulting in this feeling of dislike. Anne indicated that she uses different assistive aids inside and outside of her home suggesting that particular aids are environment-specific. Anne has a foldable wheelchair; however, when using this she is dependent on another person to maintain mobility. Anne used a three-wheeled walking frame whilst participating in the go-along, see Figure 18 (on next page).

The walking frame that Anne used was multi-functional providing scope for further adaptation; Anne used the handle bars as a hanging frame for her handbag (see Photograph #7). Anne also used the walking frame as a surface to lean upon whilst she took a closer look at items on the shelf (see Photograph #8). Thus, assistive aids become part of the process of adaptation; they are not an end in themselves but a means to maintaining control of the impact of chronic pain (i.e. disability, not pain per se) and autonomy within the home and beyond.

Figure 18: Photographing adaptation of walking frame to suit needs on the move

Description of go-along setting:

The shop was part of the 'Yorkshire Trading Company' chain. This was the first shop that Anne and I entered during the go-along. The shop sold a wide variety of items ranging from tools and hardware to christmas decorations and clothing. We entered the shop at around 10:30am on a week day.

Photograph #7: Hanging frame



Photograph #8: Leaning frame



Fieldnotes:

Anne moved around the shop freely with the aid of her walker and assisted by the wide and relatively quiet aisles given low numbers of customers.

Figure notes: original photographs cropped to disguise/remove identifying features.

Some participants are reliant on walking aids to the point that such devices have become embodied; Catherine described how walking sticks had become an extension of her body: "I've got four legs when I'm walking" (C01). In contrast, Diane described David's tendency to forget his walking stick:

Diane: He came in one day and he says, 'I've just come back along the road [...] some poor body's lost their stick and it's been run over and it's all squashed.' I said, 'Oh,

have they. Where's yours?' 'Oooh, perhaps I'm the poor so-and-so who's lost his stick.' 'Perhaps you are.' (laughs)

David: Yes, it's happened two or three times. (D01)

David has a tendency to forget or misplace his walking stick; perhaps indicating that he has a lower level of dependency on the stick compared to Catherine or that he may not accept the use of such an aid. David provided several examples of subtle devices that he uses; he is not alone in his use of such aids for such reasons. The assistive devices that David has integrated into his life include: an electric tin opener, a vegetable peeler with a large sponge hand that enables David to maintain his hobby of marmalade making, an electric lawnmower, a motorised reclining chair, and a car with an automatic transmission and heated car seats that make driving easier and which David described as "an ingenious thing" (D01). David described the sense of control and autonomy that the electric lawnmower provides:

"I can't start my [petrol] lawnmower. I haven't the strength to, to pull it. [...] And then you've gotta go at a, quite a rate of knots to follow it, and every time [...] your box... [is] full, you have to switch it off. Because there's that many safety devices on the damn things now; you can't leave it running and take the box off, you have to shut it off. Well then I've got to start it again. With my electric one, I've only got to press my button and I'm away again, you know, and I can do it at my pace [...] and not keep running after it." (D01)

Going at his own pace is important to David; this supports the process of slowing down that David perceives part of ageing when responding to the CASP-19 (see Table 6.1;

p197). Diane described the situation, prior to the purchase of a new lawnmower, as: “if there’s a job that needs doing here, he has to wait until the son-in-law comes” (D01); thus the electric lawnmower may increase David’s sense of autonomy. The garden is also symbolic for David and Diane as they cite the size of the garden as a reason for relocating to a new house (see life-grid, Figure 9; p158) the garden at the previous house was too large for David to manage.

The use of assistive devices has implications for psycho-social forms of chronic pain management; such as privacy. George is conscious of the visibility of devices that he uses and therefore the visibility of his health problems; he uses a Zimmer frame, orthopaedic shoes, and callipers. George described a preference for keeping the use of these devices to within the boundaries of his home:

Gail: He was given a Zimmer frame to struggle round the house with.

Int: Did you use that?

Gail: He did a bit.

George: Not much.

Gail: You did a bit. You used it to get to the bathroom and things like that.

George: Yeah, I did use it for that. (G01)

George has orthopaedic shoes and has adapted his wellington boots, to continue wearing them, by cutting them down to the ankle. The orthopaedic shoes are cumbersome and ugly: “They’re not dancing shoes” they are instead: “silly boots” (G01) as George described. George does not wear the callipers as they cause additional discomfort. The decision not to use assistive aids outside of the home may support George’s sense of autonomy but restricts his level of activity; this supports the statement he reported in the

CASP-19: “We restrict ourselves” (G01). The integration of assistive aids may improve quality of life at the level of control and autonomy; however, the visibility of health problems through the use of assistive aids may be problematic for quality of life at higher order levels (self-realisation and pleasure).

Participants adapted themselves to fit their environment through the use of assistive aids. Participants also adapted their environments to fit their change in health needs following chronic pain related disability. Adaptations ranged from altering the function of objects in their environments (e.g. the function of a chair) to changing the environment itself (e.g. moving house). Barbara uses in addition to a walking frame – a purpose built device – alternative frames to support her body when moving including a wheeled metal television stand. Similarly, participants described using a shopping trolley to provide such support. I recorded the following observations of Edward regarding his mobility around the home:

‘Edward didn’t use a walking stick or frame, instead he used various pieces of furniture to stabilise himself as he moved through the living room through to the dining area.’ (Fieldnotes)

Similarly, Catherine has formally designated roles for specific pieces of furniture:

“I’ve got a little stool by the gate, which is what I call my ‘waiting stool’ - that’s what I sit on when I’m waiting for the bus.” (C01)

Catherine does this so that the bus driver does not need to walk to her front door therefore maintaining her sense of independence and autonomy.

Participants have altered their sleeping environments to adapt to needs relating to chronic pain; the adaptation is relative to the experience and site of pain. In response to his elbow pain David now sleeps in a reclining chair as opposed to a bed:

“I sleep in a chair. I can’t - I can’t lie on me elbows. I have to support my elbows. So I have a recliner chair upstairs [...] An electric one, and it’s good because I can, I can get just the right position on me back.” (D01)

The electric reclining chair provides David with control as it supports his body and provides flexibility that enables him to react to changes in the location of pain which is multi-sited: “the beauty of it is [...] I can alter the angle” (D01). Diane also hears David in the night: “in the night I’ll hear it whiz, going up [...] and then I’ll hear it going down” (D01). David now sleeps in the electric reclining chair in the bedroom with his wife; although previously he had slept in the living room. The electric reclining chair enables David to control his level of comfort and adapt to his fluctuating pain.

Henry temporarily relocated his bed (and therefore his sense of space in his home) from the first floor to the ground floor during the height of his Shingles and during severe pain; he spoke of this when our interview had finished over a cup of tea:

‘We talked about his garden, which was immaculate and a frenzy of bird activity and flowering plants. It was at this point that [Henry] spoke about having had to at one point in time set up his bed in the room downstairs. The room that is now the living room. This he said he had to do during his “sick days” when he was “really bad”. It was here that he could see out onto the garden and seemed to enjoy the birds. I

reflected there on the role that these birds had – a source of entertainment on a sick day, friends, comfort, activity.’ (Fieldnotes)

The adaptation that Henry made also acted to support his strategy of chronic pain avoidance/distraction watching the birds. Since an improvement in Henry’s condition he has relocated his bed back to a room on the first floor. In contrast, in response to her knee and lower back pain that impairs her mobility, Anne has permanently moved her bed from the first floor to the ground floor and also the form that her bed takes:

‘[T]o complete my description of the physical layout of the room, to my right-hand side behind the entrance door was a sofa, which had been set up as a bed with pillows and a quilt. This is where Anne would sleep each night.’ (Fieldnotes)

The changes have meant that Anne spends much of her time in the living room; she has shaped this space for convenience to suit her needs and maintain her sense of autonomy:

‘Around the base of [a tall] unit was stowed an assortment of food boxes, newspapers and magazines.’ (Fieldnotes)

For Anne the relocation of her bed to the ground floor is part of a broader adaptation of her two-storey house into a single storey dwelling such is the nature of her physical impairment, as she described:

“I don’t go upstairs at all unless there's somebody in the house. I can get up the stairs, I go up with my hands on stairs [...] I take me stick with me and I come down catching hold of the rail on one side and me stick in the other hand. And I can do that standing up but I can't go upstairs standing up, I have to crawl upstairs. [...] I want to

go up sometimes [...] to see what there is upstairs, to see if there's anything I can get rid of." (A01).

Anne suggests that the upstairs of her home has become unfamiliar citing a reason for wanting to go upstairs "to see what there is". Anne presents a determination to still go upstairs by using a crawling motion underlining her determination to maintain autonomy. To overcome the barrier of the stairs Anne has had a wet room comprising shower and a toilet installed on the ground floor of her home. Anne has also adapted the garden of her house turning the grass and vegetable patch into wood chippings and stones to reduce the maintenance needs; the alteration also has implications for Anne's sense of self and pleasure which I explore in more detail in Chapter Seven. A feature that Anne has maintained in her house is her open fire:

"I've no central [heating] [...] they keep on to me: 'why don't you have central heating?' [...] well I like my fire. [...] I said you're too damned idle for cleaning your grate out. I mean cleaning my grate out doesn't worry me I sit on that chair, because I can't kneel, I sit on that chair and [...] clean it out, it takes me a while but I do it [...] it'll make my back ache with bending over [...] but, I don't mind. I quite like it. [...] I'll have central heating when I possibly can't make my fire [...] The other week somebody rung up and said erm I can have up to £10,000 grant to have central heating in, I said no thank you I've got what I want." (A01)

In this instance Anne compromises her control over the heating of her house, as central heating would provide greater control than having to make a fire, but maintains a sense of autonomy. Anne reported low control, high autonomy but also high self-realisation

(11/15). In contrast, David and Diane have changed their heating system, as Diane acknowledges:

“We’ve got an electric fire instead of dusty fires [...] but I miss the log fire [...] but it’s much easier for us.” (D01)

In doing so David and Diane have compromised on their pleasure to achieve greater control; a basic need.

Catherine, David and Diane, Frances, and George and Gail have all moved house in later life to maintain control and autonomy as a result of chronic pain-related disability. Catherine chose to do this as her previous house had become too large: “you can’t go on living in a house that size when you’re on your own” (C01). Catherine moved to a smaller cottage adjacent to her former house; this provided an opportunity to maintain independence but also her attachment to the rural community: “I love it out here” Catherine acknowledged. David and Diane moved to downsize the garden. Frances described moving house in anticipation of health deterioration therefore to prolong her sense of control and autonomy:

“But we felt that if we didn’t make the move when we did it would be too late because we wouldn’t want to do things that we’ve done, maybe we wouldn’t have the energy or the means. [...] It was a conscious decision.” (F01)

Frances described moving whilst she still had the energy and means to do things that she wanted to do. In contrast, Henry shared his regret over not having planned ahead: “We wish now that we’d bought a bungalow [...] we’re getting old and the stairs take some climbing” (H01). In an ideal world, Henry would remove the first floor and place it

alongside the ground floor as an expression of his attachment to his home: “I think we'll stay forever anyway” (H01). George and Gail’s house move was suggested by their son following George’s stroke; having moved Gail identifies the benefits in terms of access to amenities, and therefore maintaining autonomy:

“And now we’re back here, which is lovely, it suits me. We liked it up there, but it wasn’t the - it wasn’t a place for older people when you get.... Say you can’t drive or you can’t walk anywhere, it’s a long way to walk anywhere up there. Here I can walk to the village hall and George can walk to the farm, with difficulty, but he does a bit. Erm, you know, it’s much more convenient here...” (G01)

Gail identifies the remoteness of the previous home and surrounding rural space. Gail is talking about the density and distribution of settlements and the proximity of places that form part of her routine. Gail and George have moved to the outskirts of a small village, which relatively speaking has good amenities compared to the remote farm on which they previously resided.

Participants in this study defined their own terms of rurality; constructing rural spaces as meaningful rural places. The features of these rural places were (re)constructed and utilised to support specific self-management strategies therefore integrating the environment into coping on a physical level but also a conceptual one. The construction of rurality had implications for the connection and sense of belonging that participants expressed about their dwelling; I explore this further in Chapter Seven in terms of well-being and within the frame of pleasure and self-realisation.

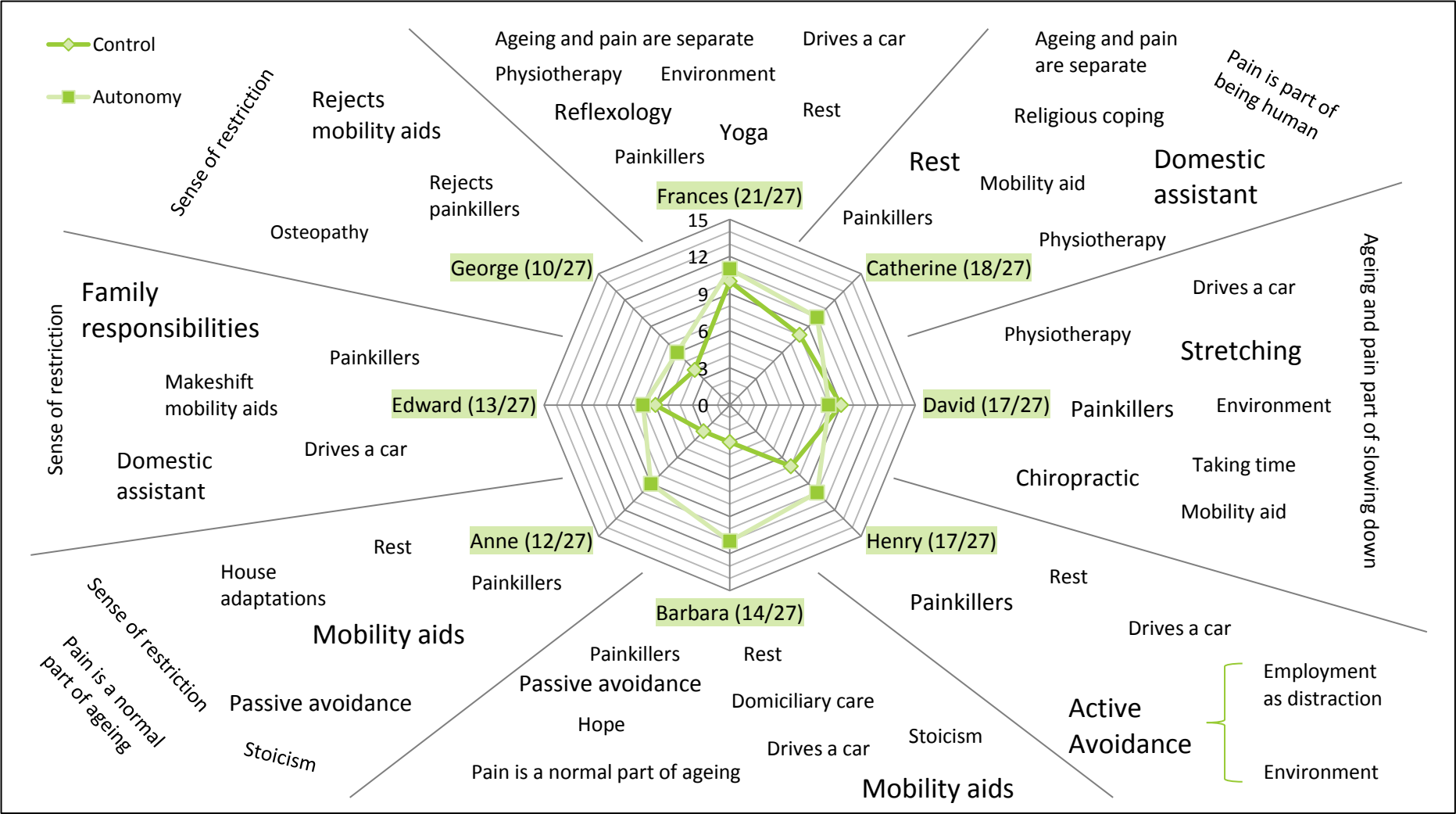
Summary

In this chapter I have explored the diverse ways in which participants seek to manage their chronic pain. In Figure 19 (on the next page) I present the combined findings from the deductive and inductive analysis to depict the ways in which participants managed their pain and supported control and autonomy.

Self-management occurs across a spectrum of dimensions like how chronic pain is experienced. Participants described techniques for maintaining control of chronic pain in which orthodox medical and alternative therapies are often combined. Participants described psychological and social techniques used to manage chronic pain in social interactions. Participants also described overcoming physical impairments of chronic pain through incorporation of assistive aids; however, assistive aids increased the visibility of physical impairments and invited stigma which had implications for self-image and identity. Participants transformed their home environments to age in place; they also shared narratives on how they inculcated the wider rural environment into chronic pain coping. Participants exhibited both rural space and place as fundamental to coping. Active coping and self-management styles, as opposed to passive avoidance styles, may better support older adults with chronic pain.

In the next chapter I explore the data relating to maintaining activity in the face of restrictions and identify additional resources that participants used to support coping.

Figure 19: Control and autonomy supported by complex pain management



Chapter Seven: Maintaining self-realisation and pleasure



The selection of photographs presented here are supplements to my fieldnotes and with these I try to represent a range of activities that participants described participating in (clockwise from top left): going to the pub (#43), village hall (#101), bird watching (#42), and taking pleasure from the rural landscape (#44).

Introduction

In Chapter Six I presented findings framed by the CASP-19 domains of control and autonomy. “Carrying on” was a central concept in maintaining control and autonomy. In this chapter, I present findings framed by the remaining CASP-19 domains: pleasure and self-realisation. These represent higher order needs in addition to love, belonging and self-esteem. I present pleasure before self-realisation as this reflects the order of items in the CASP-19 and the hierarchy of needs depicted by Maslow’s pyramid. I integrate different types of data into this chapter: interview extracts, photographs, and fieldnotes to support my findings and analysis.

7.1 Maintaining pleasure in later life

In Figure 20 I present participant scores for pleasure. The pleasure domain includes five items: 'I look forward to each day', 'I feel that my life has meaning', 'I enjoy the things that I do', 'I enjoy being in the company of others', and 'on balance, I look back on my life with a sense of happiness'.

Figure 20: Radar plot of CASP-19 scores for domain of pleasure in rank order (n=7)

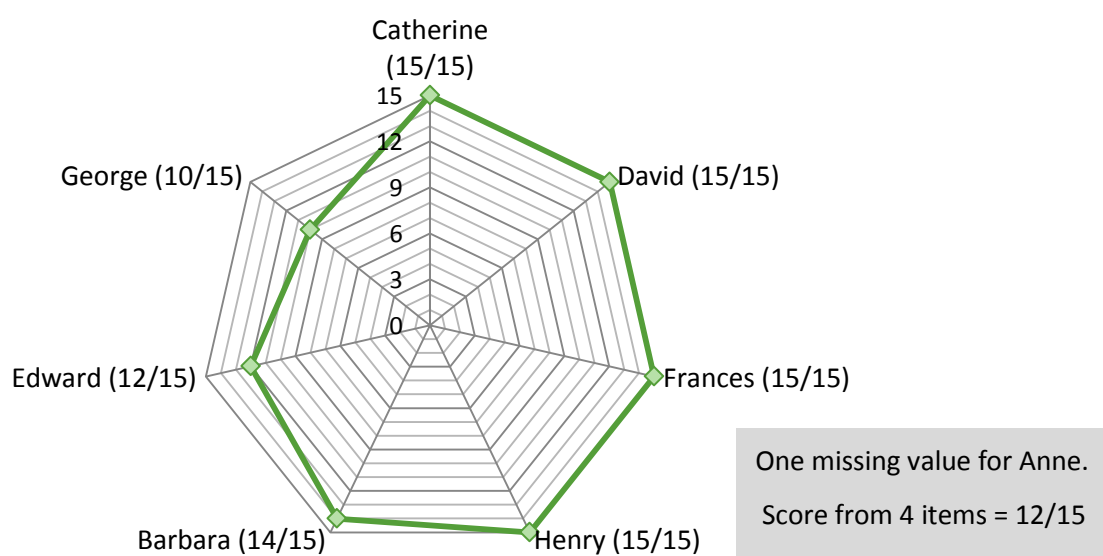


Figure notes: Missing data for Anne 'I feel that life has meaning' reason explored in text.

Catherine, David, France and Henry all scored highest (15/15) whilst Edward (12/15) and George scored lowest (10/15). I explore specific responses by these high and low scorers to each of the five items in the remainder of this section. As four participants scored 15/15, for the sake of brevity, I present the qualitative data from two of these for each item in the tables that follow; the selection is driven by the qualitative data and what it can tell us about pleasure in later life affected by chronic pain.

All participants reported to 'often' look forward to each day (Table 7.1 on next page). Thus, pain does not make living unbearable.

Table 7.1 CASP-19 Item 10: 'I look forward to each day'

Participant (Response)	Qualitative data extracts from stage one interview
Catherine (Often)	"I think always. I don't mean actively getting excited about each day, but I don't dread each day, no."
David (Often)	"Yes, of course I do. [...] I always check the newspaper to see if I'm in the obituaries and if I'm not there I must be all right."
Edward (Often)	"Mostly, yes."
George (Often)	<p>George: Not very often (Laughs).</p> <p>Gail: Oh dear, GEORGE*</p> <p>Int: Is that not often?</p> <p>George: I'm not too bad. Would you repeat the question? [...] Yeah, quite often. Yeah, mainly. [...] Often.</p> <p>Int: You seem to have changed your mind on that.</p> <p>George: [...] I was answering it the wrong way round.</p>

**upper case Indicates increased volume and emphasis*

Catherine grounded her response in pragmatism. In contrast, David contextualised his response by considering his own mortality to emphasise what each day means to him; to continue to exist. Edward's response was limited. George initially responded negatively but altered his response; Gail's exaggerated response may have instigated this change (i.e. to avoid stigma). Among the other participants, only Anne provided additional context and she shares David's perspective on mortality:

"I often look forward to the next day, because, well, I'm here; that's why I look forward to it." (A01: Anne, stage one interview)

Existence is prioritised; pain is endured.

The data suggest that relationships with significant others, family and religion provide sources of meaning in participant's lives (Table 7.2 on next page). On the other hand, the

loss of a role that represents continuity across the life-course, potentially because of chronic pain, may reinforce a lost sense of meaning. Six participants responded 'often' to this item, only George responded 'not often'.

Table 7.2 CASP-19 Item 11: 'I feel that my life has meaning'

Participant (Response)	Qualitative data extracts from stage one interview
David (Often)	<p>Diane: I think the grandchildren have brought a bit more meaning to your life haven't they?</p> <p>David: Oh, yeah, definitely [...] Although they haven't got [my] surname. But they're not so bad, they'll be all right. But that doesn't worry me that [our] dynasty has gone. [...] As you get older you think, well, it's only a name at the finish, you know, so what? [...] The name helped me when I was [...] doing my job. [...] It's only a name on a gravestone when you've finished."</p>
Henry (Often)	<p>Int: Where do you get that meaning from?</p> <p>Henry: (cough) well, through our partnership, me and Helen, mainly</p>
Edward (Often)	<p>Edward: I'm not quite sure what I mean</p> <p>Int: I think that meaning in life is about different roles that we... Is that what you mean or is there more to it?</p> <p>Edward: (clears throat) obviously there's huge pleasure with the grandchildren but erm... [pause: 00:10] belief and trust in God I think.</p> <p>Int: Is that important to you? Has it been throughout your life?</p> <p>Edward: Oh yes. Erm, not totally throughout but most of the time.</p>
George (Not often)	<p>George: Because I can't do what I want to (Laughs).</p> <p>Gail: It's like going round in a circle, isn't it?</p> <p>George: Well, all these questions....</p> <p>Gail: It's like going up alleys that don't lead anywhere (Laughs).</p> <p>George: Well, these questions are all linked together, aren't they?</p>

Anne did not provide a response on the scale for this item; she expressed the following reasoning:

"I don't know, I don't know what say about that... you can put down what you like for that, I think. [...] It is a difficult one, isn't it? I mean, what is the meaning of life... not a lot, I don't know what you put down for that I'm sure, don't answer that one (laughs). [...] I suppose it had [meaning], like years ago, I mean there was something behind it

then because you had something to look forward to, there was a kind of meaning behind it weren't there." (A01)

Anne views work as having given her purpose and drive; perhaps in the absence of a specific role Anne does not recognise her place in the world. For David and Diane the item elicits an extended narrative around the theme of family relationships (e.g. grandchildren, succession of the family name, long distance relatives, and loss of relatives). David has children, but no male heirs to continue the family name. He indicated a sense of belonging to a family dynasty; this was subsequently replaced by pragmatism about the meaning of a name and enjoys his time with his grandchildren. David revisited this issue several times during the interview and so it may represent a source of regret for him and a loss of continuity connecting his past and future. Henry establishes meaning and a sense of belonging through his "partnership" with Helen. Edward introduces his spirituality and relationship with God as providing meaning in his life. In contrast, George perceived a lack of meaning due to restrictions on activity; relating back to his low sense of control (4/12) and autonomy (6/15). George retired from farming three years prior to the interview; he would continue farming were it not for his physical disability which has implications for pleasure and self-realisation (7/15).

All participants reported enjoying the things that they do at least 'sometimes' (Table 7.3 on next page). For Catherine, the kitchen represents a room in which pain becomes exacerbated, as activities in the kitchen tend to involve standing for extended periods (I return to this in Section 7.4: p271). Edward no longer enjoys cooking because he is responsible for this daily due to the deterioration in Ethel's health; whereas previously he enjoyed cooking as a one-off on a weekend. Family responsibilities were noted by Edward

as reducing his sense of autonomy (7/15). George simply reported to enjoy “getting up of a morning and pottering about” (G01). Being in the kitchen represents an opportunity for David to be creative. David also indicates a sense of belonging (a higher order need) through his enjoyment of football, taking ownership of the term (“my football”) and belonging to a collective (“we’re not doing very well”).

Table 7.3 CASP-19 Item 12: 'I enjoy the things that I do'

Participant (Response)	Qualitative data extracts from stage one interview
Catherine (Often)	“Yes. Well, except pottering in the kitchen. Don't enjoy that anymore.”
David (Often)	<p>David: I enjoy cooking. Erm, I’m especially creative with my cooking.</p> <p>Diane: Hmm. We enjoy it when the children, the grandchildren come or the children.</p> <p>David: Yeah. I enjoy my football. [...] we’re [favourite team] not doing very well at the minute</p>
Edward (Sometimes)	<p>Edward: I used to enjoy cooking a meal when it was once a week and Saturday and my turn but when it becomes a virtually daily requirement it wears a bit</p> <p>Int: Do you find it difficult to cook now?</p> <p>Edward: Hmmm we've got a perched stool which is quite a help. [...] That's alright</p>
George (Sometimes)	<p>Int: What things do you enjoy?</p> <p>George: [...] Getting up of a morning and pottering about.</p>

The remaining respondents reply as ‘often’ enjoying what they do. Anne described the following:

“I do still try and do a bit of knitting, which I enjoy, a bit of sewing [...] because I've always enjoyed that. [...] There's one thing I don't like, that's writing letters.” (A01)

Barbara stated “what I can do I enjoy” (B01) suggesting a sense of restriction; reflected in her low score for control (3/12). Frances stated: “I wouldn't do anything that I knew I weren't going to enjoy” (F01) that reflects her strong sense of control (10/12) and

autonomy (11/15). Participants described continuing to enjoy specific activities; the enjoyment of some activities had decreased.

All participants responded as 'often' enjoying the company of others except for George and Edward who responded 'not often' to this item. The data relating to this item was limited for high and low scorers (Table 7.4).

Table 7.4 CASP-19 Item 13: 'I enjoy being in the company of others'

Participant (Response)	Qualitative data extracts from stage one interview
Catherine (Often)	"Well, I mean there are some, aren't there, but [laughs] basically yes. [...] Oh yes, always. Well, I mean nearly always, give or take. In general, yes."
David (Often)	<i>No further discussion in response to this item.</i>
Edward (Not often)	Edward: No Int: Does it depend on who it is Edward: Of course it does
George (Not often)	George: Erm not very often. I'm a bit.... Gail: He's a bit of a loner.

Catherine enjoys the company of others and attends group activities (e.g. church group, gardening group). David also enjoys the company of others elsewhere in the interview he described a rule that he lives by to speak to strangers at every opportunity (see Table 7.7). However, David has few friends in the local area and attends only one group activity at the local church; a small congregation. Continuing to support a football team may support David's sense of connection and belonging with others. In contrast, Gail referred to George as "a bit of a loner" (G01), suggesting he does not enjoy the company of others. Edward suggested that it depends on who the company is; he talked of his gardener as talking "pointlessly and boringly" (E01; as quoted Section 5.4.7: p183). George and Edward described themselves elsewhere in their respective interviews as unsocial. The

other participants did not share any further contrasting responses. The wording of the item suggests that people who do not like group activity, which includes some of the participants, may not achieve a high quality of life.

All participants reported to 'often' looking back on their life with a sense of happiness (Table 7.5).

Table 7.5 CASP-19 Item 14: 'On balance, I look back on my life with a sense of happiness'

Participant (Response)	Qualitative data extracts from stage one interview
Catherine (Often)	"It doesn't mean that I've felt - if, if I say always, looking back, but it doesn't mean that all through my life I've, I've felt happy because I mean obviously there have been times when I haven't. But in general [...] I think I've been very blessed"
David (Often)	"Yes, on, on balance, yes, I do. [...] Often, yeah. You can look back and say, 'Well, I should have done this,' or, 'I should have done that,' but you can't - it's, the worse thing is to dwell on things that might have been. Er, might have been never gets, never gets you anywhere. So, no, it's er, on, on balance, yeah, I'm pretty happy with my lot."
Edward (Often)	<i>No further discussion.</i>
George (Often)	<i>No further discussion.</i>

Catherine clarified her response to Item 14: "but it doesn't mean that all through my life I've, I've felt happy because I mean obviously there have been times when I haven't" (C01). David elaborated with the following:

"You can look back and say, 'Well, I should have done this,' or, 'I should have done that,' but you can't - it's, the worse thing is to dwell on things that might have been. Er, might have been never gets, never gets you anywhere. So, no, it's er, on, on balance, yeah, I'm pretty happy with my lot." (D01)

David's words suggest that he has learned not to dwell on regrets. Neither Edward nor George expanded on their response. Anne specified that: "I've had a happy life, although I've been handicapped lately, but I've had a happy life" (A01); this suggests that despite deterioration in her current health her impression of her life prior to this has not altered. The other participants did not share any further contrasting responses. The qualitative data suggest that previous happiness is not defined by current health condition(s) and that not dwelling on regrets is important; stoicism supports this reflectiveness.

In this sub-section I have presented quantitative and qualitative data from the integrated CASP-19 measure. The data suggest that the maintenance of meaningful activities is important in sustaining pleasure in later life. In the case of George his daily activities have altered from farming to pottering around the home; although George enjoys pottering he does not seem to achieve meaning through it. Participants who enjoy the company of others scored high on the domain overall; however, being active in groups was not a preference for all participants. For instance, George (10/15) and Edward (12/15) described themselves as unsociable. Participants remained able to achieve pleasure despite in some cases having reported low control and autonomy in previous domains.

7.2 Self-realisation

In this section I present participant responses and qualitative data relating to the domain of self-realisation. The domain includes five items: 'I feel full of energy these days', 'I choose to do things that I have never done before', 'I feel satisfied with the way my life has turned out', 'I feel that life is full of opportunities', and 'I feel that the future looks good for me'. The responses from all participants are presented in a radar plot (Figure 21, on next page).

Figure 21: Radar plot of CASP-19 scores for domain of self-realisation in rank order (n=6)

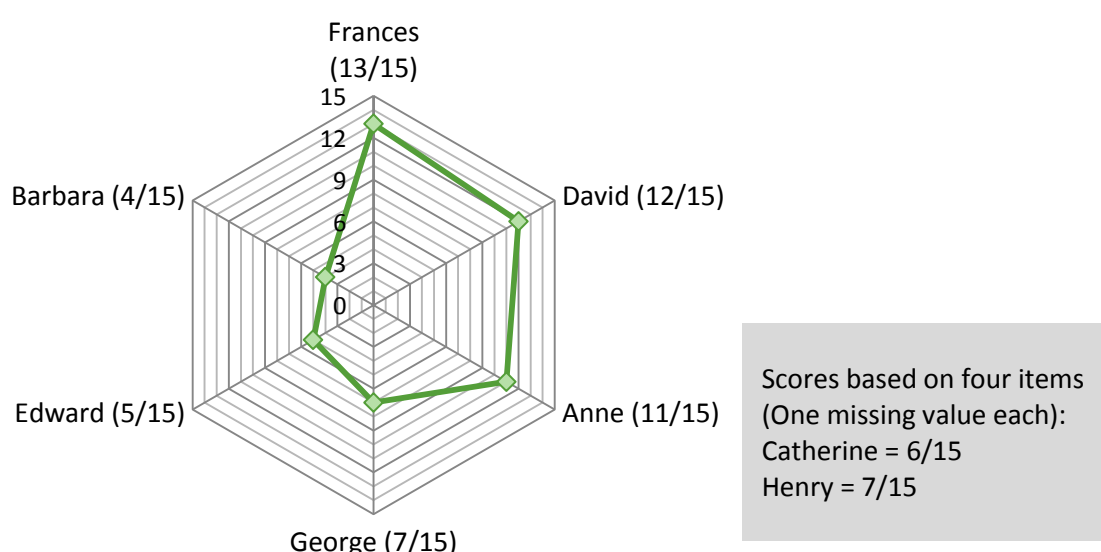


Figure notes: Missing values recorded for Catherine and Henry – reasons explored in text.

Frances (13/15) and David (12/15) scored highest on this domain, Barbara (4/15) and Edward (5/15) scored lowest. In what follows I explore the qualitative data for these high and low scorers for each item in turn in a table format, as with previous domains. I then draw in responses from other participants to identify commonalities and contrasts.

All respondents reported less than optimum energy levels (Table 7.6).

Table 7.6 CASP-19 Item 15: 'I feel full of energy these days'

Participant (Response)	Qualitative data extracts from stage one interview
Frances (Sometimes)	"(laughs) Erm...I don't feel as much as full of energy these days, sometimes I think."
David (Not often)	David: Not full of energy, no, no. [...] Not often. Int: It differs from day to day does it? David: Yes, it does, it does.
Edward (Never)	[Ethel: (chuckles)] "No, never"
Barbara (Not Often)	"I feel full of energy these days, no, no [laughs] definitely not [...] Put not often, because I mean I do get going, don't I sometimes"

The high scorers and low scorers for this domain did not provide additional qualitative data to contextualise their responses. Of the remaining participants, Anne responded as 'sometimes' feeling full of energy the others all respond as 'not often'. Catherine has informed her GP about her sense of a lack of energy:

"I haven't got the energy [...] the doctor gave me some little brown jobs. My blood was short of what? Iron. [...] And when I finished them I said, 'Can't I have some more?' And she said, 'No. Your blood's perfectly normal. You are 90, you know.' [...] I do miss the energy that I've normally had, definitely." (C01)

Catherine has experienced a decline in energy. The retelling of her medical encounter positions her GP as suggesting Catherine should not expect to be full of energy at her age. In contrast, Henry experiences low energy as a surprise:

"Obviously I'm not full of energy... I try to think I am but when you try to do things that you used to do you suddenly find that you can't." (H01)

A common response to the item was for participants to laugh when the item was read out; Frances, Barbara, Ethel all laugh in data presented in Table 7.6, as did Anne and George. Laughing is suggestive of an expectation not to be full of energy; this may relate to expectations around age, as Catherine's GP alludes. Alternatively, it may indicate how far individual experiences are from the statement.

The data in Table 7.7 (on next page) suggest high scorers on the domain share a similar outlook and try new things. Frances described a new volunteer role at a local school as an opportunity to learn something new. David described having a mentality to be outgoing and speak with strangers; although he admitted that this activity has declined.

Table 7.7 CASP-19 Item 16: 'I choose to do things that I have never done before'

Participant (Response)	Qualitative data extracts from stage one interview
Frances (Sometimes)	"Yes I do. [...] I've never been involved with a school before, it's fascinating, the whole thing and seeing how the teachers work and so on, I mean I find that really interesting, erm and so different to what I've done before. There are link ups, you know where I've done training for people, and so on, but erm...yeah, I enjoy that, I think it's because I haven't done it and because it's new."
David (Sometimes)	"Not so much as now as I did, it was always drilled into me, that nothing would give you more confidence than if you speak to a stranger every day. Er, it doesn't bother me now that if, if, if I did that, but it's certainly, it's certainly something that I, er, er, was, was taught. I mean, it's quite right; you do, the more you talk to people. Because she's always saying, if we go anywhere, er, 'Who the bloody hell's he talking to now?' and I still tend to do it [...] Not as often as I did."
Edward (Not often)	"I don't think so [...] Not often."
Barbara (Never)	"Oh no, no way, no."

Edward and Barbara did not elaborate on their negative responses to enable comparison here; however, previously Edward described having family and household responsibilities and being "unsocial", which may limit opportunity to try new things. Barbara described a restricted level of participation in activities going to bed at 5pm, for example, and a lack of control (3/12). The remaining participants: Anne ('sometimes'), George ('not often'), and Henry and Catherine ('never') provided limited qualitative data to contextualise their responses. The scores for remaining CASP-19 domains present no distinct pattern to support responses here. It is unclear whether responses are due to a sense of pain-related restriction or conversely contentment with current activities even if limited.

Satisfaction with life may be linked to whether an individual can look beyond their current circumstances, specifically health (Table 7.8, on next page).

Table 7.8 CASP-19 Item 17: 'I feel satisfied with the way my life has turned out'

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Often)	"Often I think. [...] I'm not complacent. [...] I just think I'm very fortunate [...] that I don't have any huge desires I mean I would enjoy going, I don't know, for the sake to Iceland or whatever, if the opportunity arose, and if I could afford it or whatever, but if I didn't do it, it wouldn't worry me. I don't have those sense of highs and lows. I suppose because I've sort of trained myself not to in a way and just learnt to live on [...] some extremely tight budgets. So I suppose you know a walk in the park can be just as nice and enjoyable as a you know trip to [a] Hotel or something. <i>[Frances continues to talk about travelling abroad, scuba diving, elephant rides, taking holidays with others who she describes as a "second family"]</i> I don't rush to have another holiday this year. I'm quite content to mess about in the garden. [...] I'm quite lucky in as much as that I can make happiness."
David (Often)	"Yeah, I look back and I think, 'Yeah, I haven't done so bad,' you know."
Edward (Sometimes)	Edward: Sometimes Int: Is there anything that you're not satisfied with in particular? Edward: Erm, no
Barbara (Not often)	"I'm not satisfied with the way that my life has turned out, well I'm not, because nobody would say if they were like me, would they? If they're telling you the truth."

Frances was prompted in her response to this item to reflect on her attitude to live within her means. Frances derives satisfaction from walking in the park as opposed to trips to hotels; developing her own sense of happiness; this reflects her strong sense of control (10/12) and autonomy (11/15). David was modest in his assessment of his life. Edward did not elaborate qualitatively. In contrast Barbara challenged how anybody in her situation in later life could be satisfied; this may relate to her perceived restrictions and lack of control. The remaining participants responded as 'often' feeling satisfied. Henry stated that life: "turned out the way I wanted it" (H01).

Catherine rejected the tone of the item on the measure: "I think satisfied is smug" and referred to her situation as "blessed". Catherine clarified: "that doesn't mean I'm never miserable or confounding somebody or cursing somebody." (C01). George responded in

the following way: “Often, but with trepidation (Laughs)”. George and Gail continue a theme of restriction developed in George’s CASP-19 responses indicating they have not been able to do everything that they set out to. Responding to Item 17 elicits an acknowledgement of the importance of their children:

George: When you hear of people go miles away and whatever, yeah we’re pleased that they’ve stayed round here.

Gail: I think that’s probably part of us in them; that they’re not over-adventurous.

(G01)

Both Gail and George are pleased that their children have remained in close proximity.

Frances and David seem to be positive about the availability of opportunities; David reported to maintain a level of ambition (Table 7.9).

Table 7.9 CASP-19 Item 18: ‘I feel that life is full of opportunities’

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Often)	<i>No further discussion in response to this item.</i>
David (Often)	<p>David: Oh, definitely, yeah, and you grab ‘em with both hands.</p> <p>Int: Uh-huh. Do you feel that-</p> <p>David: Because, you see, there’s no rehearsal; you’re only here once.</p> <p>Int: Do you feel that way ‘often’ or ‘sometimes?’</p> <p>David: Yeah, I still - I still feel that. I still feel I’ve got more ambition than my son-in-law</p>
Edward (Not often)	<p>Edward: No, I don't</p> <p>Int: No?</p> <p>Ethel: That's a young man's question surely (chuckles)</p> <p>Int: (laughs) Is that a not often or a never?</p> <p>Edward: Not often</p>
Barbara (Not often)	<p>Barbara: [large exhale] ... I don't know what to say about that, but I know what to say about that, ‘I feel that my future looks good for me’ no way,</p> <p>Int: You don't often feel that way?</p> <p>Barbara: No [never] ‘I feel that my life is full of opportunities’ no, both of them [signals to Interviewer to mark both statements as the same]</p>

In contrast, Ethel was prompted by the item to suggest that the topic of opportunities was age-related; relevant to “a younger man”. Barbara provided responses to the final two items.

Of the remaining participants, Anne and Catherine both responded to the item as ‘sometimes’:

“Well life is full of opportunities, but not for me, not at my time of life. It’s full of opportunities for younger ones, isn’t it? Well, you can put ‘sometimes’ to that”

Anne provided a response that does not fit her description but is the nearest point on the scale to match her reasoning. Anne’s response compares to Ethel’s as both equated early life to a time of opportunities; perhaps indicating a lack of identifiable opportunities in later life, or being restricted and unable to take opportunities that are available. In contrast, Catherine focused more on structural issues and resources developed across the life-course:

“Well, it is [life is full of opportunities] for some people. But it isn't for everybody. [...] I would feel that all the time that [...] is a fact... But [...] it isn't for everybody. I mean I think it should be for everybody, but that depends very much where you live and what your financial circumstances are and what your background is [...] Put sometimes, then, because I mean there are [...] billions of people for whom there aren't any opportunities.” (C01)

Catherine and Anne’s responses suggest they think along two dimensions of opportunity: firstly, whether opportunities exist; secondly, to whom opportunities are made available.

However, they do so in subtly different ways and the response of ‘sometimes’ perhaps does not capture the complexity of their responses.

Being content with what one has is important when looking to the future; however, participants expressed difficulty responding to Item 19. Frances and David reported being positive about the future (Table 7.10). Frances did not elaborate on her response to this item. David stated that despite physical disability he and Diane “manage”; in times of need they are willing to pay for assistance or call on the help of family.

Table 7.10 CASP-19 Item 19: ‘I feel that the future looks good for me’

Participant (Responses)	Qualitative data extracts from stage one interview
Frances (Often)	“Yes I think it does, yes, often”
David (Often)	<p>David: Yeah, because you’ve got to be happy with what you’ve got. [...] I mean if they can’t do anything with my hands, well, so bloody what?</p> <p>Diane: So, you’ll have to manage with what you’ve got.</p> <p>David: I’ll manage with what I’ve got, you know. [...] There’s always somebody that’ll come and do it for you, even if you have to pay ‘em, but, er, there’s always somebody.</p> <p>Diane: [...] Daughter A and Son-in-Law A are very good aren’t they, to us.</p> <p>David: [...] I’m happy with what I’ve got. I’ve had this one [wife] for forty-nine years, I’m not gonna train another one now.</p>
Edward (Not often)	[Ethel: (chuckles)] “Erm, not often”
Barbara (Not often)	‘I feel that my future looks good for me’ no way.

Neither Edward nor Barbara elaborated on their initial responses so comparisons are limited. However, Barbara indicated not being satisfied with the way her life had turned out due to the state of her current situation. She also expressed opportunities as not available (Table 7.9; p257); perhaps she perceived the lack of opportunity as limiting her ability take control of her situation, her future.

Of the remaining participants, Anne stated 'sometimes' the future looks good for her but that this remains mobility-dependent: "You can't [...] say any other but yes, as long as you can get about in't it" (A01). In contrast, George stated 'not often' feeling that the future looks good for him:

George: It doesn't look good for me.

Gail: It could be worse, George.

George: It could be worse, yeah.

Gail: Goodness gracious.

George: Well, at my stage of life I don't really want any more opportunities, I must be honest. [...] Me family can have opportunities, but not me. (G01)

In keeping with Anne, George also reflected on the availability of opportunities as identified in Table 7.9 (p257) and suggested opportunities should be made available to younger generations.

Catherine and Henry recorded no response to this item on the scale; both appeared to be uncomfortable about this item. Catherine suggested a positive response would be to tempt fate by predicting her future:

"There ought to be [...] a 'DK', don't know. [...] I don't know what the future is at all. [...] On the practical level I have this [...] lovely little cottage, I have enough money to live on. I've enough money to pay someone to help me and so on. But what the future is, I don't know. I might be struck with deadly cancer tomorrow or break my leg or, or something terrible might happen to the treasure [home help] and that really would be awful (laughs), so what do you put for that?" (C01).

Catherine considered her needs: shelter and financial security. She acknowledged that health is unpredictable, both hers and that of the person who provides domestic assistance. At the end of this conversation, beyond the excerpt included here, Catherine pointed out to me: “I’m not frightened of the future, by the way” (C01). Henry shared a similar perception of an unknown future.

The data suggest that a high level of self-realisation can be achieved by rural older adults experiencing chronic pain. Participants who: tried new things, looked positively on their life as more than related to the present situation, could withhold regret, perceive opportunities as still available, and were positive about the future reported high self-realisation. Opportunities and activities seem to drive the domains of pleasure and self-realisation; further facilitation is provided by additional resources, both internal (autonomy and control) but also from external sources. In the sections that follow, I explore this further through the inductive analysis.

7.3 “Starting to come inwards”: the meaning of activity restriction

In Chapter Six, restrictions resulting from chronic pain were framed in terms of basic needs of control and autonomy. In this section restrictions are framed in terms of activities and the implications such participation may have for the higher order needs of self-realisation, pleasure, self-esteem and belonging. I present findings from the inductive analysis to help make sense of the CASP-19 responses and to integrate the different data within the theme of this chapter. The quotation in the heading for this section is from the following extract of Frances’ interview:

“You're maybe doing stitching or whatever and you can't get into a comfortable position or if you go out for a walk you're only walking a little way and then you start getting the pain and you just feel as if your life is starting to come inwards. [...] I think it's up to me to try and get it more outward.” (F02)

Frances introduced a process, or flow, of life moving “inwards” as a consequence of chronic pain and “outwards” through personal effort. Frances described her chronic pain as “debilitating” (F01) furthermore she described how this debilitation reduces her capacity to participate in social activities:

“My son and daughter-in-law love walking and all her family love walking and, you know, if there is a get together and it's a walking situation, I go out and struggle towards the end, or I turn back or I don't go out at all. [...] It depends on the degree of pain, because I know I can't keep up. So yes, it does have an effect. You do think twice before you do something.” (F01)

In this instance, Frances exercised control over the situation of whether to walk or not; she balanced control of her pain with participation in this social activity. Frances reported a high level of control (10/12) on the CASP-19 and also self-realisation (15/15) and pleasure (13/15). Compromising on an activity every now and again does not seem to negatively affect her overall enjoyment in life. France supported this sense of maintaining control:

“I do tend to think about it, I have to say, and if I'm in a less than 100% position then - or 80% or whatever, I then tend to say well, no, I won't go today.” (F02)

Frances sets a high threshold for participation; this may be due to a sense of vulnerability to harm: “I'm happy to have a go, so long as I don't feel I'm going to damage myself any further” (F02). The compromise that Frances makes between social interaction and maintenance of control is positive overall in respect of her CASP-19 scores. Frances scored high for pleasure and self-realisation which suggests she has responded well to chronic pain and continues to live her life “more outward”. Other participants experience restrictions that have more negative impacts upon these domains.

Participants described restrictions in terms of domestic tasks within the home environment; such as preparing hot meals and thus satisfying a need for nourishment. For example, Catherine described her pain as worsening if she were to stand for too long; she identified working in the kitchen as a common place for standing and therefore pain to occur: “the business of cooking, if you're getting on to pain, is an absolute what's it” (C01). Cooking a hot meal has meaning for Catherine beyond nourishment:

“I've always cooked proper food like my mother did. And I just can't do it. It's bad enough just to get two cups of coffee [...] but leaning over the sink to do the washing up and that kind of thing [...] is not easy. If you want to know what's the result of [...] having pain, for me it's making meals very difficult.” (C01)

Catherine adapts to her restriction by preparing convenience food (e.g. a ready meal). To eat fresh food Catherine may go without a hot meal and instead purchase cooked meat from a local butcher, she described this as “the best ham I've ever tasted” but acknowledged “but it's not a hot meal” (C01); it is not the “proper food” that her mother would have prepared. The restriction on access to fresh food was exacerbated when Catherine's gardening activities came to an end, 12 months previously. The impact of the

loss of gardening and inability to cook a hot meal for herself may in part explain her score for self-realisation (8/15, one missing answer), although Catherine maintains a high sense of pleasure (15/15). Anne has also ceased gardening; however, the meaning of her garden goes beyond the activity of horticulture:

“I’ve got woodchip on the one side and chippings on the other because I can’t just cope with it. [...] It makes me feel cross, coz I used to love being out in [the] garden doing something, growing some things, [...] go and pick a bit of lettuce, or pull a beetroot, I used to love that, go and get feeder beans. That used to be my life. I used to love it. Especially after me husband died, it was something for pass me time with. I mean I used to dig it before he died, I used to dig it over, and then he used to help me set things, because he couldn't do it his self.” (A01)

Anne described gardening in terms of a passion for horticulture as a way of life and also a connection with her husband. Anne scored 11/15 for self-realisation, which suggests that although she has lost a meaningful activity her quality of life in this sense is supported in other ways.

The restriction on activities has implications for how people interact with the world around them; this has implications for developing and maintaining a sense of self. David used to enjoy making home improvements; however, chronic pain limits his capacity to still complete such tasks to the point where he has started giving up his tools:

“I’ve started giving him some of my tools. [...] I’ve got a saw but it’s too heavy, I can’t hold it now, so I gave him that the other week. [...] The Sunday when he was here,

he'd said that his strimmer wasn't working very well. I said, there's one in the garage there, take that with you" (D02)

David's actions are symbolic and represent an act of acceptance of limitations. To recognise the scale of this reduction in activity; David described having "dam near rebuilt" (D01) a house earlier in his life, contrasting this to current experiences where he receives assistance, for example, to mow the lawn. Furthermore, property development was also a key part of David's life (see Figure 9, Section 5.4.2; p158). David also described difficulty in maintaining a connection to farming due to his physical impairments, having been raised in a farming family and having owned a farm himself, this is important to him. The hens that David keeps at his current house represent: "a bit of my farming [...] it's my roots" (D02). However, David takes a passive role in keeping these hens; he receives assistance from a daughter to clean the chickens out. Diane suggested David will never come to terms with the restriction: "No, I don't think I ever will, no" he replied (D02). Despite these losses David continues to maintain high self-realisation (12/15) and pleasure (15/15); and so these may be supported by other aspects of his life (e.g. providing care for grandchildren, maintaining sense of autonomy).

Farming has also been an important role for George. George's lifelong activities, according to Gail, his wife, are limited to: "farming and he's done nothing else" (G01). Furthermore, Gail described the family as "entrenched" (G01) in farming. From the bungalow in which George and Gail now live, nestled among farm buildings and surrounded by farm fields, George "sees things that need doing and he can't do them" (G01). For example, he described a collapsed dry-stone wall visible from his window, presented in Figure 22. George's surroundings seem to reinforce a sense of helplessness;

this sense is further compounded by the work that George observes as being overlooked by others.

Figure 22: Mixed data referring to George's outlook from his house

Photograph #94 indicates typical view from the front of George's house



Created: 18.03.2014

Photograph #96 indicates dry-stone wall on the roadside adjacent to George's house.



Created: 18.03.2016 (image cropped)

On a visit to George's house I observed a drystone waller repairing this wall.

George talking about the drystone walls:

"[Others] seem to drive past and never see them. There's a wall, you know, falling down and they just go straight past it and never see it, or don't want to see it, I don't know which it is. It's things like that [...] I wish I could deal with." (G01)

The restriction on activities is magnified when the range of activities that a person participates in is already small. Gail inferred that George is not capable of living a normal life:

Gail: If you did a - if you led a normal - did a normal day [...] walked the dog, did the shopping, cleaned the car, did a bit of gardening or whatever, like a normal...

George: I should be struggling. [...] I don't really want to start taking these painkillers.

Gail: They say the best thing is to not be on your feet too much but potter, which he does, he potters. [...] He doesn't do anything (Laughs)... He's the brewer upper. (G01)

Contrasting George who has experienced a decline in his role from farmer to "brewer upper" (G01) and David whose role as property developer has ended, the difference in impact on self-realisation and pleasure between these two is stark: George (self-realisation, 7/15; pleasure, 10/15), David (self-realisation, 12/15; pleasure, 15/15). Whereas, David has multiple identities to draw upon to provide a breadth of self-realisation, George focuses on a single identity as a farmer. Contrast the relationship the two share with their respective spouses; Diane describes here and David's usual activity:

"If we get a free day, [we think] right, where shall we go today? [...] We don't just sit here and look at each other" (D02)

Whilst Gail describes what life is like for her and George:

"It's just a bit frustrating that we can't do what we want, because it does affect my life. I thought we'd go on walks, we'd go on holidays, we'd travel, but we don't do any of that. We go to Town B (laughs) and George waits in the car with his disabled sticker so as I don't have to pay parking and - it's a very small world really." (G01)

The small world reflects the feeling of life drawing inwards and may in some part explain the difference in responses on the CASP-19.

Edward's life-course is intertwined with being a musician; he summed this up in the following line: "I dread to think how many weddings and funerals I've played for" (E01). Edward maintains this association through playing the organ at his local church; an activity that he routinely conducts and with military precision:

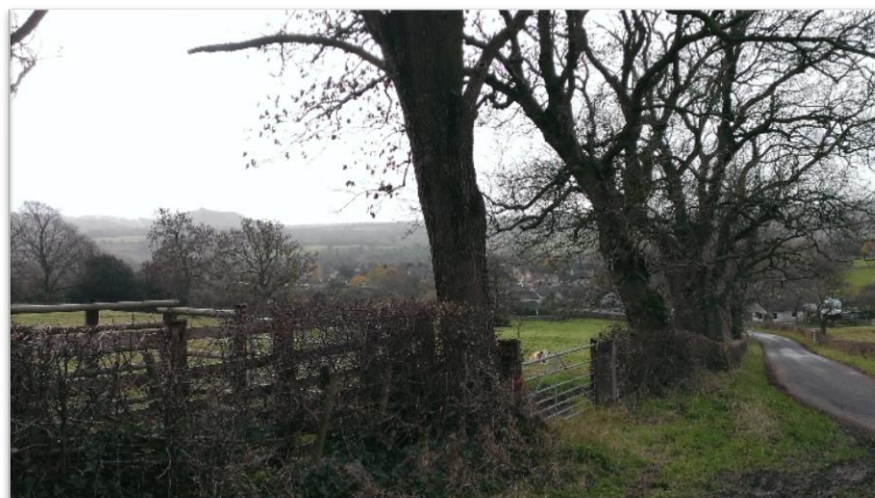
"In the car at 20 passed 10 to half passed 10, erm 2 to 3 minutes up to the church then, along path. Get the wheelchair out of the car, my wife gets in it, and we push it along this long path which is about 100 yards I would say, and seems to get longer every time I go, and then I can cope with a rather modest little organ compared with what I was used to in Town B" (E01).

Edward acknowledges the increased effort that performing this role has had; although this stems from restriction as a consequence of Ethel's health problems. This activity alone does not support a strong sense of self-realisation for Edward as indicated by his score on the CASP-19 (Self-realisation: 5/15). Perhaps the modest size of the organ leaves Edward feeling unfulfilled, compared with earlier roles and churches in his life-course.

A shrinking world is indicated also by Barbara who stated her restricted level of activity: "I just sit here and that's it (laughs). No, I don't go out, or anything like that" (B01). Barbara reported the lowest score for self-realisation (4/15) although pleasure remains high (14/15). The pleasures seem to relate to the enjoyment she takes from watching television programmes (e.g. The Jeremy Kyle Show). An example of Barbara's restriction is exemplified by her incapability to walk her dog (Figure 23).

Figure 23: Mixed data referring to Barbara's dog walk

Photograph #67 of hill that Barbara used to walk up.



Created: 15.11.2013

Barbara: I do [miss walking the dog] coz we used to walk right up the lane, right up to the top [of a hill] and back again. Yes I do miss it, but I can't do it. (B02)

Barbara's sense of restriction goes beyond walking the dog: "I have changed as a person, that's definite" (B01). The context of the conversation from which these words are taken refer to the loss of a caring role that Barbara provided in earlier life. Barbara reflected on times when she would drop everything to help someone in need; she acknowledges that she can no longer do this and posits chronic pain as the reason. As a result of this, Barbara's interaction with the world outside of her home is limited; she spends a lot of time sitting in the armchair of her lounge here she can watch television but also watch the world outside of her front window. During the photo-elicitation interview Barbara became distracted by a white van parked outside her neighbour's home (an incident described on p217):

The interview was made difficult throughout by [Barbara] becoming distracted by a large white van outside the neighbouring house. This change in the usual scenery was visible from her armchair and seemed to make her feel uneasy. (Fieldnotes)

The van altered the scene that Barbara would typically observe. There is a strong sense here of life becoming more inward. Anne also shares in this:

“When you see children about you know when it’s been nice, you’ve seen three or four of them come down on bikes and go back, even dad’s come down with them and come back you know, and it’s seemed nice when you can see, coz I mean I don’t go out much but I draw my curtain and I see then I can watch them, and it’s nice.” (A01)

Anne described enjoyment of looking outward, onto her window-scape, although this could also reinforce a sense of life drawing inwards. Where Anne and Barbara differ is in activity participation beyond the four walls of their homes; by comparison Anne is socially active (despite what she says above) which may explain her higher scores for self-realisation and pleasure than Barbara. The implications that these restrictions have for self-realisation and pleasure can be seen on a scale from Frances (self-realisation = 13/15; pleasure = 15/15) who may miss the odd social walk, as with George, for example (self-realisation = 7/15; pleasure 10/15) whose life has diminished from farmer to “brewer upper”. The extent to which life may come inwards is countered by efforts to live outwards; in the following sub-section these efforts are presented.

7.4 Maintaining sense of self and self-esteem through activity: “It's up to me to try and get it more outward”

In this section I present how participants maintained activities despite restriction to try and get life “more outwards” as Frances described. Continuing to participate in activities and roles initiated earlier in life and that seemed important for identity, as indicated by participant life-grid information, had implications for self-esteem and self-efficacy. Activities included: parenting and grand-parenting, employment, and maintaining a role in the community. David and Diane described keeping busy by maintaining a parenting role:

Diane: They [daughter, son-in-law, grandchildren] turn up for a bit of dinner, and then

David: Friday, she comes.

Diane: And then Friday, she comes after dinner, and they have their tea with us. So that's two days taken. (D01)

David and Diane have regular contact with their children and grandchildren. David's life-course suggests it may be important for him to maintain this parenting role as this was something lost to him after his father remarried (see Figure 9, p158). To maintain this role David is enabled by his geography in relation to his children (e.g. living close to children) and his ability to drive. In contrast, Edward and Ethel can no longer drive to visit their children and grandchildren who live more than 100km away. Visits from their children are limited to school holidays, as their grandchildren are of school age, and are not of a spontaneous nature as they are for David and Diane. Providing this role may support

David's high sense of self-realisation (12/15), and also pleasure (15/15), compared to Edward's scores of 5/15 and 12/15, respectively.

Henry maintains his employment role; he uses this activity as a means of distraction from chronic pain:

"And that's another thing you see, I mean driving the bus helps take my mind off it [pain]. It occupies- something I try to occupy my mind [...] if I was just sat here, I should be thinking about it all the time." (H02)

Employment fulfils multiple functions for Henry: a means to stay active, financial security (both described previously), and provides purpose in life and supports well-being "because it keeps me going and it gets me up in the morning" (H02). Financial security is important as this enables Henry to sustain participation in other activities, which support a sense of self and pleasure in later life. The following extract was recorded during the go-along:

"Every six week we come over this way to [...] this restaurant, hotel. They've got so many bedrooms, very upmarket, it's expensive. We don't go out a lot [...] but we'll always come there once every six weeks and it's brilliant. [...] It's traditional silver service [...] And waiters for everything. I mean for me and Helen on a Sunday lunch it's about [...] eighty and a hundred quid but I think it's worth it. We've been going there now fifteen year, oh longer, twenty-five years." (H02)

Work also enables Henry to maintain social relationships with work colleagues. During the go-along he stopped along the journey: "I'm just going to drop my mate's paper off" (H02). Despite the multi-functionality of employment Henry scored moderately for self-

realisation (7/12) suggesting that work is not the be-all-and-end-all; however, he maintains high pleasure (15/15). Work may therefore be more important for Henry in terms of providing opportunity to pay for pleasurable activities and also to distract his mind from chronic pain.

Participants maintained activities of earlier life, in some cases; however, the nature of participation shifted due to restrictions from chronic pain. Participants described adjusting their routines; for example, David acknowledged a need to plan ahead:

“You have to plan. You certainly plan things more than what you did. You don’t take it for granted. You’ve gotta think it through before you do it.” (D01).

David provides an example of a planned activity that he implements to avoid risking onset of severe pain. The activity is shopping at the local supermarket; the adjustment is described in the following extract:

“I do my shopping on Friday or Saturday morning. I go early when there isn’t a lot of people about, and, er, I go to Sainsbury’s. [...] The aisles are a lot wider, so that if I’ve missed something, I’m not bumping into people to get round to go back and pick it up. [...] It just suits, it suits me better, and it’s – because the worse thing I can do is to stand waiting. That’s when it gives me some stick, and if there’s a queue, well, if I, you see, and if go early morning, there is never a queue.” (D01).

By planning the visit to the supermarket during quiet mornings, David reduces the risk of queuing at the checkouts therefore limiting the likelihood of chronic pain becoming severe. In contrast, Anne is dependent on others to provide transport to carry out the task of shopping and therefore requires additional planning. Anne confirmed, “I have to

stock up because we only go about once a month food shopping” (A01); here there is cross over with basic needs of food. In accompanying Anne on a shopping trip I observed and also participated in the planning process (i.e. scheduling a time, a place, and a shopping list). Based on this experience I made a note in my annotations of the different elements that Anne’s strategy entailed:

‘I was led by Anne around the shop, I followed alongside her observing her activity and providing assistance when and where requested. Anne appeared eager to inspect as much as she could; seemingly intending to make the most of her opportunity to visit the shop.’ (Fieldnotes)

Adjustments depend on resources that are available in rural environments. Participants described adjusting the form of their participation in meaningful activities that had implications for identity. In earlier life, Catherine explored areas she would consider to be scenic (as would others); she would do this on foot or by bicycle. Catherine has stopped cycling since her health deteriorated and no longer walks the distances that she used to:

“I used to do a tremendous lot of walking [...] and hostelling with a rucksack on my back and from here to there [...] and from there to the next one [...] and up the mountains and down. [...] I loved it, but that’s a long, long time ago.” (C01)

Catherine’s physical capacity to explore as described has diminished as a consequence of chronic pain (although she reports having recently started walking daily, see Section 6.3.1: p213). Catherine experienced a heart attack; which she identified as a turning point in her life-course (and health trajectory) and her participation in long distance walking and cycling. In response to reduced activity Catherine has adapted the form of her

participation to maintain a sense of exploring nature and continue to realise this sense of self. Catherine has purchased a set of books from the National Trust which include colourful photographs of the 'scenic' places she has previously visited; the pictures prompt memories of these meaningful places. In doing so, geographical participation is transformed into imaginary participation through reminiscence:

"Just going through them [the books] and finding the walks that I've actually done and those beautiful views. There are eight of them, and I whisked through them all when I got them, and now, one at a time, I'm really going through them, and getting enormous pleasure. They're a temptation, so they're out of reach... [...] I can think, yes, that's the path I walked along and, that's the peak I climbed or, I've been there. [...] And the people I was with when I was doing it. [...] Hauling some of these teenagers (laughs) up and thinking we'll never get up, but we did." (C01)

Catherine's eyesight has deteriorated, and continues to do so, and so the transformation of her participation may be limited in terms of seeing specific details of photographs; however, Catherine has fond memories that overcome the blurred images. David and Diane provided another example of adapting their form of participation. Both experience limited mobility; however, they still enjoy visiting a nearby tourist location and explore this place using a motorised vehicle as opposed to walking. Participation in activities can be maintained albeit in different forms.

Adaptations are also made to fulfil social roles and support identity. Throughout Anne's life-course she has provided a caring role to others; as evidenced in her life-grid (refer to Figure 12; p173). The passing of Anne's mother signalled an end to Anne's caring responsibilities: "I more or less give up caring for old people then" (A01); this is presented

in Anne's life-grid. Since developing chronic pain Anne's relationship with the provision of care has changed from carer of others to receiver of care from others. To maintain identity as a carer Anne seeks to continue support for charities:

"I've [...] knit some squares and done a blanket for heroes, knit for the heroes, not help the heroes, knit for 'em [...] I mean I make mistakes but I can't help it." (A01)

Anne overlooks the mistakes that she makes as the task carries greater meaning than the end-product: the provision of charity and the continuation of a caring identity. Chronic pain interferes with the maintenance of this activity, as described in the following extract:

"I can't do much, I keep trying to do a bit of knitting or anything you know, but, it doesn't always work... you see because I get it in me hands, well now, my fingers are all pins and needles [...] I can't do much, and I've got be ever so careful." (A01)

In contrast, Barbara, who similarly defined her life through provision of care to others, does not continue such an association with caring through activities as Anne does. Anne continues to maintain a strong sense of self-realisation (11/15) in contrast to Barbara (4/15). These examples describe ways in which participants transformed their mode of participation to remain involved with specific activities for pleasure but also self-realisation.

Participants also commenced new activities rather than continue activities from earlier life or transform existing activities to suit changed needs. In retirement Frances has commenced several new activities and learned new skills despite chronic pain. Frances presented the following ambition for retirement, and her sense of self:

“I've got to the stage where by I've [...] left work for about four years and I do feel that I want to [...] do a bit more. I don't necessarily want to go and work, but I don't also want to just sit and knit (laugh). [...] I think I want to go more into the learning side of life but not necessarily to go to a university but just maybe read more books. I mean I'm interested in lots of different things, so really have more time to do more thorough reading rather than just novels and so forth, something a bit more heavy [...] I want to feel as though I'm still achieving yes, I definitely do, I don't want to feel that I've hit the rubbish heap and (laughs) that I don't want to do anything else.”
(F02)

For Frances, her career provided a niche: “I found I was a round peg in a round hole” (F01) since leaving she has come to terms with retirement and is keen to “do something different with this part of it [life]”. Frances has developed several interests and activities during retirement, for example, she invests time and passion in gardening: being out in her garden, watching gardening programmes on television, or attending shows and events about gardening. For Frances gardening has multiple meanings as presented in Figure 24 (on next page). Gardening also has implications for a sense of well-being, as Frances describes:

“When you're on your own and you've got those solitary moments how can you feel alone when you can see things growing? And you're moving them onto the next stage. Your mind's thinking about other things as opposed to thinking "ooh I'm on my own, I've nothing, I've no-one here" I think it just takes you out of that scenario and gives you something to think about.” (F02)

Frances described gardening in a similar way to how Henry described driving; they both use these activities as a distraction from their feelings, whether such feelings are about pain or loneliness.

Figure 24: Photograph #34 and data extract from interview with Frances

“I am by nature, a nurturer, so yes, it [gardening] [...] sits with me quite happily, I'm not having to force it or anything [...] it's just nice to see them grow, and they don't talk back to you (laugh)”



“I can feel that enthusiasm, it's quite wonderful really, that from a seed you can get a plant and possibly a fruit or a vegetable [...] or a nice flower (laughs). No I just think it's lovely.”

“I found out of it, and I like getting my hands in the [...] compost or the soil. I like that. I enjoy that, which I didn't think I ever would, so I've learned a [...] little about myself.”

Gardening also acts to connect Frances with the surrounding environment and culture. I ask if Frances considers whether her garden shares similarities with farming; reflecting how she described farmers as working the land: “it's getting back to nature and living with the cycles of it” (F02). In contrast, all other participants except Henry described a sense of restriction in terms of gardening; and so they may miss out on the meaning that such an activity can endear. Frances does not only garden she has a diverse range of activities that she is involved with. For example, Frances attends classes organised by the

University of the Third Age (U3A). Frances has learned skills such as embroidery and interior decorating. Attending these classes has been useful for Frances in terms of developing a social network since relocating to Village A; she entered these classes with this intention planned. Frances enjoys learning new craft skills; however, is wary of becoming complacent:

“If I felt like I was just going to be here and do my crafts, which I enjoy, don't get me wrong and I like learning something new, but I don't actually think it actually uses my grey matter that much.” (F02)

Frances also spoke of wanting to learn computing skills so as not to be caught out by her grandchildren should they ask her a question: “a sense of pride. I'm not ready to have my shawl and sit in the corner (laughs)” (F02). Mobility is important for Frances to participate in the activities that she does; whether that is physically gardening or continuing to drive to attend locations in which activities take place. Other participants rely upon others for them to maintain participation.

Anne provides a contrasting example to Frances as someone experiencing mobility restriction because of pain yet who continues to participate in activities. The social groups and activities that Anne participates in are with a cohort of similarly aged people, predominantly women, from the surrounding area; these activities are organised by regional voluntary organisations that provide door-to-door transport. Involvement with these groups provides opportunity for Anne to play games, share a meal with others, visit new places, and to get out from the “four walls” of her home:

“It’s just a little get together to get out because we all like it because we think it’s just a get out for an hour or two from four walls, I mean we’re picked up here, I’m picked up here by a minibus and brought back and same with luncheon club they pick us up and bring us back, I mean we’ve nothing, I’ve no walking to do much or anything.”
(A01)

Anne also attends a night of bingo in the nearby village; the opportunity to share a conversation with others is important to Anne: “it’s surprising how that helps you, because you’ve got company and that” (A01). Anne expressed a deep sense of loyalty to such groups: “I shall keep going as long as I can” and also indicated a sense of ownership, particularly towards the luncheon club that she has attended since its inception: “I like my luncheon club” (A01). Anne assumes a collective identity with these groups; the luncheon club is an extension of herself. During the go-along Anne purchased several items for the luncheon club presenting a commitment to the group:

[In Shop A] Anne added to her satchel pens for bingo and a book of raffle tickets, both of which were for the benefit of the luncheon club [...] [In Shop B] On our way to pay for the cards Anne noticed some Christmas earrings behind the till, she asked the shop assistant if she could have a closer look; and then with her help chose some. Anne explained that she would wear these for the luncheon club Christmas meal.
(Fieldnotes)

This seems to be Anne’s way of supporting the group. These groups are not for everyone, as Barbara implied; she attends these but does so under pressure from her daughters. Barbara does not experience the same connection as Anne to these group identities. In comparison, Catherine, who previously described how she struggles in the kitchen, has

recently started attending a local luncheon club; she focuses upon the opportunity to receive a hot meal and reconnect with the “proper food” of her upbringing and with the image of her mother, rather than identifying with the group itself.

7.5 Developing networks to support activity maintenance

During the interview, Frances expanded upon her sense of “living outward” to indicate the importance of other people in supporting this:

“I don’t think I’m a depressive or anything like that, I always try and look outward and look forward and be fairly positive, but I think it’s important to have other people around you, and I learnt that of myself a long, long time ago.” (F02)

Frances may also perceive having people around her as a buffer against loneliness; participants who prefer to avoid social groups (e.g. Barbara, Edward, George) may take a contrasting view. In addition to the support received from healthcare services (predominantly general practitioner services), participants described utilising several other resources to maintain control and autonomy but that also provided opportunities to facilitate social participation and maintain activities and roles. Participants described diverse relationships developed across the life-course and those developed in later life: social networks (e.g. friends, family, neighbours), community spirit, transport, public and third sector services.

Living into later life also meant the loss of some relationships; an inescapable experience of ageing these losses had significant impacts on some participants in terms of their support network. Anne and Barbara are both widowers of 10 or more years. Anne’s husband died over 20 years ago; however, a sense of grief remains:

“I miss me husband more now than I did when he first died, because I'm getting older and you have to make all the decisions yourself.” (A02)

In contrast, Barbara who is twice a widower does not acknowledge grief and is instead matter of fact: “I've lost my husband and that's it...” (B01). Both Anne and Barbara share a sense of loneliness, the latter acknowledged this in the following words: “I get lonely, I'll own up to that, I get very lonely” (B01). Loneliness is indicated by Frances (who also lives alone) but not by the other participants.

Of the study participants David, Edward, George and Henry continue to share their lives with a spouse or partner. David and his wife are approaching 50 years of marriage together. The marriage provides a sense of togetherness and of sharing problems, as Diane stated: “we manage between us” (D01). If one of them were to live alone Diane anticipated: “I think it'd be very different if there was only one of us” the tone of her voice indicated that this would not be for the better. Tasks of daily living are also shared; for example, David takes responsibility for the supermarket shopping as Diane experiences episodes of dizziness. They also share support for one another's activities; for example, David attends church with Diane, who says: “but I think you support me” (D01). Similarly, Henry describes sharing a supportive relationship with Helen, who represents a source of emotional stability:

“She's a brick... I think I was a difficult person to live with, anyway, you know, when I'd got so much pain” (H01).

In addition to the support that a spouse may provide these relationships also present opportunity to share pleasures and activities together; Henry described expensive dinners and holidays that he and Helen have shared (see p260).

Participants described sharing lives; however, this also meant sharing health impairments through roles as informal carers. In Section 7.3 (p261) Gail described the small world that she and George are restricted to on account of his health impairments. Edward described his wife, Ethel's decline in health before his own when asked about his general health:

"Yeah, well to give you the all-round picture we should really start with my wife. [...] In this room, got up from this table walked over there to pick up the Radio Times and as she walked back looking at the paper she fell over the cat and smacked her head on the table (thumps table) and had subsequently two spinal operations and has been dependent [...] on the frame and the wheelchair ever since." (E01)

The priority of Ethel's health problems was further exemplified during the following episode that I recorded in my fieldnotes:

[Ethel] offered to make the drinks; however, Edward had responded "no, I must" – this reflected the feeling I was getting throughout the interview about the caring role that he provided to his wife. This caring role put significant strain on Edward and it was mentioned a number of times during the interview. (Fieldnotes)

Health is a shared experience by both people in a spousal relationship. The spousal relationship may support and/or restrict participation in activities; Edward reported low self-realisation (5/15) as well as control (5/12) and autonomy (7/15), within these needs

the restrictions imposed upon Edward by Ethel's poor health may interact at these levels of needs.

Participants described receiving support from their immediate family but also extended family members (e.g. nephews, nieces); for some the extended family assumed greater importance in supporting autonomy and enabling participation in activities. David and Diane described younger generations of their family as an important source of support; this included children, their spouses, and grandchildren. The availability of support is limited by the availability of transport for younger generations (private and public transport):

David: [grandson aged 17 years old] will come and do some gardening.

Diane: He'll do anything for us, you know, but it's getting here that's his problem, you know, because he can't catch buses and things or anything. So his mum has to bring him. (D01)

The availability of support provides a sense of reassurance for David: "they're there if we need them." (D01). George and Gail describe a similar sense of reassurance regarding their family network: "They will rally round if necessary" (G01). Barbara experiences a close relationship with her daughters, one of which she claims knows everything about her: "so if you ever want to find anything out about me go to Daughter A (laughs) if I'm not here" (B01). She receives two phone calls from her daughters during the three hours that we spend together in interviews, indicating the regularity of contact.

Anne described receiving support from a son, granddaughters, nephew and great niece; each provide support in terms of domestic activities, food shopping and cleaning but also

socialising. Anne is dependent on her family visiting her as she is not able to use public transport and does not drive. This is similarly experienced by her peers, as she describes her sister and brother-in-law:

“They used to come every week at one time, but then her husband will be ninety-three in January and she'll be [...] eighty-six at Christmas. [...] They've given over driving now and got rid of the car, so we [Anne and her nephew] don't see them unless we go.” (A01)

The availability of public transport also acts to dictate the time that Anne gets to spend with family members; her granddaughter is dependent on the bus service: “so she isn't here long” (A01). Anne is dependent on the invitation of others to provide transport and therefore access to family: “Me cousin rang me up coz he knew I wanted to go and see his sister” (A01). In addition to helping to maintain social networks, family provide Anne with access to health services as her nephew will often transport her to her general practitioner and hospital appointments. In relying on extended family there is the likelihood of informal caring responsibilities for family members, as Anne acknowledges of her nephew:

“He's got his own mother to look after, [...] she's eighty odd. [...] He's sixty-two his self. I don't like putting on him. [...] I say to him sometimes [...] ‘you mustn't bother about me if your mum wants you [...] your mum comes before me’.” (A01)

Anne's nephew has competing demands on his time; and is in himself an ageing resource for Anne but one that remains essential to her.

Frances developed a close relationship with her sister over the life-course: “we tended to migrate towards one another over the years” (F02). This led to them both relocating together to Village A after having retired; both were living alone, neither are married, Frances’s sister does not have any children. The relocation was a new experience and a new environment (houses in centre of the village) for them both; they support one another to integrate into the community and maintain activity:

“I think having two of you is easier, definitely. I mean, yes, you can do it on your own but it may take more effort you know to actually go out of the door and meet a new group of people.” (F01)

Frances attends social activities and new groups with her sister; this is reflected in Frances’s CASP-19 scores (13/15 self-realisation; 15/15 pleasure). The relocation also represents a step in her plan for future care provision:

“One of the other reasons why we moved up together was that my son has agreed that he will look after [my sister] if it comes to that at the end.” (F01)

Frances and her sister have directly addressed the subject of end-of-life care and have planned for this. Family, both immediate and extended, provide important sources of support for autonomy but also to enable participation in activities; there are barriers opposing access to these resources such as transport, age-cohort factors, and competition (i.e. from other relatives that are older adults and in need of support).

Friendship networks also have an important role in the provision of support for participants; these networks are often relied upon in the absence of a spouse or family and also provide access to activities. For example, Catherine maintains a vibrant social

network and has been active in maintaining contacts over time, referring to people she met at teacher training college over 70 years ago: “I'm still in touch with two of the eight of us [...] the rest have died” (C01). She is also in touch with people she did voluntary missionary work with: “one of whom is my closest friend, still very much in touch. She's 90 on Sunday” (C01). The loss of friends from a similar age-cohort was a common experience for participants. A close friend of Catherine's who lived nearby died around the time of the interview; for Catherine this represented the loss of a companion:

“I used to take her round a lot in the car, wherever I went [Female F] wanted to go, and I'd [...] always got [Female F] with me” (C01).

Barbara described the loss of former work colleagues:

“Quite a few of them have passed away, to be quite honest they have. But I see the one from [Village G] quite often [long pause] but really that's the only one that I see, yeah.” (B01)

Similarly, David describes having lost his closest friend, the best man at his and Diane's wedding. Of friends David indicates: “I've only got one left now” (D01). David acknowledged that he has made few friends since childhood; this has been further compounded by ceasing employment.

In the absence of friends and family participants utilised alternative sources of support.

David remained confident that someone will always be available to provide support:

“I'll manage with what I've got [...] there's always somebody that'll come and do it for you, even if you have to pay 'em [...] there's always somebody.” (D01)

Catherine has paid for help around her home for over a decade.

“I've got a wonderful treasure who comes here every Monday. She's absolutely marvellous and golden [...] I've been in this cottage nine and a quarter years [...] I was next door before that in a much bigger house, and she was certainly with me at least three years then.” (C01)

Many of the current relationships that Catherine described included those that she has developed with service providers for example: post service, gardening, and bus drivers: “I know the four drivers very well” (C01).

For participants, whose everyday level of human interaction may be limited, the television was described as a source of pleasure:

“I do like ‘The Chase’. Have you seen that? It comes on at five o'clock on ITV. Bradley Walsh is a scream [...] and the other week they won sixty thousand, all three of them. Oh it was, he was hilarious, umm oh yes, its good fun.” (A01)

Barbara described television as providing the sense of a relationship to overcome loneliness (as described above):

“I sit here hours on me own, yeah, but... you don't have to let it get you down. That's my best friend, the television. It is honestly [...] I turn it on at the morning at about six and it doesn't go off until I go to bed.” (B01)

For Barbara, television provides company in an otherwise quiet house: “you can hear a voice; you think there's somebody there, you know?” (B01). In addition to the television Barbara also identified her pet dog as providing a sense of support and companionship.

Barbara is the only participant to own a pet, with the exception of David's chickens. Barbara described her dog as assuming several roles: hero, protector, confidant, empathiser, and faithful companion; she expressed surprise at the relationship that they share: "you wouldn't think a dog could be like that really, would you?" (B01).

7.6 Constructing a sense of rurality and belonging

In Chapter Six I presented how participants expressed place attachment through a sense of connection to the community and homes in which they lived. Participants constructed rural environments and spaces as meaningful rural places. The features of these rural places were (re)constructed and utilised to support specific self-management strategies but also to nurture a sense of belonging. Belonging is a need recognised within Maslow's hierarchy; participants described establishing this sense of belonging in rural environments through identifying with the local area, being part of the community spirit and culture, and sharing harmony with the environment. However, in some circumstances chronic pain experiences interfered with maintaining a sense of belonging.

Participants described connecting with the rural environments in which they lived in ways that supported coping with chronic pain and maintaining control over health. In the following excerpt David and Diane described using nature to improve their mental health and elevate their mood:

Diane: But if we're bored or fed up, well, as I say, we'll get in the car, and go and look at the daffodils, or [...] the crocuses. We won't sit and mope. Will we?

David: No, no. I mean, I thought, I know it's silly, but there's a church at [Town K], and the churchyard is absolutely just one mass of crocuses. (D02)

Frances described sharing a similar relationship with the environment. The narratives of Frances suggest that she has developed relationships between blue (i.e. waterfront), grey (i.e. urban) and green (i.e. rural) spaces across the life-course following several relocations (see Section 5.4.1 [p153] for Frances' life-grid). Throughout her narratives, Frances returns frequently to the topic of using outdoor spaces to restore a sense of tranquillity. The photographs that Frances created for the photo-elicitation interview were predominantly landscapes. I include Figure 25 as an example, along with the elicited conversation:

Figure 25: Photograph #33 and data extract from elicited interview data with Frances



Source: created by Frances for photo-elicitation interview.

“Yes, well... erm, you could walk through the town, but in the summer that was hard going because of all of the seaside visitors or you could just go along the front which was less, less frantic, I just found that going from college to home, where my parents had a small hotel, so we all had our jobs to do, it was a sort of, cutting off your day time to go do something else. It just gave you time to reflect on different things and erm, I suppose it was a twenty-five minute walk, and it just refreshed you.”

Frances reflected on her teenage years in her use of the environment. Frances continues to relate to the environment in a similar way in her current location:

“I think it gives you the sense of balance back in your life, you know, especially if you're in a high pressured job, you know, and you can't always see the trees for the wood.” (F01)

Currently, Frances incorporates moments during the course of the day to connect with her surroundings:

“In the morning at about six o'clock, if it's a nice day [...] I take my cup of tea and just go and look at it [the sky] and it sort of clears your mind for the day.” (F02)

Frances incorporates the natural environment into her strategies for health management; this provides Frances with a sense of control but also connection to nature. For Henry, the rural environment represents fresh air, good health and long life:

“I mean, you'd think the people up here would live forever, there's no dust from anything, you know, same as what's in towns.” (H02)

Henry described using activities and the environment as a means of distraction to take his mind off his pain. During the go-along we followed the route of his daily journey to work, which he said made him feel like “one of the luckiest people in the world” (H02) due to the beauty of the surrounding landscape. He also took me to some of his favourite places in the Staffordshire Moorlands; places that he would visit for a distraction, as depicted in Figure 26 together with my fieldnotes:

Figure 26: Photograph #36 from go-along with Henry: “Favourite beauty spot”



The car park overlooked a deep valley carved by the meandering river that flowed through. An old mill or factory could be seen further downstream in the shadows of the hillsides and tree overgrowth, which covered either hillside and down into the valley. In my mind this was picturesque. I took a couple of photos, which did not do the place justice. I asked Henry why it was that he wanted to show this to me, “oh, I just think it’s a beautiful place.” He told me that he would often come up here. (Fieldnotes)

During the go-along I observed how Henry became distracted, even absorbed, by the surrounding environment. Henry’s pride and passion for this rural environment in which he lives and works is clear: “You’ll have to tell me [to stop driving around], because I get a bit carried away” (H02) exemplifying how absorbed Henry is in the environment. Driving around the local area, visiting areas popular with tourists represents a lifelong ambition for Henry to own and run his own tour company of the Staffordshire Moorlands; a regret that Henry describes, which may explain in part the low score for self-realisation (7/12, one value missing). The participants who maintained mobility, especially the ability to

drive, incorporated nature into pain management strategies; moreover, they constructed rurality as aiding well-being.

Participants described sharing a deeper connection, of belonging to rural environments. Barbara has lived her entire life in the Staffordshire Moorlands; her sense of self is connected to her surroundings: “I wouldn't like to live in town, being a country girl all my life” (B01). Barbara suggests a sense of belonging within a rural environment, or countryside. Barbara indicated that the location of a dwelling does not convey a rural identity, suggesting belonging is more than dwelling:

“This person here (pointing across to a neighbour's house) on this side. Yes, he always speaks to me, but I always say he's a 'towny'.” (B01)

Barbara implied rural identity is ingrained; Barbara recalled her primary school teacher saying to her: “I can pick a country girl out from a town girl anytime” (B01). Having recalled these words, Barbara said, “and I can [too]” this indicates a shared-identity; it takes one to know one. I asked Barbara what it meant to be a ‘country girl’, to which she replied: “It means everything” (B01). Despite this connection Barbara scored low for self-realisation (4/15); perhaps the restriction of her interaction with the world (e.g. can no longer walk the dog, or be social with others in the community beyond her neighbours) has impacted on her sense of being a ‘country girl’ and of living up to her self-image.

Other participants acknowledged a sense of belonging within a rural environment. Catherine, who has lived in Village D for 25 years and has owned a property there for over 50 years, remains conscious of being a relative outsider in Village D (i.e. not having been born and raised in the village):

“The couple that take me to the lunch club [...], I said to her about six months ago, do you think I qualify for membership of the village yet? And she said, well, you’re getting there. [...] When I was looking for something smaller, it was marvellous that this came up, because I didn’t even have to leave this road.” (C01)

Catherine identified the individual in the extract as being from “the old village” (C01). Catherine described seeking recognition of membership from those she views as traditional villagers; this may emphasise her sense of attachment to this rural place. Catherine feels that she belongs even if others do not. Her ability to make connections with others in the village is restricted by her chronic pain, which she said: “prevents me trotting round the village visiting people.” (C01). Catherine suggested having a diminished sense of connection because of restriction, as she corrected herself: “I know the people in the village now [...] I knew the people...” (C01); perhaps this is reflected in Catherine’s score 6/15 (one value missing) for self-realisation. In contrast, although Anne shares a similar sense of restriction, she has lived in the Moorlands her whole life; she recalls being actively involved in village-wide events (e.g. a street party for the Queen’s silver jubilee). Anne scored 11/15 for self-realisation; perhaps her sense of belonging is preserved by that lifelong connection.

Not all participants presented a sense of belonging, or such a desire to belong. Edward and Ethel did not display characteristics of belonging to the place in which they live; this may be related to the circumstances of their move. In retirement Edward and Ethel relocated to a different part of the UK where they lived for three years. However, convenience for their children was a driving factor for Edward and Ethel’s decision to relocate a second time in retirement to Village A. Neither of their children live within the

region in which Village A is situated; but it represents the mid-point for them both. Edward reinforced feeling of being out of place through his description of the surrounding community:

Int: Do you feel part of the community?

Edward: Oh yeah, sort of, it's a funny, funny old community. It's a funny little village.

(E01)

Edward's words may suggest that he is an outsider to the community; he scored 5/15 for self-realisation. I interpret the term 'funny' to mean odd; Edward's low score indicates that he may feel out of place which limits his sense of belonging and perhaps this is linked to the reasons why he and Ethel moved here in the first place (closer proximity to children).

Participants commonly described the surrounding rural community as having a strong community spirit; whatever their sense of belonging. Perhaps this is part of a wider construction of rurality. The sense of bond is maintained through assumed roles in the community and sharing of relationships with neighbours. David previously volunteered as a school governor: "So that brings you into the community" as Diane noted (D01). The role meant that David attended council meetings. David and Diane have experienced "a big change of fortune" (Diane, D01) of the Staffordshire Moorlands since relocating there:

"We had a chappie came from [Town] - it was when they was on about closing the schools - and he got up and he told us [...] 'we have tried to give the [county] away to [a neighbouring county] for about five years', and he says, 'they don't want you,[...] we're stuck with you'. Now, it is one of THE areas to come to." (D01)

Community roles enable individuals to gain a sense of the community culture and spirit; David has experienced the transformation and been part of it.

Community roles also provide the opportunity to support identity, develop a large social network and maintain a sense of belonging. Henry, a former pub landlord, is familiar with many people in the surrounding area; as expressed during the go-along (see Figure 27).

Figure 27. Video-stills recorded during go-along with Henry

Video still A: Time into recording - 08:57



“That house there, they used to be customers at the Pub and strangely enough they’ve moved to, one, two, three, four houses away from us.”

Video still B: Time into recording - 10:24



“(Henry beeps the car horn twice) He was a customer of the pub [circled]”

Henry expressed a connection with the local community through on-going relationships: “there’s a lot of community spirit” (H02) he confirmed. Henry maintains this sense of

community and connection with others as he maintains capacity to drive around the community.

Frances also moved to Village A in retirement and described making a concerted effort together with her sister to integrate into the surrounding community in Village A:

“When we first came in the summer [...] we'd see nobody during the day, because a lot of them are commuters in the village, but gradually it's just working yourself in slowly really.” (F01)

Frances moved to Village A four years ago, she is currently volunteering in roles with the local school; she shares some of the experiences that David had earlier in his life:

“I do the governing work with the school which at certain times of the year they have quite a few meetings which this time of the year is one of those times. And with the bits and pieces I do in the school” (F01)

In addition to voluntary roles, Frances seeks to nurture relationships with her neighbours, which brings her into the community:

“We're very fortunate [...] [Male A] and [Female A] who live two or three doors down, we made friends with them, and they've been very nice, they've chatted, they've come and they've helped. I mean we help each other. We helped them decorate a room the other week. I like sewing, so I've made curtains. [...] We help each other so if I'm mowing the lawn and Male A comes along and if he's got time he might give me half an hour of his time [...] but we just generally help each other where we can.” (F02)

Sharing in neighbourly relationships enables Frances to exchange skills and help one another out.

Neighbours may also provide support in times of crisis. Catherine has three emergency contacts linked to her personal alarm; these are all neighbours in Village D:

“The next door but one neighbour [...] you have to give three names for these press buttons [indicating emergency alarm], and she’s the first one. And then the people at [the cottage next door], whom I never see, actually, and they’ve probably forgotten, but they said they’d be the second. And then there’s, just a bit further down the village, a husband and wife, who are the third. I bet they’ve forgotten too. Well, I hope I never need them.” (C01)

The villager that is first on Catherine’s emergency contact list will visit Catherine up to three times per week; however, the second and third contacts that also live in the same village seem to be relative strangers. Of another neighbour Catherine described hardly ever seeing them; however, they are available in times of crisis:

“It could be three weeks ago now I had a [blown] fuse [...] I shall have to ring [Male E]. He was round in a minute and found out what it was and put it all together again. And I said, I always say if I rang you in the middle of the night you’d come. He said, yes, I would. [...] But in fact I never see them.” (C02)

Edward shares a similar experience in which the assumption of receiving assistance despite sharing little social interaction has been supported. Edward described the time that Ethel experienced a bad fall. In these rural environments a lack of personal contact does not seem to affect levels of dependability on neighbours in a crisis; however,

because of the lack of contact this dependability seems based upon a hope that others will come to their aid. Anne described not getting along with her next door neighbour, but she is confident that if she needed someone then they would come to her aid:

“This one next door [...] I don't speak to him because he caused me a lot of trouble when grandchildren used to come. Those next door [on opposite side], I don't see them they go out to work, but if I wanted them, they'd be there. They're wonderful friends they are, because they're not always with you but they'd talk to you outside.”

Anne described a welcome balance between friendliness, dependability and maintaining autonomy. However, for Anne and Barbara the number of familiar neighbours has declined.

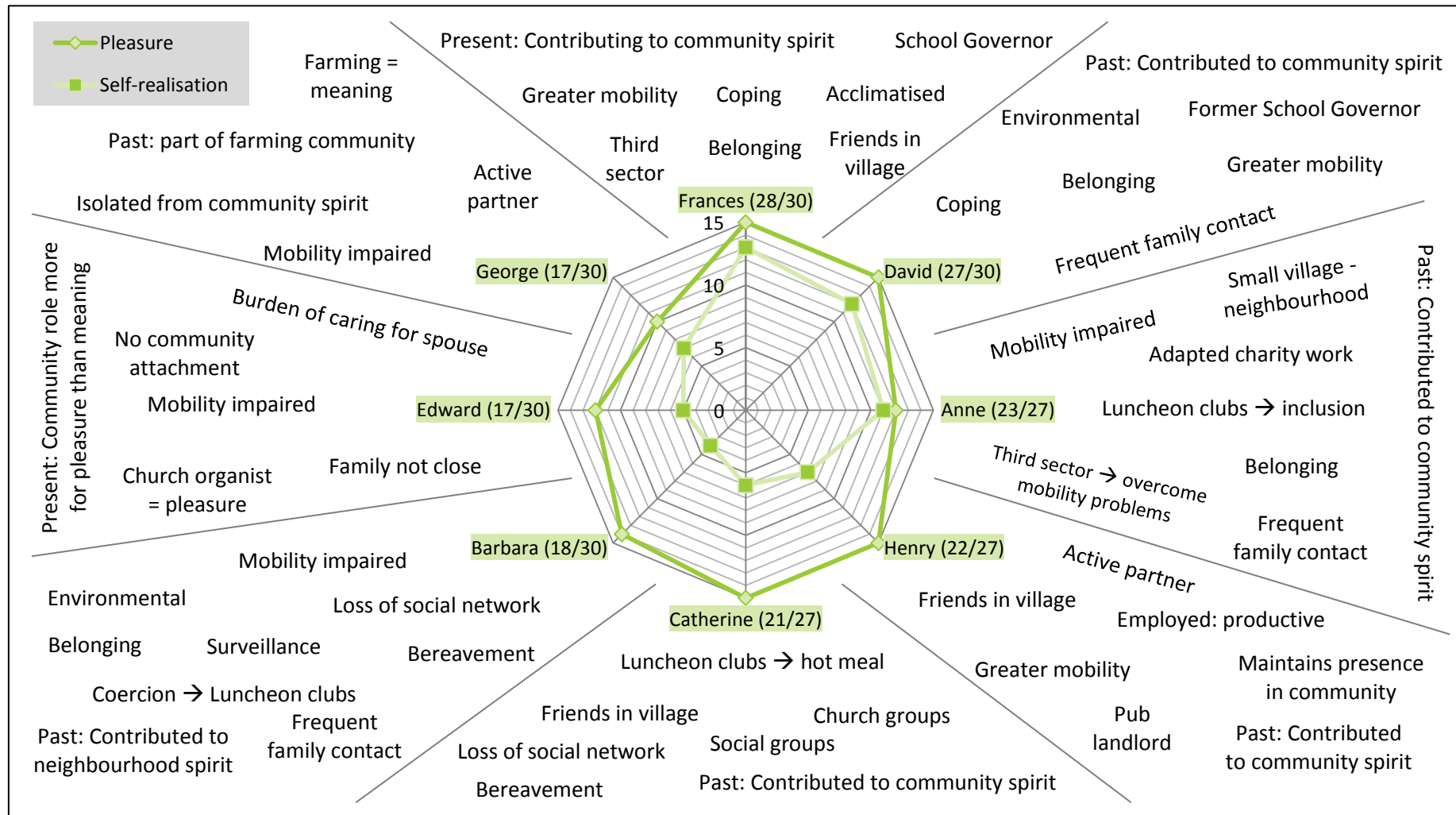
“But there aren't many of the old ones left. I think there's, what, perhaps about three or four houses with the older ones in out of about twenty-eight [...] when I first came living up here everybody was so friendly.” (A01)

Barbara has also lost the neighbours that she once knew. With the change in local population a sense of cultural shift has also occurred; something un-rural and unfriendly.

Summary

In this chapter I have presented data relating to the restrictions that chronic pain imposed on activities. I have explored the ways in which participants adapted and adjusted to overcome or compromise on these restrictions. In Figure 28 I present the combined findings from the deductive and inductive analysis in diagrammatic form.

Figure 28. Maintaining pleasure if not self-realisation through chronic pain experience



The radar plot at the centre appears to move inwards for those participants for whom activity is greatly restricted and community roles have ceased. All participants expressed capacity to take pleasure out of life. However, participants differed in terms of the meaning that they got from life and their capacity to achieve self-esteem and self-realisation; this was typically linked to whether meaningful activities – those that symbolise the performance of a specific role and support realisation of an identity (e.g. farming: farmer) – were maintained through adaptation or replacement. Participants that expressed a sense of belonging and integration within rural environments reported higher self-realisation (having a sense of place in the world among others). However, the relationship with the environment was interrupted by chronic pain experiences, as participants could no longer move freely about their local community to maintain meaningful activities and therefore identities or social networks. In this sense, restrictions meant participants were reliant upon community spirit continuing despite their own limited capacity to contribute to this community spirit.

This completes the presentation of the findings. In the next chapter I discuss the key findings and the implications that these have, in doing so I return to the literature for points of comparison and contrast.

Chapter Eight: Discussion and implications

Introduction

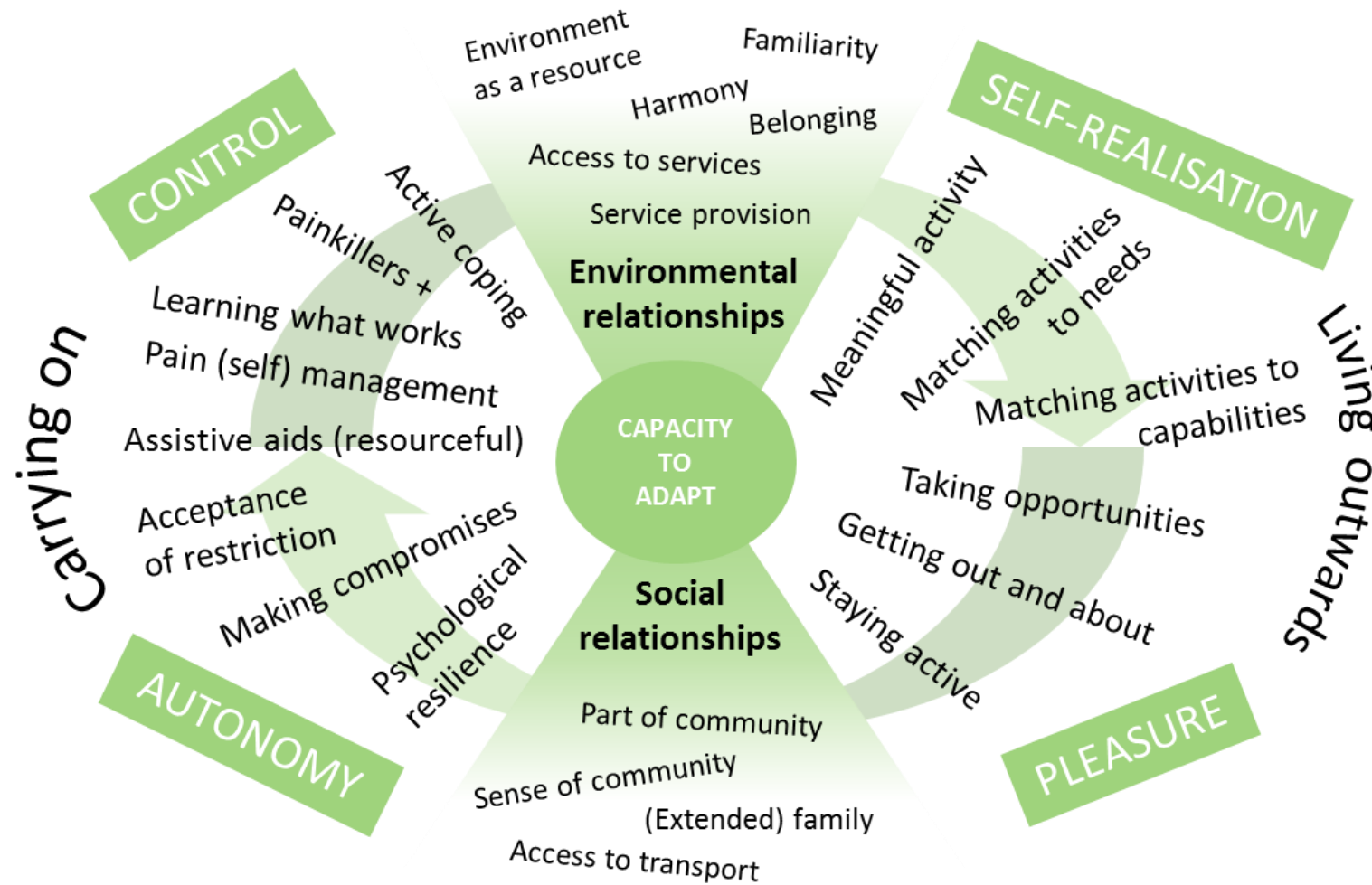
In this final chapter I discuss the key findings, presented in the previous three chapters, in the context of the research objectives and existing literature. I then discuss the strengths, challenges and limitations of the study, and share my reflections on this thesis. Finally, I describe the implications that this work has for services, policy and future research.

8.1 Responding to the research objectives

The aim of this thesis is to understand older adults' experiences of ageing well with chronic pain in rural environments. The findings from this study are summarised diagrammatically in Figure 29 (on the next page). The figure includes the important factors that support ageing well with chronic pain in rural environments set against the four quality of life domains of CASP-19. At the heart of the diagram is adaptation and maintaining relationships with the environment and in a social sense. The findings from this thesis signify how the capacity to age well with chronic pain is supported by the provision of accessible resources and the strengthening of social and environmental relationships.

Bowling (2005) identifies six factors that support ageing well in which 'good health and physical functioning' is a key component. In this doctoral research study participants described chronic pain experiences that compromised health and physical functioning and which adversely impacted the other five factors: maintaining psychological well-being, social relationships, community services, independence and control, and, to a lesser extent in this study (perhaps due to the focus on health), an adequate income.

Figure 29. Factors that support ageing well with chronic pain in rural environments



Poor adaptation to chronic pain had implications for physical health, mental well-being and quality of life, as has also been described in non-rural studies (e.g. Sharpe & Curran, 2006). I discuss the findings and draw out factors that support ageing well under the following sub-headings, the five of which correspond to the objectives described at the outset (Section 1.2: p7).

8.1.1 Dimensions of chronic pain for rural older adults

The first objective of this thesis was to explore the dimensions of chronic pain experienced by older people in rural environments. A multi-dimensional perspective on chronic pain was identified as a theme in the existing literature (see Section 2.3.2.1: p38). In this study, participants shared chronic pain experiences as occurring in: sensory, biological, physical, socio-cultural, psycho-emotional, temporal-historical, existential and environmental dimensions. These were interwoven with one another.

A sensory dimension was described in relation to feelings of pain verbalised using: adjectives (e.g. pulsing, gnawing, sharp, and stabbing) and numerical values were used, either spontaneously or following interviewer prompting. The use of similar adjectives has been reported elsewhere (Nilsen & Elstad, 2009; Clarke, Anthony, Gray et al., 2012) and both techniques form part of validated pain measures (e.g. McGill pain questionnaire; see Melzack, 1975). Discreet descriptors of chronic pain did not fully capture the sensory dimension, as pain sensations were often multi-sited and fluctuated over time. Instead, narratives were used to make sense of the sensory dimension; often these included figurative language (e.g. metaphors) that constructed pain as dynamic. Narratives also revealed a temporal-historical dimension of chronic pain, extending from concurrent instances of pain (e.g. specific sensations) to historical moments (e.g. previous sensations

described for comparative purposes) and episodes of pain (e.g. periods of relative remission from pain, or previous periods of severe pain). Participants in this study spontaneously compared concurrent pain with historical pain; yesterday's pain or last year's pain for instance, to make sense of their present-day experience.

A psycho-emotional dimension of chronic pain was revealed, primarily through coping responses; which were presented as both emotionally and psychologically challenging. Participants described active and passive styles of coping; those that relied predominantly on passive coping styles presented ruminating behaviours. In situations of prolonged rumination and isolation from others (i.e. not having personal contact to off-load emotions), low mood became apparent, and suffering and vulnerability were revealed. Suffering was disclosed by some participants, revealing the fragility of specific coping styles. A biological dimension of chronic pain informed participants coping styles; this dimension was typically described in terms of the presence of disease and a diagnostic label. Where a hereditary link was identified a sense of biological determinism of chronic pain was indicated; this determinism seemed to inform feelings of helplessness and a sense of vulnerability which had implications for pain management. Coughlin et al. (2000) argue that successful pain management is supported by increased self-efficacy about pain control and decreased external attributions. Furthermore, Cross et al. (2006) argue that external attributions of control notably lead to worse health status and higher healthcare costs (i.e. more visits to general practitioners). The cross-over of chronic pain dimensions has implications for revisiting notions of locus of control in chronic pain.

Participants described chronic pain experiences as an individual-environmental interaction. An environmental dimension of chronic pain has been identified previously

(Fordyce, 1995a; 1995b); however, such interactions have not been explored in rural environments. A relational perspective toward environments has been taken in this thesis that enables examination of levels of interaction: composition (objective), context (subjective) and collective (inter-subjective). At a compositional level, chronic pain reported by participants conferred with objective factors such as distance, predominantly in the context of restriction and in relation to social networks and services (e.g. GP, third sector organisations). However, distance remains contingent on individual levels of mobility. Consequently, compositional aspects of the environment are interwoven with physical dimensions of chronic pain. Participants described physical sites of pain (e.g. leg, knee, lower back) that were linked to sites of disease and which influenced the type and scale of disability and therefore spatial restriction.

At a contextual level, the environmental dimension of chronic pain was experienced through interactions at micro- and meso- levels (i.e. within the home and with the environment beyond). These experiences were individualized and subjective. For example, home environments could be supportive, adaptive, or bothersome environments depending on experiences of disability. At a meso-level, participants talked in terms of specific rural environments (e.g. villages) being more suitable than others; this was based on a sense of remoteness and distance to services (intersects with compositional factors). Interactions between the participants and their environments also formed part of an existential dimension of chronic pain, in which pain was represented as an embodied experience (an inter-relationship between body-mind-world). The experience of pain often fragmented this relationship transforming the body into a dysfunctional and cumbersome object; this caused disharmony in the embodied

experience. Participants described not being able to be who they wanted to be; the enduring quality of self and claim over specific identities (Kelly & Field, 1996) was threatened. Such disharmony challenges the role of narratives as a means of repairing “ruptures between body, self and world” (Williams, 1984) in narrative reconstruction.

At a collective level, the environmental dimension revealed a socio-cultural dimension of chronic pain in relation to rural environments. The socio-cultural dimension of chronic pain has not been explored with older adults in rural environments previously. Chronic pain experiences were shared in a way that revealed a sense of insider knowledge about chronic pain; moreover, responses to chronic pain were culturally embedded in notions of rurality. Participants commonly presented and maintained a sense of stoicism and privacy of chronic pain to control pain in the context of social interactions. Participants also shared responses to chronic pain that supported rural identities and values (e.g. stoicism) and the rural culture described by Brundisini et al. (2013) defined by self-reliance. I discuss this further in relation to Objective 4 (Section 8.1.4: p317).

The findings from this doctoral research study support the view that a multi-dimensional perspective, rather than a narrow bio-medical perspective, is necessary to effectively address chronic pain from an individual perspective (Smith et al., 2001; Ong & Forbes, 2005; Sofaer-Bennett et al., 2007; von Korff & Dunn, 2008; Clarke et al., 2012). The disclosure of multiple-dimensions of chronic pain, and the multiple dimensions of impact, through narratives supports the suggestion of Clarke et al. (2012) to incorporate narrative approaches alongside selected pain scales. Being able to express chronic pain has implications for feelings of legitimacy (Sofaer et al., 2005) and acknowledging suffering (Bullington et al., 2003). Not being able to find the right words can present a barrier to

effective medical consultations in which patients do not feel believed (Dow, Roche & Ziebland, 2012). The findings indicate the crucial role that environments have and how they intersect across other dimensions of chronic pain experience. Thus, the need to attend to situated experiences of chronic pain and the relational impact of the environment cannot be overstated in the context of supporting rural older adults to age well with chronic pain.

8.1.2 The meaning of chronic pain for rural older adults

The second objective of this study was to explore the meaning of chronic pain in the everyday lives of older adults living in rural environments. The meaning of chronic pain for participants was highly individualized although common threads tied individual accounts together. Chronic pain was considered a “normal” part of ageing for some, but ultimately a cause of disablement and restriction that required ongoing surveillance and management for all. Chronic pain also interfered with participants’ sense of belonging within rural environments.

The perception of chronic pain as a normal part of ageing was shared by participants who experienced the initial onset of their pain in later life (i.e. post-65 years of age). The perception of pain as a normal part of ageing has been identified elsewhere (see Harkins, 1988; Davis, Hiemenz & White, 2002; Sanders et al., 2002; Sale et al., 2006; Grime et al. 2010, Gammons & Caswell, 2014; Richardson et al., 2014). Findings in this thesis add to the increasingly nuanced picture that is emerging from this literature. Participants that experienced multiple health problems in later life perceived such accumulation and subsequent health deterioration and impairment as a later life phenomenon. This ‘later life phenomenon’ was reported by participants to have been supported by healthcare

professionals, in some circumstances. Normalising chronic pain had inhibitory effects on processes of adaptation to control and manage pain. This supports research by Gammons and Caswell (2014) who identify the normalisation of pain as a barrier to effective pain management. In contrast, for participants that experienced chronic pain in early life (i.e. during employment years) pain and ageing were distinguishable and a greater level of control was presented. The importance of life stage rather than chronological age has been identified previously by Richardson et al. (2006); life stage was important as reflected by participants in this thesis.

The experience of chronic pain meant physical disability and restriction for participants in this study. The experience of disability in home environments (e.g. through loss of mobility) threatened meeting of basic needs, resulting in a diminished sense of control and autonomy. The experience of disability outside of home environments meant restriction of activities; this threatens the maintenance of social relationships and roles that support self-realisation and identity. Restriction of activities and impact on self-worth has been identified elsewhere (Roberto & Reynolds, 2002; Maly & Krupa, 2007). In addition to identity, participant's social capital (described in the literature review p54) may have been negatively impacted, leading to the weakening of informal social bonds with others in rural environments e.g. friends, neighbours – because of health problems, greater emphasis was placed on formal (hierarchical) relationships with health and care providers (Ferlander, 2007). These relationships are hierarchically organised in terms of service providers and service users. Such relationships are therefore based primarily on bridging (weaker bonds) and heterogeneity (fewer shared characteristics); this may have altered participants' sense of connectedness within their rural places.

Participants differed in terms of achieving a sense of meaning and maintaining self-esteem; although all expressed capacity for pleasure in life. Opportunities to participate in meaningful activities were presented through social contacts, services (predominantly third sector e.g. U3A, Moorlands Homelink) provided within rural environments, and through the rural environment itself. The important role of third sector organisations identified in this thesis has been identified elsewhere in survey data (Curry, Burholt, Fisher & Evans, 2013). A gender divide was apparent (although I draw this comparison tentatively given the sample size) which supports findings elsewhere (Tollefson & Usher, 2006). For male participants, chronic pain restricted employment and productivity which seemed important for meaning. For female participants, productivity was also restricted but so too were their means to maintain social networks which seemed of greater importance than for men. For both men and women work and socialising supported engagement in the community (Arcury, Quandt & Bell, 2001; Davis & Magilvy, 2004).

Davis and Magilvy (2004) described rural older adults in their study to present 'quiet pride' as they continued to engage in meaningful activities despite experiencing chronic illness. In contrast, participants in this thesis exhibited a sense of shame linked to the restriction of meaningful activities. This had implications for quality of life and mental well-being, supporting the work of others (Day & Thorn, 2010). Acceptance of activity restrictions required psychological resilience to cope with the loss of meaning. Participants that presented as ageing well indicated capacities to adapt activities, identify new opportunities, and maintain or even continue to expand their social networks and so generate new meaning; this supports the findings of Sofaer-Bennett et al. (2007). However, there was a disparity in the availability of opportunities; access to opportunities

was supported, or not, by individual resources, social resources, access to transport and disrupted by health particularly in terms of co-morbidities. This uneven distribution of social capital reflects the arguments of Bourdieu (1986) – third sector services seem to moderate disparities in distribution to facilitate opportunities for older adults with chronic pain (and other co-morbid conditions) by providing services that meet the complex needs of individuals.

Participants vividly described restrictions as a sense of shrinking worlds, or as life coming inwards. For some participants, restrictions meant their lives became predominantly house-bound and their social networks diminished. This supports Rowles (1978, 1980, 1981, 1983) who argues the life space – the totality of phenomena including spatial and locational dimensions, that constitute the world for a person or group – becomes constricted in later life. Some participants in this thesis spent extended periods of time in their home and indicated the home as being their surveillance zone (a notion used by Rowles, 1981; Wiles et al., 2009). To counter physical restrictions imposed by chronic pain, participants engaged in imaginary participation in the outside world (e.g. via their window-scape, photographs); this activity has been identified elsewhere (see Parkhurst et al., 2014) and captured in biophilic design – a concept of designing places to bring the outside inside to facilitate a human-environment connection (see Ryan, Browning, Clancy et al., 2014). For some, this was a positive experience that supported reminiscence (e.g. Catherine). However, for others this activity was a source of frustration that reinforced feelings of isolation and constriction (e.g. Barbara, George). Participants revealed agitation and vulnerability at spending long periods of time within their home: ruminating about chronic pain, experiencing low mood, loneliness, grief, reflecting on loss of role and

meaning in life were common. The link between chronic pain and mental health, specifically depression, is well established (Bair, Robinson, Katon & Kroenke, 2003). Wenger and Burholt (2004) argue that loneliness can exist in the absence of social isolation, and vice versa. To some extent this is supported by findings in this thesis; however, living alone and lacking access to transport (i.e. being dependent on the goodwill of others to visit or provide transport) reinforced a sense of loneliness and isolation that was further heightened by the experience of chronic, restrictive, pain. Personal preference to limit activities and to seek isolation to control pain, maintain autonomy, and to protect against stigma should not be overlooked. However, not to challenge such behaviours may risk further adverse effects (Mackichan et al., 2013).

A sense of belonging, integration and place attachment within rural environments was intersected by the experience of chronic pain. Participants could no longer move freely about these environments to maintain social relationships; this weakened the social bonds important for social capital and impacted participant's sense of connectedness with others (social cohesion) – this was commonly described in terms of community spirit (i.e. sense of supportiveness from community to the needs of the individual). Chronic pain threatened the level to which participants could actively contribute to community spirit due to physical impairments and loss of mobility. Participants exemplified the changing realities of rural environments as village populations experienced transitions that threatened social cohesion and therefore community spirit; this supports the view of Wenger (2001) who challenges the myth that rural population are well-integrated and go to great lengths to meet the needs of older adults. Having said this, a strong belief remained about the existence of community spirit and although instances in which the

belief was realised were reported for some community spirit was imagined. That community spirit can continue without direct participation indicates its importance as part of the social construction of rurality and upholding the rural idyll. However, the disparity between community spirit as imagined and in-reality has implications for place attachment. Whilst the perception of high community spirit may support participants' social attachment or bonding and place identity; functional dimensions of place attachment – place dependence (Raymond et al., 2010), the functional aspects of rural environments (Burholt, 2012) – may be overlooked by those considering the implications of environment for older people with chronic pain (e.g. policy advisors, commissioners, older people).

8.1.3 The influence of life-course factors on chronic pain experiences

The third objective of this study was to explore the influence of life-course factors on experiences of ageing with chronic pain in rural environments. The onset of chronic pain was described as a life-course factor in and of its self, occurrence of additional co-morbidities, experience of loss (e.g. friends, family, spouse) and transitions in social network, employment and environment were also described. Participants also reflected on life-course events with new meaning in the context of current chronic pain experiences including sense of self. The complexity of the experience of ageing with chronic pain challenges the traditional and gerontological theories relating to maintaining activity in later life (see Section 2.2: p15). Furthermore, participants in this doctoral research study highlighted the non-linearity of the life-course (Daly & Grant, 2008).

The onset of chronic pain represented a significant life-course event for participants. The stage at which chronic pain was experienced had implications for life transitions:

employment, retirement, and migration in later life. Participants that experienced chronic pain during employment years actively managed pain to maintain an employment role and financial security. In contrast, participants that experienced chronic pain during post-retirement years presented fewer adaptations and pain management strategies, perhaps suggesting a lack of financial need prompting adaptations. Chronic pain, because of increasing physical impairment, contributed to decisions about the timing of retirement and, in some circumstances, enforced it. This had important implications for those participants who viewed their employment role as a source of meaning and self-realisation. During retirement transitions participants described relocating to, or within, rural environments. During times of greater mobility, in which participants could drive and support their own autonomy, the relocation to rural environments was positive for well-being and health. However, where driving became restricted the suitability of rural environments became problematic; increasing degrees of remoteness were identified.

Participants described the onset of chronic pain in terms of trigger points and progressive processes; this supports Bury's ideas on biographical disruption (1982). In constructing narratives about chronic pain, participants that identified trigger points as causes of chronic pain would report multiple triggers. These searching narratives were used to generate understanding and establish explanatory pathways (e.g. falls, work-related injuries) and often supported positive identities (e.g. masculinity, rural identity, productivity). This confers with Williams' (1984) concept of narrative reconstruction; however, as noted earlier such reconstructions did not necessarily "repair ruptures" in the life-course that chronic pain had caused. The predominant narrative of older adults that experienced chronic pain onset in later life was one of normalisation (as discussed

above). Collectively, this supports the work of Richardson et al. (2006) who identify the life stage and personal biography as framing such narratives.

The experience of additional health problems across the life-course, as co-morbid to chronic pain, altered how chronic pain was perceived. Co-morbidity contributed to complex health experiences; as identified by others (Rustøen et al. 2005). Participants seemed to assess co-morbid health problems in terms of the potential to cause harm (and the likely severity of harm) rather than on impact on daily functioning; for example, heart conditions and stroke were prioritized above chronic pain. Participants cognitively (re)organised co-morbid health conditions hierarchically; in which chronic pain was not typically a healthcare priority, except where no co-morbidities were present. Processes of prioritisation have been explored elsewhere. Sale et al. (2006) reported prioritisation of other health problems over pain as contributing to the under-use of painkillers; this did not seem to be supported by the findings in this thesis as painkillers represented a first resort in pain management for participants.

In addition to the potential for additional jeopardy from co-morbid conditions, participants also revealed the role of healthcare professionals and levels of engagement with self-management as guiding prioritisation strategies; this supports the findings of Morris et al. (2011). Prioritisation of own health needs also encompassed the needs of others. Participants with chronic pain described prioritising the health problems, and resulting needs, of their spouse above their own needs. This added burden of care was challenging; however, the maintenance of a spousal relationship also provided important support for resilience (discussed further in relation to Objective 4). The process of prioritisation requires further examination in the context of rural environments given the

challenges to accessing services in these areas, the lower reported rates of healthcare utilisation among rural older adults (Tripp et al., 2006), and culture of self-reliance.

The loss of relationships with others e.g. parents, siblings, neighbours, friends) across the life-course were also important factors reported in chronic pain experiences. In the absence of family living near to participants, extended family members were implicated into systems of support. Living in rural environments with chronic pain seemed to exacerbate social isolation, as reported by Mort and Phillips (2014). Bowling (2005) identifies the importance of social relationships as a resource to prevent loneliness and provide a sense of help and support. As Scharf and Bartlam (2006) report, the impact on social relationships is unevenly distributed; in this thesis, the unevenness is made sense of through life-course events (i.e. relocation in retirement, loss, children migrating). Moreover, personal preference for solitude was expressed reflecting a sense of cultural embeddedness.

Relationships with place also signified important life-course factors in the experience of chronic pain. Participants expressed strong attachment to place and a sense of place identity at micro (i.e. room, house) and meso (i.e. village, county) levels. Burholt's (2006, 2012) conceptualisation of attachment to place includes levels of social, psychological, physical and temporal attachment and is informative here. Participants highlighted the relational and transformative nature of place by either transforming home environments through adaptation to support ageing in place with chronic pain or transferring to new properties to support their change in needs. Decisions to relocate were pragmatic in response to, or anticipation of, physical impairments in later life. The choice of house, in which to create a home, remained within a rural environment to maintain a sense of

belonging (connectedness with others) (Taylor, 2001; Andrews & Phillips, 2005). These aspects speak to Burholt's (2006, 2012) social and psychological levels of attachment to place. Maintaining a sense of connection to rural environments had implications for place identity (Williams, 2002), one of multiple possible identities. For some, rural places represented lifelong attachments and were core sources of identity (e.g. Anne, Barbara). For others, rural places were symbolic of specific life-course transitions (e.g. retirement) presenting positive sources of identity (e.g. Catherine and Frances). For people like George and David, the nature of the connection with place had changed over the life-course due to increasing physical impairment; place identity too had become strained (e.g. both losing their sense of connection with farming) continuity in identity was therefore achieved through narrative (imaginary participation) not activity. Well-being is reported to be supported by long-term emotional attachment to environmental surroundings (Rubinstein, 1990; Taylor 2001). Thus, the endeavour to age in place may place such emotional attachment (a higher order need) often based on temporal/biographical qualities above more basic needs and practical considerations.

8.1.4 Coping, self-management strategies and the nature of resilience

The fourth objective of this study was to explore coping, self-management strategies, and the nature of resilience among older people with chronic pain in rural environments. A process of 'carrying on' conceptualized highly individualised self-management strategies and coping styles. The nature of resilience was disclosed through participants' capacity to adapt to changes in circumstances utilizing internal (e.g. inner-strength and resolve) and external resources (e.g. third sector services).

Participants developed diverse self-management strategies to control chronic pain. A process of learning what works to manage pain was operationalised by the participants; this reinforces the importance of individual-led pain management (Jensen et al., 2003). Incorporating mixed self-management strategies: pharmacological (painkillers), physical (exercise, physiotherapy), psychological (distraction) and alternative forms of therapy (yoga, chiropractic) better supported control and autonomy as did active coping styles. Mixed pain-management strategies are described elsewhere (Turk et al., 2011; Barry et al., 2005) with multi-disciplinary approaches shown to be effective (Burnham, Day & Dudley, 2010). Learning was typically informed by trial and error, and was contingent upon an awareness of therapeutic options, for which recommendations from others seemed important (e.g. healthcare professionals, complementary therapists and friends). However, a disparity in awareness of non-pharmacological options seemed apparent. Participants that disclosed passive avoidance styles of coping described implementing fewer pain management strategies and relied predominantly on painkillers, despite these not being a preference and reporting these to be ineffective; these participants also reported lower feelings of control and autonomy. Coping was led more by 'hoping' (that pain would relieve itself) rather than active management. There is a clear need to support and enhance awareness of therapeutic options to support active coping styles and control and autonomy.

Participants used the phrase 'carrying on' with chronic pain; this echoes notions of keeping going and perseverance described elsewhere (Carson & Mitchell, 1998; Busby 2000; Paterson, 2001, 2003; Richardson et al., 2006; Sofaer-Bennett et al., 2007) but also intersects the social roles that Morden et al. (2010) describe as part of broader self-

management. 'Carrying on' was exemplified by stoic attitudes towards chronic pain and upheld notions of suffering in silence reported by participants and echoed in previous research (Osborn & Smith, 1998; Tollefson, Usher & Foster, 2011). Stoicism has been identified as a prominent component of coping with chronic pain in research with older adults (Yates et al., 1995; Blomqvist & Edberg, 2002; Jones et al., 2005; Schofield et al., 2006; Hunhammar et al., 2009). Participants presented stoicism as an effort to control emotional responses to pain. Stoicism represented a shared value linked to privacy and helped to maintain positive identities, a sense of belonging, and protected against feelings of social exclusion. It was apparent that maintaining privacy around chronic pain was valued above potential benefits of disclosing pain to others. This supports research by others in rural environments (Tollefson, Usher & Foster, 2011; Gannon, Finn & O'Gorman, 2013), and relates to the maintenance of dignity and self-protection, but also a sustaining a sense of connection with the surrounding environment at micro- and meso-levels. However, 'carrying on' kept hidden the hard work of chronic pain, vulnerabilities and suffering; consequently, putting additional strain on inner-abilities to cope. This supports the observations of Gudmannsdotir and Halldorsdottir (2009) in older adults in care home environments. To carry on gives the illusion of ageing well and maintaining control and autonomy, when control specifically is undermined by chronic pain. Thus, phrases such as this need to be challenged to unpick self-management strategies and to better support needs. Such challenges should be made sensitively, as argued by Ong et al. (2011), as in the case of "carrying on" in this study reflects shared values, infers a sense of belonging, and the illusion of coping may be deeply engrained.

Descriptions of “carrying on” are also bound up within notions of resilience. Resilience was revealed through processes of adaptation, compromise and utilizing internal resources as well as external resources. Resilience was about adapting in the face of adversity, to some extent ‘bouncing back’, but predominantly adjusting to maintain continuity across the life-course. In this thesis, participants disclosed a series of compromises (i.e. going without, making do); this supports previous research that identified making compromises as at the heart of adaptation (Sofaer et al., 2005). Ultimately, the capacity to compromise is finite as opportunities decrease in later life. Rural environments are, and contain, important assets that support resilience. Aspects of the home and the wider rural environment both supported adaptation (e.g. culture characterized by slower pace of life) and required adaptation (e.g. changing the purpose of a room in the home to overcome the challenge of stairs). Efforts to adapt environments both indicated and supported place attachment and enabled participants to maintain place identity; specifically, in terms of home.

Pleasure was experienced through the aesthetic qualities of rural environments; these qualities were utilised as resources to relieve reported stress and low mood. An aesthetic attachment (Burholt, 2012; Burholt et al., 2014) or nature bonding (Raymond et al., 2010) was indicated by some participants who revealed a deep-rooted need to be out in the natural world (whether physically or imaginary). However, access to the natural world and ability to maintain aesthetic attachments was not shared by all. For some (e.g. George, Barbara), aesthetic features provided daily reminders of physical impairments and weakened social and physical attachments to place; this had negative implications for self-identity validation. Contrasted with the social world, a sense of community spirit

described earlier also supported resilience; however, assumptions around the existence of such spirit need to be challenged as they may not reflect the reality of social connections in these environments. Furthermore, resilience should be treated with caution; as what can appear as resilience (i.e. stoicism, carrying on) may disguise vulnerabilities. Thus, stoicism may support resilience but requires additional strategies to support coping – as highlighted by participants that maintained/adjusted/commenced new activities, engaged in social relationships whilst maintaining privacy about chronic pain (e.g. Frances, Catherine) against those who did not (e.g. Barbara, George).

What was missing in the data was a sense of collaboration at personal, organisational, and sectoral levels in the context of pain management; this indicates opportunities are being missed to support self-management and coping. Languages of pain (e.g. meaning of the term ‘chronic’) did not seem to be shared between lay and medical definitions and descriptions of chronic pain. The dissonance supports Kenny’s (2004) findings that suggest a chasm may exist between the contrasting communication models implicitly used by patients and doctor; which has implications for pain management identified by Dow et al. (2012). No healthcare planning seemed to be in place that was directed by a healthcare professional other than pain medication. Importantly, there was an absence of talk about specialist chronic pain clinics, multi-disciplinary pain management teams, or health technologies even when prompted to talk about healthcare utilization and assistive aids. Living in a rural environment had implications for the provision of social care, limiting the time that home care providers could spend with individuals. Multi-agency work seemed to be actualized by participants who sought out specialists from different fields; but again, there was no integration.

8.1.5 Policy and service needs of rural older adults with chronic pain

The fifth and final objective of this study was to consider policy and service needs of rural older people with chronic pain. The needs of participants living with chronic pain in rural environments were diverse intersecting both health and social care and depended to a large degree on level of disability. The role of third sector organisations was crucial to supporting participants with physical disability (e.g. providing group activities with transport).

Participants reported accessing NHS services, both primary and secondary care, to obtain support with chronic pain management. The GP was revealed as a central figure in chronic pain management for participants. As stated above, neither pain clinics nor pain management programmes were indicated; instead, painkillers represented the predominant pain management strategy as identified elsewhere (see Barry et al., 2005). An over-reliance on painkillers was also identified, which supports the findings of Decker, Culp and Cacchione (2009). Alternative pain management strategies were reported by participants, cutting across the strategies categorized by Turk et al. (2011). However, learning “what works” was an individualized process which took time and was supported by opportunities older adults were made aware of and that were accessible. This self-discovery supports the findings of Jensen et al. (2003). There is a prominent discourse of self-management in healthcare policy and agendas for chronic illness (Morden et al., 2012). Yet, in this thesis the healthcare needs of older adults with chronic pain in rural environments could be supported better.

Rural environments present specific challenges for older adults with chronic pain. The choice of GP practice was limited by geography, distance to services, and access to

transport. Having said this, distance is a relative concept in the context of chronic pain disability; for some older adults, being 100 metres or 10 miles from the GP service had similar implications for access. In the absence of access to a car and the ability to drive, older adults are dependent on: ring-and-ride services, taxis, social network (i.e. friends, family, close and extended). Each required additional planning and challenged independence. Access to physiotherapy, other specialist care services and CAM providers was also limited and required travel to urban-centres. The loss of local services, such as community matrons, was important in the provision of healthcare in rural communities. The importance of an on-going relationship also means that services such as rural-based paramedics are not integrated at a local community-level and instead serve a wide area. Despite challenges that rural environments present in terms of distance, inter-agency work and/or integrated care seemed non-existent. Individuals described receiving care in the home; however, the provision of care seemed limited to a specific task (e.g. to redress a wound) and time. The length of a visit varied only on account of the amount of paperwork that was completed during the visit. For participants receiving in-home care relationships with carers and nurses represented a consistent source of social contact. However, these are missed opportunities to better support resilience and ageing well; time spent by the individuals with older adults during visits was short and task focused (e.g. redressing a wound, completing associated paperwork), which neglects the psychosocial importance of these regular visits.

The provision of opportunities for older adults to take part in social activities is important to support quality of life, particularly higher order needs. The data from older adults suggests that the role of the third sector is crucial to enable individuals to overcome

physical disability because of chronic pain and achieve such participation. Activities also provided opportunities for older adults to distract themselves from their pain; therefore, supporting an additional pain management strategy. Moreover, activities may provide a means of overcoming social isolation and alleviating loneliness consequential to this (as described by Anne). The provision of transport by third sector organisations is important in rural areas; however, the cost for such door-to-door services is prohibitively expensive, whilst services without transport provision presented a barrier for older adults with disabilities and who could not drive. A community bus was provided in one village in the study (Village A); this service was maintained by volunteers and provides a good model for community level support for older adults. Constructing a partnership between individuals and society is an imperative (Walker & Maltby, 2012). However, not all villages are of sufficient size, have adequate resources or are sufficiently organized to provide such access to transport.

There is a need to address the age-friendliness of rural environments for older adults experiencing chronic pain. On a compositional level, the design and management of rural environments does not typically facilitate adaptation to chronic pain (e.g. using walking aids is challenging in these environments). On a context and collective level, the assumption that rural communities and rurality implies strong community spirits needs to be challenged given the changing nature of rural populations and the in-migration of commuters. Although not entirely illusory, community spirit should not be assumed or relied upon to the extent that it is by older adults whose ability to maintain connection with neighbours has diminished. Assumptions about rural community spirit form part of the popular image of rurality; if unchallenged this image may hide: health disparity,

poverty, deprivation, crime (Cloke et al., 1995; Scharf & Bartlam, 2006) and provide a false sense of (health) security. Age-friendly design needs to figure more prominently in rural environments, to support ageing in place as well as community spirit. Providing opportunities to enhance social capital and social cohesion are important, as the Canadian age friendliness policy initiative has signified (Menec et al., 2011). The concept of social capital has influenced rural policy in the UK through prioritising community networks (Defra, 2004) but may require additional emphasis. Policy needs to be sympathetic to population change and intersect at a community level to encourage people to engage in activities that support community spirit and support the interests of others, including older adults. This was highlighted further during discussions at a community stakeholder event, at which the findings from this thesis were disseminated (see Appendix 17 for summary report). Moreover, interventions should be context-specific to ensure local resources are utilized and sustainability is promoted.

8.2 Strengths, challenges and limitations

In this section I address some of the key strengths, challenges and limitations of the research within this thesis. For clarity, I discuss these under separate headings and I begin with the strengths.

8.2.1 Strengths

The exploratory mixed methods approach represents a key strength of this thesis; this supported gathering of rich in-depth data. This approach was adopted because of the dearth of existing literature focusing on exploring personal experience. The mix of methods that were used targeted the elicitation of narratives; this was achieved, and a

substantial amount of data on lived experiences of ageing with chronic pain in rural environments was generated. Specifically, the mixed methods facilitated the exploration of particular dimensions of chronic pain, for example the life-grid helped to frame temporal-historical experiences. Furthermore, these were effective for comparing and contrasting findings data as data generated from one method could be used to support but also challenge that gathered by another.

The integration of the quality of life measure (CASP-19) into the in-depth interviews represents a key strength of the mixed methods design and a novel use of CASP-19 (Hyde, Higgs, Wiggins & Blane, 2015). The integration facilitated the exploration of responses that participants gave to individual items; this revealed a lack of face validity for some items for some participants. The creators of CASP-19 stipulate that the measure is not idiographic; however, the findings in this study suggest the contrary, as participants revealed individual meanings for specific items prompted by their own interpretations. For example, when responding to Item 2 ('I feel that what happens to me is out of my control') participants responded depending upon their interpretation of the word 'control' and in what regard or context. They framed responses in terms of the first thing that came to mind; this ranged from verbalising a sense of good health, mobility, cognitive capacity or a sense of religiosity in which a higher order was assumed to have control. In response to Item 5 ('I can do the things that I want to do') older adults responded in a way that emphasised the relative nature of 'can' (i.e. capacity to do something) and 'want' (i.e. desire to do something) in the context of activities. For participants who did not attend regular activities, or expressed the desire to do so, the 'can' was disclosed in a restricted sense. For participants, whose chronic pain worsened

as a consequence of activity, were concerned about risk of falls, or were physically disabled, the 'want' was also disclosed in a restricted sense. Control and autonomy were balanced; older adults experiencing chronic pain may choose to restrict activities because of loss of control, and in doing so protect a sense of autonomy. More broadly, individual agency seemed to hold greater relevance than autonomy.

The wording of Item 13 ('I enjoy being in the company of others') suggests priority is afforded to social participation involving group activities; this would not be to everyone's preference. Participants expressed gender-specific attitudes in which males did not seek out the company of others or to attend group activities. Also, older adults expressed ways of coping with chronic pain that sought to reduce opportunity for stigma by maintaining privacy. The wording of Item 15 ('I feel full of energy these days') invoked an ageist response; indicating that this item may lack credibility and as such was interpreted as a leading statement. Responses on these items may have indicated low quality of life in terms of a score, but behind each score is a more nuanced story and reality explored through examination of the qualitative data. These limitations in the face validity of CASP-19 have important implications for the use of this measure (Sim, Bartlam, & Bernard, 2011).

The in-depth exploratory approach facilitated the establishment and development of my relationships with research participants. The time spent with participants and the nature of the research activities shared, enabled greater access into their lived experiences. These relationships supported in-depth data gathering that added additional richness. The go-along and photo-elicitation methods were effective means of developing trust; becoming part of the activity and sharing in it helped participants to overcome limitations

enforced upon them by the environment and by their experience of chronic pain. Furthermore, by familiarising myself with the environments in which participants lived I could build rapport by sharing in the narratives and anecdotes that they shared. The use of participants' homes as the interview setting for the initial one-to-one interview also supported the development of relationships whilst providing me with an opportunity to observe the home environment as a place in which to age with chronic pain. The methods provided insight into how each one could add to research on health.

The recruitment strategy represented another key strength in terms of gaining access and developing my understanding. By making regular visits to the Staffordshire Moorlands for recruitment I had the opportunity to familiarize myself with the environments in which participants lived, and with the challenges and opportunities that these environments presented. Participants were recruited through third sector organisations and community gatekeepers; this strategy enabled me to reach people who may not normally have accessed their GP on a regular basis. The literature identified the lack of a male perspective in rural research on chronic pain. In this study half of the participants were male. The size and diversity of the sample is discussed in the limitations (see below).

The commitment to patient and public involvement and engagement (PPIE) throughout the course of the study represents a major strength and a success of such engagement. Establishing the project advisory group (PAG) helped to sustain PPIE throughout the study and facilitated my understanding of ageing with chronic pain and living in the local rural environment; this supported early development of the research objectives. Members of the PAG provided their views on study documents to ensure they were suitable for lay audiences; these formed part of the successful application for ethical approval. Members

of the group also shared their local contact networks with me; this supported initial recruitment of participants. The PAG were an excellent source of local knowledge, which I utilized to check my understanding of a local issue identified in an interview (e.g. history of the volunteer bus scheme in Village A, closing of the post office in Village A). Members of the PAG were pivotal in the dissemination of findings including facilitating table discussion during the stakeholder engagement workshop. The presence of the PAG members at the stakeholder engagement workshop enabled them to engage in broader discussions (even beyond the scope of the thesis) as stakeholders in their own local rural communities. The workshop evidenced the relevance of this research to those involved at a community level and to wider age-friendly policy discourse. Thus, the input and guidance from third sector organisations must be acknowledged also.

8.2.2 Challenges

Reconciling the three topic areas of ageing, chronic pain and rural environments was challenging as underlying each is a broad and rich literature. Although few papers focus on the intersection of all three topics, there is an abundance of research that cross two of the topic areas from which much can be taken. Recruitment presented a challenge in terms of identifying older adults with chronic pain. Lay interpretations of 'chronic' may have prevented some potential participants from self-identifying themselves as eligible, although I would commonly refer to chronic pain as persistent. Moreover, that stoicism was a key part of coping in rural environments meant that many eligible participants may have held back from identifying themselves. However, single males remained a hard to reach group as well as people living in remote settings, hamlets or isolated dwellings.

The richness of the data was challenging in terms of data management. I implemented an exhaustive analytic strategy that was inductive and deductive to integrate and optimise usage of the data. The strategy facilitated immersion in the data that verged on drowning. As the sample was small there was a compulsion to protect and to tell each individual's story of chronic pain to maintain the depth and meaning that each account offered. Each participant deserved a chapter of their own to tell their story. However, within the constraints of the research study, the analysis moved beyond individual level of experience to more abstract levels.

Managing interview time and not over-burdening participants were also key challenges. The in-depth nature of the interviews and the combination of data gathering techniques (i.e. narrative interviewing, life-grid, CASP-19, topic guide, observations) into single research visits was difficult to time-manage. As a consequence, some interviews were long, lasting up to three hours. The novelty of the techniques that I used also meant that they were unfamiliar to me. The data gathering in the research study was a process of learning on the job. The go-along presented a challenge in terms of balancing power in the researcher-participant relationship; the premise of the go-along is to enable the participant to assume control of the route. However, this was difficult to manage as the activity also presented participants with the opportunity to complete tasks beyond the nature of the research (e.g. visit the supermarket, run errands for others). But this supported the development of a trusting and reciprocal relationship, which facilitated richer data.

Interviewing participants whilst their spouse was present was challenging in terms of eliciting participant's, those experiencing chronic pain, narratives and views. The spouse

of participants who were present during interviews presented alternative narratives, perspectives and in some instances dominated conversation. The voice of the older adult with chronic pain was sometimes lost or obscured by competing narratives. Interviewing participants with their partners provided, both, support and encouragement for the participant but also a source of agitation and loss of control. Two-to-one interviews also presented additional needs for taking consent, which I had not anticipated but recorded to use the data that spouses in interviews provided.

8.2.3 Limitations

This thesis has limitations. The findings represent analytic interpretations based on data gathered with eight older adults living with chronic pain in a rural environment. The sample size is typical for an in-depth exploratory study of this nature and remains diverse in terms of: age, sex, education, time spent with chronic pain, site of pain, and attributed cause of pain. However, spectrum sampling cannot be claimed to have been achieved as the eight participants are homogeneous in terms of: ethnicity (white British), living in a single district and similar settlement (villages), home ownership, and no single men or married women were recruited (data on sexuality was not disclosed). The limitation of the sample means that important views may potentially be missing that could have implications for data analysis and findings. For example, views on loneliness and social networks may have differed had single men and women participated. The saturation of conceptual categories cannot therefore be fully substantiated as additional experiences and analysis may reveal alternative perspectives leading to alternative interpretations.

Whilst the in-depth approach taken in this study is a key strength the narrow focus means that counter-narratives are missing. For instance, I have discussed findings from existing

research based on the experiences of others, both from rural environments and those in urban ones for contrast, to further contextualize the findings. Participants described experiences and conversations shared with healthcare practitioners (e.g. their GP). However, no interviews were conducted with health care practitioners so their perspectives are missing e.g. on treatment and prescription of painkillers. Thus, only one side of the story is available. At times this can be seen to disparage the healthcare provision that participants received. However, all participants reported an admiration for the NHS and were thankful for it.

This study included novel data gathering techniques; operationalising these met with differing levels of success (discussed as challenges above). The low take-up of the go-along and photo-elicitation methods limits the potential for comparing participant experiences and observations. For the go-along method, the equipment used limited the data that was gathered; the use of a hand-held camcorder to record data whilst on the move was practically challenging. A hands-free video recorder would have been optimal to record real-time, real-action data; however, financial cost was prohibitive. Furthermore, recording of fieldnotes was conducted post-activity; thus, the accuracy of recall memory and subsequent fieldnotes cannot be guaranteed. For the photo-elicitation method, the data were limited by the equipment (a disposable camera), the participant's competence and physical capability to use this equipment, and their interpretation of the activity. A limitation of CASP-19 was the wording of some items which led to participants experiencing difficulty in finding an appropriate response. In an effort to be supportive I reflected on data from the interview with participants to help them to understand items (see Table 6.7 p206). On reflection, this technique may appear to have been leading and

have contributed to ambiguity – a personal learning point for me when conducting qualitative interviews.

The small sample size and exploratory nature of this mixed methods study limits the generalisability of the findings. The views and experiences shared by participants may not be shared by older adults with chronic pain living in other rural areas of the UK, or further afield. The thick descriptive case studies of rural locations and participants together with findings from CASP-19 enable comparisons to be drawn across the sample. The findings reveal important points of convergence in individual experiences (e.g. self-management strategies) that would be applicable beyond the participants in this study. Furthermore, the challenges that older adults living with chronic pain in rural environments experience will no doubt share similarities as well as idiosyncrasies.

8.3 Reflections on the thesis

The study fits within an interpretive paradigm, as underpinned by my view of the world and understanding of how experiences are constituted and shared. The perspective that I have taken has been shaped by my own experiences in education, employment, conversations with colleagues, and certainly by my supervisory team and their specific interests and expertise, as well as the study protocol written for the studentship and the literature. I approached this study with a background in psychology and experience of applied qualitative and quantitative methods. I had conducted qualitative research previously with people with chronic health problems (e.g. Multiple Sclerosis, Cancer, Irritable Bowel Syndrome, and Inflammatory Bowel Disease). Chronic pain has been a prominent symptom for many of the people I have interviewed for these studies. Thus, I

approached this thesis with prior knowledge of the possible experiences I might encounter and explore; however, I did not assume to *know* these.

I commenced data gathering and analysis with the intention to undertake narrative analysis; such was the focus on eliciting narratives. However, during initial analysis I realized that I would struggle to integrate the different types of data together through narratives analysis alone. A more systematic coding and building of categories allowed for a web of analysis that could connect up the different dots of data. The approach to analysis shifted as it progressed. In the first instance inspiration was drawn from by Catherine Riessman's narrative analysis approach; however, when I came to put this into practice I felt uneasy about the process and the ability to look across cases. This led to a switch to a more systematic process of coding and constant comparison, a method inspired by Kathy Charmaz and constructivist grounded theory. I was also influenced in my selection of constructivist grounded theory by discussions with eminent academics. I discussed the acceptability and application of constructivist grounded theory with colleagues during a social science discussion group (July 2014); additional pitfalls were identified. This helped in the development of the approach to analysis taken in this thesis (as described in Section 4.4: p133)

The methods used to gather data signified an attitude to support participants to maintain activity in later life and challenged assumptions of frailty. However, the reality of the situation for older adults with poor health was that they could not take part in some methods. The decision to take part in specific methods may therefore have been due more to physical capability than preference. The novel methods included in this study were chosen to provide different opportunities and contexts in which to explore

experiences. On reflection, the decision to include a follow-up sit-down interview was important to accommodate different physical capabilities of participants. However, for participants who chose not to take part in the novel follow-up methods the type of data that they provided was limited by type. One-to-one sit-down interviews were limited by the scope of prompts (these were researcher-led, not from photographs or environment) and the observations that could be made. The go-along method has greater implications for use in health research; especially with older adults as this method enabled trust to develop within the researcher-participant relationship. These methods helped to get beyond the protective mechanisms of stoicism, which prioritised privacy to maintain control.

The boundaries of my role as researcher in relation to participants blurred as data gathering continued into follow-up. My role as a researcher crossed over with that of a befriender (or family member) as I provided support for older adults to attend routine activities, providing transport, encouraging participation in activities. This researcher-participant relationship emphasised the importance of managing expectations and relationships throughout research participation and attending to exiting ethics (as described in Section 4.1.4: p127).

8.4 Implications of my research

The findings from this thesis have implications relating to research methodology, healthcare service provision and policy. The findings indicate a need for in-depth exploratory research utilising mixed methods; as this approach has facilitated data gathering that gets beneath protective coping strategies (i.e. stoicism) and has drawn out vulnerabilities without challenging these strategies. The mixed methods exploratory

approach highlights yet further the limitations of unidimensional pain scales and the need to consider pain more broadly. Furthermore, by integrating a quality of life measure into qualitative interviews supports this in-depth exploration and supports a richer deeper understanding of the relative interpretation of such measures against experience of the life-course. A need to consider rural environments more explicitly and more critically has been emphasised through the application of critical human ecology and a relational perspective. Furthermore, issues in rural health extend beyond objective problems of distance, service provision and into identity construction, sense of belonging and culture.

There are implications from this study for the provision of healthcare services. Chronic pain is a multi-dimensional experience and as such healthcare service delivery to patients in pain needs to reflect this. The qualitative data indicate that pain management strategies that focus narrowly on pain severity, and therefore pain medications, are ineffective and reinforce older adult's negative views on "taking pills". Services that acknowledge a multidimensional perspective on chronic pain, that includes eliciting chronic pain narratives, would enable more informed and contextualised pain management strategies that support active self-management, as opposed to passive consumption of painkillers. Supporting positive self-management behaviours is important to enable older adults with chronic pain to maintain independence; using routine contacts between older adults and social care or third sector services, as an avenue to do this, offers potential. Healthcare service provision needs to take into consideration the situated nature of health, the environmental contexts, and community resources to support pain management and command an awareness of alternative service providers (e.g. third sector organisations, complementary and alternative medicine).

There are implications from this study for healthcare policy. Health policy needs to reflect the service provision implications described above. Guidelines for the management of chronic pain should support a multi-dimensional approach to assessment and treatment of chronic pain. If healthcare policy is to support healthy and active ageing then notions of self-management need to be actualised as a lifestyle within the context of achieving self-realisation, not strictly as a disease management strategy. Self-management requires active engagement; thus, treatment interventions that reinforce passivity will not support patients for whom self-management is important. The findings from this study acknowledge the potential for health and social care in rural environments to be integrated; this extends to third sector services also. Participants experienced chronic pain as restricting, physically and socially, therefore the provision of opportunities to support individuals to overcome these restrictions is an imperative. Policy is therefore essential to direct integration of services in practice. Given the prevalence of chronic pain, policy that supports the development and sustainability of age friendly rural environments for older adults with chronic pain is essential (see Appendix 17). This approach requires focus on supporting individuals to enhance social capital through relationships based on homogeneity, demonstrate community spirit in action (as an activity of social cohesion), and provide opportunities for individuals to maintain meaningful activities and identity despite chronic pain.

8.4.1 Future research

The plan for publications from this thesis includes three peer-review papers based on the literature review, implications for methodology, and presentation of main findings (see Appendix 18). The findings from this study also suggest areas for future research. Further

research is required that examines: (1) the utilisation of mixed methods and mixed analysis strategies to achieve full integration; (2) the development of the go-along method in health research as a means of exploring environmental perceptions and patient experiences and journeys; (3) the integration of the CASP-19 (and other quantitative measures) in qualitative interviews to address ongoing issues of validity; (4) critical perspectives on phrases such as 'carrying on' as these may hide vulnerabilities, be mistaken for resilience, and provide the illusion of ageing well; and finally, (5) the age-friendliness of rural environments has been under-researched in comparison to urban perspectives despite these environments poses distinctive challenges to older adults.

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Appendices

Appendix 1	Research User Group (RUG) workshop (April 2013).....	376
Appendix 2	Project Advisory Group (PAG) member's backgrounds and key contributions.....	378
Appendix 3	Summary of PAG meeting.....	381
Appendix 4	PAG newsletter example.....	386
Appendix 5	Interview materials (topic guide, life-grid, CASP-19).....	387
Appendix 6	Recording fieldnotes	
	a. Blank version of post-interview summary sheet.....	390
	b. Photocopied pages from fieldnotes journal.....	392
Appendix 7	Ethical approval letters from Keele University	
	a. Original ethics approval letter.....	395
	b. Approval following amendment.....	397
Appendix 8	Participant information pack	
	a. Participant invitation letter.....	398
	b. Participant information sheet with consent to contact slip.....	399
Appendix 9	Additional participant information sheets	
	a. One-to-one interview.....	404
	b. Photo-elicitation.....	405
	c. Go-along.....	407
Appendix 10	Consent forms	
	a. One-to-one interview consent form.....	408
	b. Photo-elicitation interview consent form.....	409
	c. Go-along interview consent form.....	411
	d. Photograph sharing consent form.....	412
	e. Post-interview consent form.....	414
Appendix 11	List of photographs collected during fieldwork.....	415
Appendix 12	Examples of analysis	
	a. Identifying narratives.....	418
	b. Initial coding.....	419
	c. Annotations of transcripts.....	420
	d. Memos.....	421
	e. Coding frame.....	426
Appendix 13	Coding mind maps for each participant	
	a. Anne.....	446
	b. Barbara.....	447

	c. Catherine.....	448
	d. David.....	449
	e. Edward.....	450
	f. Frances.....	451
	g. George.....	452
	h. Henry.....	453
Appendix 14	Redacted version of a completed life-grid.....	454
Appendix 15	Full table of CASP-19 responses.....	455
Appendix 16	Summary of go-along interviews	
	a. Henry.....	456
	b. Anne.....	463
Appendix 17	Summary report from stakeholder event.....	474
Appendix 18	Thesis outputs: presentations and plan for publications.....	488

Appendix 1

Research User Group: Annual Meeting

Keele Hall – 26th April 2013

Breakout Session with Tom Kingstone

Three questions were put to 8 members of the Research User Group and discussed. Tom Kingstone facilitated discussion and Adele Higginbotham recorded notes.

WHAT ARE THE MAIN ISSUES FOR OLDER PEOPLE WITH CHRONIC PAIN IN RURAL AREAS?

1. What are the main issues for older people with chronic pain in rural areas generally?

Main themes from the discussion included:

- Facilities
- Mobility
 - Sub-theme: Personal mobility (getting around)
 - Sub-theme: Transport network (public transport – expensive)
 - Sub-theme: No home visits by GPs or Community Matrons/District Nurse
- Isolation
- Independence – do people tell anyone about their condition, or keep it to themselves to protect own independence ('struggle on' – stoic attitude)
 - Sub-theme: learning to live with condition
 - Sub-theme: is help needed/wanted?
- Communication
 - Sub-theme: not knowing what help is available
- Finance
 - Sub-theme: cost of transport and care, specifically for chronic illness (ongoing needs)
- Breakdown of society:
 - the concept of being 'neighbourly' has disappeared

2. What, in your experience makes a patient advisory group work well – Do's and Don't's to keep in mind?

Main themes from the discussion included:

- Training
- Plain English – guard against making assumption
- Listening to the group
- Respect
- Rapport
- Continuity
- Logistics

3. What do you think are the issues around being invited to be interviewed for this project?

Main themes from the discussion included:

- One-to-one interviews preferred by some
 - Sub-theme: Chaperone should be an option – suggest a family member to be there
- Arrange an initial meeting ('a warm up') in order to get to know the participant prior to data collection
- Time
 - Sub-theme: arrange a time that is suitable and convenient for the participant
 - Sub-theme: state how long the interview is going to take so that it can be planned into the person's day (not be an inconvenience)
- Be honest
- Ensure confidentiality of the conversations
- Offering money to take part may sometimes appear to mark a hidden agenda underlying the research

AGEING WELL WITH CHRONIC PAIN IN RURAL ENVIRONMENTS



Members of the Advisory Group: backgrounds and key contributions

Nancy Amison

Nancy is a retired nurse of 35 years who now lives alone in a semi-rural location outside Stoke-on-Trent. During her working life, Nancy was the first District Nurse for Smallthorne and Bradeley. Nancy also has a daughter, who lives locally, and provides Nancy with her main source of support. Nancy has developed chronic pain as a result of osteoarthritis and circulatory problems in her feet and legs. The pain that Nancy now experiences has had a major impact on her life; she is unable to leave the house without the aid of a wheelchair and someone to provide assistance.

Key contribution: Expertise in living and ageing in a rural environment with chronic pain; lay perspective on the design and acceptability of the research.

Bernadette Bartlam

Bernadette has been at Keele University for 15 years. Her current role is as a Lecturer within the Institute for Primary Care and Health Sciences and she has been involved in a number of research studies looking at various aspects of ageing including policy considerations, and health and social care provision. She also has experience in the wide variety of research methods being used in the study, and in the application of mixed methods.

Key contribution: Lead supervisor.

June Brammar

June is employed by the Beth Johnson Foundation for 15 years and began her work with the Foundation by running support groups in the Staffordshire Moorlands district – since then June has worked as a Health Improvement Coordinator on interventions for nutrition and falls prevention. Currently, June is on secondment at the Haywood hospital in the Rheumatology team where her role is to design and develop an information service for patients, carers, relatives and also research students.

Key contribution: Expertise in the delivery of health and social care services in rural areas and of local policy developments

Carolyn Chew-Graham

Carolyn is Professor of General Practice Research at Keele University having joined the staff in September 2012. Carolyn also holds an honorary Professorship at the University of Manchester. Carolyn's research interests focus on the doctor-patient relationship and in particular the recognition and care of patients in distress. Other work includes chronic illness (e.g. pain), mental health and older adults, and the development and testing of interventions for mental health problems in Primary Care.

Key contribution: Supervisor.

Vince Cooper

Vince is a retired General Practitioner (GP), having spent 28 years working in the GP practice in Waterhouses in the Staffordshire Moorlands. His main academic interest and expertise is in medical education and he is a Senior Lecturer at Keele. Vince has remained in Waterhouses since retiring as a GP where he has a small farm and also volunteers as a Mini-bus driver for a local luncheon club.

Key contribution: Expertise as a former-rural GP with knowledge of the local geography and practical healthcare challenges; clinical perspectives on the research design, Chair of Advisory Group.

Stuart and Angie Emery

Angie was born into a farming community in the North Staffordshire Moorlands. Angie unexpectedly gave up work early in order to care for their daughter; she now also experiences pain following knee injury. Stuart spent most of his youth in a semi-rural spot outside Stoke-on-Trent. Stuart, now retired, was a professional photographer. He also experiences pain due to arthritis. Both have a keen interest in research and are members of the Research User Group at Keele University.

Key contribution: Expertise in living and ageing in a rural environment; local initiatives to support older people; local challenges.

Tom Kingstone

Tom is a Doctoral researcher. This research project will go towards Tom's achieving his PhD. Tom has a background in social science research methods, specifically psychology and criminology. Between completing his Masters and commencing this PhD research Tom held a number of Research Assistant positions, working more recently on a research trial in a NHS Hospital setting.

Key contribution: to conduct the research.

Andrew Moore

Andrew came to Keele University in 2010; his role is as a Research Associate in the Institute for Primary Care and Health Sciences Currently. Andrew's current research focuses on pain and chronic musculoskeletal conditions and how pain interferes with people's lives. He also has particular expertise in visual methods and ethnography

Key contribution: Supervisor.

Roger Sugden

Roger is now retired from his career with Xerox as an Organisational and Behavioural Engineer and in consultancy roles. Since retiring, Roger has spent five years as a pastoral lay worker, working with the Moorlands Homelink luncheon club in Waterhouses, and has chaired a village facilities grant fund panel – distributing £3.5 million to local projects. Roger currently lives in Grindon within the Staffordshire Moorlands.

Key contribution: Expertise in living and ageing in a rural environment; local initiatives to support older people; local challenges.

Helen Wainwright

Helen is the Manager of a voluntary organisation, Moorlands Homelink. This charity operates across the Staffordshire Moorlands working with older people in various ways: running a day centre at the Methodist Church in Cheadle, providing outreach services to groups in rural areas, befriending schemes where volunteers work on a one-to-one basis visiting older people in their homes, coordinating a voluntary transport scheme, shopping service, information and advice service amongst other things. The charity has 300 volunteers and 35 staff members and deals with around 400 older adults.

Key contribution: Expertise in the delivery of community services in rural areas and of local policy developments

AGEING WELL WITH CHRONIC PAIN IN RURAL ENVIRONMENTS



Summary of Advisory Group Meeting

Details of meeting

Date: 30th September 2013

Time: 12.00 – 2.00pm

Location: Room 0.79, David Weatherall Building, Keele University, ST5 5BG

Attendees: Bernadette Bartlam (BB), June Brammar (JB), Vince Cooper (VC - Chair), Tom Kingstone (TK), Andrew Moore (AM), Roger Sugden (RS), Helen Wainwright (HW)

Apologies: Nancy Amison

Agenda Item 1 - Welcome and Introductions

Please see biography for brief overview of members

Agenda Item 2 - The role of the advisory group

Why has the Advisory Group been put together?

Attendees have been invited to become members of the Advisory Group so as to achieve a spread of knowledge and experience. Each member has been invited based on their expert knowledge of a particular topic area e.g. policy, practice, healthcare, academia, personal experience of rural living and/or chronic pain. Expectations of members are to provide support to TK as and when required, to share information about the research and related developments, to provide assistance with specific aspects of the work, and to provide advice on the dissemination of the findings of the research.

What responsibilities will Advisory Members have?

Advisory Group members of the group have few responsibilities, principally to act in a personal capacity and also to maintain the confidentiality of discussions that take place in Advisory Group meetings. Members have no additional management responsibilities for the research project. Anything that members can contribute will be really appreciated.

When, where and why will Advisory Group meetings be held?

The Advisory Group can expect to meet together again at the end of the research for the dissemination of results, unless an issue arises during the research where

it is felt that an additional meeting should be called for. The location of the next meeting is still to be decided upon and may take place at a venue external to Keele University. During the course of the research TK will contact each member to provide an update on progress with the research. TK may also contact members individually in the event of a particular query or issue e.g. recruitment, contacts, understanding.

Claiming of expenses

All members of the Advisory Group who are not members of staff at Keele may claim expenses (complete and return enclosed form).

Agenda Item 3 - Overview of the research project

How did the project come about?

BB and AM provided a brief history of the research. The funding for the project is for three years and comes from the University, specifically from the ACORN fund for studentships. BB and AM applied for funding for the project, designing a research project based upon their own interests and those of the Institute for Primary Care and Health Sciences (IPCHS). BB's interests lie in rural ageing and environments of ageing – how the environments in which we age, profoundly structure our capacities to age well – because of the positioning of the study in the IPCHS the focus of a particular health condition was brought into consideration, that of ageing well with chronic pain. BB acknowledged a recent House of Lords report in March which talks about the Government being woefully unprepared for the demographic shift and ageing population with specific regard for health and social care. There is a need to reframe 'older age' to look at it with a more positive outlook rather than to consider older people as a challenge for society (e.g. opportunity for volunteering roles). AM's interests lie in chronic pain and ageing, and in terms of how people self-manage and deal with chronic pain. Specifically, AM identified a lack of consideration of the context and environmental aspects around health and social care intervention and delivery within the research literature. Once funding was secured, the studentship was advertised; TK applied for the studentship and was successful in his interview.

What is the research about?

The title of the research presently is: Ageing well with chronic pain in rural environments. **Ageing well** is a process of making sense of self amid changes in later life (e.g. individual, social, cognitive, physical changes). **Chronic pain** is pain that has lasted for three or more months, so it is long term and persistent. Chronic pain can affect people of all ages, survey data suggests that the prevalence of chronic pain increases with age, the site of chronic pain varies and often can occur in multiple-sites (e.g. hands, feet, back, legs); common cause is reported to be osteoarthritis which accounts for around one-third of cases. Pain is multi-

dimensional considering emotional, social, physical, cultural dimensions in terms of how it is experienced and understood this goes beyond the simple medical definition. **Rural environments** are often considered purely in physical terms (not urban, not built up, sparse). A common definition is that of a settlement with fewer than 10,000 people. But rural also has social meaning, often considered in terms of a concept of rurality. The relationship between a rural environment and a person is dynamic and interactional, with each having influence on the other.

The group discussed how the language and meaning of 'chronic pain' may be interpreted and understood in different ways by individuals, where 'chronic' may be considered a medical term. People experiencing chronic pain, by definition, may not understand it in these terms. A point of interest will be to explore how participants understand the term chronic pain and understand their experience of it, after they have been assessed as having had pain for the last three months and therefore met the medical definition of the term.

What is looking to be achieved in this research?

The aim of the research is to understand the implications of living in a rural environment on the experiences of ageing well with chronic pain. The objectives are as follows: (1) to explore the dimensions of chronic pain experienced by older people in rural environments; (2) to explore the meaning of chronic pain in the day-to-day lives of older people in rural environments; (3) to explore the influence of life-course factors on the experiences of ageing with chronic pain within rural environments; (4) to explore coping and self-management strategies, and the nature of resilience within older people with chronic pain in rural environments, and; (5) to consider the policy and service needs of rural older people with chronic pain. The objectives are broadly focused to take into account individual participants in the context of their environments and of their lives (lifecourse perspective).

To achieve the research objectives TK will implement a mixture of data collection methods including interviews, photo-elicitation and go-alongs – please see presentation slides for further details on these methods. The methodology and selection of methods will be used in order to gain a deep and rich understanding of participants as highly detailed case studies, drawing out and upon their narratives (i.e. the stories that emerge about aspects of participant's lives). The analysis of the data will follow in this vein focusing upon participant narratives.

The plan of the research is to recruit 20 participants and conduct data collection over the course of 6-8 months. Eligibility criteria include: 65 years of age and over, self-report chronic pain, live in a rural location. Each participant will be invited to participate in an interview and then one or more follow-up methods. It is not expected that all participants will complete follow-up sessions.

The group discussed the recruitment of participants and issues relating to this. The selection process of participants is expected to be an evolving one based upon seeking people with different experiences from people previously interviewed – in order to challenge understanding as it builds through the data collection. Selection will take into account factors such as age, gender, socio-economic situation, level of isolation, level of participation in social activities (e.g. luncheon groups). The process of recruitment will be led by TK and in discussion with BB and AM.

Agenda Item 4 - What has happened so far?

The project has just entered its second year having commenced in September 2013. In the past year a great deal of preparatory work has been undertaken. This has included TK familiarising himself with the existing research and literature, completing a number of procedural and administrative tasks in the build-up to data collection, compiling documentation for the study, obtaining clearance from the University Ethics Committee, obtaining approval from an internal panel of researchers to continue with the project, creating the Advisory Group and organising a meeting, and also undertaking research training.

Agenda Item 5 - What is due to happen in the future?

From now until the end of the project (September 2015) TK will be undertaking fieldwork for the next 6-8 months which includes participant recruitment and data collection (i.e. interviews, photo-elicitation and go-alongs). Following this TK will commence the writing up of the research findings and of literature reviews. The data analysis will occur concurrently alongside the data collection and writing up phases.

The groups discussed potential hazards of the research project. (1) Weather: The prospect of participant recruitment during the Winter months and whether there was scope for flexibility and/or extension of the fieldwork should the weather become hazardous. Remarks considered that although the weather may be a challenge, it was deemed important to try to understand the perspectives of people during the Winter months – as such people and experiences are often overlooked in similar research projects. To accept that the weather and climate have a role to play in rural environments and act to add another dimension to considerations of chronic pain experience, particularly around access and mobility and coping. (2) Safety: In terms of researcher safety measures should be taken by TK to ensure that such research visits remain safe (e.g. shovel in car, emergency phone number, follow the University's lone working policy). (3) Risk to participants: It was noted how some participants may be encouraged by the presence of the researcher to undertake tasks that they may not ordinarily do – to stretch

themselves to show how well they are coping. This may in itself threaten the safety of the participant.

Agenda Item 6 - Any questions? Discussion

HW confirmed that she will do all that she can to help in the recruitment of participants through the Moorlands Homelink charity. It is for TK to visit the groups and get to know people there to build up trust and to enable a more informed selection of participants.

JB raised two issues: (1) the issue of confidentiality and whether people will want to share their feelings in front of others and whether participants will be honest. The resolution is that interviews will be carried out within the participant's home to ensure a safe and trusting setting. (2) Recruiting people with cognitive impairments. The resolution is that, as agreed with the University Ethics Committee, people that are unable to give informed consent due to cognitive impairment will not be recruited. For participants who show mild impairment or where impairment becomes apparent during the initial interview, these situations will be treated sensitively by TK to minimise the risk of unsettling the individual. The aim is to avoid such situations through careful consultation with charity representatives during the recruitment process.

The group discussed the dissemination plan. Dissemination will be multi-level including: examples to consider will be a dissemination event if funding is available, publications in appropriate academic journals, conference presentations, luncheon group presentations, publish in newsletter format, through Moorlands radio, write a piece for the Leek post.

AGEING WELL WITH CHRONIC PAIN IN RURAL ENVIRONMENTS

NEWSLETTER

JUNE 2014

The purpose of this quarterly newsletter is to provide you with an update on the progress that I have made with my PhD research.



Welcome to the second edition of my newsletter. In this edition I have included some of my highlights over the last three months, including an exciting opportunity for some funding! Thank you for your continued support! Best wishes, Tom Kingstone

An update on my activities

National University of Ireland, Galway, Ireland:

In April, Keele University's Research Institute for Primary Care and Health Sciences (PCHS) kindly paid for me to attend a conference in Galway.



I presented a poster at this two-day event, which I have enclosed along with this newsletter (A4 copy). This event was well attended by an International audience and my research was well received.

Postgraduate Research Symposium, Keele:

In May, fellow students from within my Research Institute came together to present their work at a one-day conference. I spoke at the symposium and also presented the poster I had created for my trip to Galway. I was awarded a prize for my poster!



Where to next?

British Society of Gerontology Conference: Southampton, Sept' 2014. I have been invited to talk at this year's event, and have been awarded a bursary of £300 to attend.

Canadian Association on Gerontology Conference: Ontario, Oct' 2014. I have applied to talk at this conference. I am now awaiting their response.

Funding opportunity

Economic and Social Research Council (ESRC) funding opportunity: Every two-years the ESRC organise a week of events across the UK promoting social research to the public. I have submitted a bid to ESRC for funding to host an event in the local community, to showcase my work and talk about wider rural issues. If successful, this event will take place in week of 1st-8th November 2014. I would very much like you to attend this event, so please keep these days free where possible. I will update you all in due course.

Update on progress with participants: I have recruited eight participants and recorded over 30 hours of interview conversation. This is sure to keep me busy over the course of the next three months!



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Appendix 5

ONE-TO-ONE INTERVIEW TOPIC GUIDE

Demographics

- Age / sex / ethnicity / education

Family

- Spouse / children / siblings / parents / grandchildren
- How often do you see / contact these people? Distance to family / friends

Work

- Retired / employed / Work history / occupation(s) / reason for not working anymore – same for spouse
- Role / Importance of work in life

Social/Leisure

- What activities or hobbies do you take part in? How often? Is there anything that you used to do but can't do now?
- Do you attend any local groups/meetings?

Health

- Do you have any long-standing illness, disability or infirmity? What is the matter with you?
- Does your health interfere with activities that you do? (housework / social)
- What is important to you to stay healthy or to improve your health?

Pain

- When did your pain start / what do you think caused it / what have you been told
- How would you rate the intensity of your pain right now on a scale of 0-10 (where 0 = no pain and 10 = worst possible pain) and on average (same scale)
- What does chronic pain mean to you? Can you describe your pain? Where is the pain?
- Does your pain interfere with daily / social activities that you do?

Coping

- How do you cope with your pain (what steps do you take?) / Do you receive any help around the home? Are there any tasks that you find difficult? Do you provide help to any one?
- Do you know anybody else with pain like yours? Do you talk to anybody about your pain?
- What do you understand by the word 'resilience'? Do you consider yourself to be a resilient person?
- Financial coping

Home

- Type of property / number of bedrooms / who do you live with
- How long have you lived in this house / area?
- Where did you live previously? How did previous place differ to current place?
- Why did you choose to live here? (connections in/to the area)
- What does this house mean to you? How would you feel if you had to move?

Environment

- Describe the area to me / What does this area mean to you?
- Mobility around the area (car, local transport) / how easy is it to get to important places (GP / Dentist / Shops / family)
- Do you feel part of the community around here?

Life Grid (to be used as an aid for the one-to-one biographical interview)

Date	Age	Family/ Personal	Work/ leisure	Health/ Illness	Pain	Interference / coping	Home/ environment	Other
1920	0							
1925	5							
1930	10							
1935	15							
1940	20							
1945	25							
1950	30							
1955	35							
1960	40							
1965	45							
1970	50							
1975	55							
1980	60							
1985	65							
1990	70							
1995	75							
2000	80							
2005	85							
2010	90							

CASP-19

To measure Coping, Autonomy, Self-realisation and Pleasure (CASP), validated for use with older people.

	Often	Some- times	Not often	Never
My age prevents me from doing the things I would like to	0	1	2	3
I feel that what happens to me is out of my control	0	1	2	3
I feel free to plan for the future	3	2	1	0
I feel left out of things	0	1	2	3
I can do the things that I want to do	3	2	1	0
Family responsibilities prevent me from doing what I want to do	0	1	2	3
I feel that I can please myself what I do	3	2	1	0
My health stops me from doing the things I want to do	0	1	2	3
Shortage of money stops me from doing the things I want to do	0	1	2	3
I look forward to each day	3	2	1	0
I feel that my life has meaning	3	2	1	0
I enjoy the things that I do	3	2	1	0
I enjoy being in the company of others	3	2	1	0
On balance, I look back on my life with a sense of happiness	3	2	1	0
I feel full of energy these days	3	2	1	0
I choose to do things that I have never done before	3	2	1	0
I feel satisfied with the way my life has turned out	3	2	1	0
I feel that life is full of opportunities	3	2	1	0
I feel that the future looks good for me	3	2	1	0

Contact Summary Form

Activity: _____

Date: _____

Time of interview: _____

Length of interview: _____

Location (no names): _____

Initial thoughts and feelings from the interview:

Interviewee, settings, surroundings, atmosphere

Who else was present during the interview?

Relationship

Did any of these people seem to influence the respondent's answers?

How much influence did they have? In what way did they influence participant?

Did the participant experience difficulty answering any questions during the interview?
Answered questions, answered some not others
Was the respondent affected by any other problems during the interview?
Eyesight (showcards), hearing difficulties, language, cognitive
Anything else?

Appendix 6b

Fieldwork - one bone CP001F 23rd October 2013.

I had met the participant a couple of times at the local luncheon club so recognised her well. Welcoming woman if not overly friendly - happy to help as was her nature but there seemed to be an edge, a sterness to her. I parked up on the curbside outside the house having identified the house number in a row of very similar looking houses (terraced row). Open fields to front and back of property; the quarry works could be seen in the near distance. The house stuck out as being one with an added bay window in aluminium. I was shown through to lounge (though the porchway and main door, and to left, front facing lounge). Open fire, arm chair, sofa lined into bed, wooden chair, patterned carpets, raised pattern wallpaper, pictures in frames on shelves of family. Cracked blanket over back of arm chair. Snack boxes on floor beside chair. House felt cold except for lounge, dark in kitchen when we had a break for a "cuppa". Sunny but windy day. Hotel-size kettle (adapted). Very quiet surrounding area. Interviewer got underway, talked freely.

Fieldwork - one bone CP003F 13th November 2013

First observation I made on arrival to participant's home was that there was post in the letterbox sticking outwards - I asked if participant would like me to bring it in for her but she said no as it was there on purpose so that "Postie" could collect it on rounds (flawing of rules?).

On my first visit to the area I found it a struggle to find the house to begin with, on Google Maps it was not all too clear, on approach in car I slowed down to take a look for a house name - but couldn't find one on a plaque or sign on wall or gate. Roadside parking seemed a bit risky / dangerous. There were farm vehicles on route and this was a long straight road where drivers could build up speed. Instead I drove down towards what seemed like the centre of the settlement. In truth it was a single main road running down into a more built up housing area in the village - there were a few tributary roads leading off to local nearby

CP004M Follow-up interview

23 April 2014

On approaching the participant's home my first observation was that three local residents took a keen interest in the car and me as I drove passed them whilst they were chatting in the front garden.

My second observation was on my entrance to the driveway, as it appeared the participant's car had been moved to one side of the two-space drive. This was something that had not been done previously.

So I parked on the driveway and picked up my bag from the passenger seat and exited the car to walk to the front door and ring bell. A note on the weather: bright, sunny and clear albeit a little

hazy — it began to cloud over and drizzle during the interview. Participant's wife answered door and let

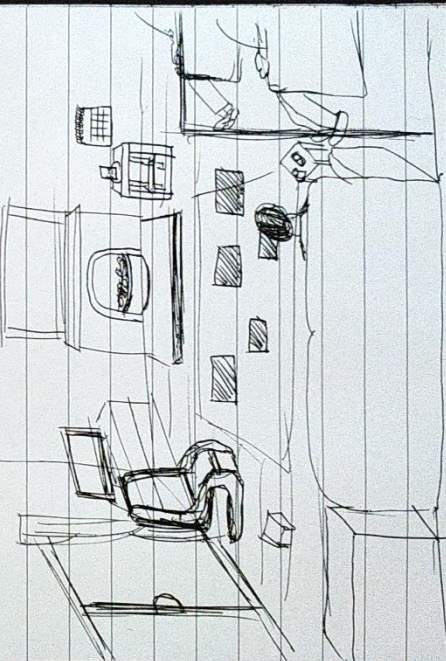
me in. She showed me through to lounge, walking through a dining / front room, door mat on floor, stairs to left

Lounge is at the back of the property overlooking back garden — The observation onto garden and

birds (a distraction at times during interview). The wife of participant asked if I would like a cup of tea

ally

which I accepted, I started to unpack my paper on the sofa as the participant descended the stairs. In the time I had done I took a look at my surroundings: laminate floor (as throughout), neutral decor, blue sofa where I sat and yellow twin arm chairs, a separate chair and there were some children's toys left out under the chair and near to patio door. Old style photographs on the wall behind the sofa — hadn't noticed these previously

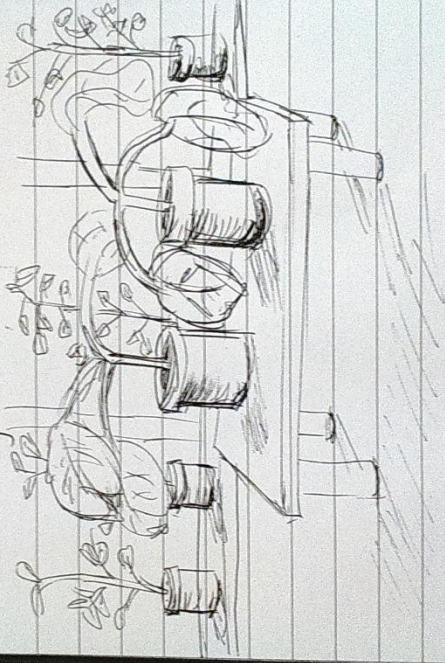


CP006F Photo-elicitation Interview 28.05.14

The day of the interview was wet, grey and generally miserable. The drive over to the participant's house was uninterrupted except for the strange noise coming from my recently discovered broken windscreen wiper (since replaced) — the noise on every wipe became the sound track to the journey. I decided to park in the, seemingly closed, Post Office car park. It was empty with no sign of life in the office itself. On the layby outside of the Post Office adjacent to the school was a cheese tanker having some repairs done. I crossed the road to the participant's house and before I could knock, I'd had a look/glimpse around the immaculate front garden. The door opened and I was greeted by the participant. I was running perhaps 3-4 mins late so I thought that perhaps she had been looking out of the window to see where I was which is why she was quick to answer the door. I was shown through to the lounge as on previous visit — and asked if I'd like to have

cup of tea. I accepted. On her way to make drinks she began to talk about how much her pot plants (vegetables: tomatoes, courgettes) had grown since the last time I had visited to pick up the disposable camera. I followed her through into the kitchen and then she showed me through to

the conservatory...



She was clearly, enthusiastically proud of her efforts. I sensed at this point her close connection with nature and nurturing of plants — as a new pastime.

Appendix 7a



RESEARCH AND ENTERPRISE SERVICES

13th September 2013

Tom Kingstone
Arthritis Research UK Primary Care Centre
Primary Care Sciences

Dear Tom,

Re: 'Ageing well with chronic pain in rural environments'

Thank you for submitting your revised application for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel. The panel discussed the proposal and it was agreed that the project can be approved, following the update of the following section:

- In Appendix C please state how you have obtained the information about the person you are approaching.

The panel would like to thank you for your application and thank you for an excellent submission.

The following documents have been reviewed and approved by the panel as follows:

Document(s)	Version Number	Date
Appendix A: Summary Proposal	1.0	01.08.2013
Appendix B: Flowchart – Participant Pathway	1.0	01.08.2013
Appendix C: Letter of Invitation(s)	1.0	01.08.2013
Appendix D: Study Information Sheet	1.0	01.08.2013
Appendix E: Additional Information for One-to-one Interview	1.0	01.08.2013
Appendix F: Additional Information for going along on activity	1.0	01.08.2013
Appendix G: Additional Information for interview using photographs	1.0	01.08.2013
Appendix H: Letter - Participant cannot be contacted	1.0	01.08.2013
Appendix I: Letter - Confirm meeting	1.0	01.08.2013
Appendix J: Letter - Did not attend meeting	1.0	01.08.2013
Appendix K: Letter - Thank you for participating in this study	1.0	01.08.2013
Appendix L: Consent Form – For one-to-one interview	1.0	01.08.2013
Appendix M: Consent Form – Going alongs	1.0	01.08.2013
Appendix N: Consent Interview and Photograph Release Form	1.0	01.08.2013
Appendix O: Consent Form - For Use of Quotations and Audio clips	1.0	01.08.2013
Appendix P: Photograph Release Form for Researcher Photos	1.0	01.08.2013
Appendix Q: Interview Schedule for one-to-one interview(s)	1.0	01.08.2013

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK
Telephone: + 44 (0)1782 734466 Fax: + 44 (0)1782 733740

Appendix R: Quality Assurance Sign-off	N/A	01.08.2013
Appendix S: CRB confirmation	N/A	21.03.2013
Appendix T: Confirmation of Insurance	N/A	23.07.2013

If the fieldwork goes beyond the date stated in your application you must notify the Ethical Review Panel via the ERP administrator at uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

Yours sincerely



JP

Dr Jackie Waterfield
Chair – Ethical Review Panel

CC RI Manager
 Supervisor

Appendix 7b



RESEARCH AND ENTERPRISE SERVICES

30th September 2014

Tom Kingstone
Arthritis Research UK Primary Care Centre
Keele University

Dear Tom,

Re: Ageing well with chronic pain in rural environments

Thank you for submitting your application to amend study for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel.

The following documents have been reviewed and approved by the panel as follows:

Document	Version	Date
Invitation Letter	1.0	25/09/2014

If the fieldwork goes beyond the date stated in your application you must notify the Ethical Review Panel via the ERP administrator at uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on uso.erps@keele.ac.uk Stating ERP1 in the subject line of the e-mail.

Yours sincerely

PP

Dr Jackie Waterfield
Chair – Ethical Review Panel

CC RI Manager
 Supervisor

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK
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Appendix 8a



>Insert date<

Dear Sir or Madam,

Research study: ageing well with chronic pain in rural environments

This letter is to invite you to take part in a research study about the experiences of older people living in rural areas who have chronic pain (pain a person has had for more than three months). At a recent event we spoke briefly to one another about your experiences of this. OR / A representative of >insert charity name< thought that you might be interested in this research study and so has distributed this information on my behalf. I would be interested to speak with you again.

Further details about the study are in the enclosed information leaflet. The leaflet explains what will happen if you agree to take part. Please complete the enclosed 'consent to further contact' form attached to the information sheet and return it to me in the pre-paid envelope saying whether or not you are interested in participating and would like me to contact you.

Who am I?

Here is a picture of me (right). Should we meet one another in the future for the study, please be assured that I will be wearing my Keele University identification badge. In the mean time I would be happy to answer any questions you may have about the study and if you would like to talk to me please contact me either by phone or email (details below).



Thank you very much for your time in reading this letter and enclosed information.

Yours faithfully,

Tom Kingstone

PhD Researcher

Tel: 01782 734721

Email: t.a.kingstone@keele.ac.uk

Enclosed: *Study information sheet, consent to further contact form, pre-paid return envelope*



Ageing Well with Chronic Pain in Rural Environments

STUDY INFORMATION SHEET

This study is being undertaken by myself, Tom Kingstone. I am PhD researcher at the Institute for Primary Care and Health Sciences at Keele University (Staffordshire).

Before you decide whether or not you wish to take part, please read this information sheet which explains why the study is being done and what it might involve. Please take your time to read it carefully and discuss it with friends and relatives if you wish. My contact details are provided at the end of this information sheet so please contact me if there is anything that is unclear or if you would like more information.

What is the purpose of the study?

The study is about understanding what life is like for older people in rural areas living with chronic pain (pain that has lasted for three or more months).

Why have I been chosen?

You have been invited as someone aged 65 years or over, living in a rural location and who has chronic pain.

Do I have to take part?

No. Taking part in this study is completely voluntary. If you do decide to take part you are free to stop at any time without giving a reason. If you do decide to stop, you can decide then whether any information you have already shared can still be used in the research, or whether you would like that removed from the study.

What will happen to me if I take part?

If you agree to take part you will be invited to join in a number of activities. You do not have to take part in all of them; just let me know which, if any, you would like to take part in.

To begin with, I would like to conduct an interview with you to talk about your experiences of chronic pain. This will take place at a location of your

choosing (e.g. your home). If you agree, I would like to audio record the interview. During the interview you will be free to ask for the recording to be paused, stopped, replayed or edited at any time. If you agree, following the interview I would like to telephone you to double check that I have recorded information that you have provided accurately.

At the end of the interview I will talk to you about further follow-up activities that you may like to do. The activities that I will invite you to do include: a second interview (similar to the first); *and/or* I would like to go along with you on a daily activity (e.g. a walk around the garden, shopping, taking a bus ride) to see what daily life is like for you, and perhaps take photographs; *and/or* I would like you to take photographs (a camera can be provided) of objects and places that have meaning for you, or to share photographs that you have previously taken. We can discuss these photographs in a second interview.

Before deciding whether you wish to take part in the study you will have the opportunity to discuss the activities and ask any questions. Prior to any activity taking place I will check again that you are happy to go ahead, and if you are I will ask you to sign a consent form to confirm this.

How long will I need be involved in the study?

This is up to you and will depend on how long you wish to participate for. Depending on which activities you wish to take part in, your involvement may last from single interview of around one and a half hours up to a maximum of six months if you decide to take part in all the activities (all of which will be arranged at times/days to suit you).

What are the possible benefits of taking part?

Although any direct benefit to you is unlikely, what I might learn from the study may help older people in rural areas with chronic pain in the future.

What are the possible risks (if any) of taking part?

During the research activities you may talk with me about certain things (e.g. events in your life, people in your life) that may cause you to get upset. If at any point you do begin to get upset the interview/conversation can be stopped. Please be assured that I will treat such moments sensitively and help you to identify opportunities for support if you feel that you need such support.

Will my taking part in this study be kept confidential?

Any personally identifying information that you provide to me will be dealt with in the strictest confidence under the terms of the University Code of Research Conduct. All such information and documentation relating to this study will be stored securely on password protected computers or filed in locked cabinets at Keele University. All information collected during

interviews (i.e. audio recordings, written versions of interviews, photographs, researcher notes) will be stored for up to 10 years in accordance with the Medical Research Council guidelines.

How will information about me be used?

The information that is collected during the activities will be anonymised (any information that could be used to identify you will be removed – unless you specifically asked to be named in some or all of the research). The information might also be used in future studies. It may be that audio clips or photographs might make you identifiable so please bear this in mind when you are deciding whether or not to give consent to their use.

What will happen to the results of the study?

The results will not be available for about two years. The results will be published in academic journals and reports, and will also be presented at a variety of conferences. The results may include photographs and audio clips, if you have given consent for their use. You will be asked if you would like a summary of the results to be sent to you in due course.

Who is funding and organising the study?

The study is funded by Keele University's ACORN fund and is organised by the Institute for Primary Care and Health Sciences at Keele University. The University Research Ethics Committee at Keele has reviewed this study to ensure that it meets the highest standards.

What do I do if I want to take part?

Please complete the form entitled 'Consent to further contact' that is attached to the back of this information sheet and return it using the pre-paid envelope provided. Alternatively, you can contact me by phone or email (see below).

What if there is a problem during the study?

If you have any concerns about any part of this study and wish to speak to me, I will do my best to answer your questions. **Please use me as your first point of contact.**

Dr Bernadette Bartlam is the Lead Supervisor for the study and will also be happy to answer any questions.

If you remain unhappy about the study and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Nicola Leighton who is the University's contact for complaints regarding research.

<p>Tom Kingstone PhD Researcher</p> <p>Primary Care and Health Sciences, Keele University ST5 5BG</p> <p>Tel: 01782 734 721 Email: t.a.kingstone@keele.ac.uk</p>	<p>Dr Bernadette Bartlam Lecturer</p> <p>Primary Care and Health Sciences, Keele University ST5 5BG</p> <p>Tel: 01782 733 939 Email: b.bartlam@keele.ac.uk</p>	<p>Nicola Leighton Research Governance Officer</p> <p>Research & Enterprise Services, Dorothy Hodgkin Building Keele University ST5 5BG</p> <p>Tel: 01782 733306 Email: n.leighton@keele.ac.uk</p>
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Thank you for taking time to read this information leaflet.

The 'consent to further contact' form is attached overleaf



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Ageing Well with Chronic Pain in Rural Environments



CONSENT TO FURTHER CONTACT

In light of what you have now read, would you like me to contact you about participating in this research study?

Please put your initials in the appropriate box:

☐

Yes, I wish to be contacted again

☐

No, I do not wish to be contacted again

Please provide your details so that I can contact you:

Title: Forename:

Surname:

Your Address:

.....

.....

..... Post Code:

Home telephone: Mobile telephone:

Email Address:

Best time to contact you:

Please return the form in the pre-paid envelope provided. You do not need a stamp.

Thank you.

Ageing Well with Chronic Pain in Rural Environments



ONE-TO-ONE INTERVIEW – ADDITIONAL INFORMATION

- The purpose of this interview is to help me to develop my understanding about what life is like for you living in a rural area with chronic pain
- The interview will take place in your home or an alternative location that we have agreed
- During the interview I will be asking you questions about your life and your experience of rural life and chronic pain
- The interview will last for approximately one to one-and-a-half hours
- Before the interview starts I will ask for your permission to record the interview using an audio recorder
- You retain the right to withdraw from the research at any time and do not have to give a reason
- If, during the interview, you do not want to talk about a particular topic please let me know immediately and the interview can be stopped and the recording device switched off, or the topic of conversation can be changed and the interview continue.

Ageing Well with Chronic Pain in Rural Environments

INTERVIEW WITH PHOTOGRAPHS – ADDITIONAL INFORMATION

WHY TAKE PHOTOGRAPHS?

It is often said that ‘a photograph can speak a thousand words’. I would like to talk to you about photographs of objects and places that have meaning for you. These can either be existing photographs from your own collection, or those you have chosen to take as part of this research. If you want to take them as part of the research, please don’t forget that I can supply you with a disposable camera!

WHAT SHOULD I PHOTOGRAPH?

The photographs can be about anything (places, things, events etc), just so long as they have meaning for you. So it could be a garden, or a shop, or a pub that you particularly enjoy visiting, or used to visit and find it difficult to get to now. Perhaps the photographs might show how your area has changed, or even remained the same over the years.

Please DO NOT take photographs of children or other people as I will not be able to use these in my research.

HOW MANY PHOTOS SHOULD I TAKE?

This really depends on you, and how many you want to take and/or share. It’s probably a good idea to have a minimum of half a dozen.

THE INTERVIEW

The interview to discuss your photographs will take about one and a half hours, at a location to suit you (such as your home). Before the interview, please let me know if you want me to develop any of the photographs.

Continued overleaf....

HOW WILL THE PHOTOGRAPHS THEN BE USED?

The photographs may be used in reports and publications, in which case you may be identifiable. Please consider this when you are sharing the photographs with me, and in any case this is something we will discuss during the interview to make sure you are happy to go ahead.

Ownership of all photographs is yours. However, for them to be used in the research, and in any publications, you will need to share ownership with me. I will discuss this with you in detail at the interview, and if you are happy to share ownership with me, I will ask you to sign a consent form. But please remember that you do not have to do so and that you can withdraw from part of, or all of, the study at any time.

If you are sharing existing photographs that are only in hard copy, I will ask your permission to copy these at the time (using a digital camera).



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Ageing Well with Chronic Pain in Rural Environments

GOING ALONG ON A DAILY ACTIVITY – ADDITIONAL INFORMATION

- I would like to go along with you whilst you carry out a routine activity [specify in light of what has been agreed]
- During the activity I will talk with you about different aspects about the activity in order to gain an understanding about your experience of daily life in a rural area, living with chronic pain
- I will meet you at your home or an alternative location that we have agreed [amend in light of letter/agreement]
- I would like to accompany you for either part or all of the time it takes to complete the activity
- On the day I will ask your permission to record the activity using the following:
 - Photographs
 - Audio record conversations
 - Making written notes during/following the activity
- Please remember that you retain the right to withdraw from the research at any time and do not have to give a reason

Appendix 10a

Participant ID:

CONSENT FORM: ONE-TO-ONE INTERVIEW



Title: Ageing well with chronic pain in rural environments

Researcher: Tom Kingstone

Please initial the box if you agree with the statement

1. I confirm that I have read and understand the study information sheet (Version 1.0: 01.08.2013) and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary, that I can refuse to answer a question, or withdraw at any time, without giving any reason..... ☐
3. I agree to the interviews being audio recorded and transcribed..... ☐
4. I understand that the audio recordings and transcripts will be securely stored at Keele University for up to 10 years after which time they will be destroyed..... ☐
5. I understand that audio recordings and transcripts may be re-used in other research studies..... ☐
6. **Please delete whichever of these two statements does not apply**
I understand that the written transcriptions will be edited so that all personally identifying information is removed..... ☐
OR
I wish to be named in all transcripts, reports and publications from the study..... ☐
7. I agree for the researcher to contact me by telephone should he need to check information that I provide during the interview..... ☐
8. I agree to be interviewed for the purposes of the above study..... ☐

Name of participant

Date

Signature

Name of Researcher

Date

Signature



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Document version: 1.0

Date last updated: 01.08.2013

White copy: Retained by Keele University Yellow copy: Retained by Participant

Appendix 10b

Participant ID:

INTERVIEW CONSENT AND PHOTOGRAPH RELEASE FORM



Title: Ageing well with chronic pain in rural environments

Researcher: Tom Kingstone

**Please initial the box if you agree with the statement,
otherwise leave it blank**

1. I have read the study information sheet (Version 1.0 01.08.2013) and had the opportunity to ask questions..... ☐
2. I understand that my participation is voluntary, that I can refuse to answer a question, or withdraw at any time, without giving any reason..... ☐
3. I agree to be interviewed for the purposes of the above study..... ☐
4. I agree for this interview will be audio recorded and transcribed..... ☐
5. I agree to share the ownership (copyright) of the photographs that I have taken for the purposes of this research with Keele University..... ☐
6. I understand that the photographs may be used in appropriate reports, publications and presentations..... ☐
7. I understand that any information (including photographs) that I agree to share with Keele University will be stored for up to 10 years, and may be used in future research..... ☐
8. I understand that the photographs (e.g. people, house, pets, geographical features) might make me identifiable..... ☐

9. **Please delete whichever of these two statements does not apply**

I wish that all information (including photographs) be edited so that all personally identifying are removed/blurred (as appropriate).....

OR

I wish to be identifiable in all transcripts, photographs, reports and publications from the study.....

Continued overleaf terms of use of photographs...

Terms of use of photographs:

Please initial the box if you agree with the statement

- 10a. I agree for **ALL** of the photographs to be used for the purposes of the research as outlined above..... ☐
- 10b. I agree for **SOME*** of the photographs to be used for the purposes of the research..... ☐
- 10c. I **DO NOT** agree for any of the photographs to be used for the purposes of the research..... ☐
11. I wish to be named as the creator of these photographs..... ☐

***Where the use of SOME photographs has been indicated, please specify on the following lines which photos you consent to being used (referring to the printed versions of the photographs provided)**

Name of participant

Date

Signature

Name of Researcher

Date

Signature



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White copy: Retained by Keele University Yellow copy: Retained by Participant

Appendix 10c

Participant ID:

CONSENT FORM: GOING ALONG ON A DAILY ACTIVITY



Title: Ageing well with chronic pain in rural environments

Researcher: Tom Kingstone

Please initial the box if you agree with the statement

1. I confirm that I have read and understand the study information sheet (Version 1.0: 01.08.2013) and have had the opportunity to ask questions... ☐
2. I understand that my participation is voluntary, that I can refuse to answer a question, or withdraw at any time, without giving any reason... ☐
3. I agree to the interviews being audio recorded and transcribed..... ☐
4. I agree for the researcher to record observations in the form of field notes. ☐
5. I agree for the researcher to take photographs during the activity..... ☐
6. I understand that all the information will be securely stored at Keele University for up to 10 years after which time it will be destroyed..... ☐
7. I understand that information may be re-used in other research studies.. ☐
8. **Please delete whichever of these two statements does not apply**

I wish that the information will be edited so that all personally identifying details are removed.....

OR

I wish to be named in all transcripts, reports and publications from the study.....

9. I agree to be accompanied for the purposes of the above study..... ☐

Name of participant

Date

Signature

Name of Researcher

Date

Signature



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Appendix 10d

Participant ID:

PHOTOGRAPH RELEASE FORM: Photographs taken by Tom Kingstone



Title: Ageing well with chronic pain in rural environments

Researcher: Tom Kingstone

As part of this study I have taken photographs of places and people around your local area. These photographs will provide a pictorial record of life in the local area and will add to my overall understanding of everyday life for you.

To be able to use the photographs that I have taken either in your company or adjacent to your home I need your permission to do so. Please consider the following statements.

Please initial the box if you agree with the statement

1. I have read the above information and had the opportunity to ask questions.....

☐

2. I understand that the researcher will share the copyright of photographs (as described above) with me.....

☐

3. I understand that the photographs may be used in the publication of results.....

☐

4. I understand that the photographs (e.g. people, house, pets, geographical features) might make me identifiable.....

☐

5. Where images include my facial features, I would like these features to be distorted so that they cannot be recognised.....

☐

Continued overleaf for terms of use of photographs...

Terms of use of photographs:

Please initial the box if you agree with the statement

6a. I agree for **ALL** of the photographs to be used for the purposes of the research as outlined above.....

☐

6b. I agree for **SOME*** of the photographs to be used for the purposes of the research as outlined above.....

☐

6c. I **DO NOT** agree for any of the photographs to be used for the purposes of the research as outlined above.....

☐

***Where the use of SOME photographs has been indicated, please specify which photos you consent to being used (referring to the printed versions of the photographs provided)**

Name of participant

Date

Signature

Name of Researcher

Date

Signature



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care
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White copy: Retained by Keele University Yellow copy: Retained by Participant

Appendix 10e

Participant ID:

CONSENT FORM: USE OF WRITTEN AND AUDIO QUOTATIONS



Project: Ageing well with chronic pain in rural environments

Name of researcher: Tom Kingstone

BOX A	To be completed by researcher
Details of activity	
(e.g. interview):
Date of event:

Please initial the box corresponding to your answer

	Yes	No
1. I agree to the use of written quotations from the research in reports, publications and presentations from this study.....	<input type="checkbox"/>	<input type="checkbox"/>
2. I wish all <u>written</u> quotations to be fully anonymised,.....	<input type="checkbox"/>	<input type="checkbox"/>
3. I agree to the use of audio clips/quotations from the research in reports, publications and presentations from this study.....	<input type="checkbox"/>	<input type="checkbox"/>
4. I understand that the anonymisation of <u>audio</u> quotations cannot be guaranteed as someone might recognise my voice..	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant

Date

Signature

Name of Researcher

Date

Signature



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Appendix 11

List of photographs created during fieldwork

Number	Activity type	Description of content
1	Go-along (Anne)	Starting out on the journey to Town
2	Go-along (Anne)	Car park in town
3	Go-along (Anne)	Pavement in town_1
4	Go-along (Anne)	Pavement in town_2
5	Go-along (Anne)	High street_1
6	Go-along (Anne)	High street_2
7	Go-along (Anne)	Shop 1_1
8	Go-along (Anne)	Shop 1_2
9	Go-along (Anne)	Shop 1_3
10	Go-along (Anne)	Shop 2_1
11	Go-along (Anne)	Shop 2_2
12	Go-along (Anne)	Shop 3_1
13	Go-along (Anne)	Restaurant_1
14	Go-along (Anne)	Restaurant_2
15	Go-along (Anne)	Supermarket_1
16	Go-along (Anne)	Supermarket_2
17	Go-along (Anne)	Supermarket_3
18	Go-along (Anne)	Supermarket_4
19	Photo-elicitation (Barbara)	Photograph 1
20	Photo-elicitation (Barbara)	Photograph 2
21	Photo-elicitation (Barbara)	Photograph 3
22	Photo-elicitation (Barbara)	Photograph 4
23	Photo-elicitation (Barbara)	Photograph 5
24	Photo-elicitation (Frances)	Photograph 1_Walk in the park1_1
25	Photo-elicitation (Frances)	Photograph 2_Walk in the park1_2
26	Photo-elicitation (Frances)	Photograph 3_Rural landscape_1
27	Photo-elicitation (Frances)	Photograph 4_Rural landscape_2
28	Photo-elicitation (Frances)	Photograph 5_Rural landscape_3
29	Photo-elicitation (Frances)	Photograph 6_Walk in the park2_1
30	Photo-elicitation (Frances)	Photograph 7_Walk in the park2_2
31	Photo-elicitation (Frances)	Photograph 8_Sunset
32	Photo-elicitation (Frances)	Photograph 9_Beachfront_1
33	Photo-elicitation (Frances)	Photograph 10_Beachfront_2
34	Photo-elicitation (Frances)	Photograph 11_Hobby_1
35	Photo-elicitation (Frances)	Photograph 12_Hobby_2
36	Go-along (Henry)	"Beauty spot"_1
37	Go-along (Henry)	"Beauty spot"_2
38	Go-along (Henry)	"Beauty spot"_3
39	Go-along (Henry)	Outside of Henry's house
40	Go-along (Henry)	Religious landmark on journey
41	Go-along (Henry)	Tourist sign on journey
42	Go-along (Henry)	Tourist sign before journey

43	Go-along (Henry)	View of pub (lunch)
44	Go-along (Henry)	View from pub (lunch)
45	Fieldnotes	Staffordshire Moorlands landscape_1
46	Fieldnotes	Staffordshire Moorlands landscape_2
47	Fieldnotes	Staffordshire Moorlands landscape_3
48	Fieldnotes	Staffordshire Moorlands landscape_4
49	Fieldnotes	Staffordshire Moorlands landscape_5
50	Fieldnotes	Staffordshire Moorlands landscape_6
51	Fieldnotes	Staffordshire Moorlands landscape_7
52	Fieldnotes	Staffordshire Moorlands landscape_8
53	Fieldnotes	Staffordshire Moorlands landscape_9
54	Fieldnotes	Staffordshire Moorlands landscape_10
55	Fieldnotes	Staffordshire Moorlands landscape_11
56	Fieldnotes	Village A and surroundings_1
57	Fieldnotes	Village A and surroundings_2
58	Fieldnotes	Village A and surroundings_3
59	Fieldnotes	Village A and surroundings_4
60	Fieldnotes	Village A and surroundings_5
61	Fieldnotes	Village A and surroundings_6
62	Fieldnotes	Village A and surroundings_7
63	Fieldnotes	Village A and surroundings_8
64	Fieldnotes	Village A and surroundings_9
65	Fieldnotes	Village A and surroundings_10
66	Fieldnotes	Village A and surroundings_11
67	Fieldnotes	Village A and surroundings_12
68	Fieldnotes	Village A and surroundings_13
69	Fieldnotes	Village A and surroundings_14
70	Fieldnotes	Village A local amenities_1
71	Fieldnotes	Village A local amenities_2
72	Fieldnotes	Village A post office
73	Fieldnotes	Village A closed down business
74	Fieldnotes	Village B and surroundings
75	Fieldnotes	Village B thick fog_1
76	Fieldnotes	Village B thick fog_2
77	Fieldnotes	Village C luncheon club
78	Fieldnotes	Village C pavement_1
79	Fieldnotes	Village C pavement_2
80	Fieldnotes	Village C pavement_3
81	Fieldnotes	Village C surrounding landscape_1
82	Fieldnotes	Village C surrounding landscape_2
83	Fieldnotes	Village C surrounding landscape_3
84	Fieldnotes	Village C surrounding landscape_4
85	Fieldnotes	Village C surrounding landscape_5
86	Fieldnotes	Village C surrounding landscape_6
87	Fieldnotes	Village C surrounding landscape_7
88	Fieldnotes	Village C surrounding landscape_8

89	Fieldnotes	Village C surrounding landscape_9
90	Fieldnotes	Village C surrounding landscape_10
91	Fieldnotes	Village C surrounding landscape_11
92	Fieldnotes	Village C surrounding landscape_12
93	Fieldnotes	Village E surrounding landscape_1
94	Fieldnotes	Village E surrounding landscape_2
95	Fieldnotes	Village E surrounding landscape_3
96	Fieldnotes	Village E surrounding landscape_4
97	Fieldnotes	Village E surrounding landscape_5
98	Fieldnotes	Village E surrounding landscape_6
99	Fieldnotes	Village E surrounding landscape_6
100	Fieldnotes	Village E village hall_1
101	Fieldnotes	Village E village hall_2

Tabulated narrative analysis using Labovian structures to identify narratives (evaluation and coda informed coding)

Labov's Structures	"So I've got to suffer"	Constriction of Lived World	Pain & Life span
	Stage one 1-1 interview: Pg 18 Ln 10	Stage one 1-1 interview: Pg 9 Ln31	Stage one 1-1 interview: Pg 1, Ln 7
Abstract How does it begin?	Pg 18 Ln 10 How would you describe it if you could? [Oh I don't know if I can describe it very well] When its at its worst?	Pg 9 Ln 31 But I used to love going to Town A (Central England) on a Wednesday because I could have a look round and do a bit of shopping	Starts Ln 7 "Well, I haven't always had pain, well erm I really never had a lot of pain until I was about 70"
Orientation Where, when, why	Ln 12 Well, at worst you just think oh I shall have to sit down, I can't do anything, can't go no more, I shall have to sit down you see it's that bad til you can't do anything you see, I can't, I can just stand at the sink and wash up, I can just wash the pots, but I can't and its killing me for finish washing up [yeah] than I have to sit on stool for wipe them, I can't stand any longer... Ln 18 you just can't take anymore	Pg 10 Ln 1 if we wanted anything extra we used to go, well we used to go anyday when me husband retired... after he died, I loved going to Town A (Central England) on a Wednesday because I used to meet some of his old work mates and that, and go for a coffee with them	Starts Ln 9 "They always say 3 score years and 10 don't they" "I had children's illnesses" "Had a bit of pain when I had appendicitis but ... don't think there's been anything else" "At the moment I'm getting a terrific amount of pain in the bottom of my back"
Complicating Action Then what happened	Ln 19 I can't really describe it Ln 20 sometimes it hits you more than others [yeah] I mean its not too bad when I'm lying in bed, and that or when I'm sitting in the chair here, but if I'm knocking about than yes, it's there Ln 23 when you've been out a while it becomes more severe	Pg 10 Ln 5 I haven't done that for about ten years... Ln 9 because I went, I went to Town A (Central England) one Wednesday and I went in hospital in the afternoon to have my first knee done	Starts Ln15 "I've had a lot of pain with having arthritis in my knees and I've got it in my shoulders" Continues on Ln20 "I've got arthritis of the spine"
Resolution What finally happened	Ln 26 he did say that hip wasn't very good, so I'm wondering if I'm getting a lot of pain from that, or if its pain from the spine because with having arthritis of the spine [yeah] you see it can be that you see I don't know and that's what I want find out Ln 30 I'm not going to start going Hospital B (>20 miles) until I've finished heart at Hospital C (<20 miles)	Pg 10 Ln 11 I've never been since [okay] not, not on me own, on a Wednesday, to look round, I went last Tuesday, me niece took me and we did have a look round, I didn't really go food shopping, I went really to have a look round - you see it wasn't market day Ln 16 now but if me nephew takes me we only go where there's food	Starts Ln 16 "They don't want to operate... they've told me that if they operate I'll have to have steel pins... and I shall never be able to bend and I don't want that"
Evaluation So what?	Pg 19 Ln 2 a new valve and erm bypass [yeah] and it was the fourth of October last year, and the nurses are still coming three times a week, to dress it [right] because its still leaking, so I can't do anything about it til that's healed up kind of thing	Ln 18 course I have to stock up because we only go about once a month food shopping Ln 24 people don't mind bringing you food, but you can't ask them bring household stuff no, so I like go myself	Starts Ln 24 "I just keep carrying on best I can I've got a walking frame and I've got a wheelchair if I go far" "When you have that much pain you can't do anything else... I used to love getting out... but them have all gone now"
Coda What does it all mean?	Pg 19 Ln 5 so I've got to suffer	Ln 20 I have be very grateful when they take me, but It's not ideal	Starts Ln 9: "They always say 3 score years and 10 don't they" "I think I'm too old now anyway"

The screenshot displays the NVivo software interface for data management and analysis. The main window shows a transcript titled "CP004M - two-to-one - Workin" with a list of speakers and their dialogue. The transcript text is as follows:

CP004M: But I've got no feeling in the end of my fingers. I can't pick anything [TK: okay]; I can't pick anything up properly. And my hands go - I mean they're warm now - but sometimes they're that stoned cold, I have a job to get 'em warm (cough). But I haven't got the strength in them that I had.

WIFE: But we manage because you

CP004M: I manage, yeah.

WIFE: You can get equipment that helps you and stuff.

TK: Do you want to tell me a bit more about that, the equipment you get?

CP004M: Well, I've got, er, a couple of bottle opener things haven't I?

WIFE: Yeah, bottle openers. An electric one and another one.

CP004M: Yeah, an electric tin opener.

WIFE: Yeah, a tin opener. Erm

CP004M: Er, and the kids have just bought me - because as I say, I make my marmalade, and I can't, I couldn't scrape the peel, the pith off the peel, like [TK: yeah]. So they've bought me a peeler.

WIFE: And it's great, it doesn't

CP004M: And it's smashing, I can, I can crack on with that now.

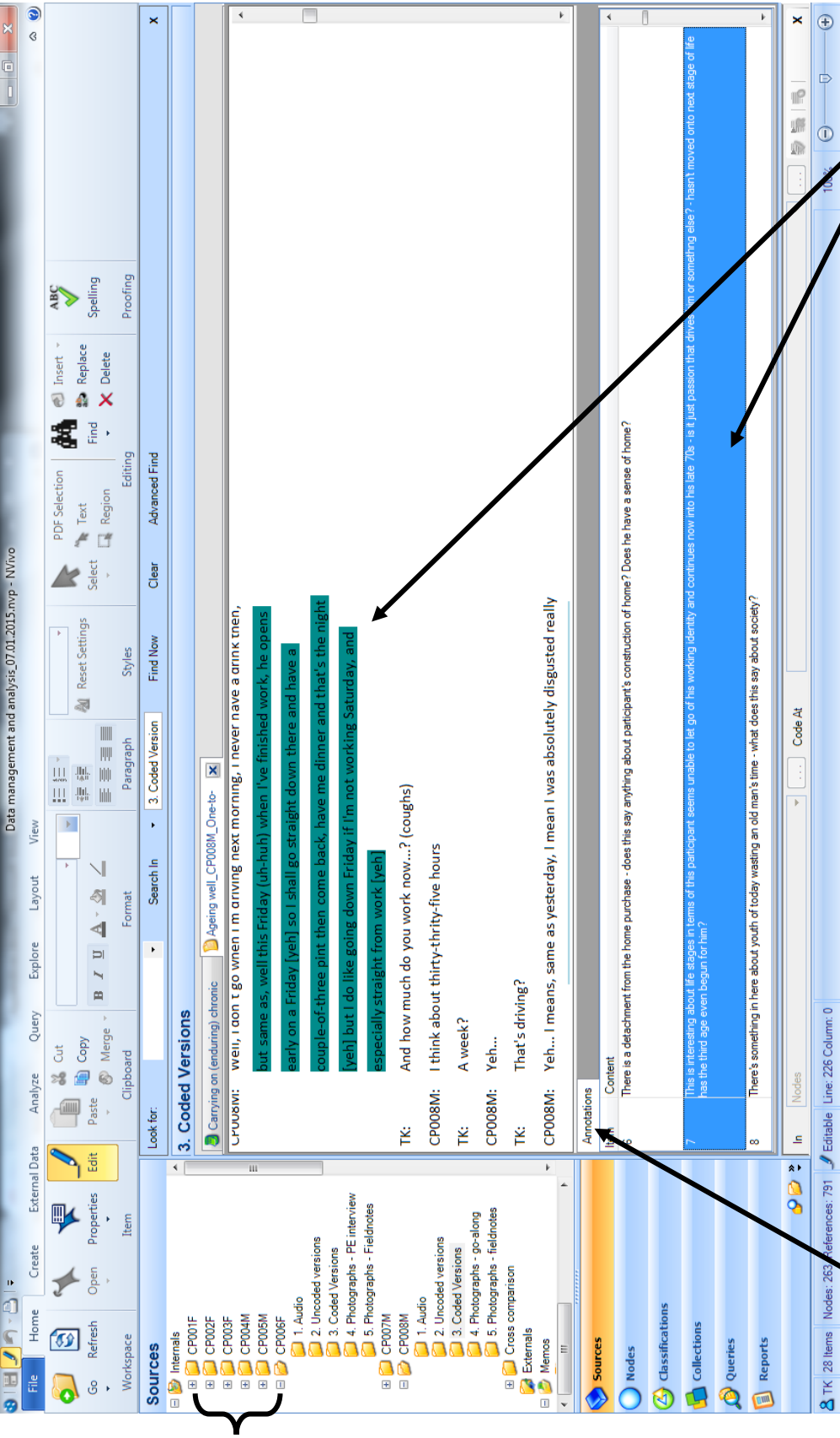
WIFE: It just peels, it doesn't take the pith as well does it?

CP004M: No, it just takes the peel off

On the right side of the transcript, a list of codes is visible, including "004 Developing rapport researcher-interviewer", "006 Revealing accumulation of health problems", "132 Describing characteristics of pain", "169 Continuing farming identity", "217 Maintaining a fragile sense of autonomy", "Establishing timing and trajectory of pain (start to future end)", "053 Being resilient", "Handling over control for self", "102 Assuming role as a patient (lack of control)", "Travelling patchifiers", "116 Searching for the cause of pain", "187 Recognising the centrality of family", "090 Using complementary and alternative medicine", "175 Getting stuck into to local culture", "030 Overwhelmed by willingness of others to help", "214 Presenting social side of self", "Identifying the cause of pain", "008 Establishing connection with family heritage", "Receiving medical intervention", "056 Contrasting old community with new one", and "Being stoical". A green vertical strip is placed next to the transcript text, indicating a coded section. A black bracket is drawn under the transcript text, pointing to the coding strip.

The bottom status bar shows "TK 408 Items", "Nodes: 330", "References: 973", "Editable", "Line: 417", "Column: 0", and a zoom level of "100%".

Coding for this transcript with strips to identify coded section



Participant ID prior to anonymised with participant code

Annotations for transcript

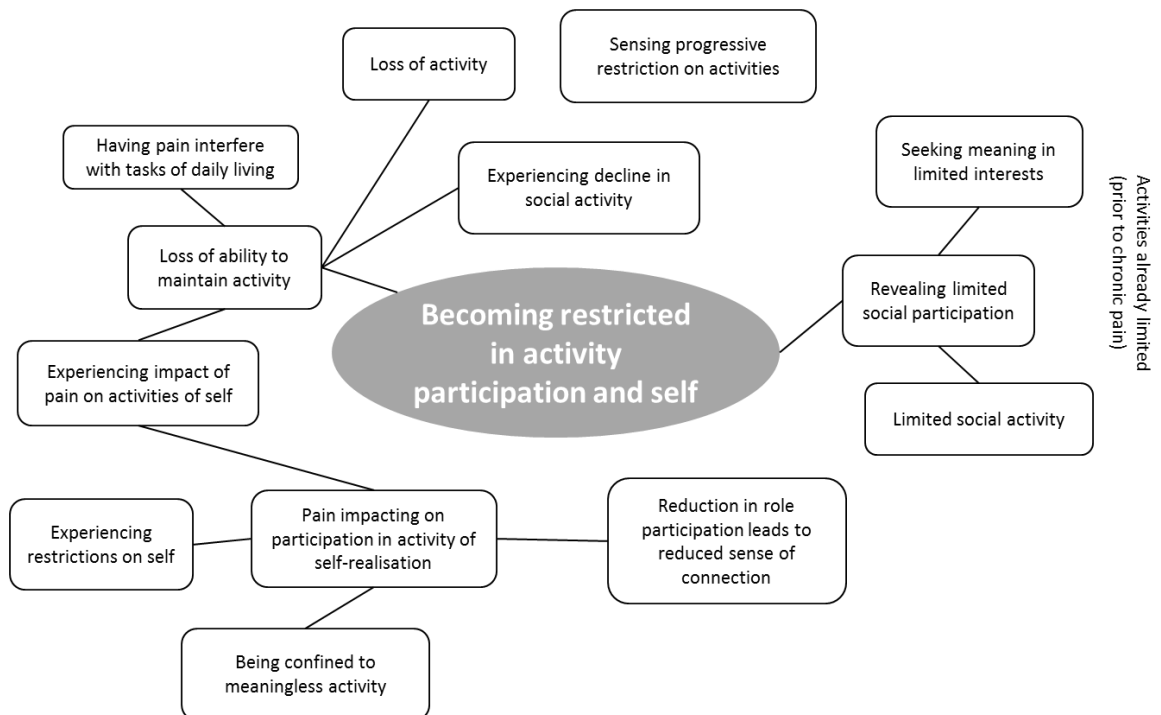
Annotation highlighted in data and described in table below data

Appendix 12d

Memo: Example A

Participant level coding converging around common category:

Becoming restricted in activity participation and self



Chronic pain is restricting in own terms but also reinforces existing challenges and restrictions. The type and nature of activity has implications for achieving basic needs and also higher order needs and sense of self. Anne maintains her desire to remain active; however, as she describes in the following excerpt she is restricted and in the times that she does get out she is dependent on others for transport:

Anne: Oh I would like to get out a bit more yes definitely because I've always been used to going out I mean I used to go to Town A on every Wednesday, market day never missed and I've been - well I'm saying I've never been, I've never been able to go on the bus and look round like I used to do, I mean I go occasionally but I can't look round the market, the only thing I go is go and do a bit of shopping and come back and somebody has to take me there.

The restriction that Anne experiences has impacts upon her connection with the past and old social networks.

Anne: I was just going to go and then I went in hospital last year, and you see with nurse coming on a Monday it makes it a bit bad for going there

Anne associates the restriction on her freedom to visit the local town with her hospitalisation; she also considers that the nurse who comes to her home every other day as a further preventative factor. Anne reflects on her restriction when answering the CASP-19 in relation to items: I can do the things that I want to do and I enjoy the things that I do.

Frances also describes being restricted in her social interactions as a result of chronic pain; her condition impacts upon her ability to join in with others close to her:

Int: Does it ever affect any other kind of activities that you...?

Frances: Erm well it does affect because like my son and daughter in law love walking and all her family love walking, and you know if there is a get together and it's a walking situation, I go out and struggle towards the end, or I turn back or I don't go out at all. Erm because if it depends on the degree of pain, erm because I know I can't keep up. So yes, it does have an effect. You do think twice before you do something. Yeah.

Frances holds a desire to go on walks and spend time with her son and his family; however, she anticipates that she may not be able to do this in comfort. That Frances admits that she cannot keep up may hold metaphorical meaning in that she feels she cannot keep up socially with her son and his family. Chronic pain holds her back; it may risk her role in this group in future she may miss out. Frances has started to turn down opportunities to socialise if physical activity is involved: "so erm...yeah I do tend to think about it, I have to say, and if I'm in a less than 100% position then - or 80% or whatever, I then tend to say well, no, I won't go today." Frances sets the marker high at anything less than 100% before altering this to 80%. The reduction in physical capability contrasts with the expectations that Frances holds of her age and cohort:

Frances: It is frustrating, because you want to be out and about I mean it's not you know, what's my last birthday, sixty-seven, I mean it's a - you know, what they turn as in your forties don't they now? Erm...and you don't feel that you want to be incapacitated. Erm so yeah, there is a frustration, yeah.

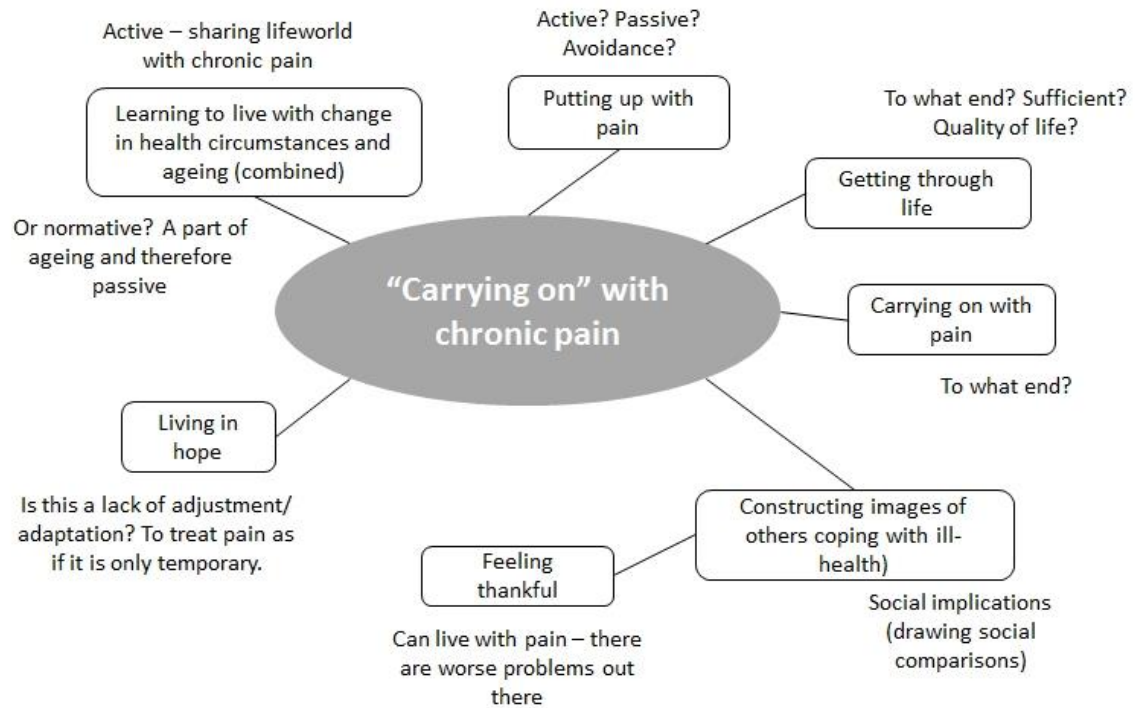
Frances admits to her frustration. Chronic pain makes Frances feel older than she perceives that she should feel and is expected to feel.

Participation in activities affected is also affected by access to transport, availability of opportunities (people, groups, interests), which cannot be overlooked. However, the restrictive nature of chronic pain has pervasive implications for maintaining activities with restriction experienced in social interactions and maintaining historical connections, restricted capacity to achieve domestic maintenance (gardening, DIY), adapting, leads to frustration, makes individuals feel older, and impacts on maintenance of roles (domestic, caring, social, family patriarch). A sense of resilience that supports a person's capacity to adapt to multiple restrictions and still maintain activities, whether to satisfy basic or higher order needs, is of central importance to older adults living with chronic pain.

Memo: Example B

Participant level coding converging around common category:

"Carrying on" with chronic pain



The phrase "carrying on" is used by Anne and Barbara the repetition caught my attention as this phrase and underlying notion seemed to be important and echoed some of the literature around perseverance with chronic pain and illness. I could imagine this phrase being used during doctor-patient consultations and being thought nothing of. Through further examination of how Anne and Barbara apply the phrase indicated the need to further unpick what it means and to what ends might they be carrying on towards. This also provided a means of comparison across other participants and a way of incorporating responses from the CASP-19 into the qualitative data. My starting assumption was that "carrying on" was a positive approach to battle through chronic pain, to endure, to keep fighting. Anne describes "carrying on" in the following ways:

Anne: it's something pain is that you can't really explain to anybody because some days it's worse than others [yes]

Int: Does it change quite a lot

Anne: Yeah, but its same as I say, I mean I'm alright, I don't feel it now, but as soon as I ever get up on me feet it'll be there so you've got put up with it

Int: Does your pain worry you at all?

Anne: Well sometimes it does when it gets very bad, but normally I just take it as it comes

TK: So do you have anyone to do you talk to anyone about your pain, just changing the subject slightly

Anne: No not really [no, no one at the luncheon club?] I don't bother, well sometimes, if somebody else comes in and says 'what's up with you' and I say 'well I've got some pain today' but [yeah] you know that's all, but I don't, I've got, I've learned to live with it [yeah] and that's what you've got to do, you've got to learn live with it and get on with life, its no good sitting moaning and thinking about it

Anne: You see, when I had this first knee done she says 'you've got very, very bad osteo, osteo arthritis' [yeah] she said, so I just taken it as it comes, I don't, its no good mithering, I don't want to work myself up about it [inaudible] and if you can get a bit of help with the pain, all well and good, have to learn to live with these things [huh-huh] and you learn and find ways of doing jobs, differently from what you used to do them [yes]...

Anne: I sit, I sit and I have a cry well and I think well what's good of crying, I've got to put up with it ...

Anne: I've got be ever so careful, I mean I went in fridge one day, picked a bottle of milk up, and it slipped straight through me fingers [okay]... see so when I get to, get in fridge and pick bottle of milk up, I have to pick it up and shove other hand in underneath it and shut door, push door to with me foot, because I'm frightened to drop anything, that's why I can't pick anything heavy up, [yeah] so I don't bother, I just carry on and I think, well I keep living [chuckles]

Anne maintains this notion of "carrying on" or putting up with chronic pain as a show of defiance in which stoicism is also important. However, underlying the defiance is a sense of vulnerability as Anne describes crying when the annoyance of the pain becomes too much and becoming frightened by a simple everyday task of picking a bottle of milk up from the fridge. Anne discloses processes of learning to live with pain and hints at process of adaptation. Barbara describes "carrying on" as a process of avoidance:

Barbara: I've had it all through my body really, to be quite honest, what for four or five years, you just take no notice, just carry on don't you, well I do full stop [chuckle].

Int: And how, how do you cope with it, what do you do?

Barbara: Just carry on, [laughs] sit down and just try and forget it, I do, I do, yeah [okay] I don't go pushing throat tablets down my throat, or anything like that, I just sit quietly and hope it'll go [okay]...

Int: Did you have your pain for a while before you went first, to the doctor?

Barbara: Oh yeah, I hoped it would go off [yeah] [laughs] oh yes, I did [yeah]...

Int: Is that how you approach life, just get on with it?

Barbara: Get on with it, [is it] I do, yes, well that's the only thing you can do isn't it, lets face it, I mean, I can sit here now and be miserable, but I've got to go, you know, no, if you can

Barbara: keep plodding on and [yep] umm I can't, you can't do anything can you

Barbara uses the notion of "carrying on" to support her avoidance style of coping. Carrying on seems to be a hopeless task as restrictions from chronic pain limit what can be achieved. Thus, "carrying on" has implications for resilience: is it a marker of resilience or does it represent a lack of resilience? What can support carrying on and therefore resilience? Is there an alternative to carrying on? What implications does carrying on have for coping, is there a spectrum of coping between coping (active) and hoping (passive). Does "carrying on" represent a cliché? How do others describe enduring chronic pain, what supports "carrying on" do some carry on better than others?

Category	Description of category	Codes	Example of data for code
Constructing a sense of rurality and belonging (relating to the environment)	This category of codes relates to the connections formed between participants and their environments and how this is negotiated through chronic pain experience - this extends from rooms, home and rural environments. Participants evaluated their fit with the environment – attachment to place and the desire to belong within rural environments and culture created dissonance between real and ideal. People within these places and who made these places were also important in ageing in place.	Being emplaced in a rural home	<p>“I'd rather stay where I am, where I know the environment. If it comes as me sight goes, I shall be able to walk about me own house, and I shall be able to get to the gate there, and back, but I don't want to move where there's a lot of traffic or anything. No, I wouldn't like that, not a bit” (Anne, A01)</p> <p>“I came to live at the Cottage... which meant getting rid of bunk beds and all sorts of things (laughs), changing its, changing its existence, so to speak...” (Catherine, C01)</p>
		Establishing community connectedness	<p>“Just happened to mention that we were having a coffee morning. Well, originally, we were gonna have it here, that was the plan, but it snowballed... We ended up at the village hall plus a marquee (laughs), and to cut a long story short, we made three-and-a-half thousand pound in about two and half hours” (David, D01)</p> <p>“Oh aye, very good neighbours... I mean we don't go in one another's houses at all but if anything went wrong and you wanted something you wanted some help, they'd be there, they'd be there” (Henry, H01)</p>
		Constructing rurality	<p>“It was a hot day, and across the field comes the landlady from the pub, with a jug of shandy. She said, ‘You look as though you lads need it,’ and I</p>

			<p>got some money out 'No, no,' she says, 'come and have a pint when you've finished,' and pay me then. Little things like that." (David, D01)</p> <p>"I quite like solitude. It doesn't worry me. I wouldn't want to be out entirely on my own, but I'm quite happy in small groups." (Frances, F01)</p> <p>"On a clear day from the village hall and even coming down from the main road down into Village D you can see the Welsh mountains... well you can't get much fresher air than that, can you? (Henry, H02)</p>
		Identifying with place (person-environment fit)	<p>"You can't go on living in a house that size when you're on your own. So I was looking out for somewhere [to move to] and these people were moving [next door]" (Catherine, C01)</p> <p>"I think at the end of the day there's a claustrophobia [about cities] you feel you've got to get out and get some fresh air. You've got the park in the city and all of that, which is nice, but nothing like coming out into wilder aspects of it." (Frances, F02)</p> <p>"We liked it up there, but it wasn't a place for older people... You can't drive or walk anywhere, it's a long way to walk anywhere up there. Here I can walk to the village hall and George can walk to the farm. It's much more</p>

			convenient here.” (Gail, George interview: G01)
		Using environment as an aid to health and well-being	<p>“You might feel it some days, and if the sun’s shining the following day, it’s a very different story, you know.” (David, D01)</p> <p>“The view to your right hand side is fantastic...I think every morning when I’m coming down here I must be- one of the luckiest people in the world to drive to work in these conditions” (Henry, H02)</p>
Making adaptations to meet own needs	<p>This category of codes considers how participants attend to their own needs from basic through to higher order needs (reflecting Maslow's hierarchy). Through chronic pain experience the linear arrangement of needs is challenged in the face of uncontrollable pain. Participants seek to protect the self that they identify with, despite challenges to this claim and loss of continuity across the lifecourse. Adaptations are at the heart of this, as needs and capacity change through ill-health.</p>	Sustaining basic needs	<p>“I don't eat a lot, I have a sandwich at dinner time, and there's many a time I don't bother cooking a dinner at night, I'd probably just have another sandwich, or if I've got a meat pie in the freezer I fetch that out and warm it” (Anne, A01)</p> <p>“On the practical level I mean I have this, this lovely little cottage, I have enough money to live on. I've enough money to pay someone to help me and so on.” (Catherine, C01)</p>
		Protecting sense of self	<p>“I can't get about and do what I want do that’s what annoys me more than anything. I get cross with myself and somebody says ‘I don’t know how you carry on like that’ well I say ‘you’ve just got carry on with it, you can't just sit and moan about it’” (Anne, A01)</p> <p>“The better part of my views and beliefs are based on my Christian belief... I hope I don’t have to go into a home, but if I do, then I must try and accept it positively.” (Catherine, C02)</p>

		<p>Making adaptations (compromises) in order to meet changing needs due to health</p>	<p>"I've got a walking frame and I've got a wheelchair if I go far but I don't want to use that if I can help it much, but erm I use sticks more than anything but err I mean there's, there's days that I have to use them about the house which I don't, I don't like"</p> <p>"I used to love going out and doing me garden and I can't do that now. I used to set it with potatoes and beans and onions and things like that, well that's going by the wayside now. I've had it turned (into) woodchip on the one side and chippings on the other because I can't cope with it." (Anne, A01)</p> <p>"Obviously, everything has become for both of us more of an effort and time consuming" (Edward, E01)</p> <p>"I don't wear a belt on my trousers, I wear braces I couldn't stand a belt around my body [due to site of pain]" (Henry, H01)</p>
<p>Carrying on with chronic pain – coping or hoping?</p>	<p>Participants described an attitude of carrying on with chronic pain - enduring the persistent pain. This was largely attitudinal seeking to contain pain within private boundaries, using stoicism as a strategy for containing pain although stoicism supported</p>	<p>Being stoical</p>	<p>"I said 'you've got to take life as it comes' it's no good complaining because nobody takes any notice of you, you've just got to get on with life and do what you can, I do what I can and what I can't do I leave" (Anne, A01)</p> <p>"I don't know what is it, well they've never really said because I don't really go and complain, if you understand" (Barbara, B01)</p>

	avoidance style coping.		<p>"I have worked through quite a lot of pain, but you don't want your staff to know, and you don't want your customers to know, so you do the best you can." (Frances, F01)</p>
		Carrying on	<p>"I like my independence, very independent but I know there's sometimes when you can't be independent but that's it, you just carry on as far as you can." (Anne, A01)</p> <p>"I've had it [pain] all through my body, to be quite honest, for four or five years, you just take no notice, just carry on don't you? Well I do." (Barbara, B01)</p>
		Maintaining privacy	<p>"I don't want anybody to see me to be down... because I know what people say about people up here, you see, they think 'well, what's wrong with her?'." (Anne, A01)</p> <p>"We don't tend to talk about illnesses or erm that sort of thing, because it's a very light-hearted situation, it's - I suppose you know we all - there's a certain amount of privacy for all of us really and so no, it's not a general discussion to be perfectly frank" (Frances, F01)</p>
		Confronting end of life	<p>"If the time came when I lost my mind, or was very ill or something, I would like to know what I would like to take with me, assuming I could take anything, than have to start wondering, you know. I'd like to be ready... I don't want to leave a lot of work for people." (Catherine, C02)</p>

Coming to terms with chronic pain	<p>This category includes data relating to the way in which participants make sense of their pain as an experience - how their chronic pain is understood, the language that they use, the experiences that they draw on to provide an interpretation of their pain. Ultimately pain is individual and unpredictable and medical terms do not fit (sufficiently) individual experience.</p>	Identifying the cause of pain	<p>"Well I don't know whether it's arthritis that's causing me pain or not..." (Edward, E01)</p> <p>"I was carrying a door – it wasn't a heavy door or anything like that, it was just a little, light door, and I was going up a little bit, and I slipped. Ooh, and I felt it [my back] go, and, err, no wait a minute, I did it playing squash" (David, D01)</p> <p>"I've got erm poor circulation in me legs and that's what causes [pain]...." (George, G01)</p>
		Establishing timing and trajectory of pain	<p>"I really never had a lot of pain until I was about 70 [yes] and then of course I've never been free from it since [chuckles] [ok] they always say 3 score years and 10 don't they [that's true] that's your life span ..." (Anne, A01)</p> <p>"There are times when I can get up from here and walk through to the front door or where ever perfectly well, slowly perhaps, but not in pain but there are other times just to get up on my feet can be hard work" (Edward, E01)</p>
		Objectifying and externalising pain	<p>"I can't [clean the house] because me hands, it's my hands that are holding me back, cause I would've been doing it" (Barbara, B01)</p> <p>"I fell on my right knee... that started the sciatica down the left side" (Frances, F01)</p> <p>"I mean sometimes [pain was] worse than others, I could be sat here at night, and then all</p>

			at once it would kick in and, oof... and Helen said my face used to turn grey when they kicked in..." (Henry, H01)
		Putting own pain into words	<p>"It is toothache in my hands" (David, D01)</p> <p>"I suppose doing it on a scale, one to ten today I would say I mean it's still there but I'm coping so I would say it's about maybe four or five" (Frances, F01)</p> <p>"I don't get the stabbing pains it's just, I can, like a continual tingle I think the nearest thing to it for you to know it would be sunburn" (Henry, H01)</p>
		Sharing own pain with others	<p>"When I get in pain, when I have a lot of pain I can understand him saying about pain killing him... he must have been in tremendous pain, he must, because he was ever such a hard lad, you know nothing, seemed to upset him" (Anne, A02)</p> <p>"Does she have pain? She does... Oh yes, she does have pain, she does. In her hands and legs more than anywhere she does, yes. We talk about it because we always say 'how are you?', 'oh me legs!' [laughs] we joke." (Barbara, B01)</p>
		Using ageing to normalise pain	"When I went to see the consultant, he says 'when you get older you do get short of breath' I said 'yes, but not as short of breath as I am' and he laughed you see, of course, it was like a joke"

			<p>(Anne, A01)</p> <p>"I probably think more of what I'm gonna do now than what I used to do, and that must come with age" (David, D01)</p> <p>"I would like to go walks like I used to do but, and then again it's old age as well... There's nothing to look forward to in old age." (Henry, H01)</p>
Seeking help and sharing responsibility for management of chronic pain (and health)	Participants engaged in help seeking behaviours in order to find relief from chronic pain - these behaviours led to participants passing on responsibility for pain to other people and interventions (generally GP and healthcare practitioner). Not taking responsibility conflicts with self-management paradigm and supports passive styles of coping.	Confronting issues of morality	<p>"I'm getting more pain on it, every time every now and again it locks I can neither bend it nor straighten, and so what do you do, put up with it until it collapses all together and then they might do something with it." (Anne, A01)</p> <p>"I find with these painkilling tablets that you get very constipated with them. That's my biggest - you start taking painkilling tablets and then you get constipated and then you've got that problem." (George, G01)</p>
		Handing over control for self	<p>"I don't know didn't really ask because they - I don't ask, I just let them get on with it, give me what they think and that's it, I'm not one of these fussy ones I like just to think well if they're helping me" (Anne, A01)</p> <p>Gail: "That's sort of a combined effort between all the different people we see; doctors, podiatrists, where they fit the boots. There's always something, there's always somebody,</p>

			and we're all like a team." George: "Keeping the Formula One driver going" (George, G01)
		Meeting of medical needs	"At the minute I'm under three specialists at the hospital... So I'm getting me money's worth out of 'em. I've paid for it, I might as well have it" (David, D01) "So I'm on a tablet a day which I was told ten years ago that I would need to take every day for the rest of my life the nurse didn't have much of a sense of humour when I say 'well, how many tablets does that mean?'. (Edward, E01) "Up [until] this lady doctor come, I were just grinning and bearing it, but thank god she sorted some tablets out. They have done me good, and she told me today to increase the dosage." (Henry, H02)
Diminished sense of autonomy	Participants expressed having experienced a decrease in their sense of autonomy due to chronic pain – the unwanted interference from others could not be prevented although it sometimes desired when not forthcoming.	Becoming dependent on others and objects	"I'm capable of walking about to get a cup of tea if I want to, in the morning I couldn't manage without them (home care assistants), I couldn't, because you've got to wash and shower, and I can't do it" (Barbara, B01) "I go occasionally but I can't look round the market, the only thing I go is go and do a bit of shopping and come back and somebody has to take me there" (Anne, A01)

		Experiencing diminished autonomy	<p>"I do what I can I do what I can same as I say, I do my washing but I can't peg it out and I can't event put it up on my rack in the kitchen, so I do it on a Monday and she comes on a Tuesday, so she either pegs it out, or she puts it up on the rack in the kitchen to dry" (Anne, A01)</p> <p>"Yeah, because my son-in-law put it together for me on Sunday" (David, D01)</p>
		Maintaining independence	<p>"I do my shopping... Friday or Saturday morning. I go early when there isn't a lot of people about, I go to Sainsbury's. A) the aisles are a lot wider, so that if I've missed something, I'm not bumping into people to get round to go back and pick it up." (David, D01)</p> <p>"[My sister] lives at number 15. We didn't join forces to buy a house together because we're used to living on our own. All people are different, and we are different, so it wouldn't suit her to live with me at the moment, and it wouldn't suit me to live with her" (Frances, F01)</p>
		Maintaining personal agency	<p>"[Friend] says 'here, there's a piece of cake, can't you eat it?' I said 'no, you've got to learn to take no for an answer, when you've asked someone to have something and they've said no' because she's a devil" (Anne, A01)</p> <p>"If I was going to the surgery at the end I used to walk along there quite happily it's not that far</p>

			but I can't do that anymore so I actually drive myself a short distance" (Edward, E01)
Drawing on diverse resource networks to support capacity	Participants described accessing and utilising resources - diverse networks of resources served participants when capacity was restricted due to chronic pain. This may be important in ageing well.	Building relationships	"I worked in the shop down here for nine years, and he's very good with me, I've only got to ring down and that's it" (Barbara, B01)
		Establishing diverse social resource networks	<p>"I've got a wonderful treasure [cleaner] who comes here every Monday. She's absolutely marvellous and golden and she's come every Monday – well I've been in this cottage nine and a quarter years and, and I was next door before that in a much bigger house, and she was certainly with me at least three years then. [yeah] So Female A's my treasure. And I can pay her." (Catherine, C01)</p> <p>"I've got a nephew he comes once a week to take me shopping or do me garden or anything like that and his daughter, she comes and does my cleaning once a week" (Anne, A01)</p>
		Experiencing loss	<p>"I used to take an old lady – an old lady – well, she was too, she was 101 when she died - she lived just down the road in the Village - called Female F. A FIERCE, former nurse, goodness (laughs). I think she was a matron, actually [uh-huh], erm, and a fierce, bossy lady, and she'd left instructions that she wanted me to take her funeral. So that was, that was before Christmas." (Catherine, C01)</p> <p>"Then I had me mother here after for a while</p>

			before she died, well me husband died he's been dead twenty, it be twenty one year come April and I had me mother for three years after that" (Anne, A01)
		Sharing lives	<p>"I went [on holiday with organised group] in April she [volunteer carer] was absolutely wonderful, she was really wonderful, and the woman that she should care for she never went with us, she always went with somebody else so because well we was on our own and it was wonderful." (Anne, A02)</p> <p>"But we are fortunate in that there's still two of us... I think it'd be very different if there was only one of us" (Diane, D01)</p>
		Utilising alternative resources	<p>"I'll manage with what I've got, you know. And, er - the, er - there's always somebody that'll come and do it for you, even if you have to pay 'em, but, er, there's always somebody." (David, D01)</p> <p>"And we have started using the internet to do our shopping like we had an order with the supermarket who have a new shop in the town" (Edward, E01)</p> <p>"[Reflexlogy] the massaging the points of the feet and it's quite strange because I mean I'm not particularly one that likes being touched as such but I did find that whatever was there it seemed to either take the pain away or ease it,</p>

			so it was much more manageable.” (Frances, F01) “I’ve got four legs when I’m walking.” (Catherine, C01)
		Experiences of loneliness and social isolation	“Oh I feel very lonely, I do feel lonely. I sit here hours on me own, but... you don't have to let it get you down. That's my best friend, the television. It is honestly... I turn it on at the morning at about six and it doesn't go off until I go to bed.” (Barbara, B02)
Learning to control chronic pain and develop routines	This category groups codes relating to control - of pain but also wider life as a consequence of pain experience. Needs of safety and morality from Maslow's hierarchy are also important in this category.	Controlling pain	“I go to a chiropractor every three weeks, for my back... I mean, one of the soft exercises that I do is, I go and make love to a dustbin (chiropractic therapy), you know, and it, it works. I mean I can take pain killers.” (David, D01) “I have pain killers, yes, I have... six, nine, I have four painkillers a day, oh yes I do, yes, so what it'd be without them I don't know.” (Barbara, B01) “I can't, I can just stand at the sink and wash up, I can just wash the pots, but I can't and its killing me for finish washing up [yeah] than I have to sit on stool for wipe them, I can't stand any longer” (Anne, A02)
		Experiencing helplessness	“Well you see I had this operation, had a new valve and bypass and it was the fourth of

			<p>October last year, and the nurses are still coming three times a week, to dress it because its still leaking, so I can't do anything about it until that's healed up kind of thing, so I've got to suffer." (Anne, A01)</p> <p>"When the carers come in, this afternoon, I shall do what I've got to do for tomorrow morning, me clothes and, go lie on bed, I can be in bed by half past five and happy to do that because I know my body's resting, and I'm not interfering with anything, it's a horrible feeling, something I've never been used to in my life" (Barbara, B01)</p>
		Lacking control of body	<p>"I can walk don't get me wrong, round me house, so I wouldn't dare go any farther, no" (Barbara, B01)</p> <p>"Because of the sciatica situation, you know, some days you can go in and it's fine, some days you're just dragging yourself around and it's not pleasant, it's not pleasant for people to see you" (Frances, F01)</p> <p>"Well, at worst you just think oh I shall have to sit down, I can't do anything, can't go no more, I shall have to sit down you see it's that bad til you can't do anything." (Anne, A01)</p>
		Routinely taking painkillers (to varying degrees and effects)	<p>"I was telling her about these pains, and she said 'well, what are you taking for them?' I said 'painkillers and I might as well take jelly babies,</p>

			<p>they'd do me as much good'." (Henry, H01)</p> <p>"With my Co-dydramol it got to as stage that eight weren't hitting it [the pain]. So, I'd knock 'em off. I'd put up with it for a fortnight and then come back on 'em, then they'd hit it." (David, D01)</p> <p>"I've got codadamol for pain but, well I could take eight a day of them but, I don't, well I had to the other week when it was that bad. I'd been without for three days and it had got that bad. I was, well I was getting desperate" (Anne, A01)</p>
Living inwards due to activity restriction	Participants described life coming "inwards" as a consequence of chronic pain and associated restrictions. Their worlds had become smaller in terms of geography and activity.	Becoming geographically constricted	<p>"No, I've not been supermarket for a long, long, well over a year, over a year, well over, because they keep on saying to me Supermarket A's is a good buy, and so and so's doing this, but I can't go, I wouldn't dare" (Barbara, B01)</p> <p>"Well I've stopped because I went, I went to Town one Wednesday and I went in hospital in the afternoon to have my first knee done, and I've never been since" (Anne, A01)</p>
		Becoming restricted in activity participation	<p>"I can't hold the [knitting] needle know [imitates knitting action]" (Anne, A01)</p> <p>"I have a job with - I cannot, I can't cut things. I can't get any pressure on me, my hand." (David, D01)</p> <p>"As you can see, we're rather restricted"</p>

			<p>(Edward, E01)</p> <p>“My son and daughter in law love walking and all her family love walking, and you know if there is a get together and it's a walking situation, I go out and struggle towards the end, or I turn back or I don't go out at all.” (Frances, F02)</p>
<p>Getting life outwards – prioritising meaningful activity</p>	<p>Participants utilised different strategies in order to continue activities - adapting themselves, their routines or the activity itself. Activities were selected and rejected on the basis of importance to meaning and self-realisation. Participants grieved for lost activities (farming, DIY).</p>	Centralising the importance of meaningful activity	<p>“You start getting the pain and you just feel as if your life is starting to come inwards, you know and I think it's up to me to try and get it more outward.” (Frances, F02)</p> <p>“I just don't think I'm that old that I should be you know sitting in the corner doing my knitting and just watching, I feel I want to be still part of what's going on.” (Frances, F02)</p> <p>“From my point of view, [the luncheon club] provides me with a meal; a properly cooked meal, and it's a social occasion, and we're a lot of old crocks, erm, but, you know, you see people” (Catherine, C02)</p>
		Maintaining meaningful activity through selection and adaptation	<p>“I do enjoy what I do, yeah [is that an often] yes an often, I mean I do still try and do a bit of knitting, which I enjoy, a bit of sewing something you know, because I've always enjoyed that” (Anne, A01)</p> <p>“I'm a bit of a twitcher, but that's something else I can't do now [due to eyesight</p>

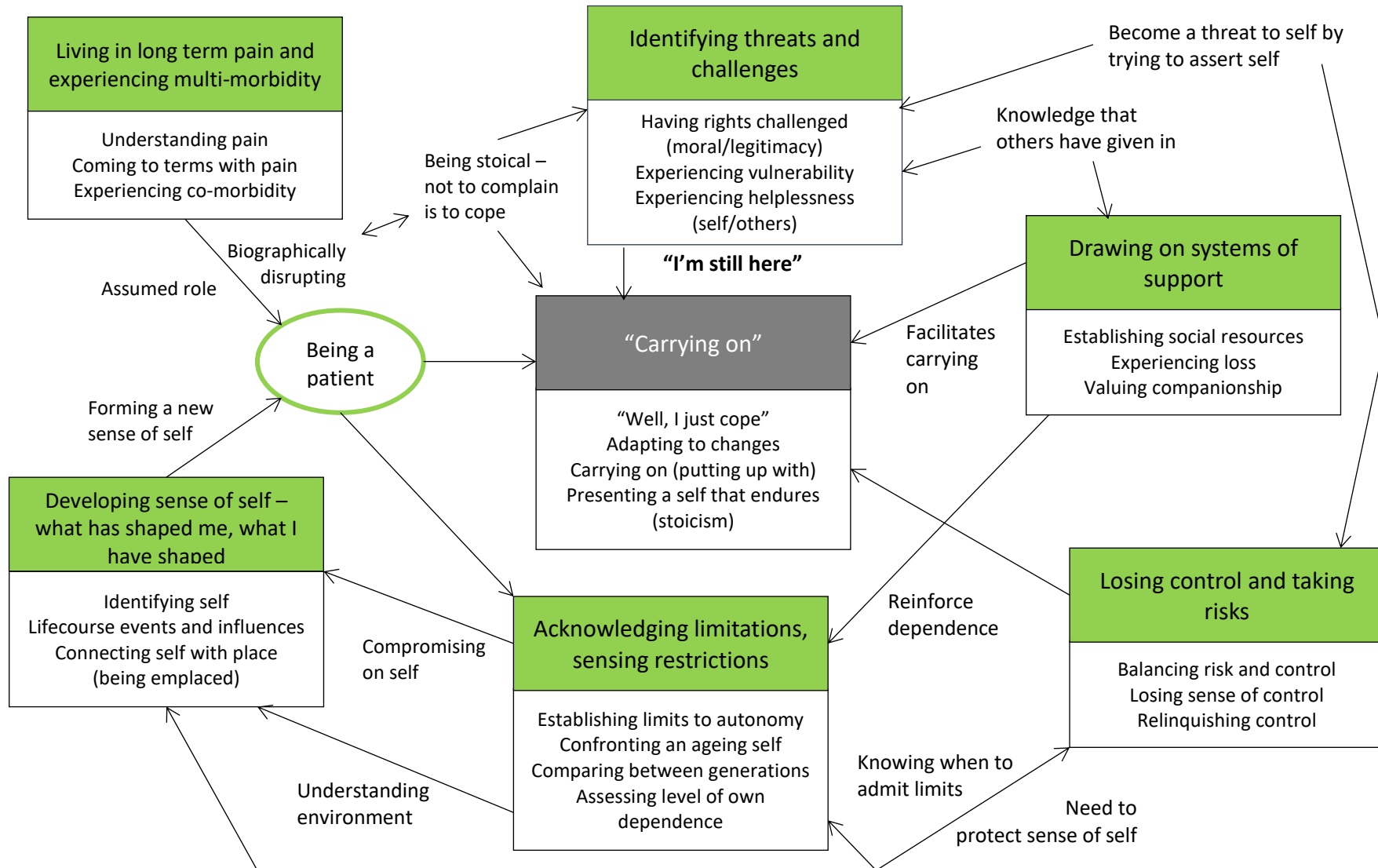
			<p>deteriorating], of course. When I get on the bus, I'm usually the only one on, 'Seen any good birds, Male J?' And this last time I was with him he said, 'I was hearing the curlews.' Well, I haven't heard a curlew yet this year... he stopped in the bus, on the bend where he'd heard the curlews. He got out of the bus to see if he could hear them again" (Catherine, C02)</p> <p>"We go to a stately home quite a lot, but we've got now that- we've only got to walk to the buggy, and the buggy takes us round the gardens" (David, D02)</p> <p>"[Routine to playing organ at local church] 11 o'clock service in the car at 20 passed 10 to half passed 10 erm 2 to 3 minutes up to the church then, along path get the wheelchair out of the car my Wife gets in it, and we push it along this long path which is about 100 yards" (Edward, E01)</p> <p>"I've done erm interior decorating with a lady up in Town D with the Community Group B, and erm...we joined the embroidery guild in Town F" (Frances, F02)</p>
Maintaining coherent sense of self across lifecourse	<p>Identity and activity were closely linked by participants. Past identities were contested due to chronic pain interfering with the participation in</p>	<p>Being shaped across the lifecourse</p>	<p>"It was a struggle for us during the war and err that you know we had to scrap and scrape and do, go out and – used to get sticks to keep the fire going coz you couldn't get the coal and all this type of thing you know and err shopping</p>

	activity-related-to-identity (e.g. farming). New identities were achieved through new activities but not all could participate in new activities. Some held on too tightly to the past.		and back, I used to have to go shopping when I come out of school and do all the errands” (Anne, A01) “I lost a kidney before I should have actually signed [professional rugby contract] on the dotted line. I couldn’t - you - in those days you couldn’t sign professional forms until you were 16” (David, D01)
		Constructing new identities in later life	“I started [going to luncheon club] when it first opened [8 years previous] and I said ‘I shall keep going as long as I can as long as that’s running’ so that’s, that’s, that’s how much I like my luncheon club, I know some days it’s not quite as good as others, but what is?” (Anne, A02) “[On gardening] You can potter, you don't have to do it all at once, and I think I was surprised, I was surprised thinking- I felt it was going to be a lot of work, but actually it's not work, you're just enjoying what you're doing so it's just an enjoyment and I think that's what I found out of it, and I like getting my hands in the, you know, compost or the soil, I like that, I enjoy that which I didn't think I ever would, so I've learned a little, little about myself, I guess.” (Frances, F02)
		Discarding identities	“[After death of mother] I more or less give up caring for old people then, but I'd had it more or less all me married life anyway” (Anne, A01)

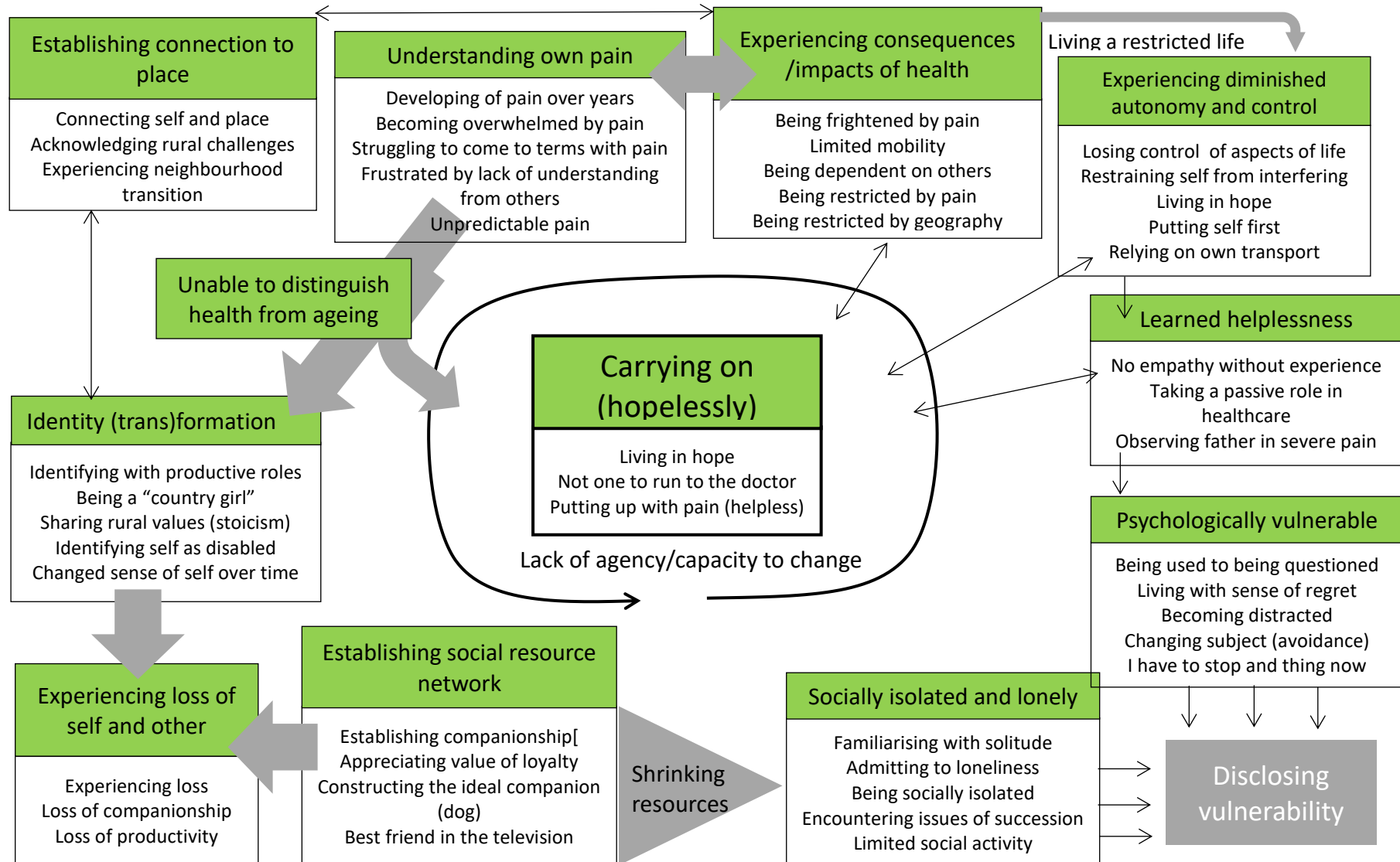
		Maintaining a past identities (contested)	<p>"It's two or three years since he stopped doing any farming." (Gail on George, G01) "They seem to drive past and never see them. There's a [drystone] wall, you know, falling down and they just go straight past it and never see it, or don't want to see it, I don't know which it is. It's things like that, you know, that I wish I could deal with." (George, G01)</p>
Understanding pain in context of total illness experience	<p>This category includes consideration of lifecourse illness experiences and current co-occurring morbidities as well as other problems like to cause distress (incontinence, deteriorating eyesight and the like)</p>	Experiencing a significant health event leading to ongoing concern	<p>"It just dropped and his arm went dead and he was having a stroke." (Gail on George, G01)</p> <p>"[The doctor] is still convinced that its Parkinson's related and so tells me I'm a ParkinsonISM, have you heard of that?" (Edward, E01)</p> <p>"I had a heart attack when I was 75." (Catherine, C01)</p> <p>"In two-thousand and nine I'd got fluid on my lungs and I went into the hospital and I was in there for five and a half week, and I lost five and a half stone I was seventeen stone" (Henry, H01)</p>
		Experiencing accumulation of impairment as a result of co-morbidity	<p>"I can't visualise anything else, that's how bad my eyes have gone, because it's what twelve months since they registered me partially blind well I'm waiting now to go and see them again, because I think its erm coming back again the fluid, because I've got that macular-deterioration" (Anne, A01)</p>

			<p>"This wretched thing stabs. [points to bunion] [okay] And it's sore. Quite a different thing." (Catherine, C01)</p> <p>"The only other thing that I've got is, what do they call it C-P-O something... COPD" (Henry, H01)</p> <p>"I'm diabetic" (David, D01)</p>
		Selecting particular health problems to prioritise over others	<p>"I'm not going to start going to Hospital B until I've finished heart at Hospital C, but I shall have to go Hospital B again with this coz that's where I started with it, so I mean, I don't want move to Hospital C or anywhere until I've finished with this heart problem" (Anne, A01)</p> <p>"Don't think it is Parkinson's, I have had two or three falls haven't I? But nothing serious" (Edward, E01)</p>
		Understanding health deterioration as linked to ageing has consequences for control	<p>"I thought well why should I bother, I'm old that's it, I think to me self well that's what comes with old age" (Anne, A01)</p> <p>"I felt nothing from the heart attack. I never think about it. I'm sure I did to begin with. You don't go racing round, but, but in fact, you see, when I had it I've been getting older ever since, so doing less ever since." (Catherine, C01)</p> <p>"I'd never been in hospital actually [yeh] till two-thousand and nine" (Henry, H01)</p>

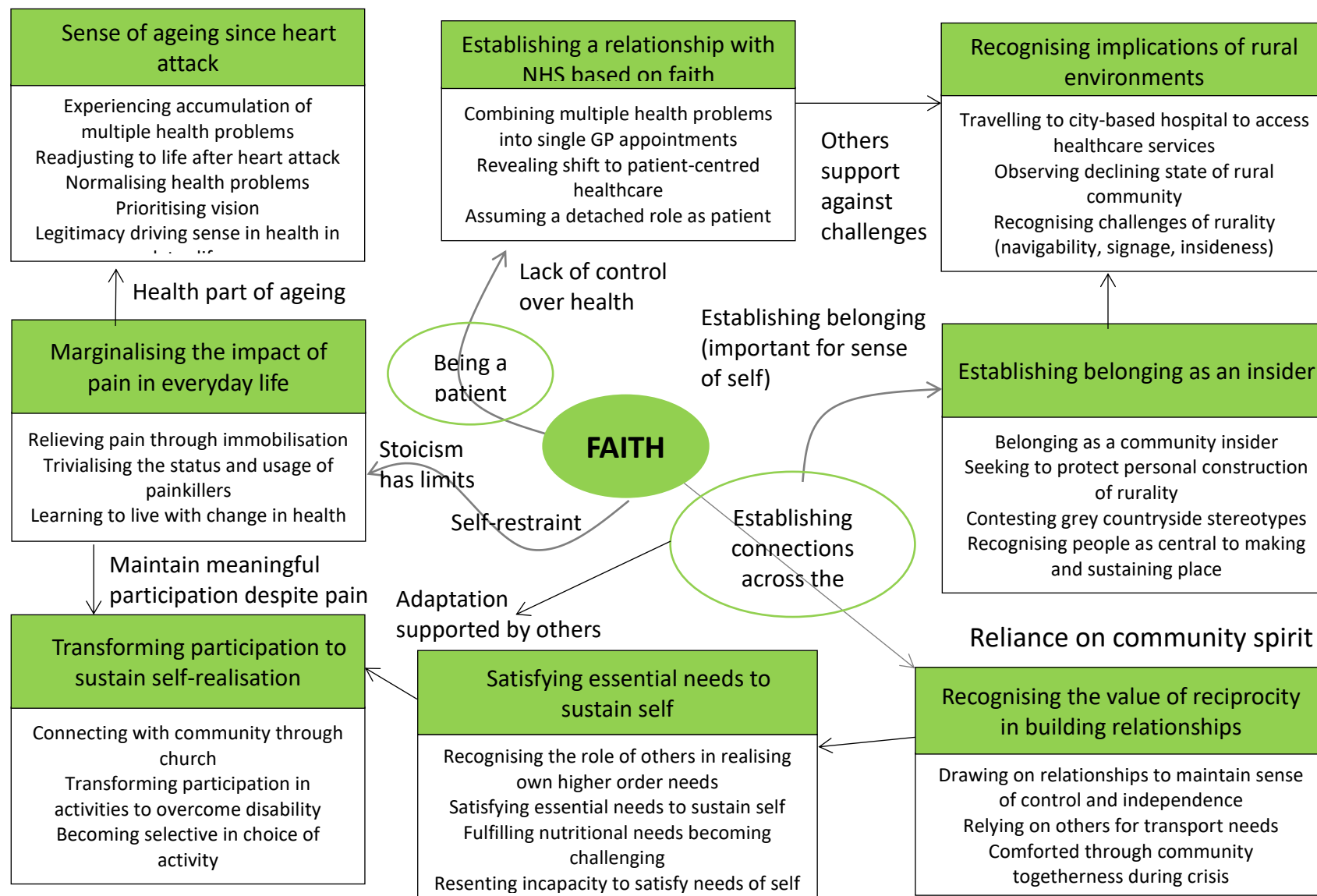
Mind map: for Anne



Mind map: for Barbara

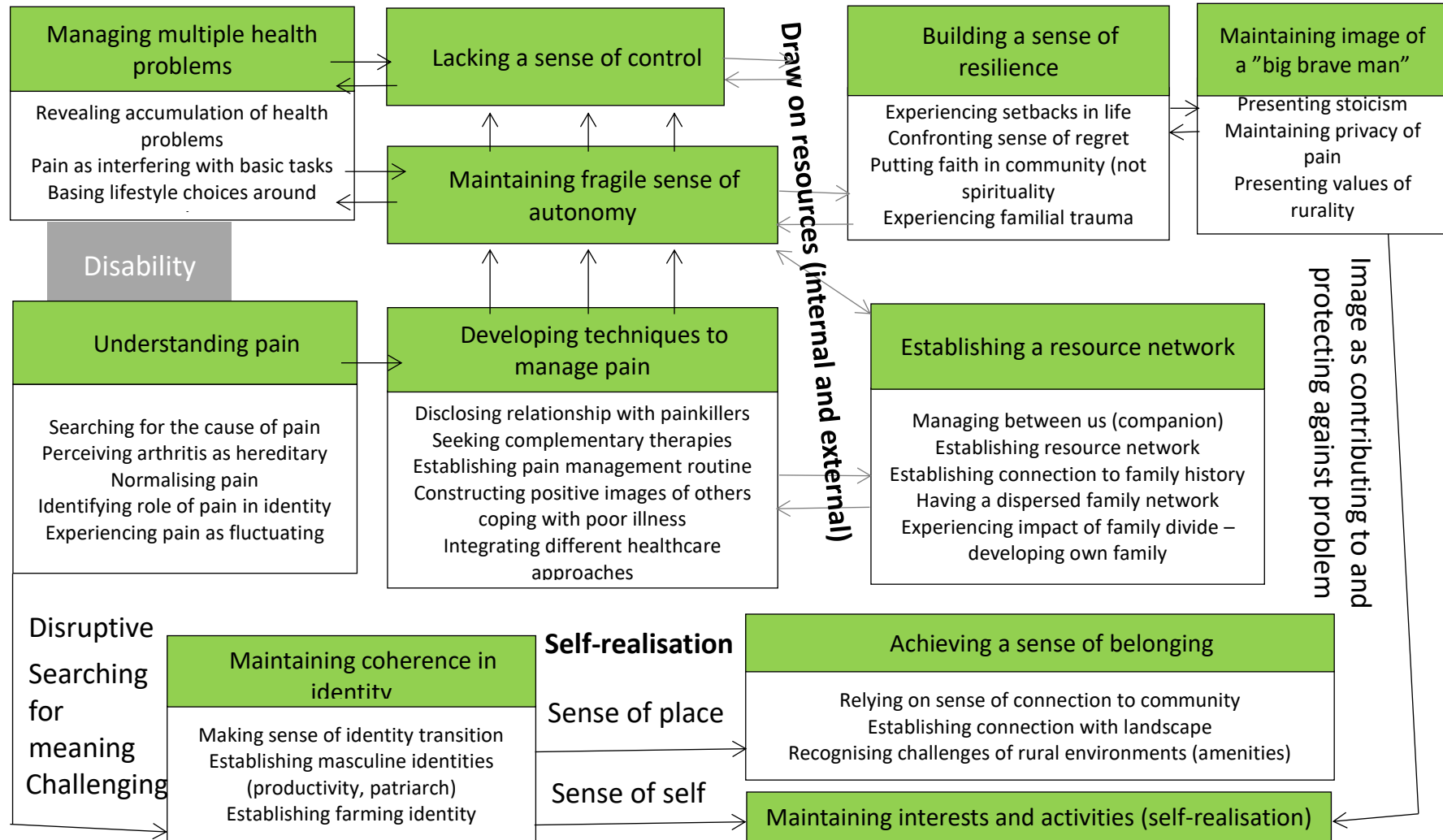


Mind map: for Catherine

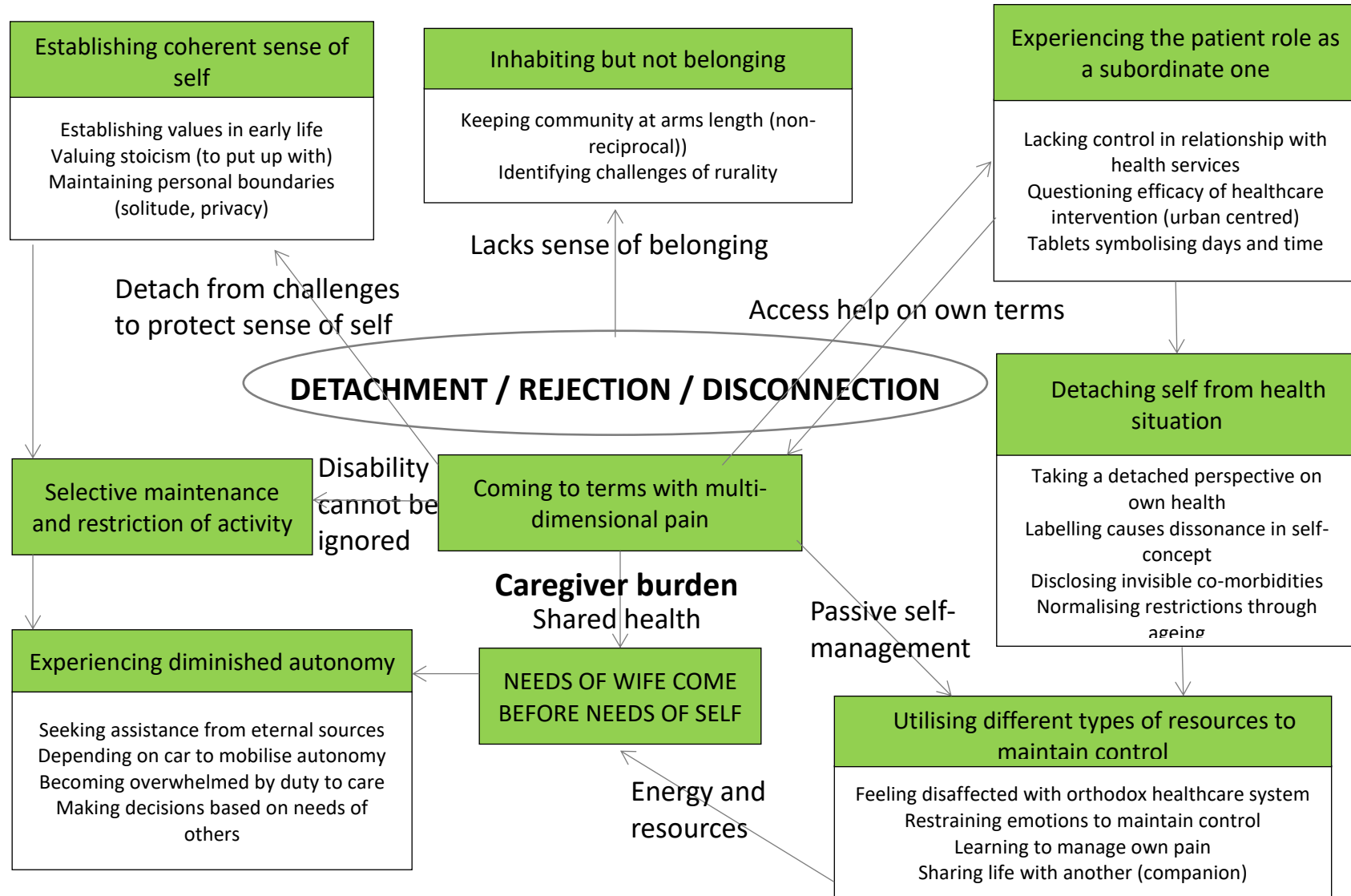


Mind map: for David

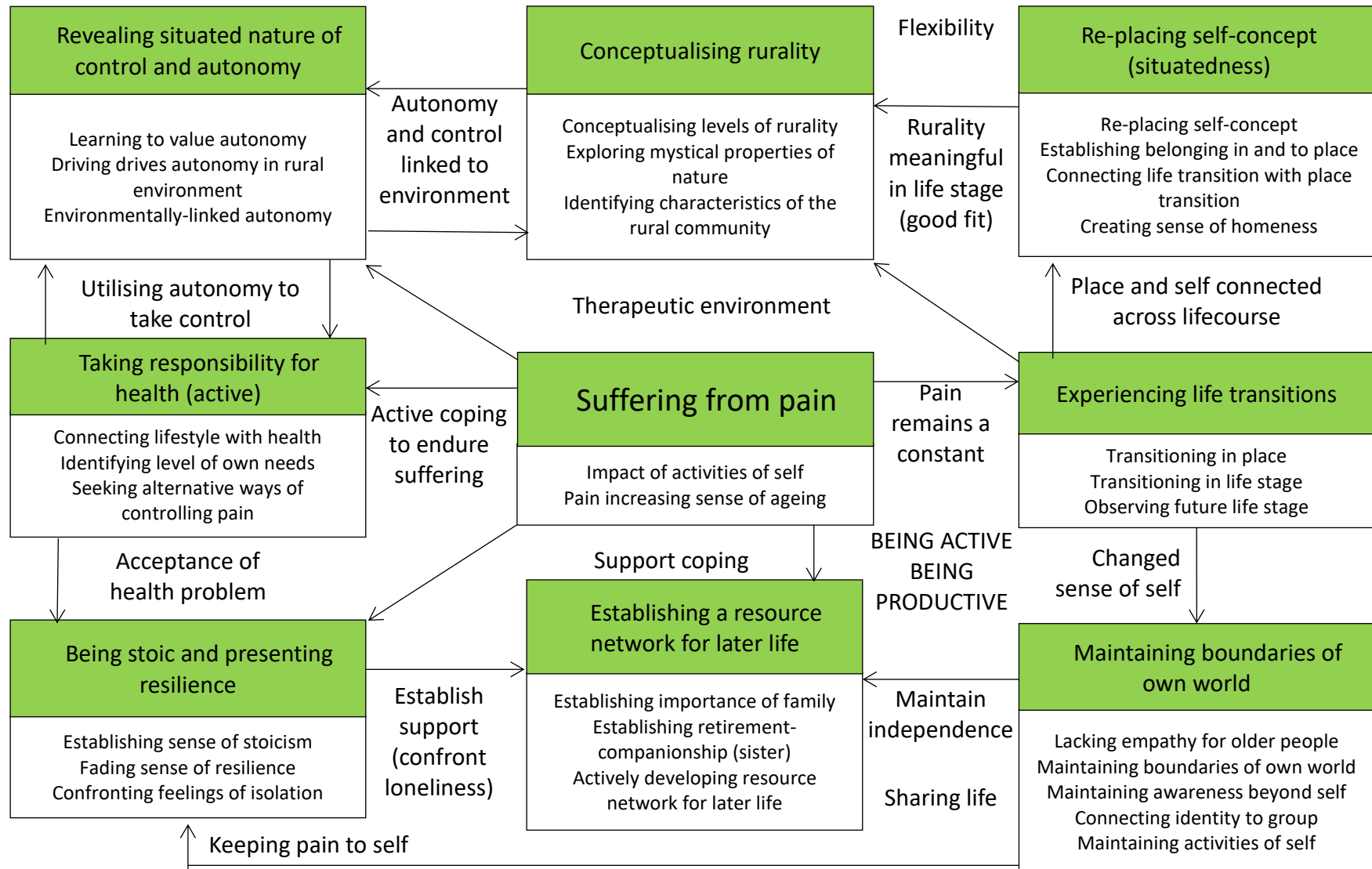
Appendix 13d



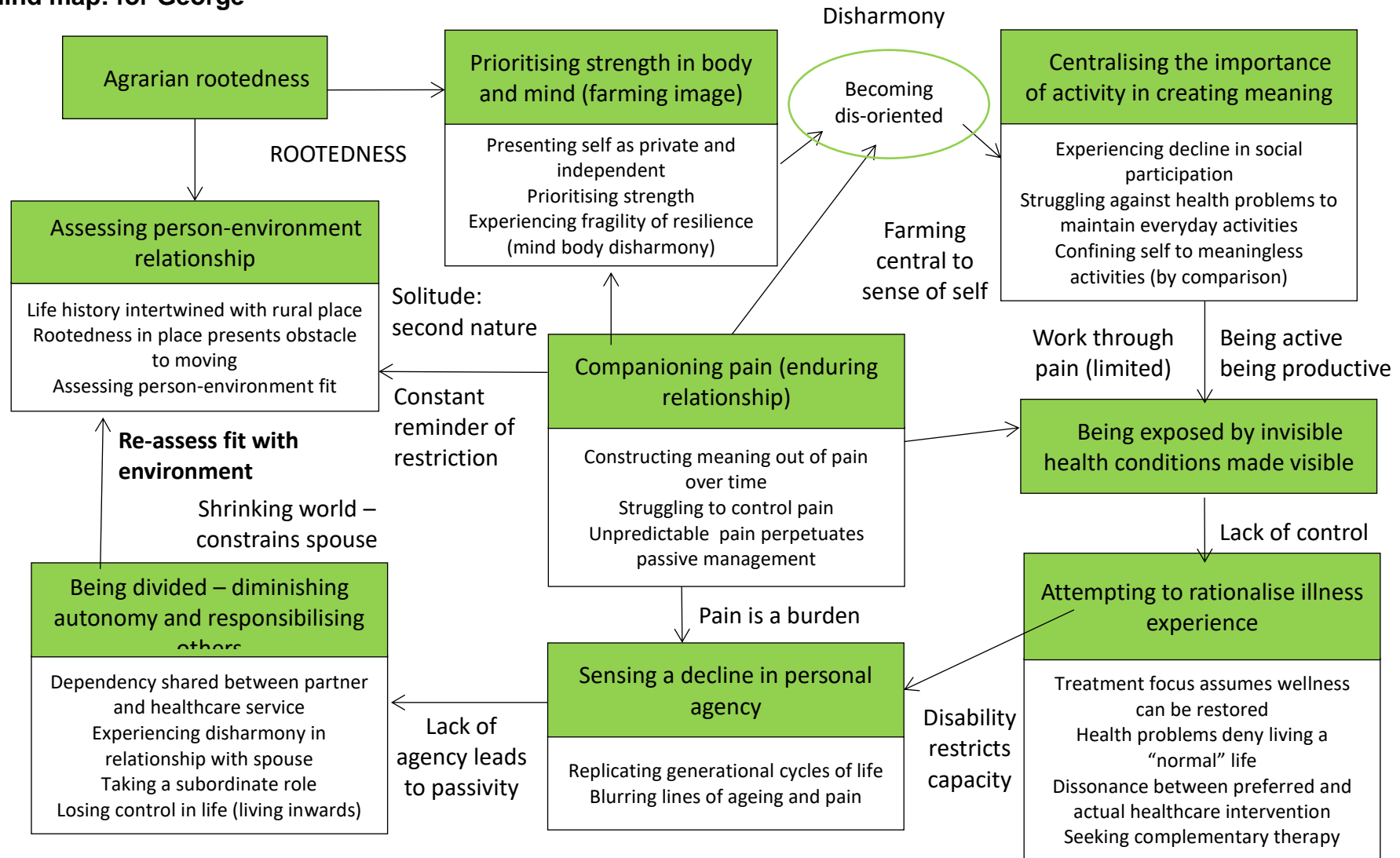
Mind map: for Edward



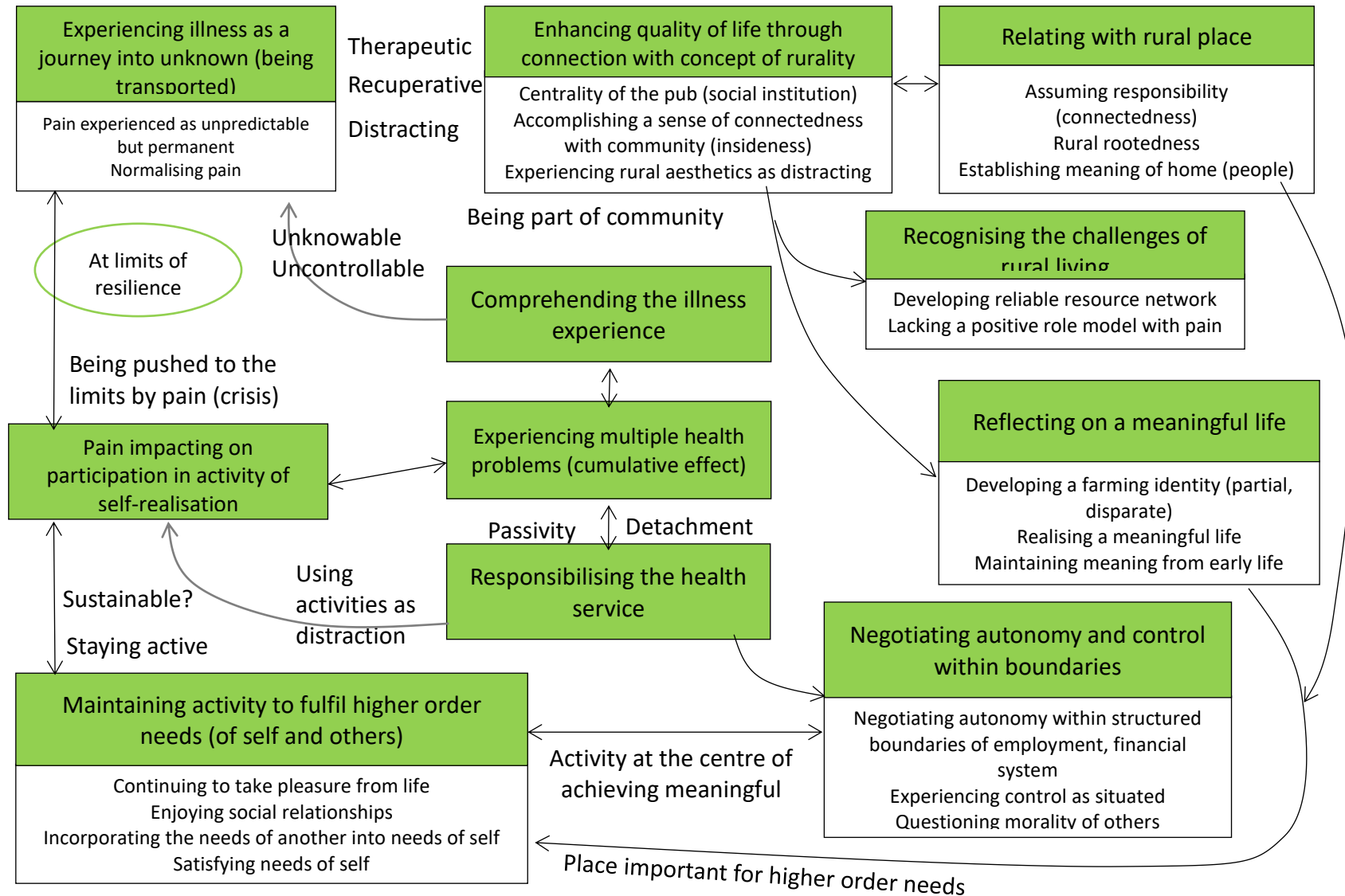
Mind map: for Frances



Mind map: for George



Mind map: for Henry



Appendix 14

Redacted version of a completed lifegrid

CP001F

INTERVIEW SCHEDULE

Life Grid (to be used as an aid for the one-to-one biographical interview)

Date	Age	Family/ Personal	Work/ leisure	Health/ Illness	Pain	Interference/ coping	Home/ environment	Other
1930	11/3/31 0							
1935	5	4 1/2 at school 2 brothers + a sister						
1940	10	1 in army	Running errands for people					
1945	15		Work in service @ 16.					
1950	20							
1955	25	1956 (brother died)	Marriage (?) @ 25 yrs (1957)					
1960	30						Unkennel / red here	
1965	35	mother-in-law died	Homehelp Caring role				Railway built here for workers. 1966 bought home.	
1970	40							
1975	45							
1980	50			Diabetes				
1985	55							
1990	60							
1995	65	mother died (97)						
2000	70	5 grandchildren * Going to market.						
2005	75			Macula - degeneration Diabetic				
2010	80	Brother died of cancer		Heart + new valve Partially blind (2012)				
2015	85	Sister (86)		2012 ← Heart Op In hospital last year				

Vict room

* Talk to anyone about pain?

Version 1.0
Date: 01.08.2013

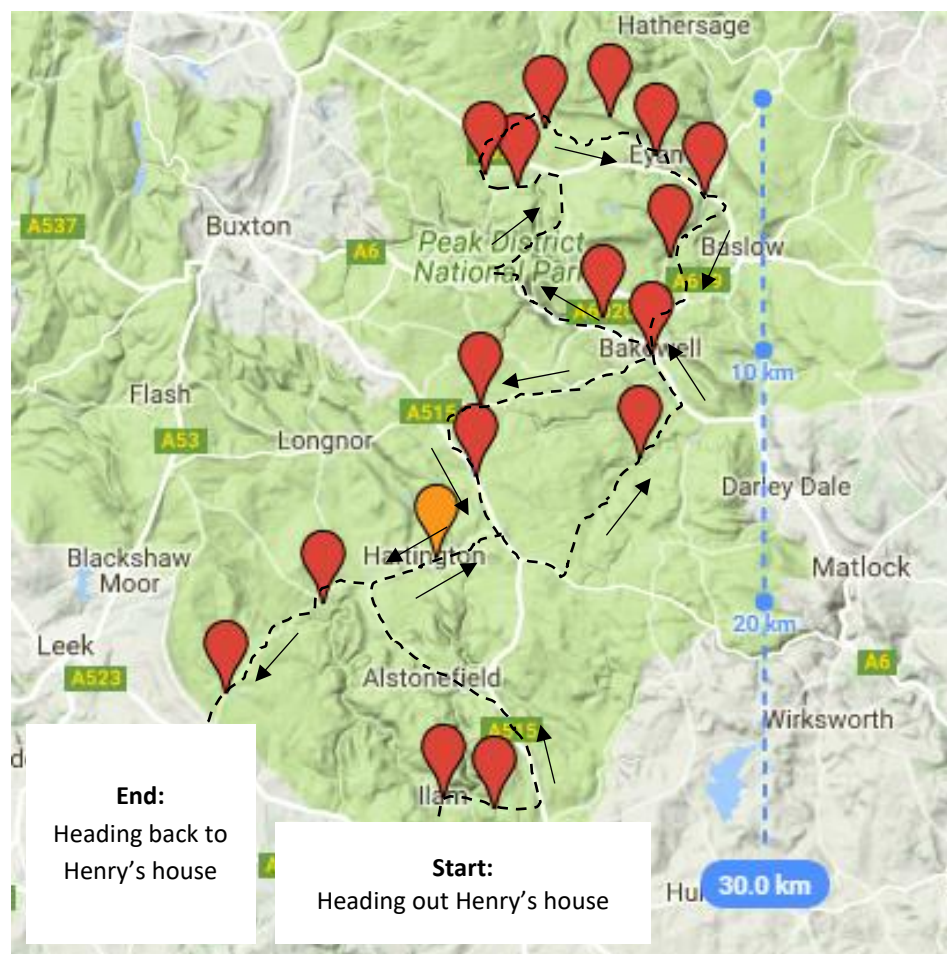
Table of full item responses for CASP-19 by participant (n=8)

Domain	Item statement	ANNE		BARBARA		CATHERINE		DAVID		EDWARD		FRANCES		GEORGE		HENRY	
		Item	Domain	Item	Domain	Item	Domain	Item	Domain	Item	Domain	Item	Domain	Item	Domain	Item	Domain
CONTROL	My age prevents me from doing the things I would like to	0		0		2		1		0		2		0		1	
	I feel that what happens to me is out of my control	1	3	1	3	2	8	2	9	1	6	3	10	1	4	0	7
	I feel free to plan for the future	2		2		2		3		2		3		1		3	
	I feel left out of things	0		0		2		3		3		2		2		3	
AUTONOMY	I can do the things that I want to do	1		3		1		1		2		3		1		3	
	Family responsibilities prevent me from doing what I want to do	3		2		3		2		0		2		1		3	
	I feel that I can please myself what I do	3	9	2	11	3	10	2	7	2	7	3	11	3	6	3	10
	My health stops me from doing things I want to do	1		1		0		1		0		1		0		1	
	Shortage of money stops me from doing things I want to do	1		3		3		1		3		2		1		0	
PLEASURE	I look forward to each day	3		3		3		3		3		3		3		3	
	I feel that my life has meaning	-		3		3		3		3		3		1		3	
	I enjoy the things that I do	3		2	14	3	15	3	15	2	12	3	15	2	10	3	15
	I enjoy being in the company of others	3		3		3		3		1		3		1		3	
	On balance, I look back on my life with a sense of hapiness	3		3		3		3		3		3		3		3	
SELF- REALISATION	I feel full of energy these days	2		1		3		1		0		2		1		1	
	I choose to do things that I have never done before	2		0		0		2		1		2		1		0	
	I feel satisfied with the way my life has turned out	3	11	1	4	3		3	12	2	5	3	13	3	7	3	
	I feel that life is full of opportunities	2		1		2		3		1		3		1		3	
	I feel that the future looks good for me	2		1		-		3		1		3		1		-	
Total Score		-	-	32	32	-	-	43	43	30	30	49	49	27	27	-	-

Table notes: Item scoring scale 0-3 where 0 = 1 = 2 = 3 = (Except for items indicated by * which are reverse scored). Total score ranges from 0-56 where a higher score denotes higher quality of life.

GO-ALONG WITH HENRY (20/05/2014)

Map 3. Go-along route taken with Henry








Fieldnotes: We began the journey at Henry's house and made our way out of the estate. Henry was in control of the route. He had asked me where I would want to go to which I replied, "I'm happy for you to be the guide, show me the places that mean something to you, but don't go too far". I could sense that Henry was excited about driving and showing me the sights. During the go-along Henry disclosed a regret regarding a missed opportunity to fulfil an ambition to be a tour guide with his own bus company. It felt as though he were living out this aspiration. Henry mentioned a few places as we set off: previous pub that he owned, current place of work, favourite beauty spot, a pub to stop for lunch, and his favourite restaurant. Henry seemed to plot a route to take in these landmarks. Henry drove with confidence in his knowledge of the area his driving ability was very assured.




Image retrieved from Google Maps, my places:




<https://www.google.co.uk/maps/@53.2276206,-1.8581528,10z/data=!4m2!6m1!1s19nqefMp3hJozRI82Fh7e2293FGk>



Timeline from recorded video data




Time (mins)	Route	Features of environment	Screen shot / photograph	Conversation topics (source of prompt for conversation)
0:00 – 5:00	Driving from home out of Village B	Housing estate Police vehicle Parked cars Property for sale (houses and land) Out of village boundary (open road)		Police vehicle: “that’s a nice machine” “Prostate problems... well, I had cancer actually” (GP appointment that morning) Crowded roads – parked cars “Should have a 7.5 tonne weight limit on road – you get 44 tonne vehicles rattling through here in order to avoid Town.” Leaving school and career progression – reflecting on farming background
5:00 – 10:00	Driving on rural road (A road)	Open road Cross roads (junction with main road between two urban centres)		Changing jobs and career progression (doesn’t miss being on call) “Everything’s changed since we’ve been here” (Env) Loss of local pub businesses Tastes of the community Food – restaurants Lots of hills to contend with (Env – Int poses question) Previous customers are now neighbours




10:00 – 15:00	Driving narrow rural roads; “the back way” to Village E	Narrow lanes Information board at road junction (inaccessible)		Beeps at a friend on the grass verge Industry spoiling the view “This is the pub” “Retired farmer... Local village hall” Housing having expanded Bowling green Sharing knowledge about Village C
15:00 – 20:00	Through village and out into rural space	Bus stops, GP service, hikers, HGV, speed cameras		Henry’s appointment at his general practice on the morning of the go-along – this was prompted by driving by the practice. This prompted conversation about Henry’s relationship with his GP (“this lady doctor”) about his pain (Henry scores it as “8 out of 10” today), change of tablets that have helped. Henry’s low mood during severe pain – Henry dismissed taking anti-depressants when it was suggested by his GP.
20:00 – 25:00	Rural main road (caution lines in road)	Road to work		Impact of Henry’s chronic pain on his relationship with Helen and her mood, Henry assumes blame (regret). Henry: “She was a brick... I was a difficult person to live with” “Comical sheep” lying in the road Connection to the countryside - Henry: “I love it”. Developing connection with countryside throughout Henry’s life and through working within this environment (farming: working the land; transport manager: taking pleasure from scenery and sense of belonging)

25:00 – 30:00	Turning onto narrow lanes	Hawthorn blossom, tourist hotspot, village in which he works		<p>Hard physical work in farming; but it kept you fit. Never seen the blossom as beautiful “Table top mountain” Henry: “I think every morning I must be one of the luckiest people to drive to work in these conditions” Spring is the finest season – In autumn everything is dying “and I don’t like it” Talking about interviewers life and wife (prompted by Henry). Henry: “this is somewhere to bring your girlfriend” (Pride in area)</p>
30:00 – 35:00	Village where Henry works	Valley, village, tourism (busy with cars), youth hostel, chestnut tree, school		<p>Henry drops a newspaper off for a work colleague Idyllic surroundings, school like a church; tourism (popular place) Talking about work Henry: “That’s my favourite tree, the chestnut... I think it’s majestic” Traffic, busy roads, tourists Tourism – pride in popularity of the local area</p>
35:00 – 40:00	Leaving village of work	Rolling hills, large HGV on rural lane		<p>Alternative routes (knowledge of local area) A young couple who are “doing up” a house (we pass this on the journey which prompts conversation) – Henry says the couple have a heating system fuelled by wood pellets Henry talks about Helen now wanting to have a wood burner although Henry dislikes the work involved, the dirtiness and not being good for the environment Holidays in Europe (Brittany) visiting oyster farms</p>

40:00 – 45:00	Hill tops	Stone walls, open fields		Holidays, other people driving “everyone drives like maniacs”, local factory, residents local knowledge, directing the route, sharing knowledge of the roads and routes, remembering passengers from work, reflecting on long days for children in the country (long distance to travel to school) History of the area: mining Long days for school children “in the country” Pointing out local pubs
45:00 – 50:00	Driving to Village C	Village, church, village centre (hotel, pub)		Emerging business in the area (crosses topic discussed by another participant, Barbara) Local shops Church on outskirts of the village: Henry: “I can never understand that” Pub: warns about being an expensive one Change in the area over time is minimal – particular villages have changed more than others (larger villages expanding) Succession in farm ownership
50:00 – 55:00	Driving up and out of Village and “deeper” into countryside	Pretty village, narrow roads, cyclists,		Pretty village, stone-built houses, open fields Interviewer asks about health behaviours and literacy: Information about shingles, pain – reading newspaper articles, keeps reading but has not found anything, reading can be “depressing” because people talk about having pain for 25 years Henry does not use the internet nor does he have a computer Helen has an iPad and will look for information for Henry Diagnosis of shingle – expectations, pain was not discussed: “was in a bad way... don’t remember going in the hospital”

55:00 – 59:12	Getting “deeper” into countryside – to a large village	Narrow lanes, entering Derbyshire Dales (bordering the Moorlands)		<p>Talks about TV programme Countryfile that included a piece about local area and walks</p> <p>Tourist highlights</p> <p>TV programme (drama series) – Henry often asked about this by tourists</p> <p>Henry asks how long the video will last for – Henry requests that we record a particular view, he is concerned the tape will run out (planning his route)</p>
<p>The video camera is turned off at 59m12s. This is at the request of the participant, Henry, who wants a particular view to be recorded further along the route (more than 30 minutes away). Henry continues to drive to show off his favourite places (including a high-end restaurant, view of the valley). Henry drives to a pub where we have lunch together, Henry then drives us to the viewing point, and then we drive back to Henry’s house taking an alternate route. The video recorder is turned on again on the route back to Henry’s house.</p>				
59:13 – 65:00	Driving into a small village	Small village, narrow village road, cars parked on sides of roads		<p>“Very old place”</p> <p>Pass by two people seen earlier in the journey</p> <p>Normal day off activities</p> <p>Gardening</p>

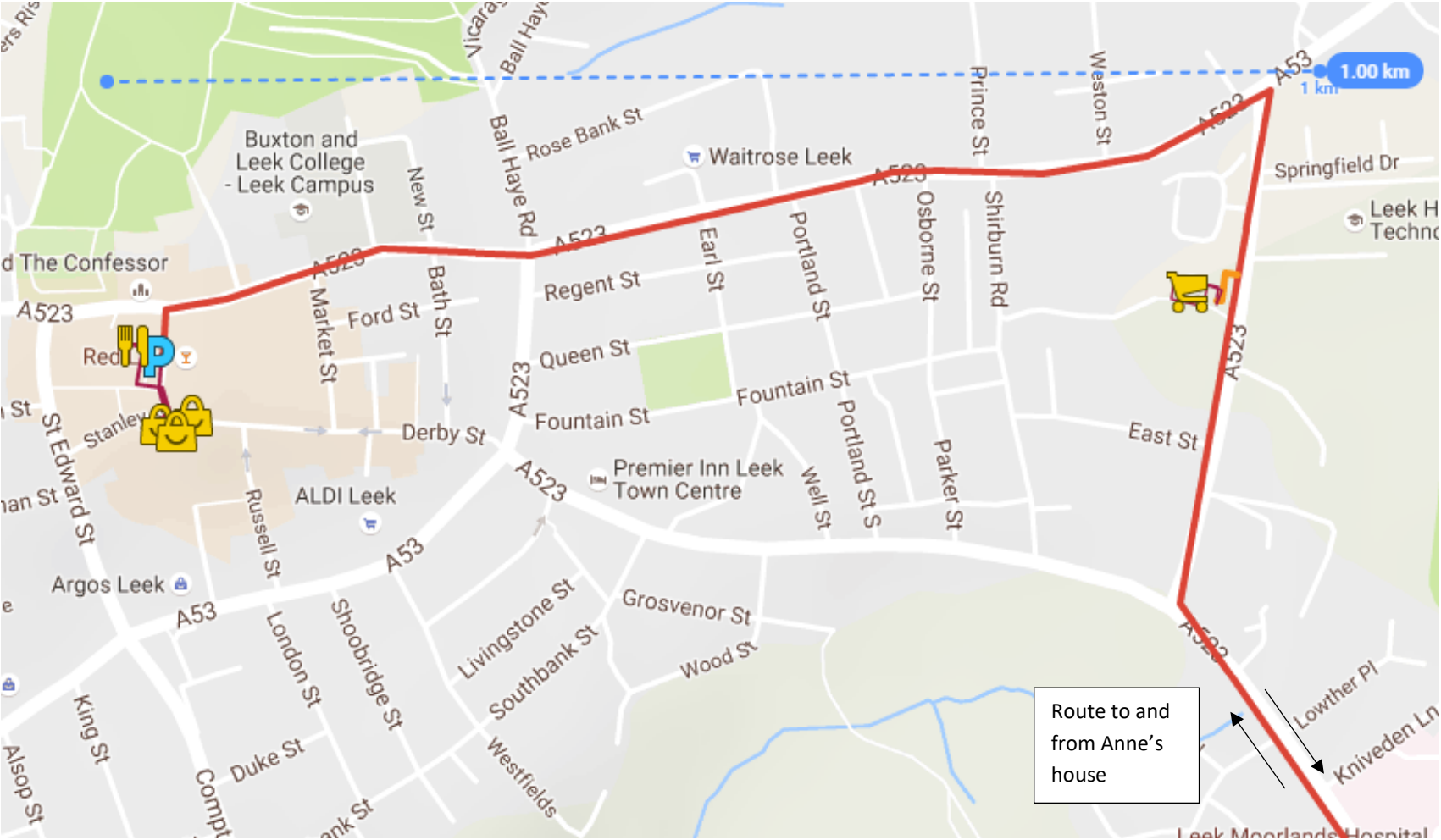
65:00 – 70:00	Driving out of village	Narrow roads, haulage company		Home improvements Relationship with Helen Tradesmen making mistakes Childlessness – former partner of Henry not having wanted children. Henry: “one of my father’s biggest disappointments”
70:00 – 75:00	Open road, “last leg of the trip”	Open roads, uphill, no traffic, wooded area, fields, few buildings		Helen’s daughter not wanting children Henry: “Do you recognise where you are now?” Going back home Methodist churches Interest in video recording equipment Beautiful countryside
75:00 – 80:00	Continuing on open road, road widens out of village	Driving down hill, coming into a large village, stone-built properties, busy village centre		Conversation is becoming increasingly limited Weather Village – busy, car park, shops

80:00 – 85:00	Out of village into an area popular for walkers,	Walking routes sign-posted, area for walkers to use: car park, toilets, café, pub, camp sites		Pointing out previous routes on the journey Camp sites (sharing an interest) Shop closing – 6 months ago “Friend of mine where I get eggs from... free range”
85:00 – 90:00	Through villages on route to Henry’s house	Farm, fields, quiet roads		The research study – routes that I have used Talking about shared contact networks Bus driving Dogs
90:00- 95:00	Main road leading crossing link road between large urban centres	More traffic on roads		“Driving home” Driving faster to get back to house before video tape runs out (game, challenge)

95:00-97:37	Arrive back at Henry's house	Enter into Village C		"There we are... we've made it haven't we?"
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GO-ALONG WITH ANNE (14/11/2013)

Map 1. Go-along route taken with Anne (Source: Google Maps)



Map 2. Go-along route taken with Anne on foot around shops



Source: Google Maps

Fieldnotes from go-along with Anne:

Arriving at Anne's house

On arrival at Anne's house I parked up on the roadside, positioning the car up onto the curb so as not to cause unnecessary obstruction to other road users. I took this precaution as given the surroundings, the nearby farms, the local industrial site at the bottom end of the lane, I pre-empted that a number of heavy goods vehicles may use the lane as an access road. Anne was waiting for me at the door when I arrived. I exited the car and we exchanged pleasantries at the doorstep. Anne seemed eager to get in the car, however I had to delay the start of the journey in order to complete the consent form and to explain the purpose of the day. We went back inside Anne's house to complete the paperwork. As I entered the living room I noticed the temperature in the living room was cool, the fire had not been lit. I presumed that this was in anticipation of my visit. I used the time it took for us to complete the consent form to enquire with Anne about where she intended to go on our journey. To this she replied along the lines of the following: "well, I thought we were going to Town, we could park up in Market Street and go to that shop that everyone's been talking about and have a look around". I agreed with her plan. I also informed her that I was relatively unfamiliar with the local town centre and so I may need her assistance in locating Market Street and the car park. Anne said that she would be fine to do that. I wondered to myself at this point how she might intend doing this, as during the initial one-to-one interview Anne indicated that she had trouble seeing me when I was no more than three metres away from her; this owed to Anne's deteriorating eye sight. After having completed the consent form and discussing how I would be recording information during the activity, we got up to leave.

Anne asked if I could fit her walker in the boot of my car, and stated that she would feel better to have that with her as it made walking around the shops much easier. I obliged and picked up the walker on my way out of the front door. The walker was a slightly cumbersome object and was heavier than it first looked, weighing approximately five kilograms. Designed with three wheels in a tricycle formation, the frame consisted of two tubular metal V-shapes. The first lay horizontal and connected the three wheels, one wheel at the front and two at the back. Each wheel looked similar to those found on child's go-kart or pram as opposed to a shopping trolley for example. The second V in the frame sprouted up vertically from the frame over the front wheel. At the end of the two stems of this V were plastic/rubber handles, one for each hand of the user. A zipped satchel was attached to the two stems.

Anne also asked if I would lock the front door to her house. I was instructed to lock the internal front door, but left the porch door closed but unlocked. I opened the car door for Anne and checked that she would be okay to get in or whether she may need assistance. She opened the door wide, in doing so Anne slightly scuffed some of the paint on the passenger door against the concrete-block front wall of her garden. Anne held onto the frame of the car, placed a foot into the foot well and promptly swung herself down and into the passenger seat. I thought at the time that this seemed like a manoeuvre that Anne had done on a number of occasions previously. I shut the door behind her and made my way around the back of the car to place the walker into the boot before entering the car on the driver's side. Sitting next to Anne in the car, she apologised to me for hitting my car door on the wall.

The car journey to Town: Distance approximately 8 miles

On the journey towards the local town Anne pointed out a number of local landmarks, an animal sanctuary, a nature spot set in the valley, and a prominent trailer-café located in a large lay-by. This is something that I had passed many times on my way to earlier preparatory fieldwork trips and noted how it always seemed to have customers. Anne commented about the £4 breakfasts

that they served there and praised the quality. I did ask Anne at this point how clearly Anne could see the landmarks and physical features of the landscape that she was pointing out or whether she was relying on her memory to describe these to me. Anne gave a mixed response, commenting on how she could “see the blurry outlines of signs and shadows” as we passed by in the car but that she knew the route extremely well regardless. Anne helped to navigate me into the town centre, taking a “short cut”, “I bet you wondered where I’m taking you” said Anne as she directed me to take an earlier turning than I had anticipated. Anne informed this was a “back way” to avoid the traffic. We travelled past a supermarket on the way into the town centre as well as a hospital-looking building which turned out to be a local secondary school. Anne corrected me on my initial assumption. In total the drive took no more than 20 minutes.

We approached the centre of town, passing a turning for Market Street and instead parked on a cobbled car park set within a square enclosed by three and four storey buildings with business fronts adorning the ground floor level. The car park was a pay and display car park, however on parking the car and turning the engine off Anne reached into her handbag to withdraw her disabled parking pass. Anne placed this in the windscreen. Anne informed me that this permitted the vehicle to three hours free parking. I exited the car to retrieve Anne’s walker from the boot and brought it round to her. Getting up and out of the car was another practiced exercise for Anne, I observed again how Anne first lifted and swivelled her legs up and out on to the car park floor by the door. Then she clung to the upper door frame to pull herself up. This was a swift explosive action. Reflecting on this, I wondered whether she had ever inadvertently knocked her head on the car as she thrust herself upwards, what are the risks in carrying out this manoeuvre. Anne took a moment to catch her breath following the sudden exertion. The cobbles of the car park were raised and seemed unhelpful for somebody using a wheeled walker (Photograph #3). The early morning rain had left a slippery top to the stones and the runnels between them made pushing three wheels sufficiently tricky. This car park had no doubt been designed to be pedestrian friendly, with cars having to drive slowly across the cobbles. However, this appeared to make Anne’s life difficult as she bounced the walker over and between cobbles taking extra care not to slip or lose her balance. We got to the pavement. Another hazard became apparent. The curb was low to the ground and had been constructed in block-paving as had the road itself. This gave the impression again of being pedestrian friendly and most likely a drop-off point for taxis and business couriers. My assumption was supported by a delivery van blocking parked up on the lowered curb blocking the pavement. This meant that Anne and I had to walk on the road in order to reach the opening of the high street. However, Anne had noticeable trouble in lifting her walker down onto the road. As the material of road and pavement were constructed of the same material, albeit slightly different colours, it made distinguishing the two difficult (Photograph #4). The result was that Anne ended up over-lifting and over-extending the walker out in front of her to traverse the step down. A move that was followed by a slight mumble and cursory glance down at the pavement.

Shop #1 General store

The shop that Anne had wanted to go to, that which her friends at the luncheon group had been talking about was located directed in front of the car park, around 50 metres from where I had parked the car (Photograph #5). This shop was our first stop on our trip. We entered to be greeted by a sudden burst of hot air from the fan above the door. This was pleasant given the cold day. The shop was spacious warehouse-like, laid out in a series of aisles interspersed with racks of clothing. Additional stock was suspended on walls high up out of the reach of customer. The shop did not appear to specialise in any particular products instead these varied quite broadly ranging from seasonal Christmas decorations, tools and hardware, clothes, stationery, and crockery and cooking utensils amongst other things. I was led by Anne around the shop, I followed alongside her observing her activity and providing assistance when and where requested. Anne appeared

eager to inspect as much as she could; seemingly intending to make the most of her opportunity to get out. Pushing and leaning on her walker simultaneously Anne investigated each section of each of the aisles in the shop. Anne hung her handbag from one of the handles on the walker and carried her magnifying glass in the top of the satchel on her walker using this sporadically to take a closer look at particular items and prices (Photograph #6). The process of 'taking a closer look' typically involved Anne hunching over the walker, leaning forward to press the magnifying glass up against the product. Just as I was about to ask Anne if she were looking for anything in particular, to see whether I could be of assistance, Anne picked a roll of duct tape from a hanging rail. She asked "is this black or grey?" to which my response was "grey", Anne said "good" and subsequently dropping the tape into her satchel. Anne explained that she needed the tape for some home repairs. Anne moved around the shop freely with the aid of her walker and wide, quiet aisles. Anne added to her satchel pens for bingo and a book of raffle tickets, both of which were for the benefit of the luncheon club. Both were dispatched into the satchel, as was a pack of envelopes. Anne commented on wanting to buy a pack of brown envelopes, as she claimed that in terms of being delivered by postal workers "they're supposed to get their quicker". As Anne was inspecting the stationery she noticed a display of greetings cards, saying out loud "oh, that reminds me I must get some birthday and Christmas cards, we shall go to the card shop after this, it's just across the way".

As Anne worked her way towards the counter to pay, she stopped en route to inspect the racks of coats. Anne tried a number of these on for size. Anne seemed disappointed when she was unable to find one in the right size, which she pointed out in hushed tones was "XL". I helped Anne to find the correct size. I reflected on Anne's reasons for wanting to purchase a coat, was this purely an opportunistic purchase, to address an ongoing need, or had a need suddenly arisen in light of the cold morning. I thought back to my earlier consideration of whether Anne had felt the cold more than she had been willing to admit. Anne showed disappointment in her body language, shoulders dropped, as she worked her hands back through the sizes on the hangers to double-check she hadn't missed an XL. Anne's "oh never mind" statement echoed the change in body language and so Anne stood rotating her head to searching the shop for further coat racks to inspect, of which there were none. Anne continued on her approach to the till to pay for the items in her satchel. The shop had few customers and so Anne was served immediately. Anne removed the items from her satchel one by one and placed them on the counter top stating: "that's all of them" following this with an apology for having to put items in her satchel claiming that she wasn't looking to steal things, only that it made life easier for her. The shop assistant was friendly and courteous telling Anne "that's okay don't worry". I considered how useful the walker had been to Anne in this shop, it provided support to aid her mobility, an attached shopping bag to save her from carrying anything in addition, and also a frame to hang her handbag from so that her hands remained free to grasp the handles. However, in putting items that she intended to purchase directly into the satchel Anne did risk being accused of stealing but also of forgetting all of the items that she had put into the bag and therefore unwittingly committing crime. I considered how often this occurred to Anne, and more widely to other older adults who use similar walkers or baskets. I maintained a respectful distance during this exchange, a conscious effort to avoid drawing attention to myself from the shop assistant but also to give Anne some privacy while she paid for her goods.

On our way out of the shop, Anne stopped to look at the Christmas decorations which she had overlooked upon entering the shop. She mentioned to me how she had wanted some lights in the porch of her house. Anne's preference was for something that did not require being plugged into the mains as she did not have a plug socket in the porch and thus it would need to be fed across and under the door. Anne was concerned that this would present a trip hazard. I helped Anne to search for lights that were battery powered but neither of us could find anything suitable: "we'll

leave it then". Thus, after approximately 30 minutes looking around the shop we exited the shop and stood outside, once more at the opening to the high street. The air temperature had risen noticeably since first entering the shop and the icy wind had subsided, or perhaps we were more sheltered between the rows of shops than we were outside Anne's house earlier. The card shop that Anne had mentioned was located across the pedestrianised street 20 metres or so away we could see it clearly from our position: "To the card shop then, Anne?" I asked, to which she replied "yes, I have a few people to buy for". We made our way across the street.

Shop #2 Card Shop

The entrance to the card shop was on a flat, however the doorway was narrow and the door itself was heavy. I entered first to hold the door open for Anne. As we entered the card shop the heater above the door blasted us both with a gush of hot air. Anne commented on the heat as "too much" making the shop an "uncomfortable" experience and questioning aloud "how do these girls cope?" referring to the female shop assistants.

There were five other customers in the shop, but with the narrow aisles and excessive Christmas stock, the shop seemed cramped and busy. The shop was essentially split into three sections. The first section at the front of the shop had an open space in which customer could queue for the tills, the second section at the heart of the shop comprised two aisles filled back to back with cards on racks, and the third section towards the back of the shop narrowed and so had no dividing aisle but was stacked wall-to-wall with cards. I observed how the other customers in the shop browsed through the shelves of cards and assorted gifts stopping on their circular route around the aisles in the central part of the shop. Often customers would stop to take a closer look at particular cards, in doing so the flow of customers around the aisles became stagnated (Photograph #8). I observed how this quickly became a source of mild consternation for those customers waiting to move around and continue the flow, there was a noticeable awkwardness in many customers as they repeatedly used the term "excuse me". In observing this I instantly considered how Anne would find this experience, as with her walker she presented a clear obstacle for other shop users.

Anne stopped to look at a box of small Christmas cards on a shelf near the door. Saying "they'll do" and dispatching the box into her satchel. At this point Anne called out to no one in particular but to the shop staff in general "I'm only putting that in my bag until I get to the till". I looked up to the shop staff who accepted this: "that's fine, don't worry". Anne then moved to the aisled section of the shop. I moved alongside and behind Anne, which made things difficult for other customers at which point I attempted to find a more convenient place to position myself. There were a few noticeable glances and rolling of eyes at Anne and towards me also as Anne blocked an aisle hunching over her walker with magnifying glass in hand to inspect individual cards. One customer, who herself was getting in other peoples' way seemed flustered by Anne. A contributing factor in all this was that both Anne and this other customer were both searching the shelves for very exact cards; such as "Merry Christmas brother and sister-in-law". Anne verbalised a list of similarly specific cards to me so that I could help in the search. I could see Anne was getting agitated and frustrated with the effort required to search through the cards. The heat, picking up and putting down the heavy magnifying glass, picking cards from low to high shelves, all the while keeping a hand in contact with the walker to maintain her balance, other customers leaning over and around Anne; all of this did indeed seem a struggle, an ordeal. Anne's tone altered during this experience. At the beginning Anne stated clearly to me that she wanted "a card with nice words in it" this changed towards the end of the search, after 15 minutes or so, Anne looked at a selection I had found for her and simply stated "they'll do" without asking to check the wording. Anne dispatched the selection of cards into the satchel on the walker and made her way to the till. As we moved towards the till for Anne to pay, I asked Anne whether she

was experiencing any pain, to see whether this may have contributed to her flustered demeanour. Anne replied: “oh it’s terrible, I shall need to sit down in a minute”.

On our way to pay for the cards Anne noticed some Christmas earrings behind the till, she asked the shop assistant if she could have a closer look and then with her help chose some. Anne explained that she would wear these for the luncheon club Christmas meal. On leaving the card shop Anne offered to pay for us to go for lunch at a local fish and chip restaurant (Photograph #9), which was located adjacent to the car park that we had used. I questioned her need to pay for me, Anne replied that “well it’ll be as a thank you for taking me out, you’ve really helped in getting those cards”. Anne also said how going to the restaurant would then “give [her] chance to sit down” and explained that stopping for lunch would be part of her usual routine with her nephew or great-niece when they would take her to the shops. On reflection, it would seem I had assumed the role that her nephew or great-niece would have occupied. Acknowledging this I automatically felt responsible for Anne and her wellbeing whilst keenly aware that in this scenario I remained a stranger to Anne and her usual routine. I wondered to myself how long she would usually take to do her shopping, how long before she tires, am I asking too much of Anne, how would I know if she was in pain how does this usually present during the day, are there certain tell signs I should be looking for, had she told her nephew and great-niece about our trip, if so how did they feel about it, was I doing them a favour by freeing up some of their time or did they resent someone else taking away a role from them. These were all questions that stirred in my thoughts, many of which I answered to myself: “Anne is a grown woman, she will tell me when she has had enough”.

Shop #3 High street clothes shop

As we walked back in the direction of the car park, which led to the fish and chip restaurant, Anne became side-tracked by a high street clothes shop (Photograph #10). As Anne altered direction to make her way towards the entrance she declared to me that she wanted to “ask them about a scarf someone was wearing at the luncheon club, it had butterflies on, and she said she’d got it from this shop”. When inside the shop, which was large, Anne seemed to notice a rack of scarves towards the back of the shop and made her way over to them. Anne looked through the stock on the racks but could not find the one that she wanted; Anne, feeling dejected and already in pain, simply stated “oh I can’t be bothered to look around anymore”. Anne asked a female shop assistant, who looked to be no more than 17 years of age, if she could help her to find the butterfly scarf that she was looking for, explaining that she wanted to purchase it for her niece, to which I inferred her great-niece. The shop assistant had a look through the scarves on the racks, as Anne had already done so herself, before stating that what she was looking for didn’t seem to be there. The shop assistant then offered to look on the shop catalogue system for Anne but then quickly altered this to say “actually you can look online to see if you can get one, you would need to pay postage and packing for it”. Anne refused this due to the cost of having it delivered. The shop assistant then suggested that Anne could visit another shop at the opposite end of the high street which might sell something similar. Anne provided a muted response to this idea. She did not verbalise that she was experiencing pain, or that she was tired.

I had taken a step back throughout the exchange in order to observe how Anne would handle this situation. I felt uncomfortable about not interjecting and trying to help, but didn’t want to be seen to take control of the situation away from Anne – a moral debate transpired in my head. I settled on reflecting on the options that the shop assistant had presented to Anne to see whether I might offer a suitable alternative: to pay extra for delivery, to look online, or to walk the length of the high street to another shop with no guarantees that the scarf would be there. The alternative would have been for Anne to have placed an order with the shop and had the scarf delivered to the shop for pick up Anne would still then need to arrange transport. Questions of

autonomy, mobility, competency with computers all converged at this point. Anne and I left the shop at this point, Anne was clearly disgruntled at not having been able to find the scarf that she wanted. Anne complained under her breath something that I struggled to hear but seemed to question the shop assistant's suggestions of trying somewhere else or using the internet. As we made our way to the fish and chip restaurant Anne spoke of her reasons for wanting to purchase the scarf, a present for her great-niece, explaining that she had already purchased an umbrella with butterflies on it and so thought that the addition of a scarf would complete the present. Anne said that had she not been feeling as tired as she was, then she would have spent longer browsing in the shop. I considered whether Anne was trying to account for the frustration that she was feeling, or whether she considered how her actions had appeared to me and was now trying to explain why she had been short with the shop assistant.

Stopping to have lunch together: fish and chips

We continued on our route to the fish and chip restaurant. This meant walking up a slight incline, which Anne struggled with noticeably. At the entrance to the restaurant an awkward step confronted us. A layer of black and yellow tape covered the step, thus designating it as a known hazard. The step was not large enough for Anne to place the front wheel of her walker onto it to gain leverage to push herself up and in through the front door. I stepped ahead to open the door and helped as best I could with lifting the walker in through the door whilst Anne continued to lean on it for support. This took a substantial amount of effort on Anne's part causing mild distress. Once in the shop Anne identified the nearest seat and immediately sat down appearing tired and in need of a rest. The seat was in the entrance to the shop, in the front window. Anne sent me to order the food and handed me a ten-pound note from her purse, requesting a small fish, chips, mushy peas and a cup of tea. I approached the counter to place our order, I ordered the same for myself. When asked where we were sitting by the member of staff I indicated that we were sitting in the front window, I was then told that we would have to move into the seating area at the back of the restaurant. After having paid I walked back to Anne to inform that we would need to move tables, I considered how she would take receive this information given her initial haste to sit down. As anticipated, Anne was frustrated with having to move, perhaps more so with having to get back up and on to her feet again given how I already knew from previous conversation with Anne that one way in which she copes with her pain is to immobilise herself.

We walked past the counter towards the back of the restaurant and found a table. Taking a seat was made difficult for Anne as the tables and chairs in this section were close to one another and the metal legs of chairs were narrow and awkward to move on the carpeted floor. Anne struggled to get to her seat, there was insufficient room to move her walker between the narrow gaps between tables. Anne's handbag which swung from one of the handles of the walker provided further problems colliding into the backs of chairs. On reaching our table, Anne, now slightly distressed with pushing the walker and banging into things fell into her chair rather than placing herself there. The chairs appeared quite flimsy and so I was concerned as to whether one might collapse. From a seated position Anne attempted to move her walker underneath the table, however it did not fit and became caught on the table legs. I helped Anne to free the walker and placed it next to our table despite this blocking the path between our table and the ones adjacent to us. Three of the six tables in the restaurant were being used by other customers. The one closest to us was being used by three teenage males, another by a middle-aged couple, and another older couple in the corner. A waitress arrived with our meals, two large mugs of tea and two slices of bread and butter (Photograph #11). Anne seemed pleased with the sight of the food in front of her. The restaurant was noisy with sounds of knives and forks against porcelain plates, after serving us the waitress cleaned down one of the other tables, and exchanged conversation with another set of customers taking their order. I took this opportunity to take out the Dictaphone, having agreed earlier in the day that I may do this during the course of the day. As

the time passed by and we ate our meals, customers in the restaurant began to leave and the quiet allowed for conversation between Anne and I (recorded and transcribed separately).

I admit to struggling to finish my fish and chip meal. I ate as much as I could so as not to appear ungrateful but could not manage all of it. Anne on the other hand, although taking her time over the meal, wiped the plate clean and seemed satisfied with her efforts. Anne was most grateful to the waitress who came to collect our empty plates and mugs. Whilst doing so, I noticed that the waitress glanced at the Dictaphone that I had placed on the table. However, she did not make any reference to it as we both thanked her for the meal. I considered whether to inform the waitress of the recording device and its purpose, but given that her verbal input was marginal, restricted to “was everything alright for you?” I decided not to obtain her consent and would simply omit her words, if not her presence, in the written transcript. Having spent an hour for lunch, we left shortly after the plates had been cleared in order to head back to the car. Navigating the treacherous black and yellow taped step on the way out of the building was less problematic than it had been on entry. Anne seemed to have more patience now and strength to lift the walker up and over the step and down on to the pavement outside. Anne did stop to murmur negatively about the step. The sun was now shining and the temperature had increased further, Anne walked with her jacket unzipped. The car was now only a short distance away. During the walk Anne posed the following question: “do you need to get back to the office for any particular time?” put a little on the back foot I said “no, not really” to which Anne then replied “well, would you mind stopping by the supermarket on our way back?” I said that this would be fine. Anne had mentioned earlier in the day that she was due to go supermarket shopping with her great-niece the following day, but perhaps saw this as an opportunity to get a few much needed items. As Anne swung herself into the car, I filled the boot of the car with Anne’s walker and her purchases before driving out and away from the car park.

Stopping at the supermarket on the way home

The supermarket that I drove to was the one that we had passed on the way into town earlier in the day. Upon realising this I wondered whether and for how long Anne had been thinking about asking to stop off here on the way back to her home. I parked the car in the disabled access space nearest the entrance to the shop. I made use once again of Anne’s disabled parking pass. Anne declined the use of her walker to move around the supermarket and instead used a shopping trolley leaning over the handle bar to steady herself. As I observed this I became aware of the risk Anne presented to herself in using the trolley in this way, the trolley was less stable than her walker and may flip up should too much force be pushed down on the back wheels. This made me feel slightly uncomfortable, but Anne reassured me that this is what she would normally do. Therefore, who was I to question her? Anne browsed around the supermarket focusing upon signage advertising special offers. Anne placed the following items into her trolley: a bunch of bananas, a punnet of blueberries “I love blueberries” Anne said, blueberry muffins, bite size shredded wheat with blueberry filling, three boxes of Cadbury’s Roses, and Thornton’s chocolate bars because “they were on offer”. I considered Anne’s choices of food. Why was Anne purchasing these sugary snacks? I reflected on having seen the empty biscuit boxes on the floor in her living room. I also then considered Anne’s health as someone with diabetes and whether if her great-niece or nephew were here would they intervene in her purchases or police what went into her trolley? I did not feel comfortable asking Anne, as it might appear that I am confronting her on her diet. On our way to the checkout Anne noticed a small display of Christmas earrings, debating out loud whether she should have held off on purchasing the earrings that she had purchased in the card shop. Anne checked a few of the earrings on the display, some of which had lights on them, but Anne put them back down again with a disappointed murmur and continued to push the trolley towards the check-out. Anne told me as we waited for her to be served at the till that the boxes of chocolates were Christmas presents for her grand-daughter and two others.

Anne paid for her goods and we left the shop, pushing the trolley to the car continuing to lean over it for support. I took the trolley back having put Anne's shopping bags into the boot of the car. The trip to the supermarket had lasted approximately 20 minutes. I then drove us back to Anne's home. I placed the Dictaphone in a cup holder at the base of the central column of the dashboard and switched it on for the remainder of the journey.

The car journey home

The car journey passed relatively quietly. Anne seemed to be showing signs of tiredness, yawning every now and again so I refrained from posing too many questions (see transcript of car journey for conversation). The journey lasted approximately 20 minutes, the roads were clear although the sun was bright and low in the sky so made driving difficult at times. I parked on the driveway of Anne's house, as she had directed me to. This made it easier for Anne to get out of the vehicle. After turning the engine off I opened the passenger door for Anne and retrieved her walker from the boot of the car. Anne passed the front door keys to me and I unlocked it for her. Anne went inside and headed straight for her armchair in the living room. I collected her bags of shopping from the boot of my car and put these in Anne's kitchen, checking first that this would be okay with her. I stayed for 30 minutes, recording a conversation with her, completing post-data collection consent and agreed that I would be in contact to show her the photographs that I had taken and to get her signed consent for me to use these.

My own reflections on the day

During the car journey back to the University I used the time to record my reflections on what I considered to be key moments during the day:

1. Anne appeared to rely upon me to open and hold doors for her during the course of the day, to find things on shelves, and to check prices of items for her. In doing these things for Anne it spared her from having to expend further effort and time. I wonder how Anne would have coped had she been on her own in the shops? Would she have visited the same shops, the same number of shops, would she have asked someone else for assistance?
2. Anne showed concern with looking like a thief – calling out in the shop to staff "I'm only putting that in my bag until I get to the till". I wondered whether this was something that Anne had experienced previously, or whether she had seen, heard or read about something similar happening to somebody else. Searching through my own memory I seemed to recall reading a newspaper article of something similar happening whereby an older adult was accused of stealing.
3. Anne said to me that if that she wasn't so tired then she would spent longer browsing through the clothes and scarves in the high street clothes shop. On reflection, I wondered again whether Anne was trying to explain her behaviour towards the shop assistant. It was clearly a moment of frustration and the shop assistant did not seem overly helpful with her suggestions. Did Anne feel threatened by the options of paying extra for delivery? Or did she sense condescension in the shop assistant's tone of "look online"? Did this highlight something Anne could not do, a loss of touch with the modern world? Or simply frustration at the whole episode and of feeling like she had let down her granddaughter?
4. It felt strange to be hanging back to observe conversation at times during the day. I felt an urge to want to see Anne as she would normally be in interactions, not attempting to

assert my own control or speak for Anne. Reflecting on this I may have appeared a little odd. What did people think of me? Was I seen as Anne's grandson? Nephew? Great-nephew? Carer? Friend? Would anyone suspect Researcher?

5. Anne's eyesight seemed to cause problems throughout the day leading to Anne becoming frustrated with herself. Acknowledging that speed was of the essence given my expectation formed from previous conversation that Anne's back would sooner or later cause her pain I acted to help Anne look for items on the shelves in the shops that we visited. For Anne, having to use the magnifying glass caused a knock-on effect of extending the time it took her to accomplish tasks and therefore raising the likelihood of pain becoming a problem for her. This was central to coping with co-morbidity; adapting to one may have repercussions to coping with another health concern.
6. In terms of co-morbidity; reflecting on Anne's notion of her heart being her priority health concern. On a day to day basis the symptoms of her heart problem remain invisible and seem to be coped with. The threat underlies the condition, but does not present itself on a day to day basis as pain and deteriorating sight do. Understandably, Anne considers that her heart problem as having had the potential to kill her twice over, firstly from the original chest pain and struggle to breath but then also secondly from the infection that she contracted whilst in hospital. The leaking wound is an ongoing concern, yet one that is managed by visiting nurses. Perhaps it is this ongoing treatment, the visible wound, the remembered risk to life that maintains Anne's concern and prioritisation. Furthermore, the heart has symbolic value.



Ageing with chronic pain: promoting age-friendliness in rural areas

Summary Report

Contents

Key recommendations of report	ii
Introduction	1
What did we find out?	3
a. What is age-friendly about rural areas?	3
b. Community support and health services	3
c. Social participation	4
d. Outdoor spaces and buildings	5
e. Housing	6
f. Transportation	7
g. Communication and information	7
h. Civic participation and employment	8
i. Respect and social inclusion	9
Discussion	10
Conclusions/recommendations	10

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Key recommendations from this report:

One size does not fit all. From the discussion we make the following key recommendations:

- Housing, service and care providers need to work closely with particular communities to identify local needs and to tailor interventions to suit their circumstances.
- Providers and communities need to work together to identify existing resources, including human and environmental, that can support age-friendliness.
- Age-friendliness needs to be considered across the generations, and the life-course.
- Consideration needs to be given at the outset to issues of sustainability, in the short, medium and longer term.
- A clear evaluation plan needs to be put in place, with objectives identified.

Introduction

Background

The Research Institute for Primary Care and Health Sciences at Keele University and the Beth Johnson Foundation (BJF) co-hosted a stakeholder engagement workshop to share the results of two research projects. The research from Keele University explored personal experiences of living with chronic pain, pain of three or month duration, among rural dwelling older people. The research from BJF examined community assets within rural areas to promote healthy, age friendly communities. Both projects were conducted between years 2012 to 2015 in the Staffordshire Moorlands, which provided the setting for the workshop.

Age friendly is a concept developed by the World Health Organisation to assist cities and communities in planning for ageing populations. The aim of the age-friendly concept is to enable older people:

“...to live in security, enjoy good health and continue to participate fully in society”¹

Chronic pain is highly prevalent in older age; population survey data suggest that as many as 50% of people aged over 75 years of age experience chronic pain (England only)². Thus, age-friendliness in terms of people living in chronic pain is something that needs to be taken into account when considering community development. Furthermore, the focus of previous age-friendly research has been on urban areas, and the challenges facing rural areas have been under-researched despite rural areas having higher proportions of older people living within them than urban areas.

Objectives of the workshop

- **To share** the results of the research
- **To raise awareness** of the challenges and successes of older people in rural areas
- **To engage** a diverse audience in discussion about age-friendliness of rural areas
- **To explore** solutions and prioritising of age-friendly problems within rural areas.

What did we do?

A total of 28 people took part in the workshop. A diverse range of organisations were represented: Age UK North Staffordshire, Your Housing Group, Moorlands Homelink, the Royal Voluntary Service, Staffordshire County Council, and the Arthritis and Musculoskeletal Alliance. Members of the public and research participants also took part.

The results of research were shared through talks and interactive visual displays. Over the course of four hours, with a break for lunch, participants discussed the eight features of age-friendliness: community support and health services, social participation, outdoor spaces and buildings, housing, transportation, communication and information, civic participation and employment, and respect and social inclusion³. Three questions were asked of each age-friendly feature (housing is used as an example here):

1. What is age-friendly about rural areas in terms of *housing*?
2. What are the challenges for *housing* in rural areas?
3. What are the priorities/solutions for *housing* in rural areas?

The questions were selected to replicate similar work undertaken in Canada⁴. Discussion notes were recorded throughout using post-it notes; these were placed onto a table display.

A selection of images created during the workshop:



What did we find out?

In the following sections the recorded information from discussion is presented. At the beginning of the workshop participants were asked to discuss what age-friendliness meant in a rural context; this is where we start the summary of results and then discussion relating to each of the age-friendly features is presented.

a. What does age-friendly mean in a rural context?

The key words from the discussion of what age-friendly means in a rural context are presented on the front page of this summary report¹. Participants identified a sense of community as central to promoting age-friendliness in rural areas. Community was described in terms of a community spirit, being self-sufficient, of sharing close-knit relationships with other residents, having good neighbours, helping each other out, and some identified a specific farming community. Participants also identified the sense of belonging that rural areas provided. Living in safe, secure housing and in areas with low crime rates were recognised. The provision of local services and businesses were identified as age-friendly features in rural areas, including: General Practice (GP) services and pharmacies, social care, friendship groups, Post Offices, shops, community transport (e.g. minibus), and mobile libraries.

b. Community support and health services

1. What is age-friendly about rural areas in terms of community support and health services?

- Community cohesion based on small scale communities and close-knit relationships
- Resources of support included family, friends, and neighbours
- Support from the third sector (e.g. adult learning, activity groups, community alarm services)
- A local GP service was felt to be important; specifically, a GP that was integrated into the community
- Access to information has been enhanced through involvement in Clinical Commissioning Groups (CCGs)
- Good transport links were also acknowledged as positives.

“Health and support services are vital to maintaining health and independence in the community”³

2. What are the challenges for community support and health services in rural areas?

- Not all rural communities share close-knit relationships
- Lack of facilities in rural areas

¹ Produced using Wordle: <http://www.wordle.net/>

-
- Physical and social isolation leading to difficulty distributing and accessing information
 - Rural GPs important sources of information but were perceived as too busy
 - Knowing where to access information may be challenging and older people may be unwilling to ask for help
 - Limited access to internet due to service provision but also technical proficiency
 - Paper-based leaflets may be ineffective (unread or unnoticed)
 - Many older people rely on bus services to access community and health services
 - Distances between rural locations mean health, social and third sector staff face difficulties and are limited in the numbers of people they can visit
 - Rural older people lack opportunities to participate in social activities in evenings
 - Funding for service providers and a lack of inter-agency collaboration posed threats to the sustainability of services
 - Recruiting volunteers made difficult due to the ageing rural population meaning many volunteers would be older people themselves
 - Bureaucracy was identified as a challenge; top-down politics posed a threat to community spirit.

3. What are the priorities/solutions for community support and health services in rural areas?

- To implement strategic collaborative multi-agency working (e.g. public, private, third sector) that focuses on long term planning and that is supported by local community forums
- To develop low level early interventions
- To promote a culture of “from cradle to grave responsibility”
- To seek devolution of power to local levels, including budgets, to overcome bureaucracy and respond to needs of community
- To increase social media access and use.

c. Social participation

1. What is age-friendly about rural areas in terms of social participation?

- Community-wide events bring all ages together (e.g. village fetes)
- Older community residents share a commitment to the local community and offer a broad range of skills
- Opportunities for inter-generational working

“Allows older people to continue to exercise their competence, to enjoy respect and esteem, and to maintain or establish supportive and caring relationships”³

-
- Informal social contacts and traditional organisations including Women’s Institute, Mothers Union, and church groups provided social opportunities
 - Rural areas perceived as places in which people of different ages, interests, backgrounds, could be engaged to celebrate difference.

2. What are the challenges for social participation in rural areas?

- Transport provision and distances to cover
- Access to information
- A lack of helpers for community events or a lack of funding to paying people to help
- A decrease in the number of local activists to support local views (i.e. people who would take a lead in the community)
- A lack of collaboration between agencies (public, private and third sector)
- Some residents may not want to participate in social activities; this should be respected
- Older people not engaged in discussion/development around age-related issues
- Identifying older people as a challenge may cause offence.

3. What are the priorities/solutions for this feature in rural areas?

- To encourage better co-ordination and collaboration between multiple agencies
- To provide better and more accessible information about social activities
- To engage older people on ground level in community development and for the community to define priorities
- To enhance awareness of care needs (e.g. chronic pain) in order to improve sign-posting services
- To facilitate an individual- and community-centred asset based approach (i.e. matching people to available services).

d. Outdoor spaces and buildings

1. What is age-friendly about rural areas in terms of outdoor spaces and buildings?

- Outdoor space is available in abundance and is richly diverse
- Outdoor space perceived as picturesque
- Providing access to fresh air and opportunities for physical activity that promoted healthy ageing
- Outdoor spaces have a role in good mental health
- Outdoor space helps create a sense of belonging and attachment to the environment.

“The outside environment and public buildings have a major impact on the mobility, independence and quality of life of older people”³

2. What are the challenges for outdoor spaces and buildings in rural areas?

- Rural areas may not be suitable for everyone
- An attitude of complacency; assuming that positive characteristics of rural places would simply continue to exist and always be there
- Outdated ideas of what rural *should be* could present challenges in terms of future planning and development
- Some buildings may be derelict and therefore not age-friendly

3. What are the priorities/solutions for outdoor spaces and buildings in rural areas?

- To provide suitable, affordable and accessible housing
- To increase opportunities for home adaptations to enable older people to age in place
- To ensure facilities are sustainable
- To improve accessibility of walking routes such as canal paths.

e. Housing

1. What is age-friendly about rural areas in terms of housing?

- Rural areas perceived as picturesque places for homes
- Rural communities perceived as safer and more secure than urban communities
- Some communities enjoy a strong community spirit.
- Rural spaces may also be pet friendly.
- Rural housing considered to be structurally reliable

“Housing and support that allow older people to age comfortably and safely within the community to which they belong are universally valued”³

2. What are the challenges for housing in rural areas?

- New rural housing developments perceived by rural residents as negative
- Buildings are old and may be energy inefficient
- A lack of space for building
- The rural housing market perceived to be disjointed in terms of supply and demand (as with wider UK)
- Houses in rural areas are spread out leading to geographical isolation
- Problems of identifying property were recognised as a result of the use of traditional addresses and postcodes, which may cross two or more county boundaries.

3. What are the priorities/solutions for housing in rural areas?

- To promote new housing developments as these may enable older residents to remain in rural areas
- To engage with older people to ensure housing interventions are not pre-emptive
- To help support integration of assistive technology into daily lives of older people
- To support winter fuel payments as these are important in relation to energy inefficient housing
- To identify opportunity for reserving housing stock / buildings within the community.

f. Transportation

1. What is age-friendly about rural areas in terms of transportation?

- | | |
|---|--|
| <ul style="list-style-type: none">• The current council funded car sharing scheme• Informal car sharing (i.e. giving lifts to each other)• Community mini-bus service• Dial-a-ride in the Staffordshire Moorlands• Churches perceived as resources for organising and communicating opportunities for transportation. | <hr/> <p>“Transportation, including accessible and affordable public transport, is a key factor influencing active ageing”³</p> <hr/> |
|---|--|

2. What are the challenges for transportation in rural areas?

- Over-reliance on volunteers being available to provide transportation
- A decline in church attendance made these places less effective at providing opportunities and information for transportation
- Different seasons posed different risks (e.g. winter conditions)

3. What are the priorities/solutions for transportation in rural areas?

- To maintain the car sharing and community transport schemes
- To coordinate minibus shopping trips and promoting these trips as social opportunities compared with going in own car (may increase demand for such services which is linked to funding)
- To improve access to benefits such as: disabled parking through the blue badge scheme and Motability.

g. Communication and information

1. What is age-friendly about rural areas in terms of communication and information?

- | | |
|--|---|
| <ul style="list-style-type: none">• Council and church newsletters• Community notice boards (shops, post offices, and churches)• Local newspapers• Local radio stations (however, the popularity of these service were perceived to be dwindling) | <hr/> <p>“Staying connected with events and people and getting timely, practical information to manage life and meet personal needs is vital for active ageing”³</p> <hr/> |
| <ul style="list-style-type: none">• The mobile library• GP service with pharmacies located in easy reach• Access to information technology provided access to social networks (e.g. smart phones, tablets, laptops)• The postman/woman plays important dual roles: service provider for customers and acting as a ‘look out’ on to the community for customers. | |

2. What are the challenges for communication and information in rural areas?

- Tensions between third sector providers competing for the same funding opportunities rather than being encouraged to work collaboratively
- Barriers to the use of information technology
- Many services provided online payment facilities only, which excludes people who cannot or will not use the internet.

3. What are the priorities/solutions for communication and information in rural areas?

- To ensure organisations maintain flexibility and consult with older people about what form of communication works best for them
- To encourage third sector organisations to work collaboratively between each other and with statutory providers.

h. Civic participation and employment

1. What is age-friendly about rural areas in terms of civic participation and employment?

- Social participation and the inclusive activities between social groups
- Rural older people perceived to have a strong civic pride and ethos defined by local "patriotism"
- The smaller size of rural communities (compared with towns and cities) enables voices to be heard.

"Options for older people to continue to contribute to their communities, through paid employment or voluntary work if they so choose, and to be engaged in the political process."³

2. What are the challenges for civic participation and employment in rural areas?

- Enabling older people to contribute with skills, experience and knowledge
- A lack of funding to support services that promote and facilitate participation
- Less structure to activities due to small scale reduces opportunity for funding
- Less opportunity for work in rural areas.

3. What are the priorities/solutions for civic participation and employment in rural areas?

- To encourage age-friendly businesses
- To alter the culture and not let age be a defining feature in employment
- To integrate generations rather than segregate.

i. Respect and social inclusion

1. What is age-friendly about rural areas in terms of respect and social inclusion?

- Potential for intergenerational work and events
- Residents hold historic family ties to an area
- Potential to be accepted as part of a close-knit community
- Stable populations facilitate social inclusion
- Shared links between schools and social groups (e.g. luncheon clubs); this includes schools inviting older people to support the library, reading to children, and school governor roles.
- Use of the internet can increase feelings of social inclusion if it is used
- Older people have skills, experience and better health that can benefit voluntary roles

"The extent to which older people participate in the social, civic and economic life of the city is also closely linked to their experience of inclusion."³

-
- Voluntary services can provide opportunities for older people in rural areas
 - Voluntary roles can have positive impacts on confidence and self-esteem.
2. What are the challenges for respect and social inclusion in rural areas?
 - Lack of respect for older people in which the opinions of older people are not valued
 - Older people experience difficulties accessing existing groups, which exacerbated feelings of exclusion
 - Negative responses accepted as a fact of ageing rather than being challenged
 - Activities and roles imposed rather than selected by some older people
 - Wider society perceived to be changing with a decrease in respect generally.
 3. What are the priorities/solutions for respect and social inclusion in rural areas?
 - To challenge the perceived role of older people in rural communities
 - To proactively seek older people for voluntary roles (funding likely to be available for this)
 - To promote a positive image of ageing in society based on knowledge and skills
 - To deliver public health messages in schools to raise awareness, respect and understanding of older people
 - To encourage collaboration between schools, third sector and NHS (e.g. GPs)
 - To focus on utilising existing resources
 - To create opportunities for older to continue education.

Discussion

A strong sense of rural community spirit underpinned many of the age-friendly features, as defined by the World Health Organisation. Discussion of rural age-friendly features highlighted the blurring of boundaries between different features e.g. transport was identified as a challenge for accessing community support and health services, access to information as a challenge to social participation. Key age-friendly priorities focused on improving engagement with older people; encouraging use of social media; proactively seeking older people to provide voluntary roles; encouraging inter-agency collaboration between sectors (public, private and third) to improve efficiency and effectiveness; and to help maintain existing projects that were working well (e.g. car sharing schemes). Furthermore, as rural populations are changing complacency about community strengths such as community spirit should be avoided. For instance, the lack of affordable homes and employment opportunities may result in the fragmentation of rural communities and family ties. The change may result in older generations left without access to support networks that they may have been looking to rely upon.

Conclusion/recommendations

One size does not fit all. From the discussion we make the following key recommendations:

- Housing, service and care providers need to work closely with particular communities to identify local needs and to tailor interventions to suit their circumstances.
- Providers and communities need to work together to identify existing resources, including human and environmental, that can support age-friendliness.
- Age-friendliness needs to be considered across the generations, and the life-course.
- Consideration needs to be given at the outset to issues of sustainability, in the short, medium and longer term.
- A clear evaluation plan needs to be put in place, with objectives identified.

References

1. World Health Organisation (WHO): www.who.int/ageing/projects/age_friendly_cities/en/
2. Bridges, S. (2012) Chapter nine: chronic pain. In *Health Survey for England 2011: Health social care and lifestyles*. Accessed online (June 2015) www.hscic.gov.uk/catalogue/PUB09300
3. WHO: http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf
4. Canadian Territorial Ministers report: www.swsd.gov.nl.ca/grants/pdf/af_rural_remote_guide.pdf

Appendix 18

Thesis outputs: presentations and plan for publications

Oral presentations

Kingstone, T., 2013. *Using ethnographic methods to explore the experiences of rural older people*. Primary Care and Health Sciences Postgraduate Symposium. Keele University, UK. May 2013

Kingstone, T., 2013. *Using ethnographic methods to explore the experiences of rural older people*. Emerging Researchers in Ageing Gerontology 2013: Challenging Futures. Oxford University, UK. September 2013

Kingstone, T., 2013. *Ageing well with chronic pain in rural environments*. Centre for Social Gerontology: Emerging and Established Researchers in Ageing. Keele University, UK. December 2013

Kingstone, T. 2014. *Ageing well with chronic pain in rural environments – preliminary findings from an exploratory mixed methods study*. Primary Care and Health Sciences Postgraduate Symposium. Keele University, UK. May 2014

Kingstone, T. 2014. *Ageing well with chronic pain in rural environments – preliminary findings from an exploratory mixed methods study*. British Society of Gerontology 43rd Annual Conference. Southampton University, UK. September 2014.

Kingstone, T. 2014. *Ageing well with chronic pain in a rural environment – findings from a UK-based exploratory mixed methods study*. Canadian Association on Gerontology Annual Conference. Niagara Falls, Canada. October 2014.

Kingstone, T. 2015. *Understanding experiences of later life chronic pain in rural areas: implications for primary care management and services*. Primary Care and Health Sciences Postgraduate Symposium. Keele University, UK. May 2015

Poster presentations

Kingstone, T., Bernadette, B., Chew-Graham, C., 2014. *Ageing well with chronic pain in rural environments: using exploratory ethnographic methods*. 8th International Conference on Cultural Gerontology. National University of Ireland, Galway. April 2014.

Kingstone, T., Bernadette, B., Chew-Graham, C., 2016. *Exploring factors that support rural older adults with chronic pain and maintain quality of life: a mixed methods study*. Society for Academic Primary Care Annual Conference. Dublin, Ireland. July 2016.

Kingstone, T. 2016. *Me, myself and PPIE: sharing the Ph.D journey with a project advisory group*. Research User Group 10 year anniversary conference, Keele University. September 2016.

Plan for peer-review publications from thesis

Paper 1:

Proposed title: Rural older adults' experiences of chronic pain: a review of the literature.

Content: A critical review of the literature applying qualitative methods on rural older adults' experiences of chronic pain. To identify gaps and make recommendations for future research.

Target Journal: Ageing and society, Age and ageing, Journal of aging and health

Paper 2:

Proposed title: Ageing well with chronic pain in rural environment

Content: A focus on ageing well and the quality of life findings. Factors that support ageing well, how is it achieved what does it mean? Control, autonomy, self-realisation, pleasure, resources, adaptations, activities and opportunities. Carrying-on, living inwards and outwards.

Target journal: Age and Ageing, Ageing and Society, Journal of aging and health

Paper 3:

Proposed title: Exploring experiences of chronic pain among older adults: mixing methods, modalities and mobilities

Content: A focus on the methods used: interviews, ethnographic fieldnotes, photographs, go-along. Integration from start to finish (epistemology, fieldwork, analysis, to presentation of findings). Provide a case-study example of the mixing of methods.

Target journal: Journal of mixed methods, qualitative health research

