How do stroke survivors self-manage their life-career transitions?

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Glossary of acronyms

ABI	Acquired brain injury
AGCAS	Association of Graduate Career Advisory Services
BNIM	Biographic narrative interpretative method
BSRM	British Society for Rehabilitation Medicine
CBT	Cognitive behaviour therapy
CSM	Career self-management
CVA	Cardiovascular accident
CV	Curriculum vitae
DOTS	A tool for 'joining the dots': an analytical tool used to see where a client is in the career self- management process. It can also be used for career planning and focuses on four cyclical aspects of the career learning process: decision learning (D), self-awareness (S) , opportunity-awareness (O) and transitions (T).
DWP	Department of work and pensions
ESSVR	Early stroke specific vocational rehabilitation
FA	Framework analysis
GMC	General Medical Council
HR	Human Resources
ICF	International Classification of Functioning, Disability and Health
InPIN	When interviewees are observed by the interviewer to be near the feeling state that they were in, during the past incident being recalled
IPA	Interpretative phenomenological analysis
IT	Information Technology
MESH	Medical subject headings
NHS	National Health Service (UK)
NICE	National Institute for Health and Care Excellence
PABIR	Post-acute brain injury rehabilitation
PIN	Personal incident narrative
QoL	Quality of life
RCT	Randomised control trial
RTW	Return to work

SA	Stroke Association
SM	Self-management
SQUIN	Sole question aimed at inducing narrative
SR	Stroke rehabilitation
SSMP	Stroke self-management programme
SSSMP	Supported stroke self-management programme
SSVR	Stroke specific vocational rehabilitation
TDA	Training and Development Agency for Schools
TBI	Traumatic brain injury
VRA	Vocational Rehabilitation Association
WHO	World Health Organisation

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Abstract: Stroke survivors‘ self-management of life-career transitions

Background

Using the metaphor of life-thread, medical sociologists have drawn attention to the biographical disruption caused by stroke. However, there is little literature examining stroke-survivors' (approaches to life-career transitions after acquiring a disability. The research presented in this paper sets to address this gap.

Methodology

Interviews were conducted with four survivors of disabling strokes using the biographic narrative interpretative method (BNIM). Participants of either sex aged 31-70 years were 8 years or more post stroke and had persistent physical and cognitive symptoms. They were former professionals and had returned to their former work role, changed career direction, or decided not to return to paid work (RTW). The data were analysed combining interpretative phenomenological analysis (IPA) and framework analysis (FA).

Findings

Two major themes were identified. First, stroke-survivors experienced a number of transitions, which could be summarized as *'Before'*, *'Becoming'* and '*Beyond'* expressing concern about who their future self would be. Rather than progressing in a linear fashion, they 'mini-cycled', with self-awareness, and readiness for change determining self-management of their individual journeys. Second, stroke-survivors maintained commitment to 'work,' but views on what constituted 'work' changed over time. Retirement did not mean disengagement with 'work', rather the purpose of 'work' was redefined to incorporate portfolio careers, civic responsibilities, volunteering, family roles and study.

Conclusion

These findings suggest that stroke rehabilitation (SR) programmes need to adopt a wider perspective of life-career that reflects stroke-survivor's interpretation of 'work'. Given the cyclical nature of their journeys, interventions need to be flexible enough to support those in transition.

1: Introduction to thesis

Research context

Stroke is a common neurological disease affecting more than 100,000 people each year in the UK (Stroke Association, 2017:9). Using the metaphor of life-thread, researchers have drawn attention to the biographical disruption caused by stroke (Ellis-Hill, Payne and Ward, 2008:154). The difficulties that stroke-survivors have in transitioning back to their career are not limited to physical disabilities and emotional difficulties. For instance, some stroke-survivors report experiencing fragmentation of self (Ellis-Hill and Payne, 2000) and it was Ellis-Hill, Payne and Ward's (2008:154) recognition of the difficulties related to "*finding the new me*" which resonated with my own experience, and specifically their call for "*more detailed investigation into the ways people approach life transitions after acquired disability*" that influenced the design of this research.

Stroke-survivors experience many losses, including cognitive capacity, even after successful clinical recovery, which can affect the transition process (Jokinen et al., 2015). Loss and the reconstitution of identity and life's meaning are, therefore, central to my research.

Life-career development is a pivotal part of transitioning to their new normal. For stroke-survivors, self-management (SM) is a key strategy in making the most effective use of care resources available. It is conceived as a means of supporting and advising individuals so that they can be independent to manage their own health and wider lives. Self-management programmes (SMPs) tailored to the needs of stroke-survivors are limited. They do not currently encompass self-management of life-career, leading to the central research question: 'How do stroke survivors self-manage their life-career transitions?', which was derived from both personal experience of stroke and professional experience of life-career management.

Having outlined the problem under investigation in the thesis, what follows is the literature review, as focussed on the substantive areas outlined here, including notions of career self-management (CSM)and its role in stroke rehabilitation (SR).

2: Literature review

Introduction

This chapter provides a critical review of literature relating to this study. It initially explains how the reviews were conducted, before summarising the findings. No papers were identified about stroke-survivors self-management of their life-career transitions.

Strategy for all literature searches conducted

The chosen search terms were variations on the concepts within the study title. In all versions of the study title, it is possible to identify four interrelated concepts: self-management (SM), which has a different meaning in healthcare to life-career counselling (see chapter three), life-career and transitions. The first search was undertaken in 2015 and related to the study title and recruitment criteria at that time (see below), which were later refined. However, since then, many ongoing searches have been undertaken due to the changing literature in both the areas of life-career and stroke self-management (SSM). The latter now encompasses stroke-specific vocational rehabilitation (SSVR) and SM has also been renamed supported stroke self-management (SSSM) in recent guidelines (Nice, 2023, ILAS 2023). Additionally, electronic searching of the internet using key words was periodically conducted as well as hand searches of books, papers and information obtained at courses and conferences. The literature discussed in this chapter presents the most relevant sources from a combination of the above search strategies and the research questions that emerged from this are highlighted in bold.

Database results, search one

The original search was undertaken in 2015 in relation to the study title at that time, which was later refined: '**How do stroke-survivors self-manage their involuntary career transitions?**' This returned 19,400[1] studies by relevance; the majority of which were healthcare research papers dominated by quantitative studies. For example, Teasell, 2003. The 19,400 papers were reduced to 11,500 by

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[1] Although it is not the norm for social science research to quote statistics, a decision was taken to record the number of 'hits' for each search, to provide a detailed evidence base for the research's main audience: Health and Social Care practitioners.

limiting publication date to the last 10 years. Adding an age limit of 25-65[2] further reduced the number of papers to 486. The results were scrutinised, and the following conclusions were made. The few qualitative studies that had been conducted tended to include the views of other stakeholders such as carers, other members of the family, employers or rehabilitation professionals (Coole et al., 2012). For example, Lundqvist (2012) looked at the views of stroke-survivors, but this was done in the context of a focus group that included occupational therapists and psychologists, so foreclosing the ability of stroke-survivors to express themselves freely. Similarly, Macaden et al. (2010) used a case study approach that was not exclusive to stroke-survivors and, through triangulation, included interviews with job coaches and co-workers. However, two stroke-survivor rehabilitation stories were located (Cant, 1997 and Jones, 2004) and a few books had been authored. For instance, Garrison (2012) and McCann (2006). There was a dearth of rehabilitation literature from a long-term stroke-survivor perspective, which stimulated an interest in pursuing this line of enquiry, specifically investigating the first two research questions: **How do the stroke-survivors' experiences and expectations vary through time?** And **What does career mean to the stroke-survivors at different stages of the transition process?**

Summary of hand search one

By hand searching, I found just one example of stroke transition research conducted over time. However, as outlined, the methods used mean that Kearney's (2009) findings should be treated with caution. Kearney collected stories of post-stroke transition from stroke club members in Australia. However, there was a lack of methodological detail in relation to sampling, inclusion and exclusion criteria, and the number and duration of interviews. Some of the narratives were also told by family members, on behalf of the stroke-survivors, and others were described as *"synthesised into a single narrative to elucidate patterns of experience"* (2009:9), which is a good example of healthcare

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[2] The initial age range was later extended due to recruitment difficulties, requiring an ethical amendment, which was granted (ERP 1368).

professionals failing to understand how to work in a person-centred way. Further, Kearney admits providing the stroke-survivors with relevant transition concepts, such as change and moving on, during her conversations. This could be viewed as leading the 'interviews'.

Other literature focused on service provision (Playford et al., 2011) - in relation to this, stroke self-management programmes (SSMPs) were reviewed.

Although there are a wide range of stroke self-management programmes (SSMPs) in healthcare, dedicated SSMPs were rare. The only examples found were the Stepping Out programme, later renamed "Bridges" (Jones et al., 2013, 2016), and the Restore4Stroke SM intervention (Tieleman et al., 2014), neither of which encompassed specialist advice on career self-management (CSM). As Jones observed (2008: 540), the limited number of dedicated SSMPs is because stroke care in general focused on the early, acute phases of stroke, rather than the process of readjustment required upon returning home. To date, despite new SSMPs being developed, this continues to be the case (see recent search results). Given the magnitude of the challenge of adapting to how one's disabilities can affect career choice, this gap needed addressing. Alasweski et al. (2003:49) acknowledged this perspective, by reporting that younger stroke-survivors felt that they needed care at this stage "*tailored to their specific needs such as going back to work".* The initial focus of this research was intended to be young stroke-survivors, but Ellis-Hill, Payne and Ward (2008) concluded that stroke rehabilitation (SR) is a long-term process. Drawing on the researcher's previous experience as a life-career counsellor, it occurred to her that this process may include several intermediary steps including, for example, re-engagement with former interests/family roles or voluntary work. Each of these stages, as defined by the seminal work of Super[3] (1957, 1976, 1980, 1996), are said to form

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[3] Super's (1976) definition of career. Super described career as being lifelong, person centred and including "*the sequence of occupations and other life roles which combine to express one's commitment to work in his or her total pattern of self-development*" *(*in Chen*, 1998:438).* This approach to career has been adopted for this research and is pertinent to interpretation of the data. See '*Discussion'* for Super's full definition.

part of the life-career development process, leading also to Savickas (1997) extending his later life-space theory[4].

Databases search two and three

With a life-course perspective in mind, a further search was conducted on stroke+ employment. This search returned 208 papers when the previous age and date limiters were added. Changing stroke for CVA (cardiovascular accident) or ABI (acquired brain injury)+ career transitions returned 15,536 articles containing those key words, while focussing on 'involuntary career transitions' returned 15,654. Adding age filters reduced that to 1,757. The researcher was still unable to find literature that answered the central research question and because Ellis-Hill, Ward and Payne's (2008) life thread approach to SR appreciated that identity and self, grow and expand through discursive opportunities, she began focussing on narrative research, starting with life-career self-management. She was keen to explore the third research question: **How do stroke-survivors perceive and manage their transition/s to an ordinary life?**

Hand search two

The researcher was already familiar with CSM literature and reviewing more recent papers revealed that these increasingly focus on narrative approaches, for instance Young and Collin (2004). However, this approach is not reflected in Western SR practice, as noted by Ellis-Hill, Ward and Payne (2008), so the next round of literature scoping examined stroke self-management (SSM) literature from East Asia.

Hand search three

In an attempt to further understand the existential/spiritual aspects of stroke, Google Scholar was searched for Stroke+ existentialism and Stroke + Buddhism. The former led to the discovery of Chan et al.'s body-mind spirit model in health (2006), which replaces a focus on self-efficacy with

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[4] Career Adaptability: An Integrative Construct for Life-Span, Life-Space Theory, Savickas (1997:247) suggests that *"career adaptability should replace career maturity as the critical construct in the developmental perspective on adaption. Moreover, adaptability could be conceptualised using developmental dimensions … namely planning, exploring and deciding"*.rea

spirituality. Spirituality is defined as *"that aspect of humanity that refers to the way individuals seek meaning and purpose by connecting to the moment, to self, to others, to nature, to significant experience, or to the sacred"* (Consensus Conference 2009, in Chow and Nelson-Becker, 2010). The goal of the mind-body-spirit approach presented by Chan et al. (2006), and upon which Chow's (2015) SR approach is founded, is to empower the individual through spiritual intervention, which *"aims at attaining peace of mind, despite physical deterioration, through facilitating the search for meaning, especially during the most teachable moments of sufferings and losses in life"* (Chan et al., 2006: 825). The more holistic approach adopted in eastern interventions, in which there is a stronger emphasis on *"the prevention of sickness and the promotion and balance of health*" (Chow et al., 2010:316) aligns with the narrative-based life-career interventions, which were starting to incorporate spirituality. For example, Hansen (2001).

The process of transition engages body, mind and spirit in a growth/transformation process that encourages the development of resilience. Growth, transformation and resilience are other themes that run through the wider literature and that are related to the search for meaning (Nelson- Becker and Canda, 2008). The search for meaning/purpose is a central theme in all the literature related to self/identity and, as such, it crosses several disciplines (Frankl, 1959-2004).

Chan et al. (2001) state that their approach has high efficacy in healthcare and has been used in a number of situations involving 'trauma'/'crisis' with individuals with a range of serious health conditions. 'Trauma' changes a survivor's perspective of time, enhancing their awareness of the temporality of life. This highlighted the need to take a long-term view of the way stroke-survivors self-managed the transition to their new normal, which influenced the age range of the stroke-survivors sampled for the research.

It was also noted that an emphasis on personal development was lacking in the approach used by some medical and social care practitioners, who appear to focus on the stroke-survivor out of context, presume ‘expert’ status and interpret rehabilitation as a return to work (RTW) in the short-term. To contextualise the SR literature, the concept of SM was further considered. In CSM, it generally denotes a career managed by an individual rather than an organisation (Greenhaus and Kosek, 2010). In all contexts, the SM of transitions involves making a range of adjustments and changes, both in the internal and external world (Schlossberg, Waters and Goodman, 1981). Existential theory (Frankl, 2004) and some models of transition (Adams et al., 1977) consider the way in which individuals respond to those changes.

As well as the paucity of literature exclusively focussing on stroke-survivors’ perspectives, those papers that did adopt a qualitative approach tended to be limited to stroke-survivors who were two to ten years post hospital discharge. The only exceptions to this were Kitzmuller et al.’s (2012) work, which focused on how the invisible consequences of stroke affected couple and family relationships, and Murray and Harrison’s (2004) IPA study of stroke-survivors’ experience of stroke, which highlighted some of the difficulties, but failed to explain how those stroke-survivors move on; that is the process of self-managing their life-career transitions.

Answering the central research question will contribute the perspectives of western stroke-survivors to the existential dimensions of the SM process involved in “*finding the new me”* (Ellis-Hill, Ward and Payne,2008). Furthermore, it will offer a longer-term perspective of the transition process, which, as the pilot study suggested, consists of lots of small transitions. Negotiating changed family relationships was just one of many transitions the pilot stroke-survivor made.

Stroke-survivors experience many losses, including cognitive capacity, even after successful clinical recovery, which can affect the transition process (Jokinen et al., 2015). Loss and the reconstitution of identity and life’s meaning are, therefore, central to this research.

Life-career development is a pivotal part of transitioning to the new normal. Both identity theory research and recent clinical guidelines (Nice, 2023, ILAS, 2023) now recognise that personal development is ongoing for stroke-survivors. Therefore, rehabilitation and ‘supported’ self-management needs to extend beyond the discrete period immediately after stroke. This returns us to the concept of SM and raises anther research question: **What indicates stroke-survivors' readiness for transition? .**

SM is a key strategy in making the most effective use of care resources available to stroke-survivors. It is conceived as a means of supporting and advising individuals so that they can be independent to manage their own health and wider lives (Barlow et al., 2002). Within the process, the guidance role of rehabilitation professionals is indicated by the new 'supported' prefix being added to SSM programmes, although SMPs tailored to the needs of stroke-survivors remain limited and still do not encompass SM of life-career.

Database results, searches two and three

The database searches reported next are the most recent two. A second search was run as the first revealed some new terminology, which was added to the key words used in the first search. In both searches, a strategy was developed using key words from the new study title as the basis of the searches: **Stroke survivors self-management of their life-career transitions.**

As previously, the search strategy used Medical Subject Headings (MESH) to focus on relevant papers, as well as free text key words generated from the latest study title. First, the MESH headings "stroke and "stroke rehabilitation" were used and these were combined with the following free text: "stroke* or "stroke survivor*" or "stroke victim*or "post stroke*" or "**cerebrovascular disorder***" OR "**haemorrhage***". This search was run on the core medical databases (Medline, Psycinfo, PsycARTICLES) and yielded 539,367 papers.

Subsequent searches were built up with additional free words: chang* OR transform* OR transition* OR adapt* OR flexib* OR adjust* OR progres* OR grow* OR resilien* OR recov* OR re-orient* OR return* and then finally: normal* OR purpose* OR meaning* OR ordinariness OR work* OR employ* OR career* OR predictability OR certainty OR "normative circumstance*" OR "life-career" OR job* OR employment OR “**job retention**” OR “**work retention**” OR “**employment retention**” OR "**vocational rehabilitation**" OR "**stroke-specific vocational rehabilitation**" OR **SSVR** OR "**stroke specific vocational rehabilitation**" OR “**engagement**” OR “**labour force**” OR “labor force” OR “**occupation***” OR “**vocation***” OR “**workplace***”.

On the core medical databases, this yielded 1,178 results. The same limiters were then applied as in the earlier searches. As SM is a relatively new concept in healthcare, publication dates were limited to the last 10 years and, given the intended audience, peer-reviewed papers was also a limiter. Adding an age limit of thirty-one to seventy, (see recruitment criteria in methodology) and removing duplicate results further reduced the number of papers to 628.

When run on the Philosophical databases (Academic Search Complete and Philosopher’s index), this yielded 531 papers. Limiting publication date to the last ten years, to peer-reviewed, and adding an age limit of thirty-one to seventy, as well as removing duplicate results further reduced the number of papers to 390**.**

Combining all three gave 2,265 results, which was reduced to 2,216 once duplicates were removed. The search results are summarised below.

Database searches 2 and 3 results

As with earlier searches, neither search in 2022 directly addressed the literature review question:

How do stroke-survivors self-manage their life-career transitions? Further, no papers concerning the life-career of stroke-survivors were identified, despite the concepts of SM, career and life being linked in the search terms. This is likely because a common misunderstanding is that many stroke-survivors do not need support with life-career transitions because they already have an established ‘career’ path and so can return to ‘careers’ already established pre-stroke (Culler et al., 2015). This viewpoint fails to account for the fact that stroke-survivors have experienced significant identity changes, meaning that their former ‘career’ may no longer suit them. Additionally, they may not be well placed to cope with employment transitions due to both the sequalae of stroke, such as impaired decision making, and significant changes to the life-career paradigm in recent years, requiring them to have employability skills (see chapter eight).

Studies were excluded if they did not meet the reported research's inclusion criteria, for example when they were not directly relevant to the population included in the reported research. Inclusion criteria were stroke-survivors of either sex aged thirty-one to seventy years, who were at least five years or more post-stroke and had persistent physical and cognitive symptoms, as well as the ability to hear and speak enough to share their narratives and answer questions about them.

A significant number of studies reviewed excluded stroke-survivors with cognitive disabilities and so were not included in the reviews. Stroke-survivors who were less than five years post-stroke was another frequent reason for exclusion in the more recent literature reviews as many studies continued to only report on the recovery of stroke-survivors in the short term, although stroke is recognised as requiring a long recovery period (Culler et al., 2015). The fact that the most research only looks at stroke-survivors up to five years post-stroke is probably because up to the recent NICE (2023) guidance rehabilitation was time limited. However, the researcher wanted to explore: **How stroke-survivors' experiences and expectations of the transition process varied through time?** (a further research question).

Despite being an inclusion criterion for the reported research, the status of stroke-survivors was not used as an exclusion criterion in the literature review, that is whether stroke-survivors have/had a professional or business role. This was because this level of detail was rarely reported in the literature. Given the continuing paucity of relevant literature, excluded papers were still reported on, with caution, if they contained concepts/themes relevant to the reported research.

The following themes were identified in the review: SSMPs, Transitions, Identity changes, return to work (RTW) and 'Work' retention literature; research focused on specific stroke populations (for instance, stroke-survivors from Nigeria), or interventions relevant only to particular stroke-related disabilities or illnesses, like aphasia or Alzheimer's disease. Other papers were either quantitative in nature and concerned with evaluating stroke-specific vocational rehabilitation (SSVR) programmes, IT-related interventions, or professional roles. For instance, one of just three transition papers found concerned the role of nurses in supporting stroke-survivors' transitions from acute care into the community (Camicia et al., 2021) and so it was excluded on the basis that it was not directly related to stroke-survivors.

This review now reports on themes/concepts relevant to the central research question, starting with SSMPs.

Stroke self-management programmes (SSMPs)

There has been a marked increase in the number of SSMPs over the years in which this research has been undertaken, both those that have been developed or are in process. However, as Jones et al. (2016: 478) remarked, SSM "*is still a relatively under-theorised concept".* A good example of this is Jones' (2015) international multi-site pilot trial, which was limited to improving functional outcomes of stroke-survivors. Intervention is by DVD and their paper makes no direct reference to any theoretical basis for SM. However, the use of several different scales to measure outcomes for stroke-survivors suggests a range of theories might apply. A similar lack of clarity applies to Hwang et al.'s (2021:1) systematic review of telehealth SM interventions for stroke-survivors. The support provided is very wide ranging, encompassing *"depression, obesity management, participation, functional mobility and activities of daily living",* but life-career support, which is arguably more relevant to stroke-survivors, is ostensibly absent. A clearer SSM intervention is "MYLAS" (Johnson et al., 2022), which detailed the full development of the programme, including how the team have utilised evidence, theories and patient and public involvement, as well as expertise from the SM of other long-term conditions. 'MYLAS' is "*grounded in the narrative approach and social learning theory"* (Johnson et al., 2022: 1). Of great potential value is the fact that it reportedly tailored to each individual stroke-survivor and the underpinning philosophy is patient-centred, so reportedly one of empowerment. One of the ways the programme is tailored is through an initial, compulsory individual appointment at which the stroke-survivors can *“share details of their stroke privately, for the facilitator to understand any adaptions they might need for the group sessions”* (2022:7). This was reported as valuable, likely *“because it was the first opportunity for the stroke-survivors to discuss this significant event”.* The opportunity for stroke-survivors to have their stroke stories listened to is one that the researcher has already noted to be of importance and she was keen to explore: **What the process of sharing their narratives was like for the stroke-survivors interviewed?** She also built this opportunity into her recommendations, though with a different timing emphasis, starting with the transition from acute care to home, when the RTW issue is first raised. The latter has still not been addressed in any of the SMPs found to date, including ‘MYLAS’, which was designed to address *“feelings of abandonment and providing support later in the stroke journey”* (2022:8). However, the emphasis on later support for stroke-survivors is nevertheless welcomed. It is also important to note that ‘MYLAS’ has yet to be evaluated with a feasibility study.

A new SSMP relating to stroke-survivors with cognitive impairments was also found. However, its focus is limited to stroke-survivors’ *“ability to manage everyday activities such as travel that is essential for participation in society”* (Carlstedt et al., 2017). While this might be valuable for some stroke-survivors looking to RTW, it is insubstantial in relation to their needs. Wolfenden et al.’s research (2009) focused on working age stroke-survivors and highlighted that services to support RTW were meagre and recommended that they be supported in self-managing all aspects of their RTW, while calling for further research to support RTW and work retention. While this is an important observation, such support should not be restricted to young stroke-survivors particularly since research suggests that need extends beyond that.

The final literature search also found a SM feasibility study (Caetano 2021), but this was excluded on the basis that it was for inpatients only and so restricted to promoting physical activity. This is not unusual, as Lau et al. (2022:1) demonstrated in their systematic review and meta-analysis of theory-based SM interventions, concluding that: *"the predominant theory and behavioural control techniques were social cognitive theory (7 studies) and goals and planning (12 studies) respectively. Significant and small effect sizes were found for self-efficacy (0.27) and functional independence (0.19)".* Jones, et al. (2017: 2) have also commented on the move within healthcare to *"making every contact count towards behavioural change", by recording quantitative outcomes. This is reflected in the "behavioural control techniques"* Lau et al. (2022) report on.

There are undoubtedly challenges in integrating SM approaches into stroke rehabilitation (SR), which the 'Bridges' team (2017:2) have a good understanding of. Examples are avoidance of self-management (SM) being an "add-on" provision and their reference to vocational rehabilitation (VR) as a "*time limited service".* 'Bridges' is still in the process of being adapted. Jones et al. (2013:257) have also written a paper, *"to contribute to the debate on the direction of SMP's for individuals after stroke".* Importantly, the 'Bridges' team acknowledge that psycho-social factors can impact the stroke-survivors' capacity to self-manage. In contrast, Lau et al.'s review appeared to demonstrate an exclusive focus on quantitative variables and their related theories.

Jones et al.'s (2016) paper about how 'Bridges' has developed was enlightening within the field. The fact that the team are now considering how to tailor the programme to meet individual needs, which Jones et al. (2016) anticipate will require them to consider other theories, is also encouraging and may facilitate the integration of other concepts like CSM and its related theories. Most encouraging is that the 'Bridges' team are learning how to support the enactment of SM through integration with VR practices, and training and feedback with healthcare teams. This approach has inspired the 'Bridges' team to move away from "*SM approaches based on behaviour change methods"* toward "*SM support as a multiple and open ended process"* (2016:478). In other words, what is being observed here is a rare shift from variance to process thinking, which aligns with a life-career SM approach. Other SMPs, such as “BUS TRIPS” (Carlstedt et al., 2017) and Harel-Katz et al.’s (2020) *“participation focused Stroke SMP”* seem less progressive in this respect, possibly because they are relatively new in comparison to ‘Bridges’. ‘Bridges’ was the first stroke-specific SMP to be developed, and is now “*used by healthcare professionals within acute and community stroke rehabilitation across the UK and in some parts of New Zealand and Australia”* (Jones et al., 2016: 471).

There is also a growing body of literature about evaluating SSMPs and VR, reflecting the need to prove cost effectiveness. This acknowledgement has led to an increasing focus on quantitative research, particularly randomised control trials (RCTs), which Kersten et al. (2010) rightly question the relevance of in rehabilitation, suggesting that RCT’s are less helpful for answering how and why questions. Instead, they recommended finding other evidence bases by *“learning from different fields”* (2010:1028), because of a need to *“focus on research that identifies the best way to operationalise and implement findings in delivery of rehabilitation*” (Kersten et al., 2010: 1032).

Further, Lo et al. (2013) conducted a systematic review of theory-based SSMPs but found inconclusive evidence in relation to their effect on recovery, although they were thought to potentially benefit self-efficacy and quality of life (QoL). If SSMPs were to support life-career development, they could potentially benefit occupational identity formation. The latter is a more significant process for stroke-survivors, that the reported research suggested encompasses both self-efficacy and QoL. Similarly, Martin-Saez and James (2021: 1051) found that *“the experience of occupational identity loss was intimately connected with a perception of a devalued self”*. They also concluded that:

> *“Identity continuity is an important concept in stroke rehabilitation that is vital for stroke wellbeing as it creates a sense of coherence over time. When an individual’s sense of continuity is broken due to a major illness like stroke, an unplanned transition begins to integrate oneself in the past, present, and future as the same person.”*

The second relevant theme found in the review was Transitions. As noted in earlier literature reviews, an emphasis on personal development is lacking in the approach used in healthcare. However, Todres, Galvin and Holloway (2009) are now calling for "*humanization of healthcare",* which is described by Galvin et al. (2020) as a new way of understanding person centred care. Theoretically, this should enable practitioners to address the issues identified by Ellis-Hill, Payne and Ward (2008) in their life thread model. However, due to what Charon (2006: 193, in Todres, Galvin and Holloway) described as *"wholesale refusal to take into account the human dimensions of illness and healing",* this approach requires large-scale training and the willingness of all tiers of the healthcare system to embrace such an extensive change. As Ellis-Hill et al. (2022:1037) note, the principles of lifeworld-led practice and research *"challenged many of the usual ways of thinking and working within research and healthcare contexts".* There is still some way to go, which explains the lack of response to Ellis-Hill, Payne and Ward's (2008) call for more information about ways in which people approach life transitions following acquired disability.

Transitions

On the subject of transitions, only two papers related to stroke-survivors' transitions were identified in the search and both were excluded. Oyesanya et al.'s (2021) paper reported on patients with moderate to severe traumatic brain injury, family caregivers and healthcare providers, so was not confined to stroke-survivors. Further, although the patients were interviewed three times, the second and last interviews were one month and two months after hospital discharge so, in comparison with the reported study, did not provide a long-term recovery perspective. Hughes et al.'s research (2018) concerned the way in which social workers managed the transition for stroke-survivors back into the community and was excluded as the focus groups included care givers. The paper also lacked methodological information. A further paper was identified following a hand search. However, again, Glass et al.'s (1992) paper, while intended to study change over time, only followed stroke-survivors for six months and, as it was a quantitative growth curve analysis, it was limited to functional recovery.

Hand search four

Hand searching also revealed Muenchberger et al.'s (2008:991) research on identity transitions following traumatic brain injury (TBI). This concerned individuals recovering from motor vehicle accidents, who were interviewed at multiple time points, including twenty-five+ years since injury. However, they were not necessarily stroke-survivors and were aged between twenty-two and forty-nine at the time of interview. The research was also excluded because it was outside the time period of the latest literature search and focussed solely on identity transitions, rather than life-career transitions, of which identity is a component part. Nevertheless, as there is a relationship between the two, it is helpful to know that their findings were in line with the reported research, and it is also worth noting that a person-focussed approach to rehabilitation was recommended. They additionally affirmed that identity transition is a dynamic process, reporting that:

> *"The current findings draw attention to the experience of personhood following brain injury and the toll of liminality where self-doubt and ambiguity act to inhibit personal growth and prohibit perceptions of achievement. Finding ways of navigating this personal identity transition process and valuing desired outcomes for individuals with TBI is an important focus for future rehabilitation and research efforts."*

In addition, Maitlis (2009) examined the value of sense-making in traumatic growth. Again her work was not specifically about stroke-survivors, though her former colleague, Meyerson (2019), has written about her experience of rebuilding her identity post stroke and she also shares that of other stroke-survivors she interviewed. However, her book does not detail the self-management of identity transitions, though it does make valuable points about identities being multiple, dynamic, social and a choice.

In contrast, the reported research details how stroke-survivors navigated their life-career transitions, which incorporated identity transitions. The stroke literature on identity transitions is considered next.

Identity transitions

As well as Meyerson's contribution to the stroke literature, four other papers were located about identity changes post- stroke. Anderson and Whitfield's paper (2012) examines the effect of social interactions on stroke-survivor's identities and recommends that future studies should explore the consequences of social interactions and how they impact on a positive post-stroke identity. The reported research does this and underscores the value of networking for stroke-survivors managing the transition process. Ellis-Hill and Horn's paper (2000) additionally highlighted the difficulty of stroke-survivors envisaging a future self and recommended that clinicians be aware of the meaning of the stroke within the context of a stroke-survivors' life. Further, Hole, Stubbs, Roskell and Soundy's (2014) metaethnography of psychosocial processes influencing identity following rehabilitation found identity to be a central need in rehabilitation although they acknowledge that a limitation is that none of the reported studies included stroke-survivors with severe cognitive or language difficulties. Further, they only considered studies from 2000 onwards. The reported study in comparison includes both types of disability and examines earlier literature too.

Hand searching also revealed Gustafsson and Fleming's paper (2012) about transition to community living after acquired brain injury (ABI). An incomplete reference list meant that it was not possible to follow up the reported papers referred to in this Australian paper and those that were sufficiently detailed did not meet the criteria for the reported study. For example, Gustafsson and Fleming's paper concerned only survivors of mild strokes.

Papers about life design and implications for transition (Wehmeyer et al., 2019), working identity research (Ibarra, 2003) and transition narratives (Davey, 2009) were additionally identified through hand searches. Again, none of these were specifically about stroke-survivors, although the former did highlight the fact that career adaptability is likely to be more important for individuals with disability: *"studies of people with disabilities in the career counselling and vocational guidance literature, although sparce, suggest the relevance of the life-design approach in more positive life outcomes" (* Ferrari, Sgaramella and Soesi, 2015, in Wehmeyer et al., 2019:183).

This review now considers literature covering the lived experience of stroke. At the United Kingdom Stroke Forum 2022 (UKSF '22), the "*lifeworld approach"* to *"humanising" healthcare* (Galvin et al., 2020:1) was highlighted by Ellis-Hill. However, as the literature review shows, this has not yet fully impacted healthcare research and practice and there is still little current research about the long-term experience of living with stroke.

Experience of living with stroke

Salter et al. (2008) completed a qualitative meta synthesis on the experience of living with stroke. Of the nine included papers that met their quality criteria, only one study examined the longer-term picture. Haggstrom et al.'s (1994) paper interviewed stroke-survivors at eighteen to twenty-two months post- stroke and so did not meet the present study's inclusion criteria for this reason, or the age of the stroke-survivors interviewed, which was sixty to ninety-one years. The meta-synthesis was also too old to be included in the literature review results.

In the literature review, three other papers on living with stroke were found. Two were by the same authors, looking at the experience of Taiwanese stroke-survivors. Both papers were excluded. The first was a quantitative study, relating to the WHO Disability Assessment Schedule and access barriers to mobility, so was not directly relevant to the research subject. The second, also by Chang, Lin and Liou (2022), was excluded because of a lack of specificity, for example in relation to the duration of time since stroke for the stroke-survivors studied and because stroke-survivors with severe cognitive impairments were excluded from the study. Nevertheless, Chang, Lin and Liou's paper (2022: 1980) makes the important point that culturally-tailored interventions are needed, as they found that cultural differences impacted on both confidence and the job search approach. The point about cultural differences is also relevant to the third paper, which considers the lived experiences of stroke-survivors undergoing ayurvedic rehabilitation therapy (Baby et al., 2020). Alternative therapies, such as ayurveda, may have a more mixed reception in the UK, than in India. However, Baby et al.'s paper was excluded from the literature search because it focused only on survivors of minor strokes, of all ages.

Hand search five

Hand searching additionally identified Hawkins et al.'s (2017) paper about poststroke trajectories and the process of recovery over the longer term. However, this was excluded due to the age of the reported stroke-survivors, which was fifty to eighty-nine at the time of the stroke, and because only eight of the sample of twenty-two were cognitively impaired. Nevertheless, in line with the reported study, it described recovery as a *"complex and dynamic process",* during which *"experiences might shift over time and particularly in response to unanticipated health events or changes in support"* (2017:11). The author recommended that "*tailored support should be provided in the longer term"* (2017:12).

A number of studies covered by the review also identified the importance of return to work (RTW), yet, as I will set out below, there is great variation in what 'work' actually means and, importantly, what it means to stroke-survivors.

Return to 'work' and 'work' retention literature

Hawkins et al. (2017) make no reference to 'work', probably because only five of the interviewed stroke-survivors were 'working' prior to stroke. Therefore, of greater value to the reported study was Brannigan et al.'s (2017) meta-synthesis of barriers and facilitators associated with RTW after stroke, although this is not about transitions as such. This covers papers, written in English, published between 1994 and 2014 and makes a number of crucial points, which the reported research also found, such as "*variation in the term RTW".* For instance, "*some studies only include competitive full-*

time employment and others consider part-time work, volunteer work and/or homemaking in the definition" (2017:212). The reported research considered the changing meaning of 'work' for the stroke-survivors studied through time and demonstrated that an even broader definition is required than those referred to in Brannigan's review (see *'Discussion'*). Therefore, while a number of quantitative studies have examined predictors of RTW after stroke, lack of agreement on the meaning of 'work', variance in study design and "*definitions of the population of interest",* and data collection methods utilised, meant that rates of RTW "*varied from* 0-100%" (Brannigan et al., 2017: 212). This renders them unreliable for SR/VR practice and policy making. This point cannot be reiterated enough because La Torre et al.'s (2022: 13) overview of systematic reviews of factors that facilitate and hinder RTW merely suggested that "*great heterogeneity among the studies in terms of the definitions of work, RTW and factors facilitating or hindering RTW*" was just a "*study limitation",* rather than a major failing. This recent paper also neglects to mention the associated issues of work retention and pushes for early RTW in stroke-survivors (2022:13), presumably on the incorrect basis that work is *"a very important goal for these people"* and *"guarantees a high level of self-esteem and life satisfaction"* (2022:1).

Contrary to La Torre et al.'s perspective, Kuluski et al. (2014:10) found that key goals for the young Canadian stroke-survivors they interviewed included not only going back to work but also *"remaining active in their social and family lives".* Further, there is no *'guarantee*' that RTW will increase self-efficacy and/or life satisfaction for stroke-survivors, as evidenced by the work retention issues that have been widely reported. For example, Balasooriya-Smeekens et al. (2015); and the harms that too early a RTW led to in the reported study.

Liaset and Loras' research in Norway (2016:446) also suggests that 'work' goals for individuals with acquired brain injury (ABI) are not necessarily connected with paid employment. They explain that *"some also feel that the work itself and being able to use themselves and their resources through work participation, is more important than receiving a salary".* This observation emphasised the need to ask stroke-survivors themselves how they define 'work' and its associated goals.

The UN Convention, 2022 also "*discusses the importance of work and education and recreation in equal measure"* (In National Clinical Guideline for Stroke, chapter 4, 2023:10) although those very guidelines are equivocal. They define work as: *"different forms of occupation, including paid employment, vocational training, sheltered, therapeutic or voluntary work, and adult education"* (Tyerman, 2012, in National Clinical Guideline for Stroke, 2023:10), while simultaneously quoting research on the benefits of paid work. For example, Westerlind et al., (2020:63) who themselves note the importance of defining 'work' clearly and state the following in their limitations:

> *"Some participants that were counted as RTW after 914 days (discussed above) might not have actually achieved a RTW. Unemployment is not taken under consideration. Furthermore, the current study defined RTW as working half-time or more, and did not analyze RTW to different extent separately."*

Additionally, how to conduct research in a person-centred manner is still not fully understood, as demonstrated by Alaszweski, Alaszweski and Potter's (2006) research on stroke-survivors' perceptions and facilitators to paid employment. On the surface, this paper appears to represent stroke-survivors' voices. However, they reported only on those under sixty, who *"received guidance on the sorts of issues to record"* (2006: 1861) in their diary. Therefore, the research did not represent their unmediated voices as might be assumed, given their claims to have used "*naturalistic methodologies*" to achieve a *"person-centred approach"* (2006:1861). Moreover, their study did not extend to work retention, as the study was conducted just eighteen months post-stroke.

In comparison, the reported study takes a longer-term perspective, details the factors that prevented work retention and includes stroke-survivors over sixty, as working into old age is now increasingly common in the new paradigm of life-career.

Shames et al. (2009: 1388) also make a crucial point:

> *"RTW is a difficult challenge in rehabilitation. Productive work is functionally the highest rung on the rehabilitation ladder, requiring a certain level of combined social, cognitive-*

> *linguistic and physical skills. Frequently it cannot be achieved despite successful rehabilitation in other spheres of functioning."*

It should not be assumed that a speedy RTW is best for either all stroke-survivors or society and, as Scollon (2000) suggests, *"RTW should not be the primary measure of social recovery. Other measures such as quality of personal relationships and leisure activities may be of primary importance to the TBI patient and may indirectly influence RTW for the patients"* (Page n/k).

Although Kuluski et al.'s (2014) study reported above was excluded in the literary search because most of the stroke-survivors interviewed were just one-year post-stroke and only six were five years post-stroke, it is still worth noting that the goals of the stroke-survivors interviewed extended beyond RTW. Interestingly, Kuluski et al. (2014:9) also noted that *"stroke recovery is a… longer process, characterised by periods of stability and periods of uncertainty".* This factor is also reflected in the findings of the reported study, although over a longer 'recovery' time period for the stroke-survivors studied, all of whom, unlike those in Kuluski et al.'s study, had cognitive disabilities. Additionally, issues concerning the definition of 'work' mean that there is little reliable evidence to demonstrate how many stroke-survivors are able to sustain employment. As Macaden et al. (2010:1140) state:

"unfortunately, there are very little data available on sustaining employment beyond two years in individuals with ABI".

Of the fifteen studies included in Brannigan et al.'s (2017:20) previously mentioned final review, generalizability of the findings was limited by *"the lack of standardisation of the services for individuals with stroke on local, national and international levels".* However, Brannigan et al. (2017) also acknowledged that *"due to the worldwide economic crisis in 2008, the possibilities to return to work post stroke may have changed".*

Arguably, of greater relevance, is the fact that SR has not kept up with the changing paradigm of life-career, although an awareness of the latter was shown by the stroke-survivors studied. Brannigan et al.'s (2017: 221) understanding of this is seemingly limited to *"environmental workplace adaptions, and adjustments such as phased working and flexible work".* There is no mention of specific flexible working practices or the issues around stroke-survivors sustaining work, which have been reported, albeit in the short term, and which the research data also verified. Moreover, Brannigan et al.'s (2017:220) paper placed a misguided emphasis on "*incentives*, *such as reduced or flexible working hours, revisitation of work tasks and peer support*" as being instrumental in facilitating the *"transition to the workplace".* These adaptions are not incentives, rather they are necessities for stroke-survivors who require long-term support, the latter being a point that they at least acknowledge. Further evidence of varying assumptions regarding the nature of work in the new life-career paradigm were found in Radford et al.'s (2020:5) RTW paper. This states:

> *"Less severe stroke, non-manual work, higher socioeconomic class and Higher Education levels are known determinants of RTW after stroke. It is likely that these people held positions with greater job security, better terms and conditions of employment, greater awareness of employment law and better policies and procedures in place to support people with disability in the workplace."*

Known determinants should be treated with caution when there is no agreed definition of what constitutes 'work' and other factors cited, such as greater job security and better terms and conditions of employment, and that seem to bear no relation to the changing 'psychological contract' in the current paradigm of life-career. Further, one of the stroke-survivors interviewed was a judge with a thorough understanding of both employment law and policy and procedures to support the disabled in the workplace, while another was a manager in social services. Neither found that helped them sustain their RTW.

Hand search six

A hand search of references also revealed a systematic review of factors associated with RTW after stroke: a qualitative meta-synthesis (2016:7) by the Royal College of Surgeons in Ireland. There were three phases to this research: a review of the literature, a national survey of stroke-survivors and focus groups and semi-structured interviews with "*key stakeholders".* These were not limited to stroke-survivors and the fact that the focus groups and interviews *"included the current supports available to RTW after stroke"* would have impacted on their ability to vocalise their own views on the meaning of work, as would the inclusion of spouses, healthcare professionals and other stakeholders. In relation to their literature search, the authors noted a variation in time since first stroke "*from 7 days to 11 years"* (2016:19). They also commented that the *"overall rate of RTW could not be reliably estimated"* (2016:13), due to reasons previously described, like variations in meaning of work, study design etcetera. Their review also cited a recent review of VR on RTW rates post stroke, which concluded that "*there was insufficient evidence to support or refute the use of such programmes to facilitate return to work due to lack of high quality trials in the area"* (2016:13).

Improving the quality of clinical trials though is not the answer in either VR, SR or SSMPs. As Kersten et al. (2010) state in their exploration of whether randomised control trials (RCTs) are the most suitable approach to gathering evidence in neurological rehabilitation: "*the best answers about how to enhance rehabilitation outcomes are likely to come from a combination and integration of the most appropriate methods"* (Kersten et al., 2010:1028-1030). They also comment that *"qualitative research is ideally placed to tease out less tangible, but no less important, questions in rehabilitation, often related to the process of the intervention".* Accordingly, the Discussion chapter makes recommendations about how SSVR might usefully develop further.

Summary of findings of recent literature reviews

Despite some progress in the inter- related fields of healthcare and life-career development and an increase in qualitative studies in the last decade, the gap identified by Ellis-Hill et al., (2008) still hasn't been addressed and healthcare and policies and guidelines still prioritise quantitative data, over lived experience, despite no consensus on the meaning of work for stroke-survivors. Further, while new concepts like “access to specialist personalised support” *(ILAS, 2023:4) “emotional and social input” (ILAS, 2023:2)* are beginning to make an appearance in the latest clinical guidelines, they remain rhetoric without large scale multi-disciplinary training and involvement from all levels of the healthcare system, as Jones et al. (2020) found in their Create study. A further challenge was also identified as sustaining new practices (Jones et al., 2020:41).

Before clarifying the relevance of life-career in SR/VR, it is important to briefly set out the underpinning theories that combine to form the theoretical framework that informed both the research design and analysis.

3: Framework explaining the research design and analysis: the underpinning theories

The reported research considered three bodies of theory: career self-management (CSM) theory, existentialism and adult development theories, which inform models of transition. All three bodies of theory intersect, as preparation for transition and self-awareness are fundamental to career management (Ali and Graham, 1996).

This theoretical framework combines different orders of theory. Existential theory is a large foundation theory with universal application to life. In comparison, CSM theories are specific to domains of life and models of transition focus on a range of phenomena. Although the theories are of different orders, they blend into a useful framework for understanding how stroke-survivors self-manage their life-career transitions. Each theory is addressed in turn.

Defining self-management (SM)

SM is viewed as a key means of making the most effective use of the care resources available to people with long term conditions such as stroke (Barlow et al., 2002). They intended SM to be a means of supporting and advising individuals so that they are able to be independent and manage their own health and wider lives. Barlow et al.'s definition is regarded as a "*working definition"* (Jones et al., 2013:260) that underpins many stroke self-management programmes (SSMPs). Barlow et al. (2002:177) refer to SM as:

> *"The individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus a dynamic and continuous process of self-regulation is established. "*

However, Jones et al. (2013) question its relevance to the complex disabilities caused by stroke because *"the emotional and psychological sequelae of stroke are often not addressed adequately in the early stages or long term".* This stance aligned with the researcher's inclination to research the quality of stroke rehabilitation (SR) and vocational rehabilitation (VR) support, as this did not always align with her former professional experience of a person-centred approach. Jones et al. (2013:260) also recognise the necessity for stroke self-management (SSM) to *“reflect the diversity of individual responses and needs*”. A good example of these diverse needs are the wide-ranging identity-based roles that the interviewed stroke-survivors occupied in their life-space and the ways that they transitioned to these over time. There is therefore a strong case for stroke-survivors to receive individualised opportunities to examine all their options post-stroke through the provision of life-career counselling, which are set out in this thesis. This could be offered as part of a stroke self-management programme (SSMP). As Chaplin et al. (2013) recognised, many SSMPs are too generic and inadequately address the psychosocial factors that are relevant to living with stroke.

SM is also still seen by some medical professionals as a response to welfarism[5]. Joice (2012:45) remarked : “*There is wariness in the nursing profession that self-management is being encouraged as a means to save money and reduce the need for healthcare professionals.“*

SM is an issue regardless of economics. This argument aligns with Jones et al.’s (2013) findings that SSM should be tailored to the needs of stroke-survivors.

Nevertheless, Joice made an important point that in stroke care, the term self-care and SM “*are used interchangeably and have distinct boundaries*": *“self-care is where the individual takes responsibility for her own health and well-being” (*2012:39), and *“self-management is a means of addressing barriers to self-care, such as the attitudes of patients and healthcare professionals”.* (2012:39)

Due to the controversy around the concept of SM, it is constantly being redefined and as Wilkinson and Whitehead explain: “there is no consensual definition” (2009, in Joice, 2012:40). Evidence of redefinition was found at the UK Stroke Forum 2022, when SSM was amended to supported stroke

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[5] Parton (1994:19), who writes from a social work perspective, describes welfarism as: "*discipline shifts towards that of regulation.... of subjects in their subjectivity....*" and as drawing "*individuals and families into the sphere of government through the promotion of subjectivity".*

self-management (SSSM) with the addition of the prefix supported, presumably, to help healthcare professionals understand the need to work with stroke-survivors' SM practices, as opposed to imposing their own practices as '*experts*'.

Nevertheless, in recent years, Barlow's aforementioned definition has become more widely accepted in SR (Jones et al., 2013). Furthermore, there are more than thirty theories associated with behaviour change enabling SM (Michie et al., 2005, in Joice, 2012:40). Joice presents three of these in her paper, so this review focuses on the genealogy of SM in healthcare. It is generally associated with social cognitive theory (Bandura, 1997, in Joice, 2012:41). Although the concepts of SM in the two interrelated fields of SR and life-career management intersect, the reported research does not focus on social cognitive career theory, which many current stroke specific vocational rehabilitation (SSVR) programmes use to measure SM outcomes, for example Jones et al., 2009. To explain this decision, social cognitive career theory is summarised below.

Social cognitive career theory

Bandura developed social cognitive theory. He drew his ideas from behavioural experiments with animals and postulated that: "*self-efficacy and outcome expectancy judgements are differentiated because individuals believe that a particular course of action will produce certain outcomes, but they do not act on the outcome belief because they question whether they can actually execute the necessary activities*" (Bandura, 1997, in Swanson & Fouad, 1999:125-126).

Lent, Brown and Hackett (1994) extended Bandura's social cognitive theory. They claimed that individual difference variables like gender, class and ethnicity intersect with background and contextual variables to impact on learning experiences that play a part in developing self-efficacy beliefs (Lent, Brown and Hackett, 1994, in Swanson and Fouad, 1999:126-127).

However, Meijers (2002:149) explained that:

"*existing theories of career learning do not adequately take into account the uncertainty and rapidly changing conditions for careers in the modern world. Specifically, they view emotions, such as anxiety and uncertainty, as obstacles for career learning and career identity construction*".

Meijers' argument about emotion is an important critique of social cognitive career theory. It also applies to the parent theory of Bandura. The researcher considered that the emotional qualities of career transition are central to both existentialism and models of transition. SM theory in healthcare is too narrowly focussed on a cognitive model of change. Further, the need for SR/VR programmes to justify their existence is forcing stroke professionals to measure variables like self-efficacy, functional independence and quality of life (QoL) rather than the process of recovery from a stroke-survivors' perspective of their life-career. As Boger et al. (2013:1415) state, *"recovery following stroke is complex and multidimensional".* It therefore requires a more sophisticated approach to capture the nuances of individual trajectories. Jones et al. (2013:257) have recognised this and call for interventions to be developed that *"can be inclusive of social aspects of self-management, and identify new methods of delivery".* The researcher's recommendations for the inclusion of life-career in SSMPs (see '*Discussion'*) takes all of that into account.

The reported research broadened healthcare perspectives on SM by focusing on evolving life-career SM research, specifically Collin and Young's (1986) contextual theory of career, which was developed during the new paradigm for career intervention, in which career is viewed as part of an individual's life design. This body of research is more relevant because it pays particular attention to the changing nature of society and thus life-career.

Both Collin and Young's career theory (1986) and Frankl's work combine to form the theoretical framework and this has strongly influenced the choice of methodology. Frankl explains human experience through logotherapy. Logotherapy is not only "*concerned with ontos, or being, but also with logos, or meaning*" (Frankl, 1969:9). Frankl's anthropological accounts of his experiences are of high quality and demonstrate an understanding of the way in which significant life events affect the whole person and can be life-changing.

Collin and Young's career theory (1986) is helpful in recognising the wholeness of events. It recognises that life-career development is a process and therefore "*human behaviour can only be described and understood with its inner and associative meanings, nothing but the meanings, within the particular context*" (Chen, 1998:449).

Career self-management (CSM) theories

In addition to Collin and Young's contextual career theory, there are numerous diverse theories which focus specifically on CSM and offer different perspectives on the concept as these were developed during the new paradigm[6] of life-career.

To understand CSM within the context of SM, as defined by Barlow et al. (2002:5), it is important to understand the parameters of career. Career is a concept that has evolved as the economic situation has embraced technology and globalisation. Parker (2002:83) explicated:

> *"For many people, the purpose of work is changing from an economic or even a vocational imperative to a broader dynamic that emphasises personal meaning. Different skills are required to ensure success, and support is often sought from a professional to guide the way."*

These changes mean that individuals can no longer rely on organisations to organise their career, which is often described as the changing *"psychological contract"*[7] (Maguire:2003). This is reflected

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[6] As described by Mezirow (1991:46), paradigms within career theories are "an articulated, theory based, collectively held meaning perspective".

[7] Maguire (2003:3) summarized the different definitions literature provides for the 'psychological contract': "*The common theme underlying these definitions is that the 'psychological contract' refers to an employee's unexpressed beliefs, expectations, promises and responsibilities with respect to what constitutes a fair exchange within the boundaries of the employment relationship.*"

in the theoretical framework's focus on career self-management (CSM) theories developed over the last 25 years.

Hall's (2004:4) ”protean” career also furthers our understanding of CSM. His choice of the metaphor 'protean' might at first seem to be a useful one, as it acknowledged that a career can take many different forms. Hall described the 'protean' career as *"self-determined, driven by family values rather than organisational rewards, and serving the whole person, family and 'life purpose'"* (2004:2).

Hall (2004:4) noted that *"the main success criteria are subjective*[8] *(psychological success) versus objective (position, salary)"* (2004:4). This is an important point as it reminds us that there are huge differences between how the stroke-survivors and stroke rehabilitation (SR)/vocational rehabilitation (VR) professionals define 'success', that is, recovery for stroke-survivors. As Jones et al. (2013:261) note there are frequently discrepancies between the two and they allude to the *"tension"* which can develop between the professional and individual when *"goals and aspirations are not one and the same".* They conclude that more research is needed to understand preferences for SM and how these are expressed and negotiated, and also note the *"lack of flexibility and opportunity within services to allow time for individuals to learn the skills of SM, particularly when the timeframe and criteria for rehabilitation are fixed as is the case in many inpatient settings, and community based rehabilitation services"* (Jones et al., 2013:262).

Jones et al. (2013:262) recognise *"a greater understanding of how individual responses influence SM is warranted that take into account individual readiness for such programmes in relation to their own adjustment and reconciliation of life after stroke".*

The researcher believed that the reported research would add to that understanding and readiness was strongly highlighted in the reported findings.

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[8] "*A perspective derived from the practical interest, both cognitive and affective, they define a person's point of view that are the basis of the will to power."* (Clark, 1990, in Letherby et al., 2013:26)

Concerns about variations in individual readiness to accept responsibility for their health, let alone life-career, have already emerged in the medical SM literature.

As Jones et al. (2013:260) remark, "*the psychosocial consequences"* of stroke can be *"enduring and can have a profound impact on an individual's capacity to self-manage… mood together with social support and cognitive problems are key factors associated with progress through rehabilitation and will have an impact on readiness and adoption of self-management strategies".*

However, SM in healthcare or life-career does not imply that the stroke-survivors should not receive ongoing support with their SM from Stroke Specific Vocational Rehabilitation (SSVR) teams; the issue is that SR support was time limited until recently and services are still adjusting to the new way of working. Length and timing of support is something the researcher returns to in the Discussion chapter.

Despite differing standpoints, all theorists tried to assess the process of SM and consequently highlighted the important factors within it. However, the researcher has largely focused on those that relate to "*the structure of meaning, rather than the structure of personality*" (Marris, 1996:25), as the researcher concurred that this is "*the primary organising factor in the individual management of uncertainty"*, which was fundamental to the research design.

Defining CSM

Amundson et al. (2002:3) defined CSM as:

> "*Self-organising suggests a two-way process, whereby people, as the underlying elements in an economic system, are not only influenced by but also influence the system in their career behaviour… people make sense of the world of work through subjective interpretation of their own career experiences".*

The focus on subjective interpretation was crucial to the reported research because, while the transition process involves a range of adjustments and changes, both in the internal and external world (Schlossberg, 1981), existential theory and some models of transition consider the way in which individuals respond to those changes and so are inherently psychological. Some theorists also argue the subjective career is more relevant to today’s society. Wnuk et al (2004:2) explicate:

> *“The Subjective Career consists of each person’s thoughts and feelings about his or her own career accomplishments and expectations, and as a result it differs from person to person. Career success means reaching goals that are personally meaningful, rather than those set by others… The subjective view has become more important in the constantly changing economy as people are required to take greater personal responsibility for their own career development.”*

In traditional rehabilitation, there has been an emphasis on professionals being highly involved in guiding the process of individual goal setting and, consequently, individuals may not always feel involved (Jones, 2006:845). Some stroke-survivors have experienced this ‘guidance’ to be at odds with a person-centred approach and an understanding of the importance of goal ownership. Consequently, the research took a self-organising perspective, which Amundson et al. (2002:3) recognised as one in which “*people take more responsibility for the direction and evolution of their own careers, spanning the work experiences they pursue and the meaning, motivation, learning and relationships they develop”.*

Kanter’s (1989) comment that “*the self-organising view of career behaviour invites employability rather than employment security*” (in Amundson et al, 2002:3) also reminds us that stroke-survivors need employability skills, particularly the ability to make good decisions.

Wnuk et al. (2004:1) expand on this: *“Personal success in the knowledge economy requires having a good understanding of one’s self, one’s employment circumstances and one’s relationships, as these form the basis of sound career decision-making.”*

It is within the context of an uncertain society (Marris, 1996:1) and the new paradigm of career that stroke-survivors have to make significant career transitions. As many have impaired decision making and/or self-awareness, the support of a life-career counsellor would be invaluable.

In the new paradigm of life-career, fresh theories are emerging. As Frankl (1986:118, in Bland et al.,(2013:6) explains:

> *"It is necessary to show (clients) that the job at which one works is not what counts, but rather the manner in which one does the work. It does not lie with the occupation, but always with us, whether the elements of the personal and the specific which constitute the uniqueness of our existence are expressed in the work and thus make life meaningful."*

This is particularly pertinent to stroke-survivors because, as stated by Macaden et al. (2010:1140), "*sustaining employment after return to work is a notable challenge in individuals with acquired brain injury".*

This returns us to a consideration of how stroke-survivors might best be supported through their transitions to their new normal, one of which might involve employment, if that is a priority for the individual stroke-survivor. The researcher begins by considering the concept of transition.

Defining transition

Bridges (1980: in So, 2010:16) defined transition as the "*internal adjustment process people go through when they let go of the way things previously were and reorientate themselves to the way things are now*". Bridges' definition of transition has been adopted for the research because the way in which an individual interprets each transition is crucial to the way in which they feel and cope with it (Schlossberg et al., 1995:29). For example, the individual can see it as positive, negative or of no consequence. Therefore, as Schlossberg et al. (1995:28) note *"the transition is a transition only if it is so defined by the person experiencing it".* This has particular relevance to the loss of self that stroke survivors experience. Bridges makes a helpful distinction between change, which is a situational shift in the world around us, and transition, which are the internal processes we go through in response to the shift (Bridges, 1980, in So, 2010:6).

Researchers have found that transitions in and out of ‘work’ are directly connected with health and well-being. While satisfying employment is related to both mental and physical health (So, 2010:6), individuals who are unemployed (Friedland and Price, 2003, in So, 2010:6) or underemployed (McKee-Ryan et al., 2005, in So, 2010:6) are often in poor health. Although, as Super (1976) recognised, career transitions are not just limited to employment circumstances.

As a few examples from the full table illustrates, Schlossberg, Waters and Goodman’s continuum (see overleaf) is helpful in illustrating the genealogy of transition theories and in revealing different perspectives on the process of transition, which were drawn upon during data analysis.

Schlossberg, Waters and Goodman (1995:4) group adult development theories into four categories which form a continuum: contextual, developmental, lifespan and transition. The four categories of theories each build on the former, so for example, the developmental perspective, the second perspective on the continuum, focused on the sequential nature of adult development and builds on the concept of context, which includes phenomena like career mobility (Rosenbaum) culture (Neugarten and Neugarten), and the influence of the historical period in setting norms and constraints (Hareven) (in Schlossberg, Waters and Goodman, 1995:20).

Table 3.1: Revised Table 1.1 (Schlossberg, Waters and Goodman, 1995:20): The Adult Experience: Perspectives and Concepts, adapted and redrawn by Carol Wilson

Contextual	**Developmental**	**Life-span**	**Transitional**
Rosenbaum: career mobility. Hareven: importance of historical period in setting norms and constraints.	Levinson: invariant sequence of developmental stages.	Neugaten: individual variations.	Lowenthal, Fiske and Chiriboga: stage not age. Coping with transitions: balance of resources to deficits.
Neugaten & Neugaten: cultures provide age systems and age norms.	Eriksson and Josselson: identified hierarchical stages in resolution of inner issues and different issues for women.	Pearlin and Lieberman: differential distribution of strains by sex, age, different patterns of coping.	Kastenbaum: face issues of loss and death.

As the table is based on adult development theory, the suggested theorists and concepts do not include theorists specifically of career, although these could be slotted into the different perspectives. To illustrate, one aspect of the development perspective is the concept of age. Levinson (1986, in Schlossberg, Waters and Goodman, 1985:8) linked development periods to age. He believed that stable age-related periods alternated with transitional periods, so, for example, a midlife transition (age 40-42) was followed by re-stabilisation (age 43-50) (Schlossberg, Waters and Goodman, 1995:9).

Within career development theory, Super (1957, 1976, 1980, 1996) took up the developmental perspective and extended it over several decades, becoming one of the main figures in the career field. Although Super was theorising at a time when the paradigm of career was very different from that of today, many aspects of his theories are arguably still relevant today, as they provide the foundations for some of today’s more recent theories, for example, Savickas’ career adaptability theory (1997:248).

Other views of human development take the perspective that developmental stages are not necessarily linked to age, as an individual’s circumstances can affect the speed at which they progress through stages, assuming they progress at all. For example, stroke-survivors, experiencing depression, may become stuck within a stage.

Fiske and Chiriboga looked at gender-related factors in transition. They argued that life stages are more useful for studying transitions than chronological age (1990, in Schlossberg, Waters and Goodman, 1995:61).

The reported research was based on the premise that studying the process of transition, which is time related, rather than variance theories like self-efficacy, is key to understanding how stroke-survivors SM their life- career transitions, and the researcher considered whether age, stage of recovery, or life stage seemed to be most relevant to individual stroke-survivors. She was mindful that some aspects of the adult experience perspectives introduced were written with an idealised, healthy individual in mind. Furthermore, they were written at a time when career work focused on occupational choice, which would mean that life stages are irrelevant for younger stroke-survivors.

There are numerous theories and models of transition, which can be identified in academic disciplines ranging from psychology to CSM research, each offering differing perspectives on analysing the process.

Adams et al. (1977) stated that while there is a consistent effect of life changes within a wide range of cultures, it is vital to recognise that each transition has a different meaning and significance for each individual and so new behaviours will be required to deal with the situation. However, the search for meaning comes towards the end of the process, when the individual looks back over the transition and tries to understand the meaning of the change for their life (Spencer and Adams, 1991). This is relevant because in existential theory finding new meaning is a catalyst for change (life-career).

This distinction between change and transition is a pertinent one to stroke-survivors because as Alaszewsi et al. (2003:50) noted, over half of the professionals interviewed explained recovery for the survivor in terms of a model of bereavement and loss, a psychological model of stages of grief that individuals go through after a severe loss. Poor progress towards recovery was sometimes interpreted and understood in terms of the client ‘being stuck’ at a stage in the process and unable to move on. They questioned whether the bereavement model is evidence-based and whether it assists the individual stroke-survivors to understand and manage their recovery.

The bereavement model originated from Kubler-Ross’s change theory. Kubler-Ross was a psychiatrist (1969, in So, 2010:15). She interviewed over two-hundred terminally ill patients. Kubler-Ross proposed that there were five steps in the process of dealing with grief: denial, anger, bargaining, depression and acceptance. She believed that the five steps could be applied to any form of significant personal loss. Many of the transition models are built on Kubler-Ross’s conception of loss (Schlossberg, Waters and Goodman, 1995:20). This is compared later to the existentialist perspective on crisis.

The research framework focused on Bridges’ theory, as the researcher thought it was the best fit with the opportunity for transformation that an existentialist perspective offers. Bridges (1991) postulated that “*transition is a three-phase process which always begins with a loss”* (in So, 2010:16).

During the first transition stage of ‘ending’ or loss, people leave behind the way things were in the previous situation and can be left searching for new ways to redefine themselves. In order to move on psychologically, they have to let go.

The positioning of ‘loss’ at the start of the process means that individuals then move into what Bridges termed a *’neutral zone*,’ in which they are neither who they were, nor are going to be (see *‘existential vacuum’*), before they are able to move into ‘*new beginning*.’ The latter stage requires people to accept the reality of the change and begin to identify with their new situation. This is the point at which they have an opportunity to reinterpret a negative event and transform it into a new challenge.

As Lazarus and Folkman noted (1984, in Schlossberg, Waters and Goodman, 1995:31), the individual's appraisal of a transition is key. Analysis of the stroke-survivors' case studies will further determine relevance of particular transition models, all of which feature loss as part of the process.

Stroke-survivors as a collective could initially be categorised as people making involuntary transitions (Fouad and Brynner, 2008) as they are generally less ready for transition, both in terms of their capacity for transition and psychologically.

Readiness is a key concept in CSM. Savickas (1997:254) contextualised this as "*readiness to cope*" and "*readiness to adapt*." That links with the 4S model of transition, which seemed to provide an opportunity to analyse the coping/adaptation process.

The 4S model "*employs a ratio of assets to liabilities and allows for changes in the ratio as an individual situation changes"* (Schlossberg, Waters and Goodman, 1995:49). The researcher believed this to be over-simplistic and that it failed to account for how nuanced difficulties facing stroke-survivors, such as emotional lability, fatigue, depression and cognitive deficits, impact on transition.

However, the researcher also recognised that as an individual's circumstances change over time, so does their perspective and, as previously stated, it is the way in which an individual interprets each transition that is crucial to the way in which they feel and cope with it, which links with existential theory (Schlossberg, Waters and Goodman, 1995:29).

Existential theory

Existential theory can be summarised as follows: individuals have to face their *"ultimate concerns",* which derive from problems that arise in daily existence. Concerns include freedom (being responsible for what we make of our life), meaninglessness (the need to establish a sense of purpose in life), and authenticity (individuals must act in a way that reflects their true nature and abilities) (Cohen, 2003:196).

Existentialism is a philosophy which firmly rejects determinism[9] and other traditional philosophies based on rationality, such as positivism[10]. It therefore fits with the concept of life-career SM. Existentialism dates back to Buddhism and Christianity.[11]

As we are concerned with life-career self-management, the origins of existentialism in career theory are examined here. In recent times, logotherapy has begun to be used in CSM and the importance of this has grown with the "*Subjective Career*" (Wnuk et al., 2004:2). It is based on the psychological-anthropological model developed by Victor Frankl, who was interned in concentration camps for three years during the Second World War. Frankl, (2004:105) found that "*under all circumstances life continues to have meaning. When women and men begin to lose hope in the most adverse of circumstances, one needs to see that even in hopeless situations one can find dignity and meaning in the struggle*".

Logotherapy and existential analysis began in the 1930s (based on Freud's psychoanalysis and Adler's individual psychology). Frankl, who was a psychiatrist and neurologist, founded this approach, which he published in 1938[12].

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[9] "*In philosophy, determinism is the belief that social events are determined by prior causes.*" (Della Porta and Keating, 2008:350)

Existentialists see the world as meaningless, that is there is no predestined purpose to an individual's life. Finding one's purpose in life is viewed as the responsibility of the individual. They believe that the search for meaning is the primary motivation for all human behaviour (Frankl, 1984). The "*will to meaning*" is considered universal and thought to apply to people from all social economic levels in cultures, no matter what their gender or race (Friedman, 1964, in Cohen, 2003:200).

[10] "*Positivism is the doctrine that only statements about the world that can be verified or falsified can be accepted*." (Della Porta and Keating, 2008:353)

[11] Mastin, L. (2009) *Existence and Consciousness*. Available from:

www.philosophybasics.com/branch_existentialism.html

[12] Madeson M. (2020) *Logotherapy and Frankl*. Available from:

Logotherapy: Viktor Frankl's Theory of Meaning (positivepsychology.com)

Logo means meaning. Frankl believed that meaning is not invented or created but found in an individual's life. As meaning exists outside the person, it is objective by nature (Frankl, 1959-2004).

Yalom, who applied the existential approach to group psychotherapy, also postulated that people are particularly in need of support when they are faced with a "*boundary situatio*n", which he classified as significant life-changing events and urgent experiences. Stroke could be considered a '*boundary situation'.* When faced with these "*ultimate concerns*", individuals often develop anxiety or "*existential angst",* which can result in them using defence mechanisms such as denial to protect themselves (Yalom, 1980, in Cohen, 2003:196).

Frankl (1959-2004) termed the experience of meaninglessness in life, the '*existential vacuum*'. He summed it up as: "*feelings of frustration, emptiness, depression, boredom, and apathy stemming from a lack of purpose and meaning in life"* (Cohen, 2003:204). Prior to Cohen (2003:196) few theorists had applied existential themes to career decision-making. He suggested that "*one of the primary factors motivating vocational choice is a search for meaningful vocation. That is, people are motivated to choose a career that they believe will provide a sense of purpose to their life"* (2003:200). The researcher would also add to this that what was seen by the stroke-survivor as purposeful pre-stroke may not necessarily be conceived in the same way post-stroke and the data showed that can also change over time.

Choosing an appropriate theory of career decision making for the theoretical framework

In the new paradigm of life-career, new career theories are emerging. According to Bland et al. (2013), there are two potentially relevant theories of career decision making: existential theory and chaos theory. Both appear to address existential themes. However, the researcher selected existential theory because it offered the opportunity for transformation. As Frankl (1986:118, in Bland et al., 2013:6) explained:

> *"It is necessary to show (clients) that the job at which one works is not what counts, but rather the manner in which one does the work. It does not lie with the occupation, but always with*

> *us, whether the elements of the personal and the specific which constitute the uniqueness of our existence are expressed in the work and thus make life meaningful."*

The researcher also felt that chaos theory, through adapting existing career intervention techniques, and consequently integrating with previous paradigms of career, moves away from the person-centred counselling approach founded by Rogers (1959) that is fundamental to the research methodology and potentially SR/VR. Furthermore, when chaos theory is utilised in interventions some of the techniques being reported by Pryor and Bright (2003:8), such as the Luck Readiness Index, which uses dimensions such as self-efficacy and flexibility, demonstrate variance thinking rather than the holistic process approach that the new paradigm of life-career requires.

Choosing an appropriate theory for career counselling interventions with stroke-survivors

Despite quoting Frankl, Bland et al. (2013) appeared to overlook the use of logotherapy in career interventions. Schultze and Miller (2003) and the researcher considered its utility to be of relevance as it has its philosophical roots in existentialism and phenomenology and it is already utilised in psychology, psychotherapy and gerontology (Kimble and Ellor, 2000). However, during analysis, a decision was taken to use the DOTs[13] model (Law and Watts, 1977) to illustrate the CSM process, as the stroke-survivors' comments about their increasing self-awareness and opportunity awareness through time highlighted its relevance to them. However, neither model precludes the use of the other by the individual Career Counsellor, who will select what is most appropriate to the individual they are working with.

Linking existentialism to models of transition, the researcher postulated that Bridges' '*neutral zone*' could be an '*existential vacuum*' for some stroke-survivors. Another perspective on this is Jacobsen's. Jacobsen (2006) conceptualised the '*existential vacuum'* as 'crisis', which Corbett and Milton noted is

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[13] A tool for 'joining the dots': an analytical tool used to see where a client is in the career self-management process. It can also be used for career planning and focuses on four cyclical aspects of the career learning process: decision learning (D), self-awareness (S) , opportunity-awareness (O) and transitions (T).

a term that is sometimes used reciprocally with ‘trauma’ (Du Plock, 2010, in Corbett and Milton, 2011:8).

Schlossberg, Waters and Goodman (1995:28) preferred not to use the term ‘crisis’, because it is associated with negativity. However, the researcher felt that it accurately reflected the emotional intensity of the losses experienced by stroke-survivors, particularly the loss of meaning in life. Furthermore, existentialism advocates reconceptualising ‘crisis’. Jacobsen linked ‘crisis’ with the opening of existence (2006:46). As Corbett and Milton (2011:12) described: “*when the ground opens up before us – when the carpet is swept from under our feet – and we are disturbed, distressed and deracinated – that we potentially have a rare opportunity to work with awareness not previously experienced*”. Jacobsen (2006:39) also explained that “*the path to possibility goes through pain; the positive is reached via the negative*”.

Jacobsen contextualised the existential understanding of ‘crisis’ by clarifying that it is one of three views of what a ‘crisis’ is. One of these lenses for ‘crisis’, which Jacobsen described *as “catharsis-oriented bereavement therapy”* (2006:40), in which grief needs to be expressed, is the Kubler-Ross model of change previously mentioned. The impact of ‘trauma’ can also be diagnosed as post-traumatic stress disorder, in which the individual is perceived as overwhelmed by the ‘trauma’, which is viewed as external and requiring treatment; or the psychodynamic approach, which focuses on the ‘crisis’ reaction as *“co-determined by childhood experiences”* (2006:40). The latter, which is associated with Freud’s work, is believed to require extensive therapy. This is relevant to stroke-survivors because strokes are classified as on the ‘trauma’ pathway. However, as Kettlewell et al. (2021:761) note:

> *“Rehabilitation services in the UK (and likely in other countries) have developed piecemeal, usually in response to specified problems, such as stroke, spinal cord injury, amputations. This means the system is fragmented and has not developed with a strong theoretical framework, nor has it developed in a patient-centred way.”*

It is therefore important that the specific needs of stroke-survivors are not amalgamated with the needs of other ‘trauma’ survivors; a person-centred approach is required. Relating this point to the different lenses for ‘crisis’, according to Jacobsen, while each of these approaches has its value: *“all view* the ‘crisis’ *as something that should be treated and overcome. They view the ‘crisis’ as an anomaly… reducing the multifaceted nature and quality of human life”* (2006:41). Jacobsen refers to Bollnow’s claims (1959, in Jacobsen, 2006) that life and ‘crisis’ co-exist and have two meanings when traced back to Greek and Sanskrit: ‘crisis’ as potentially cleansing the individual and ‘crisis’ as personally decisive. Bollnow (1959, in Jacobsen, 2007:73), an existential philosopher, believed ‘crisis’ had three dimensions: “*each crisis has three dimensions: loss, adversity and what we may call an opening- of-existence. The individual plunged into crisis loses something. They face adversity. Yet they also have the opportunity to let their life take root on a deeper level than before”.* This returns us to Alasewski et al.’s (2003) question about whether Kubler-Ross’ change model is an appropriate model for stroke-survivors. Like Jacobsen, the researcher believes that existentialism provides a better alternative – the opportunity to develop and therefore address the ‘*meaninglessness*’ phase of transition. Jacobsen (2006:43) explained that in addition to physical losses, “*the individual that is hit by a crisis loses part of the unfolding of his own life and hence part of himself*” as well. In short, the stroke-survivors’ pre-stroke identity. Furthermore, ‘crisis’ involves the individual’s *“loss of meaning and world view”* (Jacobsen, 2006:43-44). However as Schlossberg (1995:50) observed: *“the transition process consists of reactions over a period of time. As reactions change, an individual’s perspective can shift from feeling ‘this is forever’ to one of ‘this too shall pass’*.”

Ellis-Hill et al. (2008:156) also explained that in two studies, levels of anxiety and depression post-stroke “*were highly correlated with the degree to which people felt lost”.* The way that significant life changes can cause fragmentation of self, leading to identity reconstruction is a theme that runs through all the literature (Chan et al., 2008). Identity reconstruction is often undertaken through the naturalistic practice of narrative, which is associated with the process of meaning making that characterises transition. Consequently, it is the basis of many therapeutic approaches and life-career counselling.

Although Ellis-Hill et al. (2008:154) suggested narrative reconstruction as an alternative approach to SR, they also acknowledge that the process of *"finding the new me"* is not well understood in healthcare and call for more detailed investigation into the ways people approach life transitions after acquired disability. The reported research was designed to address this gap and a subsidiary aim was to explore how narrative practice might form an essential part of a SSMP. To illustrate the latter, a narrative approach was a significant part of the methodology, which is detailed in chapter four. However, it is important to first briefly set out my own lived experience and then position as a researcher.

My position as a researcher

In 2009, I was a self-employed career consultant, delivering a national contract for the Training and Development Agency for Schools (TDA). My work involved using a life-career counselling approach to careers guidance and I specialised in working with adults with higher education (HE) qualifications looking to change career, which is reflected in my experience and main career-related qualification (MA career education, information and guidance in HE).

At the age of 42, I had a bilateral carotid dissection, which resulted in a major stroke, leaving me both physically and cognitively disabled. After unsuccessful attempts at returning to work (RTW), both to my business and the kind of senior educational roles I had pursued prior to that, I decided to apply for a professional doctorate and wrote rehabilitation stories as part of my preparation process (my hospital story is in the reference list).

These experiences have informed the way in which I have approached this research, in particular my interest in SM during a period when the nature of career is changing and the use of narrative and logotherapeutic techniques in counselling are now available to clients. This context also influenced the recruitment criteria as I wanted to utilise my experience and knowledge of life-career change.

My interests can be summarised in the two research aims: to illustrate how stroke-survivors self-manage their life-career transitions and a subsidiary aim: to explore how narrative practice might form an essential part of a stroke self-management programme (SSMP). Both require clarity about the meaning of career.

Conceptualising career

As my research is concerned with life-career self-management, it is necessary to begin by examining the chosen concept of life-career within the research strategy.

The concept of career has been utilised by many different disciplines to detail the pattern of 'work' experiences throughout an individual's life. Adamson (1997:245) outlines changes to the concept over the last 70 years and notes that "*interpretations of career have… been dominated by considerations of structure, succession, and status"*. He also acknowledges that this simplistic perception of career is in danger of ignoring "*the richness and value of the concept*". Chen (1998) offers three different perspectives on career: career as life process, career as individual agency, and career as 'meaning making'. Many career theories are based on individual agency, such as social cognitive and variance theories (Mohr, 1982:35). They are based on thin concepts like self-efficacy and goal setting, and do not authentically capture the depth of experience that is relevant to the transition process. Career as a life process has some validity, but "*career transition in the current world of work goes beyond the common sense of time and rationale which are embedded in, and explained by, the traditional life-stage theories"* (Chen, 1998:441).

Therefore, my position on career is one of 'meaning making' which places the stroke-survivors' experiences of transition at the heart of the life-career process. I will be attempting to capture their 'meaning making' process by collecting and analysing stroke-survivors' language and narratives.

I have chosen Super's (1976) definition of career because of its breadth, particularly its person-centred nature and emphasis on growth opportunities. This emphasis is lacking in the approach used by some medical and social care practitioners because they have a very narrow focus on RTW. For example, Jones (2006:845) has noted in SR, professionals have traditionally guided the process and some individuals "*may not always fully participate in their own goal setting process*".

Super (1976) defined career as:

> "*The course of events which constitute a life; the sequence of occupations and other life roles which combine to express one's commitment to work in his or her total pattern of self-development; the series of remunerated and non-remunerated positions occupied by a person from adolescence through retirement, of which occupation is only one; includes work-related roles such as those of student, employee, and pensioner together with complimentary avocational, familial, and civic roles. Careers exist only as people pursue them; they are person centred.*"
>
> (in Chen, 1998:438)

Career professionals view career as integral with a person's life. As Chen (1998:439) states "*while one's career experiences always intertwine with other experiences in life, the person's life experiences can well reflect a general picture of his or her career development. From this sense, life means career, and vice versa*". It is this notion, that career is ordinary life, that led to the development of the single research question that was used to elicit the stroke-survivors' narratives (see Appendix II).

Having outlined the theoretical underpinnings of the research and the reasons for the choices made, the next chapter introduces the methodology used in this study.

4 Methodology

In this thesis I explore how stroke-survivors self-manage (SM) their transition/s to a life-career post-stroke, using an adaptation of Interpretative Phenomenological Analysis (IPA) combined with Framework Analysis (FA). As the self-management process can be viewed from several different angles, according to the way in which both career and SM are conceptualised, I consider both concepts separately before integrating them in the chapter on Career self-management (CSM).

I begin this chapter by focusing on my own position in relation to the research, followed by a discussion about how this influenced my methodological approach. Adopting a phenomenological approach to knowledge production, I planned to capture the stroke-survivors' feelings, thoughts and perceptions of their transition experiences. In reporting on the kind of knowledge I aimed to create, I set out the methods I used and their rationale, the assumptions I made about the worlds I studied and how I conceptualised the role of the researcher. Also detailed is the overall study design, sampling strategy, recruitment, analytic method, data analysis, ethical considerations, and the philosophical underpinnings of the methodology. I begin with how I planned to create knowledge in stroke rehabilitation (SR).

Creating knowledge in stroke rehabilitation

The research questions outlined in the literature review, were designed to inform the central research question's focus on the stroke-survivors' self-management of transitions. I needed to understand the way stroke-survivors organised and brought order to their experiences. As people make connections between events and interpret them by constructing narratives (Chow, 2015), this directed me towards a narrative approach. Casey et al. (2016:10) examined three narrative approaches commonly used in healthcare and found these to be particularly relevant to circumstances of "*trauma or illness*" due to the storied nature of human experience and the use of narrative in sense making.

With a particular focus on career through narratives of life transition, the research is intended to address a recognised gap in SR practice and a call by Ellis-Hill, Payne and Ward (2008:157), for more detailed investigation into the way stroke-survivors approach life transitions after acquired disability. I also planned to investigate whether sharing their narratives was helpful to the stroke-survivors, as they indicate that further research into application of the Life Thread Model, a biographical approach to SR, is needed due to the "*complex cultural changes that are necessary for successful implementation*".

Study design

This is an interview study of stroke-survivors. Respondents were interviewed three times using social and psychological methods. All interviews except the pilot, which was conducted in person on university premises, were conducted by video link, audio recorded and transcribed.

The methods used and my rationale for this

My personal experience of stroke and professional experience as a former career consultant impacted my decision making process about both the chosen methodology and conduct of my research. It enabled me to tailor my methodology to the stroke-survivors' individual needs.

The chosen methodology is pluralistic, combining the biographic, narrative interpretive interview method (BNIM) with interpretative phenomenological analysis (IPA) and framework analysis (FA). I initially focus on the theory behind the BNIM interview method before explicating its structure. There is a considerable amount of theory underpinning BNIM methodology, but I only used the BNIM interview method, so I have restricted the theory discussion to that.

BNIM was advanced by Chamberlayne, Bornat and Wengraf (2000). During interviewing, it means using a strategy that minimises, for as long as possible, the interviewer's concerns, to allow the "*system of value and significance, the life world of the interviewee*" (Wengraf, 2001: 69) to emerge; that is the Gestalt, to complete itself fully and so be exposed for analysis (Wengraf, 2001: 113). In practical terms, that means being able to appreciate the *"interrelation of structural linkages that* *individuals perceive"* (Murray and Holmes 1994:60, in Jones, 2003). From my own experience of sharing my hospital story, in which I unconsciously used prison imagery throughout (see reference list), I would add that these linkages were not always consciously 'perceived' by the stroke-survivors. They included latent emotions, which frequently surfaced during the succession of interviews.

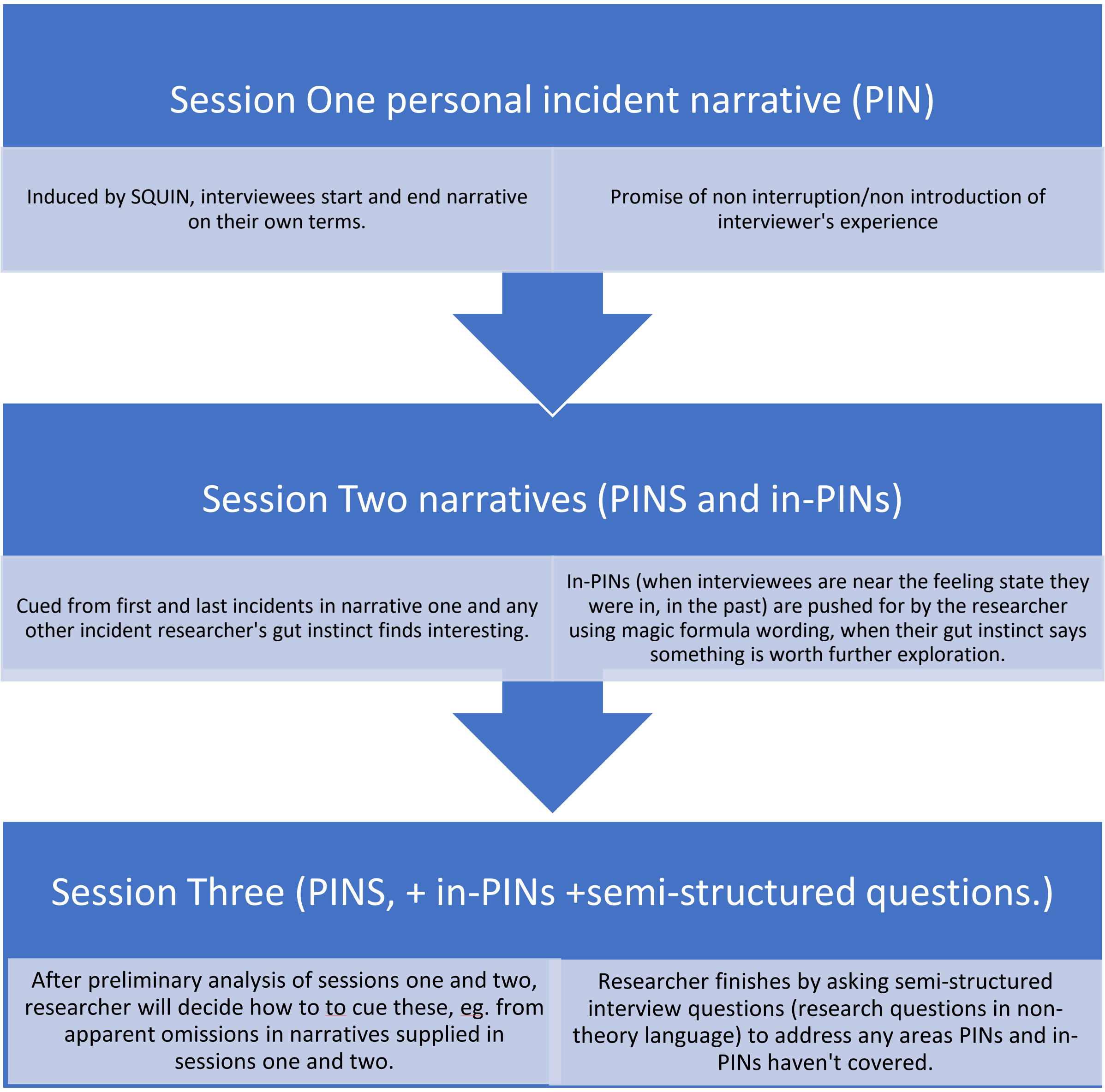
Gestalt theory was developed by Perls, Posner and Goodman in the 1930s. It perceives each person as a unity of mind, body, emotions and spirit, that consequently has unique life experience (The Gestalt Centre, London, 2017).

As I hoped that my research could illuminate how working with career consultants, specifically those experienced in free association narrative interviewing techniques, might support implementation of the life thread model, I wanted to demonstrate the potential of the method underpinning BNIM. BNIM is used in healthcare as it approximates counselling strategies, in its potential to facilitate coherence (Casey et al., 2015).

Given the *"gap between personal and professional realities"* reported by Doolittle (1992), it was important that stroke-survivors were able to share their experiences in such a way that they had control. A characteristic of BNIM is that the interviewee's initial response is prompted by a sole question inducing narrative (SQUIN). The narrative is not followed up with questions to direct or clarify the course of the first interview (see flowchart overleaf for an outline of the interview process).

As BNIM is already used in healthcare (Corbally and O'Neill, 2014), I felt that the technique could be a way of readily incorporating a life-career emphasis into a stroke self-management programme (SSMP). As Collin and Young (1986:848) explain, "*career is a process which the individual perceives as biography".*

Figure 4.1. Flow chart showing sequenced structure of BNIM interviews, adapted from Wengraf, 2006 and redrawn by Carol Wilson. **Source: personal collection.**



Session One personal incident narrative (PIN)

Induced by SQUIN, interviewees start and end narrative on their own terms.

Promise of non interruption/non introduction of interviewer's experience

Session Two narratives (PINS and in-PINs)

Cued from first and last incidents in narrative one and any other incident researcher's gut instinct finds interesting.

In-PINs (when interviewees are near the feeling state they were in, in the past) are pushed for by the researcher using magic formula wording, when their gut instinct says something is worth further exploration.

Session Three (PINS, + in-PINs +semi-structured questions.)

After preliminary analysis of sessions one and two, researcher will decide how to to cue these, eg. from apparent omissions in narratives supplied in sessions one and two.

Researcher finishes by asking semi-structured interview questions (research questions in non-theory language) to address any areas PINs and in-PINs haven't covered.

My assumptions about the worlds I studied

Whilst agreeing with Collin and Youngs’ (1986) conception of career as a life-long ‘meaning making’ process I also recognised that, despite some shared social and cultural experiences, many aspects of each stroke-survivors’ experience are unique, not least because the nature of their strokes are different. I was particularly interested in how the their stories had been fashioned over time and context through telling and retelling, and this initially stimulated an interest in BNIM analysis.

Repeated narration is likely to have occurred with members of the stroke-survivors' changing acquaintanceship (Ellis-Hill, Payne and Ward, 2008). For example, they will have repeated their story with different rehabilitation professionals and discussed it with family, friends or acquaintances, potentially changing it to suit different audiences.

Ellis-Hill and Payne (2000), in their self-body split project, explicate that in circumstances of chronic illness the interruption to an individual's life story undermines their sense of coherence so that the future becomes uncertain and unpredictable, a process termed *"biographical disruption"* (Bury, 1982), as it separates the past person from the self they hope to become. Narrative methods offer the narrator opportunities to restructure their story by highlighting some aspects while downplaying others. This process can help the narrator create coherence between the past and an uncertain future while also potentially changing their perspective to one in which there is *"cognizance of order, coherence and purpose in one's existence"* (Reker and Wong, 1988, in Macdonald et al., 2012: 357). Time is an important factor in transitions: a biographical approach "*transcends the barriers of self/society as well as those of past/present/future"* (Miller, 2000:60, in Jones, 2003).

Conceptualising the role of the researcher and the research process

BNIM, the interview methodology, demonstrates how inviting narrative/s and requiring the attribution of meaning can offer stroke-survivors the opportunity to self-manage transition/s between past and present/future lives. While practising narrating parts of their life can also offer reflexive opportunities, and thereby facilitate coherence, and potentially the impetus for change, it is not designed as a therapeutic technique (Wengraf, 2001).

However, it is worth noting that another reason I was attracted to BNIM is that I recognised it was a person-centred approach; the same approach that underpins life-career counselling and all helping relationships focused on the personal growth and development of the individual. The person-centred approach aims to give *"a greater sense of control amidst a complexity of life developments"* (Ali and Graham, 1996:12).

My task was to ensure stroke-survivors felt safe and comfortable enough to provide detailed narrative accounts of their experiences and to provide opportunities for them to reflect upon and, if necessary, amend their narratives before I analysed these in a clear and systematic way. It did not matter whether what stroke-survivors described was an accurate reflection of their experiences, because I was trying to gather phenomenological knowledge; that is the quality and nuanced nature of the experiences themselves (Willig, 2013). My role was similar to a person-centred counsellor, actively listening to each narrative empathetically without questioning the external validity of what the stroke-survivor was sharing.

Person-centred interviewing is informed by the work of Rogers (1957), who suggested that there needs to be "*basic empathy"* (in Ali and Graham, 1996:26-27) between the two parties. This is built upon three elements: unconditional regard (accepting the stroke-survivors' feelings as real and avoiding being judgemental); rapport (communicating verbally and non-verbally that I wish to tune in to their experiences and emotions, so I can walk in their shoes for a while), and congruence (to create an atmosphere in which the stroke-survivor feels able to self-explore deep seated personal issues in the knowledge that they won't be rejected by me, while being honest about my own emotions (these were recorded in both the field notes and on the transcripts). Rogers (1957) believed this self-exploration process stimulated change (in Ali and Graham, 1996).

However, I was also aware, from both my professional practice and experience of sharing my own hospital story, that there may be some latent meaning, associated with the emotional changes stroke causes, which made me acknowledge that there may be times when to fully understand the stroke-survivors' experience I would occasionally need to adopt a more *"suspicious*" approach (Holloway and Jefferson, 2000). Using an example from the pilot study, Brian rarely mentioned his wife during the first two narratives and also frequently used *"me"* instead of *"we*". This led me to wonder whether his stroke had led to relationship problems, which is common. However, during the third interview session he made references to his egocentricity, which his wife had noticed and that he felt was a “*necessity”* in terms of his recovery. This made sense of the way in which he had structured the first two narratives around his own feelings/needs and his references to *‘me’* instead of *‘we*’.

Relationships are a particularly emotive subject, and I was mindful that some stroke-survivors might use avoidance tactics if they were uncomfortable revisiting their emotions. I managed this by using transparency to build rapport. For example, acknowledging that the question I was about to ask felt like it might be difficult for them to answer and by alternating difficult questions with easier ones. Before the second and third follow-up interviews, I also reminded the stroke-survivors that they were free to refuse to answer any question at any time and could also take regular breaks if they wished to (Wengraf, 2006).

Throughout all three interviews, I focussed on the need for transparency and empathy, while also building rapport by using verbal and non-verbal means to demonstrate that I was tuning into the told stories. I think some stroke-survivors were able to access latent emotions because of my understanding of the power of silence and experience of when to use it during the interviews. This gave space for them to reflect on and gain awareness of their situations. I adopted Wengraf’s (2009) suggestion to focus on shuffling my papers, to alleviate any discomfort they might have felt. Once rapport had been established, in the follow-up interviews, I also used Wengraf’s (2009) *“magic formula”* – a specified BNIM technique – to gently probe anything I felt might have been unconscious prior to the interviewing process starting. This involved repeating the stroke-survivors’ words back to them and probing these further by then asking them to recall a related moment/time/incident/example/day in more detail, describing how it all happened.

My non-directive interviewing style developed through my professional experience of working with non-disabled and physically and mentally challenged clients as a career consultant. Despite my efforts to follow the BNIM process as far as possible, at times my gut instincts took over. This largely occurred when adaptions had to be made in the interest of ethics, which were a priority for me over and above the BNIM technique. For example, when I sensed a stroke-survivor was anxious about whether the details they were sharing were appropriate, I reassured them everything was relevant and also paraphrased or summarised what they had told me if I felt they were losing their thread.

One of the stroke-survivors interviewed (Philip) had lost his memory, so interviewing him required a considerable degree of adaption to the BNIM procedure, which was a steep learning curve for myself. For instance, I decided to let him have the interview questions in advance of each interview to help him prepare for and feel comfortable with them. This decision was made after consulting with a close friend of his, who had offered support. Philip then sent me a written response in advance and, across the three interviews, I gradually moved him from reading out his answers to feeling able to reflect on and develop them on the spot.

Recollection was initially impossible for Philip and so the experiences he shared were largely what family and friends had told him about events. He learned his answers before each interview and by the third, to my surprise and delight, even he was reflecting on and sharing his previously latent emotions, in addition to the answers he had written in advance.

As already explained, over the succession of interviews, my non-directive interviewing style and gentle pushing for more detail also revealed what the stroke-survivors found hard to express or did not intend to say; that is their latent emotions. This was primarily facilitated by the use of a carefully worded SQUIN (sole question inducing narrative) which, as Bryman observed (2008, in Corbally et al., 2014:36), "*uncovers what the participants want to say, not what the researcher wants them to say, as is often the case in semi-structured and structured interviews".* The SQUIN (see Appendix II) gave the stroke-survivors a voice and empowered them from the beginning, something that could potentially have been lost through the use of alternative styles. Crucially, it promised non-interruption. Avoiding breaking the narrative flow and minimal further interventions are unique characteristics of free association narrative interviewing styles, of which BNIM is one example. Other narrative interview designs can have a high level of intervention (Wengraf, 2001: 112), which would not have been helpful for stroke-survivors with communication and/or confidence difficulties, and I felt it was important to distinguish my interviewing style from narrative therapy for ethical reasons.

Subsequent interviews used Wengraf's 'magic formula' (see Appendix II): a pattern of wording designed to elicit personal incident narratives (PINS) and inPINS[14], which offered the stroke-survivors comfort and familiarity in relation to the direction of the interview, helping them to trust me and to open up. The third interview included some semi-structured interview questions, as advised by Wengraf, but I was careful to differentiate these from the preceding narrative questions. Furthermore, by this stage, the stroke-survivors had found their voice since trust had been established.

I will now discuss my sampling strategy.

Sampling strategy

The approach was to take a purposive sample[15] of stroke-survivors. Purposive sampling enabled me to interview stroke-survivors who have had transition experiences, ordered through time, towards a final 'cause' (the new normal of life-career). I based the career categories on my personal and professional experience of the options that I perceived were available for stroke-survivors after a stroke and modified these after the pilot.

To facilitate the use of IPA[16] for analysis, which I intended to combine with BNIM, I made the sample homogenous.

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[14] An in-PIN is when interviewees are observed by the interviewer to be near the feeling state they were in, during the past incident being recalled (Personal communication, Wengraf, 30.11.16).

[15] A purposive sample is" *a non-probability sample that is selected based on characteristics of a population and the objective of the study*" (Bryman, 2004). The researcher's judgement is used to select "*information rich cases for in-depth study*" (Wengraf, 2001: 102).

Smith, Flowers and Larkins'[16] (2009) version of IPA was eventually used only for the first theme: Transitions. The second theme, CSM, was analysed using a combination of IPA and FA for reasons explained next.

That is, certain characteristics of the individuals were held ‘constant’ (Smith, Flowers and Larkins, 2009), enabling me to identify other characteristics that illuminated the dimensions of how stroke-survivors experienced the phenomenon of transition.

Box 4.1: summary of inclusion criteria

- Survivors of major strokes;
- Stroke-survivors of either gender, aged thirty-one to sixty-five*;
- Stroke-survivors with both physical and cognitive impairments;
- Stroke-survivors who have/had a professional/business role;
- Stroke-survivors who are able to hear and speak enough to share their narratives and answer questions about them.

*The age limit was later extended to seventy, in line with changes to pension ages, to widen the field for recruitment.

I will now outline my homogenous criteria and my rationale for using these. Career theorist, Super (1957), identified five stages of career development, linked to chronological age. While the relevance of these stages has undoubtedly changed in recent years, with changes like greater access to Higher Education (HE) and maternity/paternity rights, his seminal work forms the foundation of more recent theories, such as Savickas’ career adaptability theory (1997) and career construction theory (2005), and his broad definition of career has become even more pertinent with the changing *‘psychological contract*’, in which the onus is firmly on the individual to manage their life-career.

Since Super’s stages are based around change (Ali and Graham, 1996), they were used as a starting point to access stroke-survivors who were in an established career pre-stroke and who could reflect on the transition/s they had made over a period of time.

Thirty-one is the minimum age: the period Super identified that the individual would normally be securing their position in ‘work’ (stabilisation within the establishment stage) and sixty-five is the cut-off point (decline), when he postulated individuals are moving into retirement or a reduction in ‘work’ role. Sampling stroke-survivors between these stages, rather than young stroke-survivors, increased my chance of accessing those who shared the experience of having had an established ‘career’ pre-stroke and who were able to reflect on their life-career transition/s post stroke. However, I later extended the cut-off point to seventy, to reflect changes to pension age and the fact that many people are still active in retirement.

The second inclusion criterion were stroke-survivors with physical and cognitive impairments. Since cognitive impairments are a significant predictor of the ability to return to work (RTW) (Kauranen et al., 2012), including cognitively impaired stroke-survivors in the sample was a way of accessing stroke-survivors who have experienced transition difficulties related to a variety of impairments and those that particularly impact on paid work.

The third inclusion criterion was that stroke-survivors could hear and speak enough to share their narrative and answer questions about it. This was a pragmatic decision. I had no experience of working with stroke-survivors with aphasia or dysarthria (speech and language difficulties) and realised that to do so would require an additional time commitment and potentially interactive IT resources. However, the pilot stroke-survivor had previously experienced dysarthria and reflected upon this, so, through recovery over time, this type of impairment was included in the narratives shared.

For similar reasons, I decided to focus on major stroke-survivors: some major stroke-survivors also experience minor strokes in the preceding period and so that experience could be included in narratives provided.

The final inclusion criterion was stroke-survivors who have/had a professional/business role. This was because their cognitive disabilities were more likely to impact on their ability to return to a former role in which they had management responsibilities. From my own stroke experience, I knew that a significant barrier could be the loss of executive functioning skills, which include cognitive processes such as planning, initiation, monitoring, problem solving, or the ability to make judgements/decisions.

I now summarise the exclusion criteria, before considering recruitment.

Summary of exclusion criteria

Box 4.2: summary of exclusion criteria

- Survivors of minor strokes;
- Stroke-survivors below or above the age limit;
- Stroke-survivors who only has physical impairments, as cognitive impairments are a significant predictor of the ability to RTW (Kauranen et al., 2012);
- Stroke-survivors who have not had/do not currently hold a professional/business role.

Box 4.3: recruitment

I proposed recruiting up to four stroke-survivors. In addition to meeting the inclusion criteria outlined, they had to regard their post-stroke career status as matching one or more of the four possible career categories identified:

- Returned to their former work role;
- Changed ‘career’ direction;
- Taken the decision not to return to work (RTW);
- Been forced into early retirement or redundancy.

Using exponential non-discriminative snowball sampling[17], I proposed recruiting up to four stroke-survivors. In addition to meeting the inclusion criteria outlined, the selected stroke-survivors had to regard their ‘career’ status post-stroke as matching one or more of four possible ‘career’ directions

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[17] Snowballing refers to a method of selecting a sample in which potential participants are asked whether they know of other people with relevant characteristics and experiences who might be approached. Snowball sampling is often used to find and recruit “*hidden populations”:* groups not easily accessible to researchers through other sampling strategies (Shinebourne, 2011). The pattern of snowballing referred to as exponential non-discriminative means that *“the first subject recruited to the sample group provides multiple referrals*. Each *new referral is explored until primary data from sufficient amount of samples are collected”* (Research Methodology.net).

that I had identified. Namely, returning to their former work role, changing ‘career’ direction, taking the decision not to RTW, or being forced into early retirement.

The first three categories reflected the three options a stroke-survivor potentially has after leaving hospital and the last category was based on the pilot survivor’s experience. It was possible for stroke-survivors to identify with more than one due to changes that occurred to their ‘career’ status over time.

Sample size is low because IPA’s (Smith, Flowers and Larkin, 2009) main concern is to fully appreciate each participant’s narrative/s (case), requiring samples to remain in-depth. They suggest three to four interviewees, given the fact that there are repeated interviews with each participant.

One disadvantage of BNIM was that it impacted on my ability to recruit directly, as it prevented me from presenting my research to local stroke groups. In BNIM researchers do not introduce their personal experience at any stage of the research process as it could affect the way the respondent tells their story. None of the stroke-survivors knew anything about my background until after the third interview, when I answered any questions they had.

Recruitment was difficult. I originally planned to recruit stroke-survivors through a snowballing approach, using my pilot stroke-survivor as a gatekeeper. However, the one stroke-survivor he recruited from the Stroke Association (SA) for me then had a suspected series of strokes, so I later recruited one from a local support group: Strokes ’R’ Us (the secretary of the group via email) and another through a personal contact. When the latter stroke-survivor decided to withdraw after the second interview, I then recruited a further stroke-survivor through my second supervisor, who is a member of the UK Stroke Forum Steering Group. The age range was expanded at this stage, to broaden the recruitment field.

Many of the stroke groups I approached were unwilling to support research as they were protective of their members’ leisure time. In addition, a stroke-survivor I approached for the pilot was happy to complete a questionnaire, but withdrew when he realised he would have to share his story with me: not everyone was emotionally able or willing to relive the traumatic experience of having a stroke and its aftermath and this may have also been at the root of the browser problems that the stroke-survivor, who later withdrew, developed after the first interview. This prompts me to clarify how the research was ethically managed.

Ethics

The study received ethical clearance from Keele University's Ethics Committee (see Appendix I).

Consent

All participants were given a minimum of two weeks to consider the letter of invitation, information sheet and consent forms (see Appendix I) prior to the interviews. They were also encouraged, through the information sheet, to discuss participation in the research with an immediate family member, the gatekeeper (pilot stroke-survivor), or another person with whom they have a close personal relationship. I also offered them the opportunity to discuss with me what consent would mean, and any practicalities, prior to interviewing. Consent was granted on 17.7.18 (ERP 1368).

How the interviews were conducted

Interviews were scheduled at mutually convenient times and stroke-survivors were made aware that they could reschedule interview two if they needed to. All of the stroke-survivors, except Philip, were able to complete the first two interviews on the same day, with a break between, in line with BNIM procedure. I suggested that Philip's interview was scheduled about a week after the first to allow him preparation time, and he agreed to that arrangement. Third interviews were always arranged after the stroke-survivors had had an opportunity to read the transcripts for the first two interviews, as an aide memoire and an opportunity for reflexivity. This was normally at least a couple of months later as I was reliant on an external transcription service and had to check and amend transcripts before sending them on to the stroke-survivors.

On the subject of reflexivity, I both deliberately and accidentally used silence during the interviews. I often pause when I'm thinking and as a stroke-survivor myself, the pauses might have been longer than what might be considered normal. I discovered during the pilot that this worked to my advantage as Brian, who always chose his words carefully, frequently corrected himself as he reflected on his words. He also asked if he could change the ending to his story after taking a break, following interview one, which I invited him back into the room to do. At that point he told me about his Personal Independence Payment tribunal.

As explained, I was alert to the fact that re-visiting parts of the stroke experience is emotional work and, had I detected any sense of resistance or stress during the interviews, either through refusal or body language, I would not have pursued that line of enquiry. At the end of the first interview, I provided each stroke-survivor with helplines for both the Stroke Association (SA) and Anxiety UK and suggested they may wish to use one of them, if they felt any emotional turmoil post-interview or when reading through the transcripts.

Due to funding difficulties, only the pilot stroke-survivor was interviewed face-to-face at university in a building with disabled facilities. An ethical amendment (ERP1368) was sought and granted on 13.9.18, to interview the remaining stroke-survivors via video link. As they were interviewed in their own home, this had the advantage of being convenient for them. However, despite my attempts to keep the process as simple as possible by providing technical support and clear instructions, the first stroke-survivor to be interviewed in this way had problems with her computer browser, which was difficult to resolve remotely. This impacted on the success of the second interview and she subsequently withdrew from the research, requiring me to recruit a replacement stroke-survivor. Consequently, the remaining stroke-survivors were offered a practice connection session prior to interviewing, which worked well and helped build enough rapport for them to open up about their world.

After interviewing each stroke-survivor, I made debriefing notes around the experience, which was an opportunity to acknowledge and reflect on my emotions and what memories, ideas, etcetera, the interview stimulated in me. These were also noted during data analysis, which I discuss next.

Analytic method

As a phenomenological researcher, I assume there is more than one world that can be studied. However, I appreciate that there are differences in the extent to which phenomenological research focuses on the possible meanings, varying from descriptive to interpretive approaches.

With a healthcare audience in mind, I used a version of IPA[18], which originated in health psychology. IPA requires a data collection method that *"will invite participants to offer a rich, detailed first person account of their experiences of phenomena"* (Shinebourne, 2011).

Although it is frequently used with semi-structured interviewing approaches, Smith, Flowers and Larkin's (2009) emphasis on dialogic interviewing techniques has led some researchers to combine BNIM with IPA (Russell, 2015). I decided to adopt this approach after exploring the BNIM analytic method further, alongside other options.

In relation to the optional analytic method of BNIM, Wengraf (2009) stresses that BNIM's life history track allows the interviewer to uncover a respondent who is dishonest or unconscious of truths about him or herself, which is necessary to prevent the interviewer from being beguiled by the story told and that the researcher should be critical.

As discussed, my priority as an interviewer was to be largely empathetic, not critical. This is where IPA differs from BNIM's analytic approach, in its commitment to *"an understanding of the participant's point of view and a psychological focus on personal meaning-making in particular contexts"* (Smith, Flowers and Larkin, 2009: 79).

That is not to say that I did not analyse contradictions, omissions and repetitions etcetera. Merely that, as a stroke-survivor myself, I had psychological knowledge about what it might mean for the stroke-survivors to have these concerns. For example, in relation to contradictions, Frank (2013)

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[18] This analytic approach was later extended to include FA, which is detailed after the philosophical underpinnings of IPA.

draws attention to chaos as a feature of illness narratives and certainly aspects of at least one of the stroke-survivors' stories fell into that category. The meaning that the stroke-survivor makes of that lived experience is the primary concern of IPA, making the analysis a joint product of the researcher and stroke-survivor.

Furthermore, I did not feel that the use of IPA hindered the ability to let stroke-survivors' unconscious truths emerge. I believe this was achieved through participant reflection during the interview process itself. For example, Brian moved from feeling that he was not egocentric post-stroke, although he admitted his wife had noticed this trait, to concluding in the third interview that it had been essential to his recovery.

However, combining the two methodologies did involve adhering to the preliminary stages of the BNIM analytic process as these inform the structure of the successive interviews. For instance, I selected the first and last incidents in the stroke-survivors' narrative (first interview) to probe further in the second interview, alongside other incidents that my instincts suggested were worthy of further investigation, in the exact order that they were introduced in the first interview. I also took Wengraf's (2009) advice to arrange a third interview that began with requests for further PINs and ended with semi-structured questions that explored any aspects of the central research question that had not been answered by the PINs provided to date.

However, I did not follow the full BNIM analytic process, which involves a twin-track approach to analysis, facilitating investigation of both the individual's life story and life history. I made this choice because my research focuses on how stroke-survivors transition towards an end state (the new normal of life- career), so their contextual history is merely a starting point for the transition process, with the potential to inform interpretation of the narratives.

I chose IPA because Smith and Sparkes (2006) state it allows the researcher to *"explicitly seek out idiographic[19] meanings in an attempt to understand the individual which may or may not offer general insights"* (in Finlay, 2009:9). It is developed around significant verbatim data extracts, emphasising the importance of the interviewee's voice. That accorded with my desire to give stroke-survivors control of the interview process.

While IPA's foundations originate in phenomenology, Smith, Flowers and Larkin's (2009) version of IPA is a hermeneutic phenomenology, focused on "*that which is experienced in the consciousness of the individual"* after Husserl (Smith, Flowers and Larkin 2009: 13). The method he advocated proceeds through a sequence of reductions, each offering a different lens for considering the phenomenon. As everyone has unique perceptual experiences, the intention was to access what lies at the core of the subjective experience of the phenomenon, practical and emotional features. Husserl's work was limited to processes but is a useful reminder of the importance of reflexivity.

Reflexivity has relevance because it relies on interpretation to probe layers of, sometimes latent, meaning. This is another reason I considered it a good fit with BNIM. It is a psychological phenomenological approach, which recognises the role of both the researcher and the respondent as interpretative, described by Smith (2008) as a "*double hermeneutic*", as opposed to the more descriptive approach used by Giorgi.

Descriptive phenomenology pertains to capturing experience exactly as it presents itself without attributing meanings from outside the account itself, while the researcher's role in the interpretative phenomenological approach taken aims to consider the broader social, cultural and psychological meanings of the narrative accounts themselves. As Smith and Sparkes (2006: 104, in Willig, 2013: 73) explain, IPA *"positions the initial 'description' in relation to a wider social, cultural, and perhaps even*

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[19] *"Starting with the detailed examination of one case until some degree of closure or gestalt has been achieved, then moving to a detailed analysis of the second case, and so on through the corpus of cases."* (Smith, Flowers and Larkin, 2009:41)

theoretical, context. This second order account aims to provide a critical and conceptual commentary upon the participants' 'sense-making' activities".

Interpretative phenomenology was selected in preference to a purely descriptive phenomenological approach because I believe that respondents reflect on and sometimes amend their words and the researcher vigorously builds themes, forging connections as they seek to understand the data. Sense-making therefore involves a degree of interpretation for both parties, which returns me to the subject of reflexivity.

Reflexivity

In my experience, interpretation occurred at all stages of the research process. I have already made reference to this during the interview process, and I now refer to the transcription, analytic processes and writing up.

Due to the time constraints of the Professional Doctorate, I transcribed the pilot data in its entirety myself, which helped me to embed it. However, because of my own disabilities, I decided to use an external transcription service to assist with the remaining stroke-survivors, which required a further ethical amendment. However, the transcriber's lack of familiarity with rehabilitation processes and the stroke-survivors themselves resulted in a number of errors, so I spent a lot of time checking recordings and amending the other stroke-survivors' transcripts. This merged with the first step of analysis: reading and re-reading, providing a holistic view of each stroke-survivors' experience. In relation to my reflexivity, I wrote my thoughts directly on the transcripts both during transcription for the pilot stroke-survivor and when checking transcripts for the other stroke-survivors.

While I valued each stroke-survivors' own interpretation of their experiences, I was inevitably looking at their recovery through my own lived experience, both as a stroke-survivor and in my former professional life. Consequently, while I used IPA for the initial analysis, I also later combined it with FA so I could interpret the stroke-survivors' experiences through the lens of life-career.

As explained earlier, interpretation occurred at all stages of the research process. Both my lived experience as a stroke-survivor and former professional role impacted my decision making throughout the research process, both in terms of methodological choice, which I've already discussed, my analysis and write up.

I have already made reference to reflexivity during the interview process, and I would add to that, that I knew from my own lived experience, as a stroke-survivor with cognitive disabilities, that the respondents would need to break the interviews down into manageable steps, which also influenced my choice of BNIM. I will now refer to reflexivity in the transcription, analysis and writing processes, starting with the analysis.

Data analysis

I adapted IPA using FA, as explained below. Once the interviews were completed, initially analytic procedure followed that described by Smith, Flowers and Larkin (2009). It involved adhering to IPA's idiographic principle by analysing each stroke-survivors' interview in its entirety and writing up each case, while it was fresh in my mind, before moving onto the next stroke-survivor.

During initial noting and through discussions with supervisors, I learned to dig deeper into some of the language interpretations, reflecting on why the stroke-survivor was using particular words and what it meant for that particular situation, in other words the meaning they were attributing to it. As a former career consultant, I was trained to look for metaphor and Brian, in particular, frequently used metaphor to indirectly express feelings that were sometimes difficult to describe and/or acknowledge. An example, is his references to his *"inner child"*.

Occasionally other stroke-survivors' experiences resonated with my own, making bracketing particularly difficult, although my supervisors mitigated any attempt to solely draw on my personal experience of stroke during interpretation by pointing out alternative lenses for the situation. An example of this was Susan’s description of herself as feeling like “nobody nowhere” because she identified herself by her former professional role. This resonated with my own experience, I was also uncertain how to introduce myself to other people once I could no longer call myself a career consultant.

Partially due to the difficulty bracketing my professional experience as a former career consultant and partly due to my decision to use an explanatory framework during data analysis, we decided the second theme of CSM would be better analysed using FA as I was combining IPA’s inductive approach with a deductive approach, which was more theoretically informed.

Once I had assembled tables of themes for all three interviews for each stroke-survivor, a master table of themes for each stroke-survivor was then compiled by considering the theme headings and looking for themes to cluster. When I had selected a set of themes that I felt best told their story, I then removed any that did not contribute to answering the central research question or that could be subsumed within larger themes. For example, although all stroke-survivors shared their hospital experiences, these were not all directly relevant to the central research question and so regrettably had to be discarded at this point. At times the reduction process was hard because I had vast quantities of rich data, and so I moved forward by starting to draft the case studies before later returning to the reduction process. I found that this helped me prioritise quotations and view the stroke-survivors’ experiences in a more objective way. Once I had finished reducing the data, the remaining themes were used to construct an individual case study for each stroke-survivor, which was presented alongside their master table (see Appendix III).

As the analytic process was time consuming and complex, I now present an example of how data was interpreted to arrive at an overarching theme, using quotes from Susan’s interviews, to illustrate how they fed into the transitions theme. This is also illustrated in the diagram that follows for clarity. The analytic process began with reading and re-reading the transcripts, starting with the first interview for each stroke-survivor and then their second and third interviews. I noted my thoughts/ feelings on the transcripts in the margin during that process.

In the first interview Susan said: *“the redundancy in 2004 was horrific”.* She had been made redundant from her management role in Housing services before her stroke and I noted this was an involuntary transition. In interview two, she explained about how she had been *“finished”* from her new job in social services because, after having a breakdown, she felt unable to return to work, in the expected timeframe. She said: “*It wasn’t marked by anything, there was no card, no thank you, no collection, no leaving do, you know?”* I noted that she perceived the fact that her rite of passage had gone unmarked as an injustice and that she felt devalued by that. In interview three she told me about her cognitive behaviour therapy sessions and said that she had learned about: *“not being measured… solely in terms of my working life. What I earned, you know, my career.”* In each interview she was clearly talking about changes in different stages and roles in her life, in other words transitions. I then listed the emerging subthemes from each of these quotes, which were involuntary transition, injustice (feeling devalued) and fulfilment (feeling valued) at that stage. I put potential sub-themes in brackets initially while I worked out which were most important in terms of the coding, I then attempted to cluster the subthemes, to avoid any overlap, so I considered how they related to each other. For example, Susan’s sense of injustice led to her feeling devalued, so under the overarching theme of transitions, injustice was one sub-theme and feeling devalued was another sub-theme.

After working through all the transcripts line by line for each of Susan’s and the other stroke-survivors’ three interviews, all the themes and sub-themes were reduced to a master table. At that point, I grouped the subthemes into polar opposites to demarcate the start and end of the transition process. For instance, a journey from injustice (feeling worthless as a result), to fulfilment (feeling valued), and a journey from loss and suffering (lack of choice) to surviving (choice). There were two overarching themes: transitions and CSM. In Susan’s case, subthemes were involuntary transitions, voluntary transitions, misunderstanding her disabilities; self-management of disabilities, loss and suffering (lack of choice), surviving (choice), injustice (feeling devalued) and fulfilment (feeling valued). As I repeated the process for each stroke-survivor, these were discussed in supervision meetings, changes to wording often occurred at that stage. For example, one of Brian's subthemes was allegations of incompetence. That was reworded to injustice. Once each stroke-survivor had a reduced master table of themes, I then started to look for convergence and divergence between themes, in order to produce a master table of themes and subthemes for them all (see Appendix III). I then moved on to writing up.

Writing up

Writing up was a further opportunity for reflexivity and I used that to help me move forward when I was stuck with the analysis. For example, I decided to capture each stroke-survivors' story highlights by writing case studies and the thought process involved helped me to later return to the data analysis. Similarly, writing the abstract for the UK Stroke Forum helped me to work out the key findings. As I often think diagrammatically, I also experimented with different templates to produce diagrams and models, which helped me to simplify some of my thoughts and findings. I now present one of those diagrams to provide a worked example of the progression from a line/code within the transcript to building themes and sub-themes, using Susan's transcript as an example.

Figure 4.2

How data from the interview analysis was interpreted to arrive at an overarching theme: the journey of a quote from each of Susan's interviews to a theme and corresponding sub-themes.

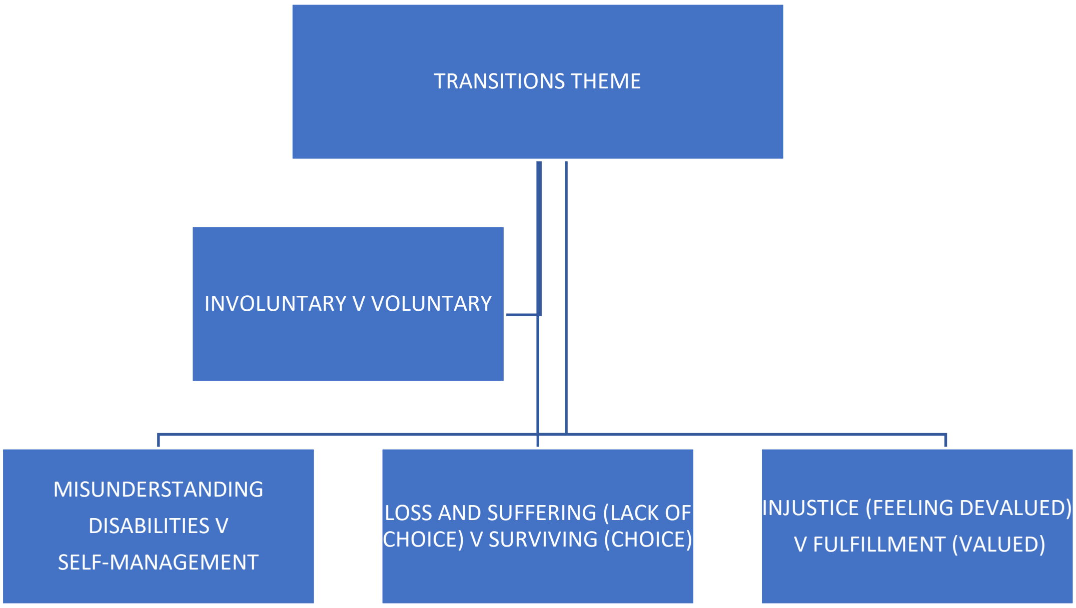
Interviews

1 Susan was made redundant from her management role in housing services (an involuntary transition pre- stroke):
"The redundancy in 2004 was horrific"

2 Susan was ***"finished"*** from her new job in social services after experiencing a breakdown (post stroke) because she was unable to RTW in the time frame HR expected:
"It wasn't marked by anything, there was no card, no thank you, no leaving do, you know?"

3 Susan talked about her CBT sessions. She had learned about ***"not being measured solely in terms of my working life, what I earned, you know, my career".***

EMERGING SUB-THEMES FROM EACH OF THESE QUOTES



SUB-THEMES WERE THEN CLUSTERED AND PAIRED INTO POLAR OPPOSITES (denoted by v) TO DEMARCATE THE START AND END OF THE TRANSITION PROCESS

I then repeated the whole process for the CSM theme. Due to word limitations, I won't detail the whole process again. Instead, I will just explain how Brian's words led me to identify the sub-themes of self-awareness and opportunity awareness within the CSM theme. In interview one, he talked about looking for the right opportunity to further advance his career: *"I will just have to see if the right opportunity comes up."* That screamed opportunity awareness at me!

In interview three, he talked about being classified as a "*pragmatic activist*" in psychometric tests when going for promotions earlier in his career. This was a clear example of self-awareness. Both are parts of the CSM process, as illustrated by the DOTs[20] model and other examples of components of that model were also evident as I continued analysis, which led to me adapting the DOTs model (see chapter eight).

After completing four master tables of themes and four case studies, the same process was followed to devise a master table for the entire data set (see Appendix IV). At all stages, the analysis was checked and audited by the supervisory team. It was at this point that a decision was taken to use FA for the CSM theme and its related sub-themes. I consider this further after explicating my chosen IPA methodology.

A key reason for choosing Smith, Flowers and Larkin's (2009) IPA, over other versions, is the fact that it is consistent with the epistemological position of my overarching research question. Rogers (1957), who developed non-directive interviewing to facilitate self-exploration and stimulate change, also advocated phenomenology (De Carvalho, 1991).

IPA is developed around significant verbatim data extracts, emphasising the importance of the interviewee's voice, and therefore it comfortably sits with the person-centred approach and

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[20] A tool for 'joining the dots': an analytical tool used to see where a client is in the career self-management process. It can also be used for career planning and focuses on four cyclical aspects of the career learning process: decision learning (D), self-awareness (S) , opportunity-awareness (O) and transitions (T).

philosophy underlying the BNIM interview method. Smith, Flowers and Larkin (2006) explain the researcher's role is to *"explicitly seek out idiographic*[21] *meanings in an attempt to understand the individual which may or may not offer general insights"* (in Finlay, 2009:9).

The emphasis on the idiographic, narrative element is growing in popularity in healthcare research (Finlay 2009). IPA's main concern is to fully appreciate each participant's narrative/s (case), requiring sample sizes to remain small.

I selected four respondents on the basis that I was interviewing each one three times. As stated earlier, Smith, Flowers and Larkin (2009) advise this is an appropriate number for a PhD in these circumstances.

Biggerstaff et al. (2008) explain that Smith (1994) developed IPA to *"allow rigorous exploration of idiographic subjective experiences and, more specifically social cognitions".* Both of those are pertinent to IPA's philosophical underpinnings, which I detail next.

Philosophical underpinnings of IPA

The importance of "*Dasein" (Heidegger,* 1927): human beings in the world, lodged in our culture and wider society was recognised by Heidegger, who described us as being "*thrown*" into the world. By this he meant that chance or destiny causes the circumstances of a person's birth, like country, place of birth, family and environment. (Watts 2001). In the case of stroke-survivors, after a stroke, they are unexpectedly plunged into a new normal, in which everything is unfamiliar. Heidegger believed that during times of heightened anxiety, the sudden perception of nothingness/emptiness can open up understanding to the true nature of being (Watts, 2001). My research considers how stroke-survivors perceived this change to their circumstances post-stroke and the way in which that affected how they self-managed them.

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[21] *"Starting with the detailed examination of one case until some degree of closure or gestalt has been achieved, then moving to a detailed analysis of the second case, and so on through the corpus of cases."* (Smith, 2004:41)

Husserl on the other hand, saw phenomenological research as studying the life world that a person lives, by "*systematically and attentively reflecting on everyday lived experience… either first order activity or second order mental and affective responses to that activity"* (Smith, Flowers and Larkin, 2009:33). As previously explained, the stroke-survivors were provided with transcripts for each interview, facilitating reflection between interviews and silence was provided during interviews for the same reason.

In addition to Heidegger and Husserl, IPA is also influenced by Merleau-Ponty and Satre. Merleau-Ponty stressed the importance of embodiment, which is *"the interdependency of mind and body, self and world"* (Jackson, 1983, in Becker1999:52). This is particularly pertinent to stroke-survivors. As Ellis-Hill and Payne (2000:731) explicated in their self-body split project on stroke, immediately after a stroke: *"the body becomes something foreign and separate from the self".* This is because it is unfamiliar and therefore no longer easily controlled by the stroke-survivor, who will notice things like sudden unreliability of body parts and not feeling like the person they previously were. Ellis-Hill and Payne (2000) recommended that rehabilitation practitioners used narrative methods so they can understand the meaning of the individual's body within the context of their new life and highlighted that lack of embodiment can last for at least a year. They concluded that the meaning of a new body is socially defined, which links with Sartre's emphasis is on the influence of others in the way we experience our lives, which, as explained, is a fact that is especially relevant to illness stories, returning us to my choice of BNIM as an interview method that gives stroke-survivors a voice of their own, rather than one channelled through rehabilitation professionals.

I sought to investigate a particular type of illness narrative (the transition/s from illness to the new normal of life-career) through my central research question: 'How do stroke-survivors self-manage their life-career transition/s?', and the research questions, which inform it, which are detailed in the literature search.

As the research had specific questions of a phenomenological nature and a pre-designed sample, it also lent itself to Framework Analysis (FA), which I shall now briefly explain.

Framework analysis

FA, developed by Ritchie and Spencer (1994), is characterised by theoretical flexibility (Willig, 2013) and comes under the umbrella of thematic analysis, which has become increasingly popular in multi -disciplinary health research (Gale, 2013). It has six key stages.

These had already been completed during the IPA process: familiarisation with the data and identifying a thematic framework, charting and mapping the data, in which the data is indexed and arranged into tables of themes. Finally, the analytical framework is applied to the data. During this process, which overlapped with IPA, and specifically that of eidetic reduction[22], I identified emerging themes and reduced them to their essence. It was at this point that the application of my prior knowledge as a career consultant became apparent, which I discussed with the supervisory team, leading to the decision to use FA for the second theme of CSM and its related sub-themes. Care was taken not to force the data to fit a priori issues.

However, as illustrated by Brian's quote overleaf, the strength of the data and its connection to CSM models could simply not be ignored, particularly given the subsidiary aim of the research to demonstrate how a narrative approach might form a successful part of a stroke self-management programme (SSMP). Coding the CSM sub-themes related to the DOTS model (Law and Watts, 1977), because I noticed, after analysing Brian's data, that he had a high degree of self-awareness. For example, he reflects on his work as a Stroke Ambassador as follows:

> *"As I was going for more senior posts, I would have to have psychometric assessments and always came out as a pragmatic activist. Now I actually understand what that means."*

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[22] *"The eidetic reduction… involves the techniques required in order to get at the essence - the set of invariant properties lying underneath the subjective perception of individual manifestations of that type of object."* (Smith, Flowers and Larkin, 2009:14)

(Session 3, Changes Pin, 101-106)

I used my professional knowledge to code the data in this way, because I believed it would help to simplify my interpretation of the CSM themed data for a wider audience. The DOTS model is particularly suited to adults preparing for career transitions (Young, 2019). In addition:

> *"The Association of Graduate Careers Advisory Services (AGCAS) has promoted the use of the DOTS model throughout their mission and vision statements, embedding it into their developmental approach and their lobbying. It is supported by the UK's Higher Education Academy, the Association of Graduate Recruiters and the Quality Assurance Agency for HE."*
>
> (Stapleford, Stanbury and Kuma, 2005, in Young, 2019)

The epistemological and theoretical orientation of the study

Although FA is not tied to a specific theoretical approach, the themes identified represented the stroke-survivors' experiences of Transitions and CSM, as reflected in the central research question and the phenomenological approach taken throughout the study. They had already been interpreted using IPA but, as explained, I later decided to use the DOTS model (Law and Watts, 1977) to help make sense of the phenomenon of CSM. Each letter of DOTS is an acronym for one of the four main aspects of CSM, which together position someone for employability (Watts, 2006, in Young, 2019). On the basis of the stroke-survivors' experiences, I developed and enhanced it by adding the concept of readiness, which precedes self-awareness. As Yin (2003) explains, a benefit of this multi method approach is that it produces a more detailed and structured data set, allowing me to validate the findings and thus strengthen their reliability. However, FA also has its weaknesses. One of these is that the researcher is so committed to the a priori codes, identified on the basis of the literature and theory, that they do not enable fresh insights to emerge from the data (Willig,2013). However, as explained, this was avoided because the decision to use DOTS was taken after the themes had been inductively analysed, as per the IPA approach.

The fact that I started with IPA analysis, which uses a homogenous sample, meant that a further weakness of FA was also mitigated: the fact that it cannot accommodate heterogeneous data (Gale et al., 2013). Starting with a homogenous sample facilitated comparison of differences in the final stages of analysis.

Summary of methods chapter

In this chapter I have explained why I chose pluralistic methods in preference to other possibilities and in doing so I have outlined their philosophical underpinnings. I have also explained the ethical approval, recruitment and sampling process I used and I have detailed my position, as both a stroke-survivor and former career consultant, with regard to the research. In the next four chapters, I present the findings of the research followed by a discussion of their implications for current policy and practice. The final tables of themes and case studies are presented in the appendices, due to limited space. I start with findings relating to *'Before'.*

5: Summarising the stroke-survivors' experience of transitions: *'Before'*

Introduction

In this section I begin to report on the results of my interviews with four stroke-survivors. Detailed case studies are provided in Appendix III but, in short, I identified two major themes from the research: Transitions and Career self-management (CSM). I have organised my report into four chapters. The Transitions theme and its related sub-themes are structured into *Before*, *Becoming* and *Beyond.* I follow this with a chapter on CSM and its related sub-themes.

I begin with the theme of Transitions. I have adopted Bridges' (1980) definition of transition for this research as he makes a helpful distinction between change, which is a situational shift in the world around us and transition, which are psychological processes stroke-survivors have gone through in response to the shift (Bridges 1980).

The Before stage *('Before')* identified in all the narratives described life after the stroke and before the stroke-survivors transitioned to the new normal; a period of *"limbo*" (Becker, 1999) in which the stroke-survivors were neither their former selves nor the person they were about to become (Turner, 1969).

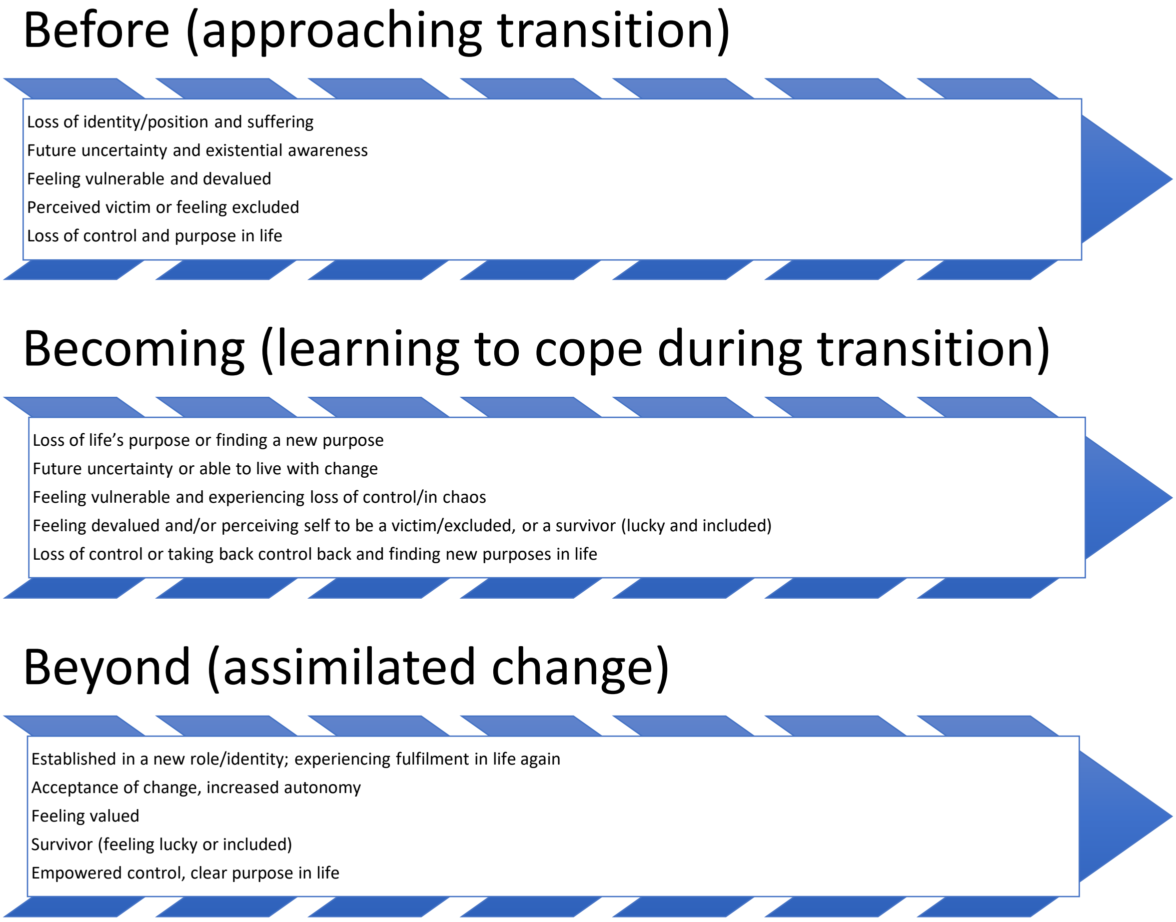
In the subsequent Becoming stage, they were concurrently learning to cope with the dynamics of their new normal and struggling to accept the evolving self that was developing from their post stroke experiences *('Becoming').* The third identified stage is life beyond, expressing concern about who their future self would be as the sudden life changes, caused by stroke, had been assimilated *('Beyond').*

The Transitions identified had five sub-themes and the stroke-survivors journeyed through these at different rates. The sub-themes are shown in the diagram overleaf, which illustrates the relationship between the three transition stages and the sub-themes. Katie's paintings head up each chapter, to further illustrate the meaning of the three transition stages identified. For instance, the title of the painting in '*Becoming*': "Who am I?" profoundly summarises her uncertainty about her new identity and significant sense of loss.

Throughout the transition stages, the stroke-survivors were learning about themselves and their new normal. This involved them developing CSM skills, which is the second major theme of the research. I report on this theme in chapter eight and the relevant sub-themes are detailed in the diagram in that chapter (Figure 8.1).

I now detail the three stages of transition identified, beginning with the data relating to before the transition process began. All three transition stages and their sub-themes are illustrated in Figure 5.1. overleaf.

Figure 5.1. Transition process diagram demonstrating 'mini-cycling'



Before (approaching transition)

Loss of identity/position and suffering
Future uncertainty and existential awareness
Feeling vulnerable and devalued
Perceived victim or feeling excluded
Loss of control and purpose in life

Becoming (learning to cope during transition)

Loss of life's purpose or finding a new purpose
Future uncertainty or able to live with change
Feeling vulnerable and experiencing loss of control/in chaos
Feeling devalued and/or perceiving self to be a victim/excluded, or a survivor (lucky and included)
Loss of control or taking back control back and finding new purposes in life

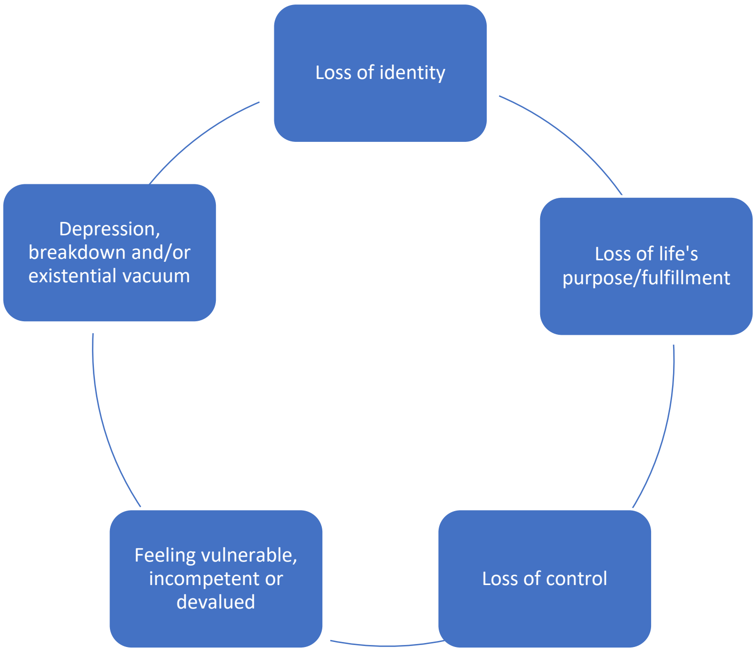
Beyond (assimilated change)

Established in a new role/identity; experiencing fulfilment in life again
Acceptance of change, increased autonomy
Feeling valued
Survivor (feeling lucky or included)
Empowered control, clear purpose in life

The transitioning process did not resemble a linear progression for any of the stroke-survivors. They all experienced greater or lesser changes of direction and intention, sometimes more than once. As the previous diagram shows, although the stroke-survivors eventually progressed through all three stages, they also re-cycled through earlier stages at varying times, for example after 'failing' to maintain the work positions they had returned to. This is known as 'mini-cycling' (Super, 1957), represented by the chevrons between the stages in figure 5.1.

This ongoing process of transitioning was interpreted by the stroke-survivors and I as learning and CSM. I initially focus on learning.

Figure 5.2. Before the transition: cycle of ‘failure’: “*It was doom and gloom for a while”*



As Bridges (1980) explained, transitions begin with loss. The data also showed that these losses are non-linear, as illustrated in figure 5.2. The cycle is potentially continuous, reflecting the stroke-survivors’ initial sense of being trapped by their circumstances. As a consequence, not all the learning, that they conceptualised as transition, was positive in nature. I clarify in this chapter how the stroke-survivors released themselves from the *“doom and gloom”* (Brian, Session 1, 114).

I begin with the time when the stroke-survivors were identifying what they had lost before beginning the process of managing their losses, which are a part of their new normal.

Loss of previous identities and purposes

Katie’s paintings reflect the various transition stages described in the thesis. As these stages are not necessarily discrete, she was also reflecting ongoingly on who she had now become. The painting below illustrated the person she was and the brain’s central role in controlling this.

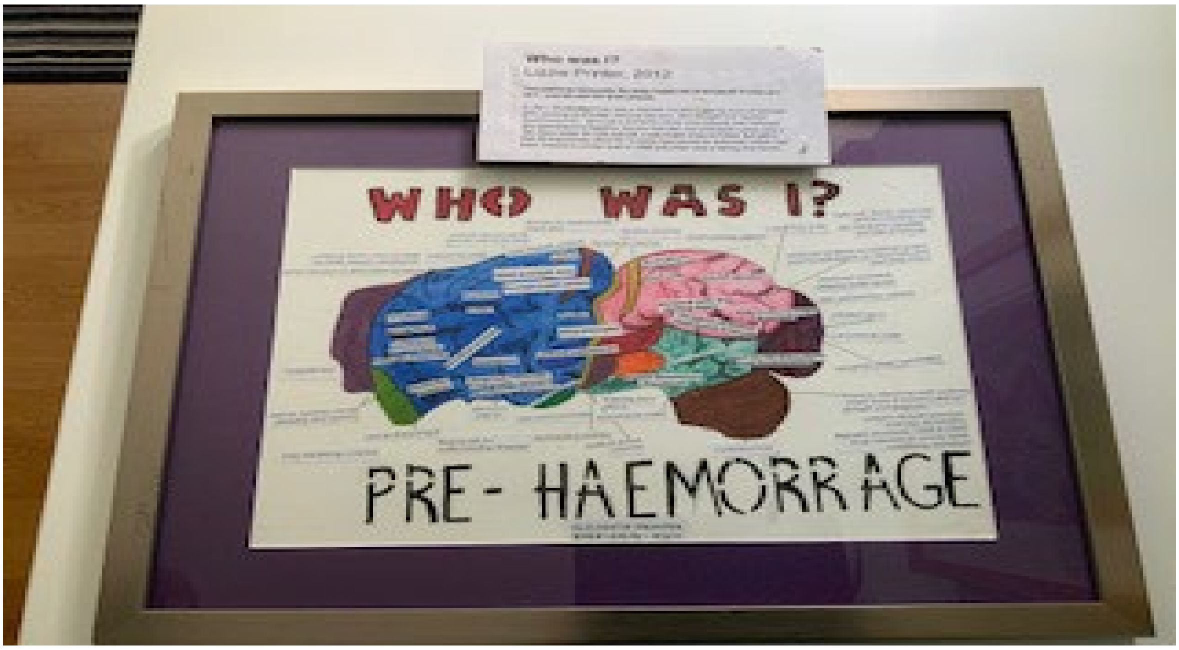
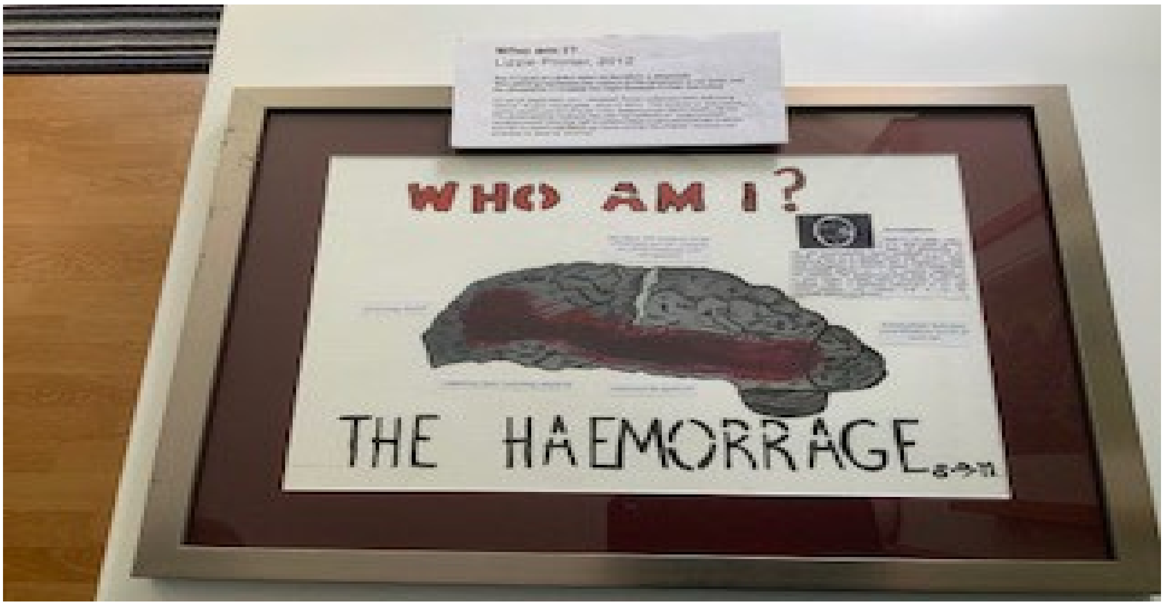


Figure 5.3

Box 5.3.1

“A picture of my pre-haemorrhage brain which was really bright and bold and busy and it’s got all the stuff I did as a result of my brain on the first one and that describes Katherine.”

(Katie: Session 2, 223)



Box 5.4.1

"And then I had my haemorrhage brain which shows the night I had my haemorrhage and the torpedo-like aneurism and the blood going through my brain and that's the night Katherine died."

(Katie, Session 2, 224)

The stroke-survivors commonly reflected on life pre-stroke with a sense of nostalgia. During her first interview Katie (previously Katherine) reflected that she was an expert multi-tasker pre-stroke, juggling a demanding position as a district court judge with her roles as a wife and mother to two daughters. As can be seen from the first painting, she represents this busyness with strong colours and numerous labels. She is starting to come to terms with the loss of all of Katherine's roles in this painting, which emphasises the totality of her multiple losses.

When compared with the painting at the start of the '*Becoming*', (also shown above) her radical identity transformation and the adjustment required was even more apparent. The second painting's heading: 'Who am I?' illuminates her sense of losing all the different facets of her previous identity. Her uncertainty about her identity left her unsure about what the future would hold, and, this combined with her near-death experience, meant she had lost all sense of her purpose in life. Her emotions and those of the other stroke-survivors are represented by the next sub-theme:

Future uncertainty and existential awareness

Three of the stroke-survivors experienced a stroke before state pension age. Brian and Katherine's strokes were caused by an accident, rather than co-morbidities, and both were keen to stress their health and fitness pre-stroke and the horror of their subsequent losses. Brain was formerly a keen cyclist and Katherine was a marathon runner.

Brian described his initial fear as the impact of his losses hit him:

> *"Financially and emotionally…secure and physically fit and healthy…to be suddenly faced with all that taken away. It was terrifying."*
>
> *(Session 2, Hospital pin, 154-6)*

It was while still coming to terms with his losses that Brian attempted to return to work (RTW). He described the difficulties he had resuming a new post. Brian had just accepted this role at the time of his stroke, a promotion to head of the faculty of science:

> "*I resumed a totally new post, and it was hell! "* (Session 1, 100)

His description of this as *"hell",* a place of the dead, likely signifies the fact that he was concurrently adjusting to being knocked off his bike by a motorist on his way to work, his subsequent disabilities and an extremely challenging new position.

His existential awareness was clearer when set in the context of his hospital experience. In the same interview he had earlier talked about the 'horror' of being placed on a ward for the elderly and infirm:

> *"It was all … just horrific. There is no other way to describe it. Erm, the ward was full of these octogenarian, doubly incontinent, men. The guy, the guy in the bed next to me was lactose intolerant. But nobody took any notice of that, with his diet. So, he had constant diarrhoea, which… He was err, cognitively impaired. And he had, persistent … bladder infections. So, he*

> *was… because he wasn't being cared for properly... He would, when he'd defalcated… he'd smear the excrement over the walls. The stench… was just disgusting! And, I woke up one morning with this awful smell filling my airways and I pulled the bed sheets over my head and closed my eyes. And actually, literally thought and prayed, that I wouldn't wake up again. Now, that's not me, at all. But that was the psychological… bomb shell, that really had been… landed on me by being on that ward."*
>
> *(Hospital pin, 1-15)*

At the time, I noted that he chose the word *"horrific"* very carefully. It is a strong adjective, normally used to describe things that are frightening to mention. Combined with the phrase "*psychological bombshell*", it made clear the psychological impact of his life literally being blown apart, in a fashion normally associated with the battlefield. His earlier use of the word *"terrifying*" was an extension of the hell metaphor, which started in hospital and continued when he was describing his RTW experience. The following sub-theme described how his experience impacted on his sense of self, which was similar to the feelings of the other stroke-survivors at this stage.

Feeling devalued and vulnerable

Brian's reflection on his vulnerability effectively conjured up the suddenness of his future plans being unequivocally shattered in that moment and the sense of him feeling trapped in an irreversible situation, palpable fear and new awareness of life's temporal nature. For example, he later commented that:

> *"For the first time in my life I was surrounded by death…"* (line 30)

And:

> *"…it sounds very depressing, but it was!"* (line 32)

His child-like reaction of hiding under the sheet from the nightmare of devastation surrounding him on the stroke ward related both to the abruptness of his life change, which disrupted his expectations of "*order and normalcy" (Becker, 1999:12)* and the uncertainty of his new future. At this stage of his life, Brian was left questioning his own frailty and feeling unable to escape it. He reflected on his response as follows in the second interview:

> *"You know, it was the sudden realisation that if this is the rest of my life, it's going to be pretty horrible."*
>
> (Hospital pin, 189)

He later commented as follows on his momentary desire for death to remove him from the situation:

> *"Probably… it was like a post-traumatic stress response…*
>
> *but nobody had diagnosed that and I wasn't aware of it."*
>
> (Session 2, RTW pin, 72-73)

Brian frequently referred to his *"inner child"* (Changes pin, line 180) as a metaphor for his initial vulnerability. His consequent suffering is clear from this example as he prayed for death to alleviate him from a life he felt he no longer wanted to live; a feeling that he struggled to associate with the person he was before his stroke: *"that's not me at all".*

He resolved his discombobulation by describing his emotions as his *"inner child",* a part of him that he sometimes felt ashamed of, such as when they surface in the form of *"laddish" humour,* as detailed*:*

> "*I think the area of the brain that was damaged, you know, the blocks had been taken off.*
>
> *Erm, I didn't have a vulgar sense of humour, but became very sort of childish; laddish.*
>
> *Which wasn't me. And my kids noticed. Erm, I'll give you an, give an example. Something that I did, which was interpreted by them in a totally different way. I'm being a, I'd been to the cashpoint and while I was there, this little old lady had asked me to check her balance, so I kicked her stick out of the way! The boys just looked at me in horror. They didn't see it as a joke. They thought I'd actually done something like that. And, that was the first time I*

> *realised, gosh, they really do think I've changed a lot. And, I think it's probably those sorts of changes, which don't really go reported, but can lead to breakdown in relationships.*"
>
> (Session 2, Volunteering pin, 98)

As he reflected on *'Before'*, Brian distanced himself from the *"laddish*" person he had initially become post-stroke. This is because by the time of the interviews he had moved his identity on and did not want to own who he was in the earlier stages of adjustment. For the same reason, he often used examples, from other stroke-survivors he worked with, to explain his own difficulties, for instance with dysarthria. Philip used the same tactic when describing his emotional lability.

Brian alluded to his initial post-stroke vulnerability by making frequent references to his "*inner child",* to illustrate the part of his emergent self that reacted and felt like a child. An example of this was his decision to participate in the 'Roller Skating' trial:

> "*It appealed to the inner child, I suppose."*
>
> (Session 1, 138)

This metaphor for his stroke-afflicted self in the early stages of recovery first appeared in the Radio personal incident narrative (PIN), when he described his loneliness in the early post-discharge days and observing children at the school opposite his home. This was the source of his metaphor about his "*inner child",* as he had reflected on their freedom and he described the meaning of the metaphor for him after his stroke here*:*

> *"You actually become a child again. Erm, in lots and lots of ways. And so, you need to have, an environment where you are nurtured. Where you are encouraged, and where you're…given guidance."*
>
> (Changes pin, 180-183)

The metaphor illuminated his numerous mentions about his egocentricity, which he saw as *"a necessity*" (Q3, 91) for recovery and he also commented that his wife had noticed this change in him (Q3, 88-99).

Although no one else used the same metaphor, it was clear from their narratives that the other stroke-survivors had also had to accept help from others, which involved them giving up control of aspects of their lives. The next sub-theme represents this.

Surrendering control/accepting help

Brian's reference to surrendering to his inner child is interesting given that people are often said to revert to childhood as they age and/or become more vulnerable and dependent on others (Covey, 1993). It also makes clear that he was in no way ready to resume work, as evidenced by his subsequent breakdown. He retrospectively described his RTW as *"an impossible ask of myself"* (RTW pin, 91).

Philip also highlighted his child-like nature:

> *"Even though she was my younger sister… I referred to her as 'she became my Mum' because she taught me to do things your Mum teaches you growing up as a child."*
>
> (Session 2, 474-476)

He was brought up as an *"extra son, just a very old one"* (Session 3, 237).

Phillip described what his sisters had told him about this time:

> *"I was quite difficult, erm, it was described to me as, I was like a rather old and awkward child… Because obviously when you are learning everything from scratch, erm, you don't fully understand things, so it was difficult for her… How I've been told it's like toddlers, old people like me need to be watched all the time. Ha, ha."*
>
> (Session 3, 234-237)

Philip used humour a lot to alleviate the difficulty of describing potentially embarrassing incidents, like surrendering to accepting help from his sister with bathing.

He also had aphasia at this stage, so communication was difficult with anyone outside his family. In the third interview, when he talked about staying with his older sister at weekends, he said:

> *"When you don't like meeting people and you've got no memory, you avoid conversations."*
>
> (Session3, 244)

Katie also practised avoidance. As a keen runner, an early strategy to manage the feeling of being overwhelmed, was to run away:

> *"Well it is you know, I've, over the last seven years, erm I've run away a lot and that is an example of when things get too much I just have to get out."*
>
> (Session 3, 156)

Avoidance was an early strategy for managing her *"catastrophic emotional dysregulation"* (Session 3, 153), which Katie felt she had no control of. Similarly, Brian and Philip felt unable to control their emotional lability in the early days, as Philip described:

> *"I try and avoid things that will upset me because when I was volunteering on the stroke ward, if a stroke patient started to cry, I usually ended up joining them."*
>
> (Session 2, 58)

However, Susan expressed her vulnerability as feeling lost, in her new normal, an unfamiliar post-stroke world, in which she felt she had little control over her circumstances. Her strong sense of alienation initially manifested itself in her getting physically lost en route to a work meeting.

She described her disorientation experience as follows:

> *"I was dropped off and then I, was walking towards this meeting and I had done this before. It wasn't the first time that I had been to this place. And, I don't really know what happened, whether I had turned around then, or something. I don't really know what happened, but I find myself standing there, and not knowing where I was and not knowing how, where to go, to get to where I needed to go. And then I remember this sheer… panic. I don't know if it was a panic attack, or anxiety attack, or how you would describe it, but I just, and it all sort of caved in on me, I guess and I, I… I just thought it, it became a sort of a sense of who am I, what am I doing here? I didn't forget any of that, it was just at that moment. Erm, I couldn't remember what I was meant to be doing."*
>
> (Session 2, 191- 200)

Susan explained the sudden confusion she experienced when visiting a familiar place. She used the phrase *"sheer panic"* to explain how uncontrollable her anxiety had become. She struggled to describe this frightening experience, but settled for *"it all sort of caved in on me".* I think her choice of this synonym is interesting as it explained that she collapsed under the force of the panic, a feeling similar to being overcome to the point of almost being suffocated by her confusion and anxiety. She then clarified that she hadn't actually forgotten who she was or the purpose of her visit, it was just a momentary lapse, but, nevertheless, frightening enough to destroy her confidence in her recovery, leaving her completely unable to focus on the meeting afterwards. She also explained how she got herself out of the situation and its impact on her, and ended her recount by repeating the word *"terrified*" to emphasise her extreme fear:

> *"Erm, and I remember standing in Sheffield. town centre, just not knowing what to do and I, just had the presence of mind to ring a colleague and say 'Please come and get me' and I, I told them where I was and they came. And then, she just took me into the meeting, I don't remember the meeting at all, and obviously it happened. And then I went back, was taken back to work. But it was, it terrified, terrified me."* (Section 2, 201-204)

Philip also described being confused in the early post-stroke days before his blood pressure medication was reduced. He explained how different he felt when it was reduced:

> "*As I walked, I lost weight and as I lost weight, my blood pressure came down and then my blood pressure and medication was halved. And it was only when it was halved in a few months later that the body would get used to the lower amount of perindopril that I actually started to think and it was only then that I was able to do things. Erm, and then I got involved in education, but that wouldn't have been possible before."*
>
> (Session 2, 170-172)

Loss of life's purpose and fulfilment

Philip, who had lost "*all my memory from the whole of my life, erm so I lost a lot of abilities"* (Session 1, 3), identified himself as "*effectively unemployable"* (Session 2, 129-30). He explained how he felt in '*Before*', after the suddenness of his career change from an Managing Director of his own Financial Service company to "*a vegetable*":

> *"And so, I did nothing, having an honours degree from Middlesex University and not being able to read or understand things, is very frustrating. So, it was, it was a nothing time."*
>
> *(Philip: Session 2, 155-7)*

Philip aptly described it as a "*nothing time"* because his complex disabilities meant he was initially unable to do anything other than "*just function*" (Session 2, 212). He captured the feeling of being useless in his initial description of himself as an inanimate object; a baseline he used to put his rehabilitation achievements into context, as can be seen here:

> *"Err, so that's how I run my life. Err and I'm taking an active part in real life, which is…an achievement for me because considering where I started because in the early days, I was just a vegetable. Err and I couldn't speak immediately after the stroke. But I can now get around; I*

> *only travel locally… preferably by metro because I find buses chaotic. But I've got a relatively normal life now."*
>
> (Session 1, 109-115)

Being able to *"take an active part"* in his life was vital to Philip as during this stage he found himself frequently excluded by his disabilities. For instance, here he describes how "*degrading*" it was to have to rely on 'Age Concern' to manage his bills:

> "*Most people don't realise is that when you lose your ability to read, you actually lose your privacy. You can't do anything about it until they've told you what it is and they've already read it. It's very degrading but there's no other way around it."*
>
> (Session 2, 41-48)

The following sub-theme describes his experiences and the similar perceptions experienced by the other stroke-survivors.

Feeling devalued and perceiving self to be a victim

Katie (formerly Katherine) also felt her value was significantly reduced post-stroke. After falling into a category 3 coma, following an aneurism, she found her post-stroke self so alien that she could not associate it with her former self and consequently adopted a new identity. Here, she describes the disbelief she felt upon awaking to her new life, if indeed it can be described as life, as she was *"almost dead".* In addition to her existential awareness, she made reference to confusing terminology, used by medical staff, and had difficulty reconciling herself with the frail and elderly image she previously associated with stroke 'victims'. She likened her reduced self to being "*like grandad in the corner*". I envisaged this as an elderly person in a hospital chair with a blanket on their knee. Their insignificance is summed up with the fact that they are hidden in a corner of the room:

> *"And then on the 8th Sept 2011, I literally dropped down, almost dead, in my, in my house. Thankfully with my daughter by my side. So, I knew nothing about this and I was in a coma*

> *for two weeks and erm, gradually came round afterwards and don't really understand what's happened to me or why I'm in hospital. And when people say I've had a stroke, I don't actually really believe them because l thought, oh you've got to be in a wheelchair and you just be sort of, like grandad in the corner, rather than a forty-six-year-old. So, I didn't believe them and I hadn't realised really that I had this serious vision impairment even because all everyone spoke about was inattention and how I was suffering from inattention and neglect."*

(Session 1, 19-28)

She later expressed her identity change as follows:

> *"So, it wasn't me, I just knew Katherine... wasn't there anymore."*

(Katie: Session 3, 302)

The stroke-survivors conceptualised the suddenness of being thrown into a new life as either a time of 'crisis' or 'chaos', which is summarised as the following sub-theme.

A life thrown into chaos/'crisis'

As Becker (2009: 80) explained, "*disorde*r", in the way that Katie described here, has a way of pervading the body and thereby "*plunges people into chaos*", which may signify for them the approach of death. As she struggled to reconcile her knowledge of who she once was with her new more dependent self, Katie felt as though her former self had died and she concluded that she had become a new, more vulnerable person, whom she believed at that stage of her recovery was more authentically reflected in her choice of the name Katie. Her new name reflected her gentler persona, a shadow of her former self. Her choice of pastels with which to paint her new brain, also echoed her feeling of being diminished (see *'Beyond'*).

Katie was, in her own words, "*profoundly* depressed*"* (Session 3, 127), which also contributed to her sense of being someone else. Ahlzen (2011: 330) explains how mental illness affects the sense of self: "*Mental illness is, in its very essence a change in the meaning structure of the self. The depressed* *person is ill… In the sense that her whole way of being in the world has undergone a gradual shift towards darkness, inertia, hopelessness and anxiety".*

Not all the stroke-survivors saw this as a time in which stroke had caused death of their former selves, like Katie.

Susan experienced this phase as disorientation rather than as death of her former self.

Like Susan, Brian experienced a breakdown, when he RTW:

> *"I just crashed out. Just before Christmas… a total wreck. I just crashed out… both psychologically and physically exhausted."*
>
> (Session 1, 111-112)

All of the stroke-survivors experienced some form of 'chaos' and slipped into an '*existential vacuum'* during this phase, as illustrated by Katie seeing herself as "*grandad in the corner***"** (Session 1, 19-28), Philip's description of it as a "*nothing time*" (*Session 2, 155-7 and 161-163)* and Susan feeling like "*nobody nowhere*" (Session 1, 177). This can also be conceptualised as a time of "*crisis*" (Jacobsen, 2006) or 'trauma', as Brian explained earlier when he talked about experiencing a **"***psychological bomb shell"* **(**Hospital pin, 1-15) that was "*like a post-traumatic response*" (Session 2, RTW pin).

Interestingly, Philip described himself as being in an *"educational vacuum"* (Session 3, 122) because his memory loss meant he had also lost all of his basic skills, and education later proved to be his escape route from:

> *"A nothing time*, in which *it… just it took me all my energy and being just to get through the day…. Yeah, it was a pointless life."* *(Session 2, 161-163)*

He was initially reluctant to take control of his own life and had to be repeatedly prompted by his sisters to attend the 'Living with Stroke' event that "*changed my life"* (Session 2, 265).

The next two chapters examine in more detail how each of the stroke-survivors transitioned to their new normal and transformed their identities in the process.

However, it is worth remembering that there was some overlap between the stages of transition, which varied in relation to the progress of the individual stroke-survivor. For example, Susan's emotions impacted on both '*Becoming'* and *'Beyond'* and it was only after reaching her sixtieth birthday that she was able to move on from her anger. Similarly, Katie only really progressed after winning her court case.

Brian retrospectively reflected on the way in which the "*the path to possibility goes through pain"* (Jacobsen 2006, in Corbett and Milton, 2011:8). He described his transition from '*Before*' to *'Becoming'* with another metaphor:

> *"And so, it was doom and gloom for a while, but its… you know, the sun's come out again."*
>
> (Session 1, 114)

Brian frequently used a metaphor to express what is difficult to put into words. His light metaphor appeared a number of times throughout the three interviews. His description of the light being extinguished could be viewed as a way of expressing death, lack of energy, or low mood, which Brian experienced prior to his breakdown. He clarified that he wasn't depressed, just "*fed up*" after "*pushing and pushing*" (Session 1, 75-76) himself to get back to work full-time. In career terms, this is often referred to as burn out: "*to fail, wear out, or become exhausted by making excessive demands on energy, strength or resources"* (Freudenberger, 1974: 159). This appears to have been the case for Katie, Susan and Brian prior to experiencing a breakdown, because they were so dedicated and committed in their professional roles. For example, Katie very quickly became overworked when she returned to her role as a district judge, as a result of not having sufficient support for her disabilities, as described:

> *"I mean I spent most of my time every day when I was working on the phone to ATOS computer engineers because the IT didn't work. And so, I could go into work for sort of half past eight and spend sort of two hours on the phone to an engineer saying that I can't see, this is not working and I think if I had a PA then, they could have managed that type of stuff*

> *while I got on with my work. And then that wouldn't have taken up so much of my time, I wouldn't have got so exhausted, and my fatigue wouldn't have been the killer at the end of the day. [Pause]. Erm, what prompted my retirement was having a complete emotional and mental breakdown, because, I suppose I couldn't cope and I couldn't bear the lack of support and the fact that the Ministry of Justice wasn't prepared to put in place what I needed to be able to do my job readily."*
>
> (Session 2, 143-148)

She also described the exact circumstances that prompted her breakdown:

> *"Well, I had a meeting at work on the... 9th January 2017, about what was going to happen and the human resources woman who had come down from London just said "Well Judge K. you need back, to be back to work full time in three months". And I knew I couldn't go back to work full time and they were just putting so much pressure on me and it was things like 'why are you sitting into lunch?' and it was like well, I was sitting into lunch to get everything done. I never went without doing my full day's work. They didn't even, they made no reasonable adjustments, to take into account that I was going to take longer, so… I just, I left that meeting, went back to my room and just sobbed. And so, I made an appointment to see my GP that day and I didn't see my normal GP, I saw another GP and I just literally blurted all my upset out and, and he signed me off sick for a month and he has since been the GP I would go to, because he is so caring and prepared to refer me. And so, from that point on, I never went back to work. And I was assessed by the Ministry of Justice occupational health consultant in the April, who suggested that I probably would never go back to work and that I should probably be medically retired. [Pause] Which I hated and still hate to this day."*
>
> (Session 2, 155-163)

Katie understandably “*hated”* the loss of her long career at the bar and her future career ambitions, largely because she felt the injustice of not being given sufficient support to accommodate her needs, particularly in respect of the IT equipment and extra time she needed due to her vision loss, as described:

> *“And if I’d even gone back you know a day or two a week, that would have been enough to stop me feeling this enormous sense of loss. And you know not just in terms of my job, and in terms of my income, but also in terms of my self-esteem, so yeah I think I could have done something but [Pause] I’d run out of fight, I think.”*
>
> (Session 2, 167-169)

With hindsight, she also reflected that providing her with a PA could have alleviated some of the issues she experienced.

Returning to Brian’s light metaphor, and the subsequent reactions of all three stroke-survivors, draws attention to this stage as something that is changeable, if responded to by finding new meaning in life. It can change, like the weather; a passing storm. Freudenberger (1974: 165) explicates that when someone has burnt out: *“Something has died… it may be the loss of something within yourself, something you treasured and valued – your ideals. You will need time to replenish that loss, to find new good people to surround yourself with, new activities to give you gratification.”*

All of the stroke-survivors managed to achieve this, as I outline in subsequent chapters. Due to their considerable tenacity, they all progressed through all three transition stages, as opposed to becoming permanently stuck in ‘*Before*’, which I anticipated could have been a possibility with stroke-survivors experiencing depression.

‘*Before’* was the most difficult stage for all the stroke-survivors, who all suffered considerable hardship, impacting on their sense of fallibility and awareness of life’s temporality. This often lasted into ‘*Becoming’.*

Conclusion

I summarise the interlinked sub-themes, identified in ‘*Before’*, in Figure 5.1.

All of the stroke-survivors interviewed managed to free themselves from the *“cycle of ‘failure’”* (Figure 5.2). This is because they learned about their new differently-abled selves and worked to construct the person they wanted to be, which I shall go on to illustrate in the subsequent chapters, starting with ‘*Becoming*’.

6: Summarising the stroke-survivors’ experience of transitions: Becoming

The first conception of transition, which I deal with in this chapter, uses the metaphor of learning as becoming. This phase represents the stroke-survivors beginning to explore their post-stroke identities. The second approach to transition is concerned with life-career progression, specifically the self-management (SM) of this by stroke-survivors (see ‘*CSM*’). Both are concerned with the development of the self and in this chapter we see how stroke-survivors adapted their self-image after learning about it through participation and interaction with others. However, it is worth noting that without opportunities to participate, or the motivation to do so, their potential for learning would have remained untapped.

The transitions are represented by the sub-theme titles which indicate how far the stroke-survivors had progressed. For example, from the loss of their previous identities and purpose in life to finding new identities and purposes.

From loss of previous identities and a sense of life lacking purpose, to finding new identities and purposes

As all four stroke-survivors illustrated, their identity transitions related to other transitions, primarily the transition from life lacking purpose to finding new purposes. The latter provided a new sense of fulfilment in life as the stroke-survivors progressed from feeling devalued and unwanted by others, to being valued as a person and wanted by others, something which Philip described as *"the greatest therapy in the world"* (Session 2, 349).

Susan's high self-awareness after cognitive behaviour therapy (CBT) helped her to explain the way in which her identity was anchored to her job and thus her direction/purpose in life:

> *"The loss of my health was one thing, but the loss of my career; all that I valued at that time, what I saw as a vocation, the value of the work, my identity just disappeared overnight."*
>
> (Session 1, 175)

All the stroke-survivors moved on from the loss and struggle they experienced, which was described in the last chapter, and that they conceptualised as a learning process.

For example, Brian, whose deep-rooted interest in science motivated his interest in participating in stroke trials, explained how during the process of 'becoming' he learned and progressed his recovery as he transitioned through a variety of voluntary roles:

> *"I'd learn more and I could do more."* (Session 3, Changes pin, 133)

Philip similarly conceptualised his 'trial and error' efforts to manage his disabilities as a learning process:

> *"You are finding out about yourself all the time. You're learning what works and what doesn't."*
>
> (Session 2, 999-1000)

Katie also reflected that:

> *“I’ve had to go through transitions of not being able to work, transitions of trying to mend relationships with my children.”*
>
> (Session 3, 535)

And:

> *“I have had to accept help, in the form of a PA; I had to accept the support of the brain injury case manager.”*
>
> (Session 3, 535)

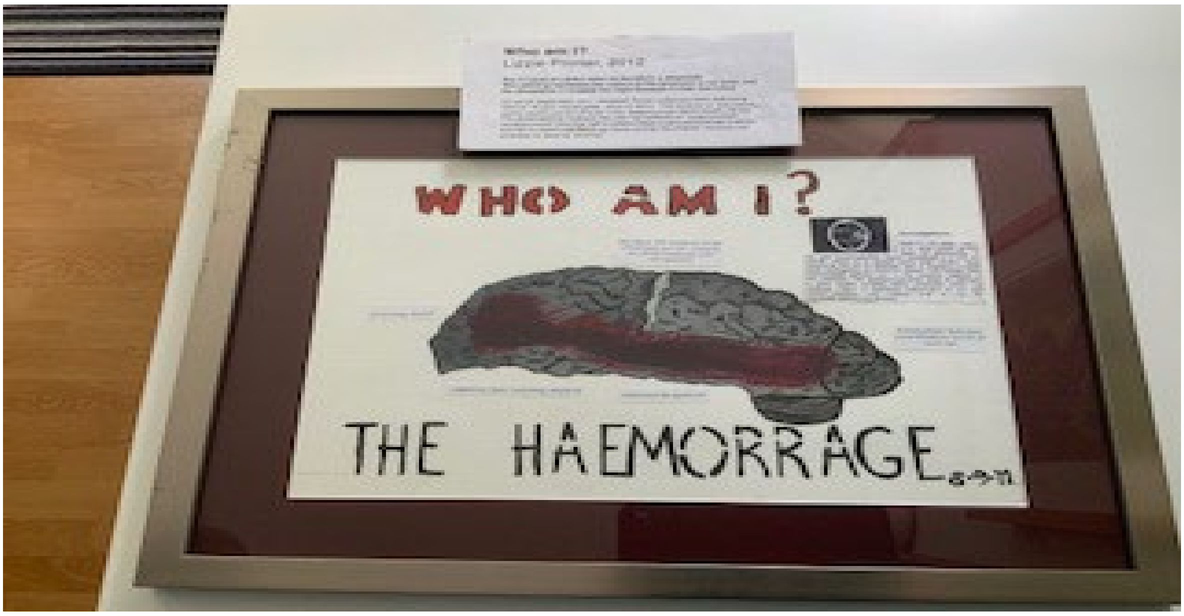
She concluded:

> *"All that stuff is very difficult, if I hadn’t gone through those stages, I wouldn’t have now been, now able to sort of start to move on.”*
>
> (Session 3, 537)

The fact that she described herself as *“now able to sort of start to move on”* suggests that she had learned from her transitions.

I now detail how this learning process occurred, starting with Katie.

Figure 6.1



Box 6.1.1

"And then I had my haemorrhage brain which shows the night I had my haemorrhage and the torpedo-like aneurism and the blood going through my brain and that's the night Katherine died."

(Katie, Session 2, 224)

As we can see from her description of her painting, after her stroke Katie initially perceived her old self (Katherine) to have died. She provided the most extreme example of identity loss by adopting a completely new identity post-stroke, which she starkly illustrated in her paintings.

During the *'Becoming'*, all the stroke-survivors were coming to terms with their *"emergent"* (Nasr et al., 2016:7) self and beginning to redefine their lives. This involved revising their identities and positions in relation to others. This transition is condensed into the next sub-theme.

From feeling devalued and vulnerable to valued

Katie described why she saw herself as a much frailer person than Katherine was:

> *"I've had in the last 12 months, 4 emergency appointments, and that's not right, you know, I'm 53… that's what's happened and that's really hard."*
>
> (Session 2, 262)

She also clarified what she has had to come to terms with post-stroke:

> *"I've had to accept I need weekly treatment physically… all this stuff I didn't have in my life before and, and to go with whatever rehab has been recommended and to go with whatever medication so yeah, I've had to have lots of different doctors assess me."*
>
> (Session 3, 536)

Her family had struggled with her "*catastrophic emotional dysregulation"* (Session 3, 153), *"a clinical definition"* (Session 3, 151) which has increasingly led to her estrangement from them and the family unit breaking down:

> *"I think my family have tried within their abilities, but it's never been quite enough for me, with my disabilities."*
>
> (Session 2, 69)

This caused her to question whether she was still loveable:

> *"I think because of the way I am now…I am almost paranoid that… I'm not good enough and because I'm so different, why would anyone love me?"*
>
> *(Session 3, 206)*

Katie's use of the word *"paranoid"* related to both her mental health deterioration and the acute uncertainty of no longer knowing who she is. Her sense that she is not "*enough"* suggested that her relationships/close bonds with others were under threat, which made her fearful for her future. She acutely understood the impact of her emotional dysregulation on her family but was unable to control it: *"I think it's just the conflict in the family that it causes"* (Session 3, 194).

Susan also reported initially feeling devalued by her husband post-stroke. Shortly after her disorientation experience, she experienced a breakdown, characterised by her inability to concentrate at work, fear of failure, and ensuing depression. This subsequently led to her job loss, which sadly enhanced her sense of feeling lost, as she described:

> *"I just knew that I felt like nobody, nowhere" (Session 1, 177),*

which she explained was because:

> *"Who I was, was very much defined by what I did, what I earned, my value as an employee."*

(Session 1, 184)

The first comment referred to her multiple role losses, her career and role identity being just one of the 'blows' she endured. For example, with her daughter now at university, she was no longer needed as a mother, in the way she was pre-stroke, and the loss of her job was *"a blow beyond a blow"* (Session 1,173).

Like Katie, at that point, she felt so devalued by the totality of her experiences that she also questioned her current husband's love for her:

> *"If I'd called him for his tea and I'd said 'Your tea's on the table' and he didn't come immediately… I would get so upset with him. And say: "This is all I can do'."*
>
> (Session 2, 268-70)

Susan described how these small incidents made her feel:

> *"So angry and then you'd go down this ridiculous spiral of thinking… you know, he doesn't love me anymore and he's going to leave me on my own… Where am I going to live?"*
>
> (Session 2, 273-8)

The latter comment had particular resonance for Susan. Due to her former management role, allocating emergency housing to the homeless, she knew all too well the difficulties she would likely encounter.

The suddenness of all this change left her feeling worthless. Susan described herself as "*on the scrapheap"* (Session 1, 180) after her dismissal.

Similarly, Brian used the metaphor of feeling like rubbish on a scrap heap to emphasise that he was no longer wanted at work or considered useful by the school principal. Back then, Brian had struggled to stand up to his principal's "*bullying*" (Session 2, Hospital pin, 445) because of the

"*total… crushing loss of self-esteem and self-worth, the stroke created"*.

As he explained here:

> *"No, I think probably the err, experience of going back to work was… even though it was erm, over eighteen months, it was still far too short a time, to really repair that total… crushing loss of self-esteem and self-worth, the stroke created. I don't think there is a quick fix. I think its something that is drip fed."*
>
> (Session 2, Hospital pin, 478-480)

His use of the word “crushing” suggested to me that he was like rubbish being crushed to something smaller by a bin lorry. With hindsight, and after building a successful career in retirement, he was able to put his experience of returning to his former workplace into perspective. He commented:

> *“You can actually do something positive with your life after a stroke. You’re not on the scrapheap.”*
>
> (Changes pin, 151)

This identity transition is summarised in the next sub-theme.

From victim to survivor

Brian was forced into early retirement after “running on empty” (Holiday pin, 104), which led to him having a breakdown, after he was perceived as not being *“competent enough”* (Session 3, Q1,79) to do his job. He described how he was “bullied” into this by his senior managers:

> *“I was told that if I didn’t apply I, the college would apply for a grievance against me. You know, they were really warm and fluffy after 25 years of, of… being there.”*
>
> (Session 1, 113-118)

However, he volunteered to run the Stroke Association’s Communication group and began to assess his own dysarthria at this point. This role, along with his continuing participation in stroke trials, helped to rebuild his self-esteem up to the point that he found he had developed ambition again.

Katie also transitioned from someone who perceived herself to be a victim and was on suicide watch after losing her career at the bar. She was also forced into early retirement after Human Resources (HR) began:

> *“… bullying me to return to work in just 3 months, when I hadn’t had a proper stab at it, with the support I should have had.”*
>
> *(*Session 3, 90)

Katie was only able to move on after winning her court case against a neuroradiologist, who missed the aneurism that caused her stroke. Once she had received a settlement, she employed a brain injury manager, who found her a PA, to support her disabilities. She was then able to reorder her life and, regarding her ambition to write a book, she commented:

> *“Yeah, I have written hundreds of pages but I need to put it all together. I’ve shared it with my… brain injury case manager and PA. My PA is preparing to proofread it now so that’s*

> *good... I still have an aspiration and I've just got to now, fulfil it and make sure I create a life that enables me to fulfil it. [Pause] I hope so, I hope so."*
>
> (Session 3, 777- 792)

By the third interview, she had just started to transform from having a sense of self that was challenged by her existential awareness, to someone who wanted to utilise this to make the most of her life, although she was still unable to recognise her transformation at that stage. Her change of mindset is apparent though when comparing her progress with writing a book, to the way she initially spoke about her lost career using funeral imagery, as described here:

> *"When I was medically retired, that was the final, sort of erm sword in the coffin, in terms of it being a death knell, August 17, I could no longer call myself a judge and that was a huge loss."*
>
> (Session 2, 49)

Interestingly, she described the coffin being stabbed by a sword, rather than a nail, which is the more common idiom, because she was keen to emphasise the size of the loss and its impact on her "*whole being"* (Session 2, 52). This metaphor for her suffering reminded me of the magic trick in which a woman has swords thrust into a box from all sides. However, Katie didn't emerge unscathed, in contrast the 'final sword' effectively killed her career at the bar.

Nevertheless, by the third interview, she too had found a new sense of purpose, albeit a "*little" one* (Session 3, 548). This is detailed in the next chapter.

Throughout '*Becoming'* all of the stroke-survivors learned and transitioned, often in ways they only recognised with hindsight. They learned more about themselves and worked to construct the person they wanted to be. Additionally, they became survivors who had learned to self-manage their life-careers, each in different ways; a point that I will return to in chapter eight.

The stroke-survivors all resolved the issues of losing their identities and its associated competence in different ways. Philip adopted a 'fake it till you make it' approach, because his memory loss led to others perceiving him as *"thick"* (Session 2, 1371). He tackled the difficulty of overcoming this stigma by adopting a comfortably familiar business-like persona for the formal meetings he attends, in his new role as governor of an NHS Trust:

> "*I found a way of dressing more formally by wearing a jacket attending the meetings… it's the persona of what used to be the BBC News."*
>
> *(Session 3, 13-46)*

His ‘BBC News’ persona was a way of convincing others that he is personable, reliable and committed to doing a good job. These desirable values meant that he was not just vote worthy, but that the points he made at meetings were taken seriously by the other attendees, meaning he was given a chance to take an *“active part”* (Session 3, 192).

In contrast, Brian pioneered a new role for himself as a ‘Stroke Ambassador’ after his competency was questioned by his principal and he was forced into early retirement. Here, he describes how what he could offer to stroke research eventually became more widely appreciated:

> *“By 2010, I’d applied to join the National Stroke Research Network and… lay forum… I was appointed to the Rehabilitation Clinical Studies group, erm in 2012, and that’s when I suddenly started to be recognised on a national level, in terms of my capabilities.”*
>
> (Session 1, 175-177)

The transition the stroke-survivors made in terms of their life purposes are represented by the following sub-theme.

From losing purpose in life to finding new purposes

Brian achieved his new identity and status by substantially building his social capital through participation in stroke trials and working with other stroke-survivors and stroke professionals. As Mc Ardle et al., (2007:249) explain, “*capital refers to the personal variables that may affect one’s career advancement*”. Arthur (1994) clarifies that these variables include the ‘*knowing how’* competencies, which are the knowledge and skills developed through occupational learning and professional development that make individuals distinctive. By investing in themselves, individuals increase their social capital and build employability.[23] Social capital also encompasses the interpersonal or ‘*knowing whom’* competencies, which networking cultivates, that is the influence of mentors and friends. Eby and Buch (2003) found that who one knows is pivotal to influencing a person’s self-perception. Networks can also be a source of social support, as all the stroke-survivors discovered. This resulted in Brian having: “*so many choices now, I don’t know what to do with them” (Session 1, 267).*

Brian’s quote links into the sub-theme of Opportunity awareness (See ‘*CSM’*). However, Brian’s reflection also provided me with an insight into the way dispositions develop through life.

---

[23] *“Employability implies something about the capacity of the graduate to function in a job, and is not to be confused with the acquisition of a job.”* (Yorke, 2006:7)

All of the stroke-survivors' data supported Bloomer and Hodkinson's findings (2006:40, in Reid and Bimrose, Ed's.) that "*learning as becoming is influenced by positions, dispositions and interactions in the field".*

As they explain, *"social structure interpenetrates the person, through their dispositions"* (2006:37).

An understanding of Susan's disposition to demonstrate her commitment to her vocation by delivering everything to a high standard made sense in light of the difficulties she had in trusting that she was ready to RTW after her breakdown:

> *"It wasn't the findings of the work, jobs, so much. It was more the expectations that, of any job… that you attend regularly, you do a good job, you take your responsibilities seriously and I didn't think I could do that."*
>
> (Session 3, Changes p1, 322-323)

Susan understandably felt the loss of her rite of passage when she was forced to leave her long career in Housing management, after feeling unable to resume work, following her breakdown:

> *"It wasn't marked by anything, there was no card, no thank you, no collection, no leaving do!"*
>
> (Session 2, 273)

Through CBT, she learned about valuing herself in a different way:

> *"Not being measured s…solely in terms of my working life and what I earned, you know, my career."*
>
> (Session 2, 260)

This helped her be open to volunteering 'work', so by the time she began to undertake a voluntary role as a Spiritual Companion, created by her diocese, she viewed herself in a markedly different way:

> *"That was extraordinary because that gave me a real sense of value and purpose."*
>
> (Session 3, part 2)

Although she said it was the expectations of the job that prevented her RTW post-breakdown, she also explained how CBT changed her retrospective view of that. As Susan's self-awareness developed through CBT, she was able to learn more about her new self and, specifically, how to pace her life and modify her expectations of herself:

> *"When you're tired and, something happens, your sense of perspective and ability to reason is distorted. Your sense of perception just goes sometimes, and I, so I have to be careful of that. It's tied up with a sense of value and this, your worth, I'm not worth it, sort of thinking, you know."*
>
> (Session 2, 280-283)

She also reflected that she could not initially understand how to combine the many aspects of her work-life and:

> *"Still do everything that was expected of me, by them, and probably more importantly by me."*
>
> (Session 3, P1, 209)

I now briefly return to Brian's disposition. His openness to participating in stroke trials meant he was able to transfer his scientific knowledge and skills from his former work role to stroke research. As he did so, by chance, he discovered the power of networking (see '*CSM'*). He also found a new purpose in life and observed that he had regained his sense of career ambition despite no longer 'working' in the same context:

> *"I have ambition again, as a consequence of being involved in stroke research."*
>
> (PhD Pin, 46)

Specifically:

> "*I quite fancy being a patient representative as a nonexecutive director... on a NHS trust*".
>
> (Session 1, 263-4)

Using Brian's progression as an example highlights how these learning experiences can be seen through two alternative lenses. The transitions he went through can be viewed as the transfer of knowledge, skills and understanding from one context to another (Bloomer and Hodkinson, 2006:40, in Reid and Bimrose, Eds.). Alternatively, from a collegial perspective, his learning can be viewed as a mixture of belonging to a community and engagement in activities (Bloomer, 2006:40, in Reid and Bimrose, Eds.). By belonging to different stroke trial networks, he participated in trials, met and worked with other stroke-survivors and stroke professionals. This enabled him to progress his recovery and concurrently increased his awareness of stroke and its related disabilities, leading to him creating a new 'work' role for himself.

Through networking, all four stroke-survivors progressed their life-careers and, simultaneously, their recovery. Brian described how participating in stroke trials set off a "*ripple effect*" (Session 2, Hospital pin, 263) and Susan talked about several roles she had developed in the Christian community she is part of. For example, Fellowship Coordinator:

> *"It's mainly worship on a Sunday morning, but we also do things outside of that, like we have a group of non-students that meet together… for fellowship and I organise that."*
>
> (Session 3, p2, 127)

This community is one of many networks she belonged to, which illustrated how she transferred her Christian vocation, experience and skills in helping others in a number of paid and unpaid roles.

In my field notes, I recognised her initial reluctance to share all of these new roles with me, which I later realised was because she was trying not to be "*overactive*" (Session 1, 220). Despite her new self-awareness, I noted through successive interviews that she was still taking on more and more; a hard habit to break! Given Susan's earlier breakdown, it is worth considering that, according to Friedenberger (1974:62), burnout is associated with a *"personal need to be accepted and liked".* This is very likely to be why she was still taking on so much. Susan's self-esteem was very fragile and, throughout the interview process, she regularly sought reassurance from me that her story was relevant.

In addition to organising Christian fellowship, Susan was the secretary of her local stroke club, a carer for her friend with muscular dystrophy, an exam invigilator, she helped with her friend's ministry, volunteered in the local library, had become a Fellowship Coordinator and Spiritual Companion, and was also a mentor to other spiritual companions. This is in addition to reinstating her pre-stroke hobbies, which included amateur dramatics, walking and singing in a choir and at Gilbert and Sullivan festivals.

Susan also anchored her validity to the ability to earn an income. She explained what getting an invigilation role meant to her after she lost her former career:

> *"I also do some, invigilation at Kingston university for exams and I enjoy doing that. It was really important to me financially for a few years, less so now I'm getting my pension."*
>
> (Session 2, 335-336)

Although Susan's second husband was happy to support her, the financial issues that she had had with her first husband meant that maintaining her financial independence was of great importance to her. She believed her ability to contribute to the family income was part of her value to others, something she later learned to revise through CBT.

Capacities to generate development opportunities varied according to the stroke-survivors' disposition, disabilities and motivation. This is the "*knowing why*" (Arthur et al. 1994) aspect of career, which can also vary according to identity, personality, values and family. For instance, Brian stated:

> *"I had three sons.. who were my motivation really. You know, I didn't want them to see their Dad, in a wheelchair."*
>
> (Session 1,58-59)

However, even Philip, who had lost *"all my memory from the whole of my life" (*Session 1, line 3), was able to engage in and see the value of networking. After being persuaded by his sisters to attend a 'Living with Stroke' event, he commented:

> *"I met loads of people who changed my life over the following years."*
>
> (Session 2, 1481)

These life changes occurred because Philip was introduced to a number of organisations that helped him find ways of overcoming the disability-related problems he initially experienced. For instance, he went back to school to relearn cooking skills, "*which kickstarted my brain"* (Session 3, 149), and this led to Philip finding further learning opportunities for himself when the course ended which, in turn, enabled him to develop greater self-awareness of his learning style and needs. Each change he made then created new opportunities for Philip in a self-perpetuating way.

He explained how the 'Living with Stroke' event was the catalyst for him developing a more positive new normal:

> *"That's when all of my different parts of work and education, I say work, its unpaid. All my different parts of work and education started from that point."*
>
> (Session 3, 222-224)

While at school, he also developed a strong working relationship and subsequent friendship with a Teaching Assistant (Euan), who helped him enter a competition about overcoming adversity. Although his entry was unsuccessful, Euan was so impressed with the strategies that Philip had developed to manage his disabilities, that he offered to help him build a website so that he could share them with other stroke-survivors and their families. Philip avidly monitored the website statistics and noticed the following about the way it is used by visitors worldwide:

> *"The main one they seem to look at is my story, because that has, the reason, the reason why we did it on my development… We've done the, my story in chronological order of my recovery and it allows… the families to pinpoint the area that they are at and give them tips on how to develop and improve and apparently that's, that's made a fantastic difference to lots of people."*
>
> (Session 2,1383)

Euan was instrumental in encouraging and assisting Philip with many of the IT systems that he began to use, like an electronic diary. He also assisted him with his interview preparation and his election statement when Philip wanted to become a governor of his local NHS trust: a suggestion *"probably made by someone I bumped into on the stroke ward"* (Session 3, 582).

Becoming a stroke ward volunteer was just one of Philip's new role-related identities. He was also repeatedly elected as a governor of his local NHS Trust and became a 'Living with Stroke' committee member himself, because of the important "*turning point… meeting those people*" (Session 3, 545) was in his own life.

However, he sagely reflected that:

> *"When you're learning everything, there's a limit to what you can learn, but some of the meetings were once a week, some of them once a fortnight, with a bit of organisation from somebody else, I could fit them all in, but I wanted to do them all."*
>
> (Session 3, 216-217)

His determination to learn from and through all these roles and responsibilities was undoubtedly because Philip had realised that *"you get a really good feeling when you've actually helped someone"* (Session 2, 345).

Learning was not a linear process for any of the stroke-survivors; transitions in one area frequently facilitated changes and/or transitions in another. For example, all of the stroke-survivors learned to value themselves more as they transitioned to their new normal.

It is worth reiterating that all the stroke-survivors in my study were at least eight years post-stroke when I interviewed them, so, by '*Beyond*', they were all considering or had already started a new future, which I have detailed in the next chapter.

I conclude by summarising in diagrammatic form what the data showed about the non-linear transitions all the stroke-survivors progressed through (see Figure 5.1).

Before transitioning to '*Becoming*' they all experienced 'failure'; either a 'failure' to sustain their former careers, or in Philip's case a 'failure' to re-learn to read. However, they all learned to free themselves from the *"cycle of 'failure'"* and rebuilt their life-careers, so ultimately achieved success, on their own terms, in having transitioned beyond the suffering to a new normal.

Philip's total skill loss initially led to him being perceived by others as "*thick"* (Session 2, 1371), but he later reflected that he was able to write a "*competent application"* (Session 3, 583) for his voluntary role as a governor, with the help of his friend Euan. His new competent identity was initially demarcated by his repeated re-election.

However, unexpectedly for both of us, participating in the interviewing process enabled him to progress his reading ability, something that even one-to-one tuition had not achieved. He described reading his answers to my interview questions prior to the third interview:

> *"For the first time this morning, I actually read them to Euan. I have never been able to do that up until now, so that was quite a, that was fresh out of the blue that one because even Euan and I both realised after I started doing it, because neither of us were expecting it, I just started doing it."*
>
> (Session 3, 522-523)

I had been very gently pushing for additional unprepared information from Philip as the process had progressed, primarily in relation to his latent emotions and, as he described, his memory had started to return:

> *"In the course, well, in the early days before we started this, the things were improving, in the course of this, I got a lot more competent, in terms of I couldn't have written out my answers on my own and given them to Euan."*
>
> (Session 3, 812)

The process that all the stroke-survivors journeyed through reflect Bloomer and Hodkinson's findings (2006:40 in Reid and Bimrose, Eds.) that *"becoming is a balance between continuity and change".* That is, they transferred some of their existing skills, values, roles and hobbies to the new normal, but also experimented with new identities, developed new skills and pioneered some new roles and identities as a consequence. I conclude by clarifying how the sub-themes overlapped.

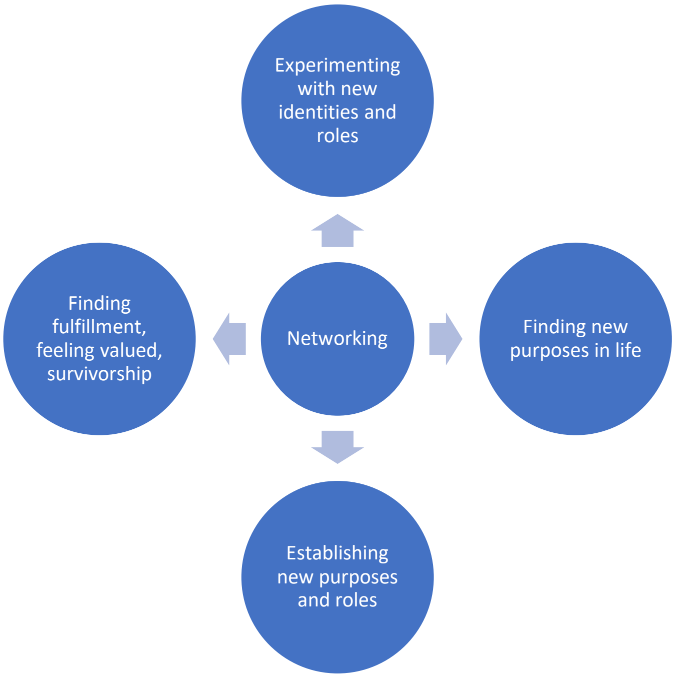
Conclusion

As illustrated by the stroke[-survivors and observed by Bloomer and Hodkinson in Reid and Bimrose, Eds. (2006:43), albeit with different respondents, "*learning to become through the process of becoming",* that is, recovering for stroke-survivors, was a lengthy process.

The sub-themes for this part of the transition process are summarised in figure 6.2 and from this we can see how growth in one area, such as trialling new identities, led to the development of another, like feeling valued. Networking is in a central position because, as explained earlier, it was fundamental to the progression of all the stroke-survivors through the transitions to the point of them creating, or in Katie's case simultaneously planning, a new life-career (a new normal).

In the next chapter: '*Beyond',* I examine how the stroke-survivors used their learning experiences to either actively build, or in Katie's case, plan and tentatively step towards a new future for themselves.

Figure 6.2: *'Becoming'*: Diverging Radial diagram of Career transition 'success': *"the sun's come out again"*



7: Summarising the stroke-survivors' experience of transitions: *'Beyond'*

By the Beyond stage, most of the stroke-survivors had moved past the chaos described in '*Before*'. They had worked out who they wanted to be post-stroke, although they were still becoming that person in the *'Beyond'*. This stage of rehabilitation/recovery is about the stroke-survivors moving beyond concern about who their future selves will be, towards actively reconstructing a new future for themselves. For example, as Katherine's painting shows, at this stage she had accepted that she was no longer the person she once was and had taken on a new, more vulnerable personality: Katie.

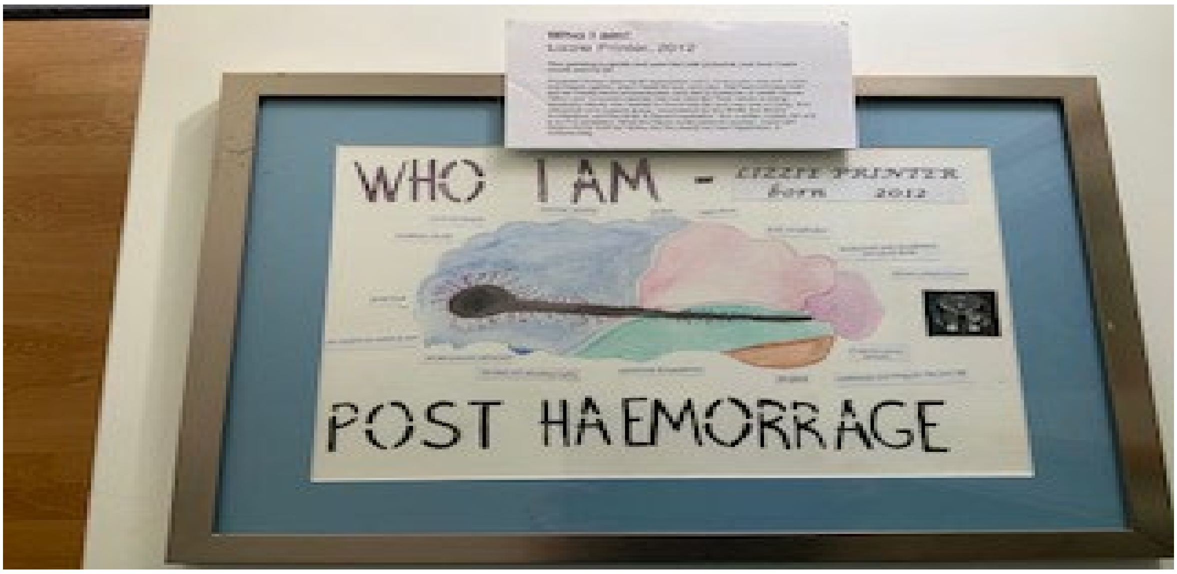


Figure 7.1

Box 7.1.1

"*The third painting is of my post-haemorrhage brain, which is very gentle and pastel coloured and light and its almost something that doesn't know what it is and that's when Katie was born."*

(Session 2, 225)

In her quote, Katie's newfound optimism is demonstrated by her talk about re-birth. The breach in her sense of identity and the impact of her diagnosed *"catastrophic emotional dysregulation"* (Session 3, 153) on family life led her to believe that Katherine, her former self, had died. By the third interview there was little of her old self left for her to anchor to, which was reflected in her comment that "*I think, undoubtedly, I'm a different person now, to what I was in 2015, 2017"* (Session 3, 541).

The literature on transition theory demonstrates that *"facing change with optimism helps to ensure it can be managed successfully, rather than endured"* (Reid, 2006:14-15, in Reid and Bimrose, Eds.). As already explicated, all the stroke-survivors learned about themselves and their new place in the world at different rates. As they learned to become a new version of themselves, they went through phases of greater or lesser proactivity during their transitioning work. All of them changed direction and intention more than once as part of the ongoing learning process about their *"emergent"* (Nasr et al., 2016:7) selves. That is, the stroke-survivors' new identities were being reworked ongoingly and throughout their learning experiences. I now briefly explain how their experiences can be interpreted in relation to the key principles of learning theory. I refer to learning theory because the stroke-survivors conceptualised their transitions as an ongoing learning process, as described in earlier chapters: '*Befor*e' and '*Becoming'*.

Sfard (1998) postulated that learning could be understood as acquisition of knowledge and learning in partnership with others. The first lens focuses on what learning a person realises and how they realise it. From this perspective, learning is about transferable knowledge or skills, something that both Brian and Katie capitalise on as they start to create their new life-careers. Alternatively, from a collegiate stance, learning is a combination of belonging to a community and engaging in its activities or practices. Susan, Philip and Brian provide good examples of this perspective as they participate in multiple networks that they learn from, such as the voluntary activities Susan engages in, like assisting with running her local library and Christian community-based roles (see *'Before'*) and her stroke club. She explained what the latter means to her below:

> *"I'm secretary for the local stroke club. A great bunch of people. I never thought I would be such good friends with those people who are all very different. We have something in common that we've all had strokes. It draws us together and binds us together in a way*

> *that's hard to describe. So, you know, I'm lucky, we're lucky. My life is great. I'm busy and fulfilled. I sing in two choirs. I do amateur dramatics with my husband. And we sing in the Gilbert and Sullivan festival once a year: fabulous! Erm, so I can't say that I'm not fulfilled, it's just sometimes I struggle to define who, where I am and who I am, in terms of this language of retirement and post-work, do you know what I mean, to, the mess? Most of the time it's ok, and then, if I'm tired or if I'm low, it suddenly seems to matter."*
>
> (Session 2, 352-365)

Brian's learning community was related to the stroke research trials he participated in:

> *"As a consequence of being involved in the study, at Birmingham...Glynn Humphries was professor at that time. And it was then, from participating in that study that I…2009, when I joined West Midlands Stroke Research Network, I, err… Kate Wilde knew I was interested in the cognitive aspects of stroke, because of me teaching A level Psychology… And, starting to understand the reality of cognition… When things go wrong because I am experienced And, she arranged for me to have a meeting: Kris Humphries And, was then referred to Wai-Ling Bickerton And I was then in the Birmingham University cognitive stream, which was… BCOS …at the time was revelatory for me. There's no better way to describe it. It was a Damascus moment: Because… I had a go at doing the BCOS screen and it was so superior… To the one that I'd done when I tried to get back to work and I had cognitive screening. Because it made me realise what was wrong. What had been wrong."*
>
> (Session 2 Roller skating trial pin, 30-49)

He also mentored a stroke-survivor for the Stroke Association (SA) and led their communication group. Leading the group enabled him to transfer his teaching skills to a new context:

> *"I was waiting for my early retirement decision. So, I didn't want to be at home… And this was an opportunity to use the skills, I knew that I had."*
>
> (Session 2, Volunteering pin, 6-8)

It also allowed him to reflect on how he could recover from his own dysarthria[24] and its associated anxiety, as this example shows:

> *"I witnessed one gentleman, in his mid-eighties. That hadn't spoken for 6 years. Who by, getting him to… feel confident, he suddenly started speaking... And, I also learned about anxiety, from a lady who'd been a teacher… The effect of that just one question, just completely threw this leg. So, it was a really, really powerful lesson, in terms of being prepared for the unexpected… And also, what the consequence of anxiety was, post-stroke."*
>
> (Session 2, Volunteering pin, 46-48 &80-83)

Reflection was a critical part of the learning process for them all and a possible explanation for why their transitions were time dependent, which Katie's ongoing transitions illustrate. During her first interview, she talked about how her *"organic depression and …personality disorder born out of my erm, brain injury"* (Session 1, 111) had "*fractured"* (Session 1, 107) normal family life.

I used silence during the interview process to provide opportunities for reflection, that is, for their self-awareness to grow. For example, I remained silent after Katie's comment about the impact of her *"personality disorder"* on family life and then, having paused for thought, she added "*that probably wasn't how it was, but that's how I felt"* (Session 1, 108).

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[24] "*Dysarthria is a speech impairment that sometimes occurs after a stroke. It can affect pronunciation, the loudness of the voice and the ability to speak at a normal rate with normal intonation. The exact speech problems will differ from person to person, depending on the location and severity of the stroke"* (American Stroke Association: https://www.stroke.org/en/about-stroke/effects-of-stroke/cognitive-and-communication-effects-of-stroke/communication-and-dysarthria#:~:text=Dysarthria%20is%20a%20speech).

During Katie's second interview, I explored how her "*personality disorder*" impacted on family life further and she explained how she could easily miss signs of love from her family if they were not tangible, as described here:

> "*And I think that, I mean I've talked to my husband about this, that, I mean before I was never someone who needed gifts and outward shows of affections, but afterwards, I missed the subtleties and need things to be much more, sort of clearly demonstrated."*
>
> (Session 2, 69)

I asked her to provide an example of when she had *needed "more tangible signs of being loved"* (Session 1, 109). She responded with this example:

> *"I think that our family had a lot of banter before my stroke. Banter, in terms of, you know, in terms of laughing at people and with people and it was all a big joke, but since, I just feel it's always aimed at me, so I feel that I'm the brunt of the banter, and I hate it. And I think that there's been a big divide between us because things that my family like to do, like going to see musical theatre and shows and going to the cinema, or whatever, I can't do. And I can't do, number one because of my comfort point of view, because I can't sit for 2 or 3 hours in one place. And two, from a noise point of view because I've got hyperacusis*[25] *and it's just actually painful to have to sit and listen to loud noise. And that's been an enormous divide between us, particularly when my family still go off and do that by themselves and I'm not included."*
>
> (Session 2, 71-77)

Her reference to the "*divide"* in this example reveals her growing sense of isolation (the *'fracture'* she had previously referred to). The last sentence, "*I'm not included",* reinforced how excluded from family life her disabilities had made her feel.

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[25] "*Persistent hypersensitivity to auditory stimuli following damage to the insular cortex.*" (Urnau and Touchetto 2012)

The stroke-survivors had reflective opportunities between interviews when they were invited to read the previous interview transcript. Katie also reflected on how her family had "*tried, within their abilities",* but that wasn't "*quite enough for me with my disabilities"* (Session 2, 69. See '*Becoming'*). She finished by describing how her "*emotional dysregulation*" (Session 3, 194) had affected her daughter:

> *"And what I would have wanted and what we've tried to get all along, was some family therapy, but, either on the NHS or privately, there was nothing that actually was available at the right time, to make a difference to my family. And so, 7 years on*[26]*, I think that, probably the hardest thing, is that I haven't been able to re-establish, a degree of normality within my family, that really isn't ok. And I know it's because of me and how I am and you know I want… In a moment, if I could do anything, I would, to change it. The trouble is though, for a lot of it, my 16-year-old; she is now 23, was with me when I collapsed. She had to make the 999 call and she suffers from post-traumatic stress and erm, anxiety and depression, because of what happened to me. Clearly, if you have got a 46-year-old fit mother who is running, training to run the London marathon, for her to drop down dead with a stroke, almost, is a bit of a shock and so she has become sort of hyper acutely, well, a hypochondriac in terms of any health issues. So, I know how much my actual stroke affected me and then my little 14-year-old, walked in on ambulance men who were literally trying to save my life and I stopped breathing and… She has erm, she has cut herself off from me so that she doesn't get hurt if I do die. So emotionally, we've been detached for 7 years."*
>
> (Session 2, 113 - 122)

She eventually labelled her *'personality disorder'* in the third interview after becoming more comfortable with me.

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[26] Katie reported in her first interview that she had had a stroke in 2011 and was interviewed 8 years later in 2019.

Achieving greater autonomy, empowerment and "*a little*" purpose in life

Having lost control of family relationships, after winning her court case Katie was eventually able to employ specialists to assist her, though not her family. This allowed her to assume a position of empowered control and complete her transition from having lost control of her life-career to regaining some choices about its direction. That is, the specialists she employed empowered her in a way that facilitated her to tentatively resume control of her life, as described in these three quotes:

> *"I employed a brain injury case manager and one of the first things she wanted to put in place was to have a PA."*
>
> (Session 2, 100)

She explained how the PA helped her on a daily basis and gave the example of how she supported her new life-career opportunities:

> *"And like on this Thursday, I've got a board meeting with the Brain and Spine Foundation and so she'll take me up to London and get me safely across London."*
>
> (Session 2, 97)

She found it difficult to identify one thing that made her PA so effective, but reflected on her as follows:

> *"From being professional, from being thoughtful, from being empathetic and understanding, erm, I just, absolutely wanting to do her best for me, so I think that's what makes her so effective."*
>
> (Session 3, 123)

As a consequence of getting the support she needed, she was able to look towards the future, had begun writing a book about her life and started to plan other projects:

> *"I want to do a TED talk. About brain injury and about recovery and… my life. Probably, I want there to be a film of it, erm, I'm going to create a vision board and erm, have that aim. That's my aim. Probably. That is a clear aim, yeah."*

(Session 3, 763-771)

Similarly, Philip achieved greater autonomy by accepting the support of Euan, his former Teaching Assistant friend, who taught him to use information technology (IT) to empower himself further. For example, to compensate for his memory loss and aphasia, he had developed a number of strategies, which he describes:

> *"I've got no memory, to be able to cope with the average day, I needed some strategies, which I worked out. Err, when I get up in the morning, I switch on my computer err my computer is connected to a large screen TV and I use a keyboard and a mouse…. I've got aphasia, which is a communication difficulty… But I find the text to speech seems to go to a different part of the brain which makes it easier to understand. Anyway, my working day, err or my leisure day, the two things are the same; get up in the morning, put the computer on, put the err, put the tablet on, and I look at my Google Calendar and my sent emails and look at what happened yesterday; look at my Google Calendar for what happened yesterday, look at my sent emails, and then look at my sent texts. That gives me an idea of what happened yesterday because I don't ever remember yesterday. Erm, I follow that by looking at today's Google Calendar, at what I'm doing today, erm, today's received emails and today's received texts, and I'm just learning WhatsApp as well, so I look at my WhatsApp messages to see what's happening today. And that's what I do before the start of every day, erm, to get me up to speed."*

(Session 1, 7-32)

As explained earlier, my interviewing style facilitated some of the stroke-survivors' reflexive learning. For example, during his third interview, Brian mused:

> *"It's now time perhaps, to reappraise… what I'd like to achieve."*

(Changes pin, 141)

When he made this comment, Brian was reflecting on the progress he has made in his life-career post-stroke and felt it was now time to fulfil future ambitions because he had recovered enough to appreciate that he has a fulfilling future ahead of him, that is he has moved 'beyond' the suffering of the earlier stages of transition.

By this stage, Susan had also established a number of 'work' roles (paid and unpaid), and she consequently reflected that the rewards of voluntary work were as important as the paid, because it re-established her value as a person:

> *"It's a voluntary role, it's not paid work but that doesn't matter."*
>
> *(Session 3, part 2, 11)*

It did not matter to her at this stage that she was no longer earning a living because she no longer valued herself by her earnings and her second husband had reassured her of his financial and emotional support (See *'Becoming'* for an example of Susan's voluntary work within her diocese and what that meant to her). With reference to her previous quotes about feeling devalued (see '*Before'* and '*Becoming'*), Susan also explained below how cognitive behaviour therapy (CBT) eventually helped her to accept that she was worth more than what she earned:

> *"We did spend some time in CBT talking about that, my tendencies as a person, and err, steps I could take and things that I could do that would help, help me with some of that, in terms of my identity and my sense of value. My nerves and not being measured s-solely in terms of my working life and what I earned, you know, my career. I was more than that, I was a bigger person than that. As a Christian, I know that to be true, I don't doubt for a minute that I have a sense of value as a person, as an individual, as one of God's creations. Having said that, in my head it didn't feel like... Yeah, I knew that in my heart but in my head I just didn't feel like anybody anymore, and that was against my value. It's really hard to make that connection, you know."* (Session 2, 259- 262)

CBT broadened her perception of the value she gained from different types of 'work', and so Susan began volunteering alongside her existing paid roles as a carer and exam invigilator. That is, she empowered herself by developing a 'portfolio'[27] career.

As each of the stroke-survivors began to re-order their lives, they searched for meaning by interpreting what had happened to them. As discussed already, all of them had experienced the "existential vacuum" (Frankl, 2004: 106) or "limbo" (Becker, 1999:2) period before trying out new roles and experiences, which led them to develop a fresh sense of purpose in their lives.

All except Philip, whose particularly complex disabilities made a return to paid work untenable, initially returned to their former careers before finding themselves unable to sustain these roles. This resulted in them experiencing either a breakdown and/or depression during the earlier transition periods (see '*Before'* and '*Becoming'*). Phillip returned to school, to enable him to progress his recovery. Since he had hemianopia[28] and had lost his memory of his entire life, and thus all the skills he had previously learned, he re-started his schooling by learning cooking skills alongside other disabled students. Learning new things required a lot of repetition and so he would repeat the meal he had learned that evening, as explained:

> *"Erm and if I liked it, I would cook it again that night because these things were lunchtime classes. I would cook it again at the night, to try and enforce the memory."*
>
> (Session 2, 875-876)

He described here how his learning progressed, around 6-18 months later:

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[27] "*The trend towards flexible working has led to the concept of a Portfolio career" (Agcas, 2004). "The term was coined by Handy, an expert on the future of work, to describe a career that encompasses multiple paid and/or voluntary roles, rather than a single paid role in an organization" (Handy, 1994).*

[28] Hemianopia involves vision loss on the same side of the visual field in both eyes (Costela F.M. et al., 2018).

> *“Then after that, that must have been successful because they got me on the first level of err, the literacy and numeracy class, so that was a major move forward.”*
>
> (Session 3, 557)

Relearning basic skills was a crucial way for Philip to increase his autonomy by taking back some control of his life, potentially reducing his dependency on others for help. Although he did not spell out his desire to reduce his dependency on others, he had talked in his second interview about his loss of privacy when ‘Age Concern’ read his letters (see ‘*Before*’) and used humour to deflect from ‘needing’ *“to be watched all the time”* (Session 3, 237-239) while in the care of his sisters, a further loss of privacy. The fact that he described regaining his basic skills as a “*major move forward”* also demonstrated that it was of great importance to him.

Acceptance of change

All four stroke-survivors transitioned from a feeling of future uncertainty during ‘*Before*’, caused by the abrupt disruption to their lives and identity, to being able to live with change. This uncertainty about every aspect of their lives pervaded their dynamic state of recovery. As the first two findings chapters illustrated, the process started with who they now are. Brian captured this existential uncertainty when referring to his experience of waking up on a stroke ward:

> *“I didn’t know what the future would hold.”*
>
> (Session 1, 68)

Since the stroke-survivors’ perception of themselves was so significantly altered by their strokes, their interactions with others changed too. As detailed in the last two chapters, Susan described how her job loss affected both her identity and relationships with others. In the context of being a product of her upbringing, she explained that she had been brought up in a society that defined people by their earnings (see ‘*CSM*’). This clarified why her inability to identify with professional roles was of considerable importance and how this rendered her mute and, in her eyes at that stage, devalued:

> *"Everybody always says to you 'What do you do for a living?' and I couldn't answer that question anymore."*
>
> *(Session 1, 185)*

I often had an empathetic understanding of examples that the stroke-survivors gave, and this comment particularly resonated with my own post-stroke experience. My interpretations were also formulated after developing an understanding of the stroke-survivors' dispositions across all three interviews. For instance, in the third interview, Susan explained why she was unable to return to the type of role she had held pre-stroke:

> "*In my mind, in my heart and in my head, I don't think that was sufficient a recovery to have returned to work, not in my full-time, professional capacity. To work in some way, perhaps, yes, but certainly not with the demands of the roles, that I had before I was ill. But that's the difference I guess. And I wasn't being offered anything like that."*
>
> (Session 3, 304-310)

After that comment, I asked whether she had considered reducing her work hours and she replied that there "*certainly wasn't"* any other options for her within social services, and that *"after I ended up being finished, I looked at a number of options" (Session 3, 312-313),* which she detailed:

> *"Oh, erm, I looked at 'Age UK', I applied for a job at 'Age UK'. Erm, I mean, the jobs that I was looking at were, a fraction of what I'd earned before, you know. So, it was 'Age UK', advisors, and charity, 'Douglas Macmillan'; I'd looked at something for, it was those sorts of jobs really."*
>
> (Session 3, 331-333)

Understanding that her management role, allocating emergency housing to the homeless, was viewed by her as a Christian vocation, and the excessive hours she worked, while on call, helped clarify why she felt unable to RTW after her breakdown:

> *"I just didn't feel that I could take that risk, the risk of failing again, I think so, I think that was a big part of it was just not, just so fearful of taking the risk."*
>
> (Session 3, 326-328)

Susan only managed to move her life-career on after receiving CBT as previously described.

All the stroke-survivors eventually managed to transition to a willingness to accept that life was to be characterised by change. For example, rather than fearing the unknown, Brian began to see his future as having "*turned into something which is quite exciting"* (Session 3, Q3,67) and, after initially being denied access to a disability pension by her former employer, Susan found comfort in the recognition and financial security she had achieved through finally being able to access her pension:

> *"I was sixty… it represented to me such a momentous change… at last that was my contribution, to life; my working role was acknowledg*ed*. There was this, this feeling that that was, at last that that was my contribution, to life; my working role was acknowledged and it felt, it felt so, there was relief."*
>
> (Session 1, 330-331)

By referring to her "*contribution to life*", Susan was talking about her need for her vocation, her life's purpose, to be acknowledged. This was significant because when she was abruptly "*finished" (*Session 3, 195) by her employer, receiving her pension took on the meaning of a rite of passage for her, which she had previously felt denied (see '*Becoming'*). Finally receiving her pension at sixty, therefore, marked her vocational contribution and helped her to let go of years of anger about how she had been unjustly treated:

> *"After I ended up being finished, I looked at a number of options. I looked at all sorts of jobs and all sorts of different scenarios and erm, and I, it was just, I just couldn't consider at that stage, for several years, really, putting myself through the demands of a working life again. And in the end my husband just said 'you have to, you have to leave this, you have to move on with your life and not just think about what might have been'. He supported me in reaching a position where it was sort of, ok to be at home and, you know, my life changed. But it was a huge adjustment, huge!"*
>
> (Session 3, p1, 317-321)

Her repetition of the word "*huge*" here demonstrates how accepting this change had a wider impact on her life-career. This example about how CBT had helped her to accept the strength of her anger, which had arisen from being denied access to her disability pension by her former employer, also reinforced my understanding of the impact of her former employer's decision:

> *"I do remember yeah, telling him about how it all felt. I think I was very angry. I think I said to him that I hope that anger dissipates with time because it's such a negative way to feel and it eats you up, it's so unhealthy. And I remember expressing that anger, to him at the time, about how it was, and he was very much working with me to, as how things were then and how to, manage my usual fatigue and all of that really. Erm we spent a lot of time talking about the ex and the bereavement sort of experience of losing my health and my career. We talked about the sense of value of me as a person and my identity, erm, and what matters and how that was acknowledged by me and by others. And affirmed by me and by others and what steps I could take to, not invite affirmation but to, allow that to be a part of my recovery. And I want others to be a part of my recovery, so we did some work around that. I'm a very independent, sort of a strong-minded sort of a person and I'm not very good at letting others contribute to anything that I need. I'm not very good at being supported back by people. I mean it's much more comfortable for me to want to do things for other people.*

> *And I know, I know even now that that's potentially a difficulty when, well, that I should be prepared to be supported by others, but..."*
>
> (Session 2, 246-257)

As explained earlier, she was only able to release that anger after receiving a pension at the age of sixty. She broke off mid-sentence to reflect and because her feelings were overwhelming her. In my field notes, I noted that she had sobbed through most of the second interview, and she often shut her eyes and screwed up her face when revisiting especially painful moments. Afterwards, I explained I had noticed that the interview had been emotional for her and mentioned the two helplines I would email to her should she need any further support. I also checked she was feeling ok, before I left her, and she said she was. She thanked me for listening and said it was the first time she had been able to talk about some of the things she had shared and how helpful she had found it.

The sentence in her quote about others being a part of her recovery demonstrated that Susan wanted to learn through participation.

Attaining an optimistic outlook, in which they could face the future and perceive it as offering opportunities rather than further suffering, took some stroke-survivors longer than others. This was due to their differing circumstances and the complex nature of their interacting disabilities. For example, Katie was only able to start moving into '*Beyond'* after winning her court case and Susan told me that she was glad that I had interviewed her a third time after her sixtieth birthday, as she had only just moved on emotionally.

Even the oldest stroke-survivor, Philip, was ultimately able to face the future. Significantly, he explained how fear of the future could be overcome if there is sufficient desire to do something. Philip was "*desperate"* to progress his recovery, so went back to school to re-learn basic skills:

> *"I don't remember specific things but going back to school was quite worrying. It was an unknown, but it was something I was desperate to do."*
>
> (Session 2, 855- 856)

By the end of this stage, all three stroke-survivors who had been unable to maintain a return to their 'former' work roles, had established a new career direction in retirement, as had Philip, whose complex combination of disabilities realistically rendered him "*unemployable*" (Session 3, 130). He was initially unwilling to discuss any possible future for himself, perhaps because his memory loss and age made dementia a more imminent possibility:

> "*But no, I never think about the future, I just enjoy life as much as I can. When I'm involved in any volunteering, I do it to the best of my ability, which is how I do everything."*
>
> (Session 3, 686-687)

However, by the time of the third interview, he had injured his knee, so was temporarily unable to continue volunteering on the stroke ward. At this point, his words showed an ability to move from a situation that had the potential to cause future uncertainty, to an acceptance that life is characterised by change. He demonstrated this by putting his injury into perspective and reflected that, if he was not elected as governor again, he would have to seek out new opportunities:

> "*If that was taken away from me, then I'd have to find something else, I like to be busy."*
>
> (Session 3, 801)

He also commented that:

> *"There are lots of possible futures depending upon which forks in the road you take."*
>
> (Session 3, 776)

Established in new role identities or experiencing fulfilment in life again

Susan felt that she had lost control of her life-career when she was abruptly *"finished"* (Session 3, 195) after RTW post-stroke:

> "*If I could have done anything about that I would have, there was no way that I wanted that to be how my working life ended."* (Session 3, 196)

She later demonstrated empowerment by taking up the life-career opportunities offered by her diocese and wider network. She did not plan to have a career in retirement, but the *"jigsaw"* (Session 3, p2, 112) of paid and unpaid role identities she had developed through happenstance meant she had unconsciously created one:

> *"I didn't plan it that way but that's how it worked out."* (Session 1, 277)

Brian, Katie and Philip had also created a range of role identities by this stage. For example, Katie was a trustee for the Brain and Spine Foundation, a Christian and had become a public speaker:

> *"I've given speeches for them; I've spoken at the Neurological Alliance on primary care and I've spoken at the Royal Society of Medicine on my rehabilitation, so I think I'm helping."*
>
> (Session 2, 178)

She also supported a subarachnoid haemorrhage Facebook group:

> "*Yeah, there's a subarachnoid haemorrhage Facebook group, which the Brain and Spinal Foundation have set up and I just keep my eye on it, most days, and see if anyone wants a bit of feedback."*
>
> (Session 2, 173)

After being asked for three ways in which he thought his future might develop, Brian expressed surprise that this stage of his life had turned out to be *"exciting":*

> *"There's the normal lifestyle things, you know, of, of maintaining my, no, it's more; maintaining our happiness, my wife and I, in terms of our future years. You know, we are moving into a completely new phase of our lives, and we have a choice, as to how we err, make use of that time. And, that's quite exciting. It's not something I've ever really thought about. I always saw, this period of my life, as being somewhat negative, of something not to look forward to. But, actually, it's turned into something which is quite exciting."* (Q3, 63-68)

Philip was also surprised, as was I, by the sudden progress he made in recovering his memory and consequently his ability to read, and he commented on how my interviewing style had facilitated this:

> *"It's brought about things that neither of us knew because obviously I've got no memory and it wasn't stuff that Euan could find out and obviously the way you ask a supplementary question has brought about things that neither of us could remember… And now I have, according to Euan, I've, I'm more competent on these sorts of things and he was quite impressed when I did my initial answers myself."*
>
> (Session 3, 595 & 598)

Finding purpose, and feeling valued and empowered

As they undertook identity and life-career transitions, they all concurrently shifted emotionally.

All the stroke-survivors moved their mindset from one in which they had little/no control of their circumstances, which led Katie and Brian to perceive themselves to be victims of bullying (see '*Before*' and '*Becoming*'), to one of empowerment and survivorship, generally indicated by the word *"lucky"*. Three quarters of the stroke-survivors described themselves as *"lucky"*. For instance, Susan used the word as she explained how she had inadvertently built a 'portfolio' career:

> *"So, I'm lucky that I've got this jigsaw of stuff, that is my life now, all of which makes me feel good and makes me feel energised and well and the sense of value with that."*

(Session 3, p2, 112)

Whereas Philip explained that he is on the ‘Living with Stroke’ committee *“for luck because it was so crucial”* (Session 2, 1485) to his progress. However, Brian made a downward comparison with other stroke-survivors:

> *“I’ve been really lucky, that I’ve never suffered from depression.”*

(Session 3, Radio and Choice pin, 84)

He was understandably keen to stress how much he had moved on from the ‘crisis’ stage of recovery, when he had had a breakdown (see ‘*Before’)*.

As a reminder, Katie was so *“depressed”* after her stroke (Session 3, 148) that she was on suicide watch, and she was still very fragile during the interview process. Rather than describing herself as lucky, she used the term “thankfully” when explaining her survival of an aneurism. However, *“thankfully”* carries a similar sentiment of appreciation and indicated that she felt fortunate that her daughter was present and able to summon assistance:

> ***“****Thankfully with my daughter by my side, otherwise I would have died because I fell immediately into a coma with a GCS of 3.”*

(Session 1, 21)

When asked to identify her transitions, she astutely realised that the lows are a necessary part of the recovery journey:

> *“I have had to accept I need weekly treatment physically, whether it’s physio, or erm, massage, or yoga, all this stuff I didn’t have in my life before and, and to go with whatever rehab has been recommended and to go with whatever medication so yeah, I’ve had to have lots of different doctors assess me. I have had to accept I need weekly treatment physically…all this stuff I didn’t have in my life before and, and to go with whatever rehab has*

> *been recommended and to go with whatever medication, so yeah, I've had to have lots of different doctors assess me. So all that stuff is very difficult, if I hadn't gone through those stages, I wouldn't have now been now able to sort of start to move on."*
>
> (Katie, Session 3, 536-537)

Katie's observation, during her third interview, that she had now started to *"move on"* is particularly significant because of all the stroke-survivors I interviewed, she was the one who had had the least amount of time to recover. She was only eight years post-stroke, whereas the other stroke-survivors had all had ten years or more in recovery at the time of interviewing.

By the third interview, it transpired that establishing new role identities had helped all the stroke-survivors to regain a sense of being valued and find new purpose in life, albeit only a "*little*" one for Katie. Her use of the word "*little* "indicated that it doesn't give her the same level of fulfilment that her role as a district judge did because she was under employed and capable of much more but unable to achieve that because of her disabilities, as were all the stroke-survivors. This was an important point for Katie, because the role of judge was an integral part of her identity. She explained she felt her role loss so acutely because "i*t wasn't just because of its a status, it was part of my being*" (Session 2, 52),

which is why she was keen to capitalise on her transferable skills by *"not wasting the talents, I have, such as public speaking and raising funds for charities… it gives you a little sense of purpose back"* (Session 3, 548).

Susan, Brian and Philip all found new career directions and purposes in retirement. In contrast, Philip described how his new life-career helping people gives him a *"good feeling",* which is *"the greatest therapy in the world" (Session 2, 345* and *349).*

Conclusion

Most of the stroke-survivors initially conceptualised the time of stroke and subsequent job losses as either a crisis or traumatic experience (Jacobson, 2006; Duplock, 2010, in Schultz and Miller, 2011).

However, Philip, as explained in the last chapter, similarly perceived it to be what Becker (1997) described as a "limbo period", *a "nothing time"* (Session 2, 157) because it was like being in a *"vacuum",* in which he was unable to learn anything:

> *"I went through three… years, give or take six months of an educational vacuum, I couldn't do anything."*
>
> (Phillip, Session 3, 123)

Moving beyond becoming a survivor

Through their strokes, they had all lost control of their lives, but transitioned to a position of empowered control over time. Throughout the transitioning process all of the stroke-survivors learned and transitioned (emotionally and psychologically), often in ways they only recognised with hindsight. They learned more about their new, emerging selves and worked to construct the person they wanted to be. During this process they became survivors, who had learned in different ways to self-manage their life-careers. In doing so, they managed discontinuity, by drawing on "stable anchor *points in their beliefs and values*" (Little et al., 2002:170) and:

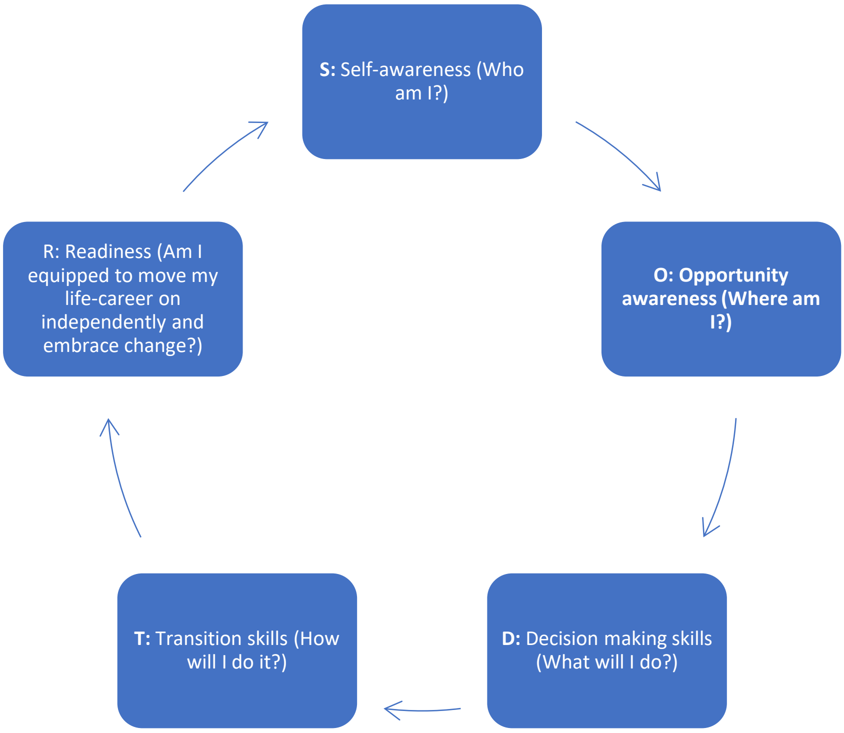
> *"By finding ways to preserve a continuity between past memory, present experience and constructions of the future, by using the experience to develop established facets of identity and by imbuing the experience with meaning and recognising the enlarged identity made possible by survival."*

I finish by illustrating how all the stroke-survivors achieved this, through the lens of CSM, in the next chapter. Before moving onto this, I provide a table as an overview of the transitions they and I identified in Appendix IV.

8: Findings: Life-career self-management

Career self-management (CSM) is the second major theme of the research. As explained in the introduction, my research had two aims: primarily to illustrate how stroke survivors self-manage their career transitions, and a subsidiary aim: to explore how narrative practice might form an essential part of a Stroke self-management programme (SSMP). Although there were many ways in which the data could have been analysed, I sought to identify initial themes that aligned with those aims. To this end, this chapter examines how the stroke-survivors' experiences of transitions, detailed in the last three chapters, relate to life-career self-management. I draw on the DOTS model (see below), which I have adapted to illustrate how the data can be viewed through the lens of life-career self-management. DOTs can be used as an analytical tool to see where a client is within the CSM process, or for career planning.

Figure 8.1. A revised DOTS CSM framework by Law and Watts, 1977, adapted and redrawn by Carol Wilson, 2021 (Source: Personal Collection)



Self-management (SM) of life-career has a different emphasis to SM in healthcare. As Watts (2006:15) explained, *"the focus of* CSM *is upon making and implementing the decisions that determine one's career".* This theme had five sub-themes: Readiness, Self-awareness, Opportunity awareness, Decision making skills and Transition skills. All of these skills/sub-themes were developed by the stroke-survivors through navigating the transitions already identified, as I will illustrate. However, this was only the case because they all were exceptionally motivated to learn and recover, which is why I begin and end the model with Readiness.

Readiness (R)

Most of the stroke-survivors were motivated to recover quickly because of concerns for their families. For example, Katie discharged herself from hospital early because*:*

> *"I'd been really conscious my daughters who were …doing their homework on my hospital floor and I didn't want that to happen anymore."* (Session 1, 34)

Susan comparably wanted to support her daughter's transition to university. Brian simply states:

> "*I had three sons... who were my motivation really."* (Session 1, 58-59)

Brian later explained:

> *"I didn't want them to suffer as a consequence of my… erm, accident."*
>
> (RTW pin, 104)

As previously explicated, despite the fact that three of the four stroke-survivors quickly returned to the familiar environment of their previous employment post-stroke, none of them sustained their positions. The data demonstrated that this is because they had low levels of self-awareness at this stage of their recovery, as I explain further.

Self-awareness (S)

Self-awareness is the ability to reflect on your current position: both understanding and accepting who you are. This is a crucial and often forgotten stage in CSM, which sequentially links to the other skills that the individual needs to acquire (outlined in the DOTs model), so that they can find, obtain, maintain and develop within a job (Law and Watts, 1977, 2003).

That is, if stroke-survivors are to realistically evaluate the suitability of the options open to them post-stroke, which may or may not include previous employment, they need a high level of self-awareness. It's the ability to be realistic about their new identity, which may still be emerging, that fundamentally reflects their readiness to move on with their rehabilitation. Savickas (1997) defines this as *"readiness to cope"* and "*readiness to adapt*", skills the stroke-survivors all learned over time.

As can be seen from the DOTS model, self-awareness is the first step towards achieving readiness and links to the other skills in the following order: SODTR. Only when an individual has all these skills, will they have attained career readiness. However, not every adult needs to go through all the stages, as they may already have some of these skills, as the stroke-survivors demonstrated.

For the non-disabled, developing self-awareness might involve taking a careful inventory of their current values, motivations, interests, skills and personal qualities. However, for all of the stroke-survivors, this crucially involved understanding how to manage their disabilities, something that could only be developed through time, reflexivity and experience, which they all only fully achieved in '*Beyond*', as demonstrated by their ability to envisage a future for themselves. For example, Philip described his initial reluctance to attend the 'Living with Stroke' event.

This latter point is an important one, as the ability to envisage a future self is indicative of still having hope in life. As Frankl observed in concentration camps (2004:81): *"It's a peculiarity of man that he can only live by looking to the future… And this is his salvation in the most difficult moments of his existence, although he sometimes has to force his mind to the task".*

Ali and Graham (1996) explicate this stage of growth further by linking self-awareness to acceptance. Stroke-survivors need self-awareness in order to accept both who they now are post-stroke and who they are becoming during recovery. Greater self-acceptance enables an individual to move forward with a realistic view of how their self might develop in a way that achieves its future potential. None of the stroke-survivors could have possibly predicted in the early post-stroke days what they would eventually achieve.

As previously explained, there is some overlap between the two major themes. During '*Before'*, the stroke-survivors frequently misunderstood how to manage their disabilities, or practised poor coping strategies. For instance, Susan explained the difficulty she understandably had combining her roles as a wife and mother; her work as an on-call Housing Officer, dealing with emergencies; several hobbies and her Christian faith, while adapting to her post-stroke fatigue:

> *"In terms of my energy levels, I just couldn't see how I could combine that, and with the other parts of life that you have to get on with…"* (Session 3, part 1, 207)

Before working out how to manage their disabilities, Katie and Philip both employed avoidance techniques. Katie was a keen runner and when her emotional dysregulation, and its ensuing relationship difficulties, overwhelmed her, she literally ran away from the situation (see *'Becoming'*).

In the early days, Philip coped with aphasia and memory loss by avoiding conversations:

> *"When you don't like meeting people and you've got no memory, you avoid conversations."*
>
> (Session3, 244)

In Transition theory, the past continues to influence the present. However, the past need not completely influence future choices, which is important to consider when the past is distressing or a source of anxiety (Ali and Graham, 1996).

After having a breakdown, Susan was referred by her doctor for cognitive behaviour therapy (CBT). Through this, she began to understand that her ability to reason was impaired by her fatigue, so she needed to pace herself and take care to balance her work and home life:

> *"When you're tired and something happens, your sense of perspective and ability to reason is distorted…so I have to be careful of that."*
>
> (Session 2, 280-281)

Katie was also able to reflect on the impact of her emotional dysregulation, though she hadn't found a better coping mechanism at this point (after her settlement, she began private yoga lessons). She explained how the "*issue*" affected her and her entire family:

> *"I think it's just the conflict in the family that it causes that is probably the issue."*
>
> (Session 3, 194)

Brian initially felt like the same person, as he was still able to drive to France for the family holiday. His lack of understanding about his disabilities meant he only perceived that he was a little slower to process information than he was pre-stroke:

> *"It seemed to be…all, as it had always been, with a little bit of, obviously difference with me, not being able to be as quick as I used to be."*
>
> (Holiday pin, Session 3, 53-55)

However, he later received a phone call from his vice principal as he had failed to turn up for the first day back at work, due to mixing up his diary dates, an example of his cognitive impairment affecting his organisational skills:

> *"And I'd got it through my head that I started work on the 15th. So, I didn't turn up for enrolment. And err, and erm, there was a phone call from the vice principal, to say 'Where was I?'…So I got that wrong in my diary. And that was the first sign of, yeh, probably trouble …I wasn't functioning properly."*
>
> (Holiday pin, 71-79)

Brian now has a high level of both self-awareness and opportunity awareness, so was able to progress his own recovery, despite his initial set back, which led to him taking early retirement after having a breakdown at work.

Opportunity awareness (O)

Opportunity awareness is the ability to find opportunities for the development of the self through research and exploration (Watts, 2006). Great ways of exploring 'work' opportunities with minimal risk are through voluntary work or work shadowing (Ali and Graham, 1996). Both of these strategies, along with studying, can also be stepping stones to renumerated work, once readiness has developed through these experiences, or they can have their own intrinsic value, as all the stroke-survivors discovered. For example, Brian assessed his dysarthria by working with the Stroke Association's Communication Group, something he described as a "*major milestone*" (Session 1, 156) in his recovery:

> *"I started to self-assess myself, in terms of how I could control what was wrong with me, through the voluntary role."*
>
> *(*Session 1, 161-162)

Philip, who had lost his memory, also sought learning opportunities. After returning to school to redevelop basic skills, he attended Further Education (FE) classes, repeating them several times, without learning the intended subject. However, during that process, he did learn what type of education did not work for him. He made the following comments about his tutor, after doing the same adult education course three times:

> *"He's not allowed to teach me at the speed of repetition that I need and I can't learn so eventually I think I saw the term out but then just didn't re-enrol because it was always going to be the same."* (Session 2, 2018)

Consequently, he began to understand the way his combination of disabilities played out in real life and adjusted his coping skills accordingly by working opportunities for repetition into his daily life.

In contrast, Katie took the opportunity to educate others about stroke by exhibiting the paintings she originally did in stroke therapy (see paintings heading last three chapters):

> *"I've exhibited them at the stroke conference last year and I've also exhibited them at the Bloomsbury Festival."*
>
> (Session 2, 224)

Susan also has a high degree of opportunity awareness and described her willingness to engage with as much physio as she could:

> *"I was desperate and eager and any opportunity I could have, I would take."*
>
> (Session 2, 69)

As each person is influenced by both significant others and society, they might have or need to create a number of networks that have the potential to provide self-development opportunities, personal and/or professional. Since learning is *"an active and social experience"* (Bassot, 2006:51, in Reid and Bimrose, Eds.), which takes place within a dynamic social and cultural context, they build social and/or cultural capital by taking up self-development opportunities.

Capital is a shared asset. Social capital can include shared norms, values, beliefs, trust and networks, that facilitate action for mutual benefits, whereas cultural capital relates to the knowledge, behaviours and skills, developed from experience, which an individual can draw on in new learning situations (Mcvee et al., 2018).

Decision making (D)

All the stroke-survivors effectively demonstrated how having social and cultural capital facilitated development opportunities. Both involve the need to make decisions about which opportunity is most suitable at that moment in time. Phillip illustrated this when he chose to use his time to volunteer as a governor, in preference to taking more FE courses, which did not include enough repetition to enable him to learn from the content:

> *"So, I realised that these sorts of things are not going to work… I've got to find a way of remembering things and I also decided subconsciously, that doing things for pleasure was never going to work. I needed to do things for reasons."*
>
> (Session 3, 404-405)

Decisions also require planning and goal setting, as he explained, when describing how he extended his horizons and independence by planning how to learn new routes in his locality:

> *"The planning routes, if I need to go somewhere, and I know I'm going to need to go on a regular basis, what I used to do is get someone to walk it with me erm, and then after a few times, I would, in the very early days, I would get them to follow me and I would do it on my own."*
>
> (Session 2, 1059)

Susan's former work role meant that she was particularly skilled at both planning and goal setting. After CBT, Susan tentatively reviewed her life-career goal:

> *"It's about living this life of balance somehow."*
>
> (Session 3, p2, 164)

Early on in her recovery, she made a joint decision with her husband to take in her friend Mary, who has muscular dystrophy. This required them to move house as she was in a wheelchair and this kindness later led to Susan becoming Mary's senior carer, a paid role, through happenstance. However, despite knowing herself well, she was initially less skilled at moving on her own recovery. As she explained:

> *"I'm a very independent, sort of a strong-minded sort of person and I'm not very good at letting others contribute to anything that I need."*

*(*Session 2, 254)

She was successful in transitioning because she had excellent networks, which enabled her to establish a portfolio career:

> *"This jigsaw of stuff, that's my life now."*

(Session 3, p2, 112)

Networking is not just for identifying job opportunities. It can also be used to access sources of advice at all stages of CSM, for example to help with a choice of role or transition skills. My interpretation of the data illuminated the fact that it was a vital transition skill for all the stroke-survivors.

Transition skills (T)

Transition skills are traditionally said to be skills like understanding how recruitment works for the opportunity of interest to the individual and effectively marketing oneself through job applications, curriculum vitae(CV), interviews and assessment centres (Watts, 2006).

Both Katie and Philip demonstrated traditional transition skills. For example, Katie explained how she applied to become a trustee of the Brain and Spine Foundation:

> *"I had to put together a proper application and went for an interview and became a trustee."*

(Session 2, 175)

In the same tradition, Brian reflected on how job application procedures are based on exam performance:

> *"I had, I had a grammar school education, and… I suppose it was seen in the seventies that, if you went to grammar school, you, you went into, went onto university, erm… And, academic excellence, was seen as getting a good degree, getting a higher degree. I … associated higher intellect, erm, err, intelligence, with… exam performance. And everybody else does. You know, that's what you present, on your CV."*
>
> (Session 2, PhD pin, 11-12 & 25-27)

Philip needed the help of his friend to market himself to other patients in order to be elected as a governor on an National Health Service (NHS) Trust. He explained part of the process:

> *"You do an election statement which obviously Euan processed mine for me about the things I believe and wanted to do."* (Session 2, 1258)

The data revealed that networking was a transition skill that was crucial to all the stroke-survivors, in today's global, dynamic society, as can be seen from '*Becoming'.*

Had the stroke-survivors been able to access life-career counselling, using narrative techniques, earlier in their recovery, then they might have been spared some of the extreme suffering they all went through: three quarters of them had a breakdown!

They would most certainly have been advised against making significant life-career decisions in the aftermath of a traumatic experience and steered towards a less traumatic period of taking stock of themselves and their new circumstances, potentially enabling advocation in relation to the adaptions they required to re-commence work. They would also have developed a more current understanding of CSM. Susan had a retrospective awareness of the need for this. At the end of her interview, she compared herself with her daughter, who she perceived has a better attitude to work-life balance:

> *"But I think we are a product of our upbringing, aren't we... And we're of a generation where it's important that you have this integrity and sense of value that commitment to what you do and you do it well. And I think it's very hard to get out of that mindset, isn't it... I say to my*

> *daughter, she's 32, and I think she has a better work-life balance than I have ever had in terms of managing the work of life. Erm, she has quite a different attitude to work. I mean young people are criticised often about their lack of commitment to work, but I think somehow there are things that she's certainly got right about it that I failed to, and I think, I think, erm, I think she thinks sometimes about, I think I feel I'm old-fashioned sometimes in my approach."*
>
> (Session 3, P2, 513-529)

Conclusion

All career theories are directly or indirectly based on learning theory (Bassot, 2006: 50, in Bimrose and Reid, Eds.), and we have already seen from the stroke-survivors' accounts of their transitions how CSM and transitions intersect at the point of learning about their emergent selves; a process which was dependent upon their social and/or cultural capital.

All the stroke-survivors in this study held professional/business roles prior to their stroke, so they either had existing cultural and/or social resources to fall back on, or they knew how to create those opportunities from their previous life-career experience. Despite this, the journey to the new normal was undoubtedly rocky for all of them. This begs the question how other stroke-survivors with fewer resources at their disposal, or the wherewithal to create them, would manage their involuntary transitions.

Watts (2016:7) has repeatedly made the case for a lifelong career service, particularly for disadvantaged adults to utilise when needed. He explains there *"has been a strong tradition of incorporating career guidance elements within voluntary and community services which can be closer to the needs of disadvantaged groups".*

He also notes that, while public employment services clearly have a key role to play, "*care has to be taken to ensure that career guidance within such services is addressed to the needs of the individual rather than to narrowly conceived outcome measures"* (*2016:7).*

To meet the complex individual needs identified by the stroke-survivors studied a narrative approach, similar to the one used in this research, is needed. This is also sometimes referred to as a constructivist, interpretative or biographical approach. Reid (2006:8, in Bimrose and Reid, Eds.) explains the key features:

> *"Constructivist approaches recognise that when we ask a client to 'tell their story', they do not provide us with a list of experiences or facts; they tell us about events. These events are not a series of unrelated episodes but form patterns representing the client's socially constructed view of themselves in the world: past, present and future."*

I believe that the data presented has illustrated this point, albeit with stroke-survivors, rather than clients.

Although the DOTs model has been used as a framework for analysis of CSM sub-themes, it is important to note that I am not advocating a matching model of life-career counselling, with which it is sometimes associated. It was used in my research because it is particularly suited to supporting transitions (Young 2019) and remains the dominant framework in Higher Education and the UK as a whole (McCash, 2006).

The DOTs model was also adopted because both Brian and Susan talked about being a product of their upbringing and how this had influenced their careers (see their earlier comments). All the stroke-survivors were close enough in age to have grown up during a time when vocational career theories and their associated concepts, like jobs for life and matching individuals to careers, were the norm. It was therefore unsurprising that their approaches to CSM were initially reflected in the DOTs model, albeit one that I adapted to meet their identified needs as stroke-survivors. However, through time, all the stroke-survivors had adapted their traditional view on careers by broadening the meaning of the concept to encompass much more than renumerated work: life-careers.

In the Discussion section, I will explore how suitably trained career guidance professionals could work with other rehabilitation professionals to implement a constructivist approach to career counselling, more suited to today's life-career approach, and that would avoid more stroke-survivors being harmed by the "*policy imperative"* (Radford, 2020:2) to RTW too quickly.

9: Discussion and precis of Key findings

Revisiting the aims of the study

The central research question of this study was: ‘How do stroke-survivors self-manage their career transitions?’ The first aim of the research was to understand how the stroke-survivors’ self-managed their transitions. The subsidiary aim of the research was to explore how narrative practice might form an essential part of a Stroke self-management programme (SSMP). This is addressed through consideration of how private career counsellors might form a part of a multi-disciplinary vocational rehabilitation (VR) team. This proposal forms a later part of this chapter and is a focus of the recommendations.

The achievement of the study’s main aim, presented in the last four chapters, demonstrated that the meaning the stroke-survivors applied to their transitions went beyond returning to renumerated work and were closer to Super et al.’s (1976) definition of career as a life-long developmental experience. This finding has implications for stroke rehabilitation (SR) and VR professionals who have traditionally focused on assisting stroke-survivors return to their pre-stroke employer. I suggest that career counsellors could be contracted by multidisciplinary rehabilitation teams, to assist stroke-survivors in looking at all their ‘work’ options and potentially provide ongoing support.

As a matter of practice, SR/VR teams and career counsellors signpost clients to the Citizens Advice Bureau and/or other organisations who support the disabled with financial matters. They can assist stroke-survivors with the process of applying for statutory sick pay and/or the relevant state benefits that they would be eligible for. The Stroke Association’s website also has advice on financial support: SA, UK.

As the data demonstrated, and Culler et al. (2015) also found, return to paid work (RTW) was too early in the recovery process. Foreclosing career choices early, without full exploration, at best later leads to discontent with choices made. At worst, three of the four stroke-survivors reported, and the wider literature previously identified this can prevent the stroke-survivors sustaining employment

(Garton et al., 2017), sometimes leading to a breakdown and/or depression with accompanying life-career dissatisfaction. Parente et al. (1991) termed the inability to sustain work the *“Return Loop Syndrome”,* although this was in the context of brain injury survivors as opposed to stroke-survivors specifically. The former includes people suffering with addictions and so it is important to differentiate stroke-survivors from the wider group of acquired brain injury (ABI) survivors as the reasons for inability to sustain work are not necessarily the same.

None of the interviewed stroke-survivors who returned to their former professions were able to maintain their renumerated work roles. Although this was only a small sample, so not generalisable, the wider research does demonstrate that there are retention issues for many stroke-survivors (Radford et al., 2022) and my research illuminated the exact circumstances that contributed to those difficulties, which are very different to those of ABI survivors as a collective.

Culler et al. (2015:333) correctly state that *“adjustment to disabilities”* is a lengthy process. My research supports these findings and the originality of it is that it clarifies both the meaning of 'work' for the stroke-survivors and the nuanced factors that contributed to their inability to sustain paid work. For example, the stroke-survivors not having enough time to experiment with incorporating new roles into their identities in a safe environment. Another example is understanding how their disabilities impact on everyday life, while concurrently adjusting to other people’s reactions to these; and learning ways of adapting to the newly abled self.

As Super et al.’s (1976) theories of career development explicate, stages of growth and exploration are inherent to acquiring knowledge about how a person’s needs, values, interests and abilities suit them for the requirements of an occupation. Since stroke has the potential to change these and the way in which a person’s roles are prioritised in the life space, it also has the potential to change a person’s life-career direction, something which requires specialised life-career counselling for many, not least stroke-survivors with potentially impaired decision making. I return to this point later.

I now present the four key findings from the main research aim to examine the stroke-survivors' self-management of transitions. Each begins with an invitation to all relevant parties to re-imagine the concept of career, in line with current life-career research and practice, in order to emphasise the need for this change in SR and VR. The first finding I present highlights the relevance of readiness and self-awareness to the life-career self-management process.

Findings: stroke-survivors' self-management of transitions

Re-imaging career: Self-awareness developed through time and experience and informed self-management and readiness for transition

The first key finding emerging from the interpretation of the stroke-survivors' narratives was that self-awareness informed life-career self-management and developed through time and experience. It was only during, or after, '*Becoming*' that the stroke-survivors envisioned the possibilities for change that their new life-career presented. This finding is significant because although readiness is a key concept in life-career management (Savickas, 1997:254), it has a different meaning in healthcare. For example, Jarvis et al. (2019: 3198) suggest walking speed should be used as *a "clinical indicator of functional performance to guide rehabilitation and inform readiness to return to work post stroke"* and the justification for this is likely to be closely linked to the state's priority of getting people back into work and off benefits. Another example of this priority is reflected in Nice's clinical guidelines for SR in adults (2023:36) which recommends that SR professionals "*consider a referral to a return-to-work programme for people who were working before the stroke*." While I would not disagree that the ability to walk well can be of relevance for some stroke-survivors, my research demonstrated that factors beyond the physical were considered important, supporting Doolittle's earlier research (1992). For instance, Susan's view that she could not commit to reliability and fulfilment of all her responsibilities was the reason she felt unable to return to work (see '*Becoming'*). This was partly because she did not feel she had sufficiently recovered from her breakdown to return to a highly demanding role and partly because she saw her role as her vocation and so she held herself to high standards in the delivery of it; that is she did not want to let vulnerable people who relied on her down and she was fearful that she would because her recovery was incomplete. Forcing her back to work too soon was quite clearly harmful. The other two stroke-survivors, who failed to sustain their RTW, provided further evidence of harms created when the drive for stroke-survivors to return to paid work is over emphasised by rehabilitation professionals, and the failure to offer other ‘work’ options is not given equal consideration.

I am not suggesting that the needs of stroke-survivors should not be reviewed every six months, which has been a national policy requirement since 2000. Rather, I suggest that this guidance should not be misinterpreted as a speedy RTW is mandatory for all stroke-survivors because of the potential financial drain on the economy of them remaining unemployed. As is beginning to be recognised, a tailored approach to rehabilitation has a greater chance of success for stroke-survivors’ needs (Jones et al., 2013) and regular reassessments are crucial, to address ongoing needs, if stroke-survivors are to sustain paid work.

NICE, 2023: 37-38) also states that in the long-term, SR professionals should:

“encourage people to focus on life after stroke and help them to achieve their goals,” which might include *“information about voluntary organisations that can support them; helping them to participate in community activities, such as shopping, civic engagements, sports and leisure pursuits;*

visiting their place of worship and joining stroke support groups”.

Based on my research evidence, I would argue that this type of support is also valid in the short-term as it helps stroke-survivors regain or establish new identities, while concurrently developing awareness of their disabilities and helping them to develop ‘work’ readiness.

In relation to ‘work’ readiness, British Society of Rehabilitation Medicine (BSRM) Brief Guidance (2021:9) additionally suggests *“career guidance and vocational counselling,” “work tasters,” “alternative avenues of occupation” and “voluntary work trials”.* In reality though, SR does not routinely include VR. As Playford et al. (2011: 21) found, *“support with job seeking and reassessment* *were the least often provided".* For this reason, multi-disciplinary teams that include appropriately trained life-career counsellors are necessary for sustained improvements in rehabilitation practice. Disappointingly, the latest NICE guidance (2023: 7-8) details the professionals who should make up a core multidisciplinary team and suggest that they "*provide access to other services that may be needed."* However, life-career counsellors are neither recommended as part of the core team, or listed as an example of other services stroke-survivors may need.

Shames et al.'s (2009: 1392) report that *"eagerness and readiness to return to work are significant factors"* in post-acute brain injury rehabilitation (PABIR) programs. Individual stroke-survivors require guidance in working out when and whether to RTW, or whether other options are more suited to their new needs once they have had time to accept and understand their disabilities. As can be seen by the DOTS model heading up '*CSM*', the data showed many other interrelated psychosocial factors also played a part in both the RTW decision and the inability to sustain work once the stroke-survivors had returned. Perhaps a better focus for post-acute brain injury rehabilitation (PABIR) would be the *stroke-survivors' "overall commitment to work*" (Super et al., 1996), demonstrated through the broad interpretation of 'work' that the stroke-survivors in the study exemplified throughout their transitions (See *'Beyond'*). Consideration of how the stroke-survivors maintained their commitment led to a second finding, that the stroke-survivors 'mini-cycled' through life-career transitions.

Re-imagining career: stroke-survivors 'mini-cycled' through their life-career transitions

Significantly, readiness for transition was further complicated by the fact that the stroke-survivors did not progress through the stages in a linear fashion because learning in one area of life-career, such as about their newly abled self, or the value of networking, frequently facilitated change and/or transitions in another. With reference to life stages, Super (1976) referred to this process as 'mini-cycling'. In particular, Super noted that job loss and life transitions can lead to 'mini-cycling', and he also identified the developmental stages that an individual progresses back and forth through:

growth, exploration, establishment, maintenance and disengagement. Although age was not related to developmental stage for the stroke-survivors studied, the transition process was flexible as the data showed evidence of 'mini-cycling'. The stroke-survivors' sense of self evolved during all three transition stages, but they were all set back at different points (see Figure 5.1). The larger arrows in the figure show that while the thrust is generally forward, denoting recovery, the smaller backward chevrons bring attention to the fact that the stroke-survivors sometimes 'mini-cycled' through earlier transition stages. For instance, Philip found himself repeating Further Education (FE) classes without learning anything, before progressing his reading. After returning to paid work, Brian and Katie were forced into early retirement, while Susan was "*dismissed"* (Session 2, 424). All went on to develop new life-career directions in their later life stages. This is reflected in the next finding, relating to the stroke-survivors commitment to 'work' over time, despite the meaning of 'work' changing for them.

Re-imagining career: Overall commitment to 'work' was sustained through time, but views on what constituted 'work' changed over time

As a feature of the transitions process is "*reactions over a period of time*" (Schlossberg, Waters and Goodman, 1995:50), it is important to consider how the stroke-survivors' emotions, motivations and identities changed over time. All of the stroke-survivors changed in respect of all of these factors. For instance, the three who were able to RTW, were all keen to return to their previous work environment, though in Brian's case it was to take up a position he had been newly promoted to just prior to his stroke, rather than a former work role. All experienced 'crises' during '*Before'* and for Katie the 'trauma' extended into other stages too. However, by '*Becoming'* or '*Beyond*,' they had all adjusted to their new normal, although that is not necessarily an indication of them no longer needing support, as they could easily revert back to an earlier stage and its accompanying emotions.

Their role-related identities also continued to develop through all three stages as they grew through their experiences. For example, Katie explained that it was now up to her to achieve her ambitions in '*Beyond'* and Brian also commented on how unexpectedly "*exciting"* (Q3, 68) he was finding his newfound ambition in the later stages of his life; that is they were both motivated to take on new life-career roles. Whereas Susan and Philip were preparing for future life-career changes. Susan had adapted for both her current and future life by moving to a more energy efficient home, closer to bus routes into town, as well as accommodating the potential needs of other household members. Philip had decided that he would have to find something else to occupy him if he lost either of his volunteering roles in the future. This was said in the context of a recent knee injury which had prevented him working with other stroke-survivors on the stroke ward. He was also aware that through policy changes, he may no longer be eligible for re-election as a governor for the hospital trust. That is, they were all embracing change, rather than experiencing future uncertainty.

Stroke-survivors ‘experiences and expectations of the transition process definitely varied through time. After their strokes, all the stroke-survivors, except Philip, whose complex disabilities realistically rendered him “*unemployable”* (Session 3, 130), expected to return to their former occupation and therefore attempted to do so. Contrary to what Ruffolo et al. (1999) reported, despite not being able to return to his career as a self-employed Financial Adviser, Philip did not *“malinger”* (Shames et al., 2009:1391) either. Instead, he returned to education to learn new skills and later became actively involved in several volunteering roles. It is worth noting that the term “*malinger”* was used in Shames et al.’s (2009) interpretation of Ruffolo et al.’s research. Ruffolo et al. (1999), who report on RTW after mild traumatic injury from motor vehicle accidents, rather than stroke specifically, did not use this term in their paper. However, the point remains the same, rather than focusing on returning to paid work a better focus would be helping stroke-survivors to develop a new purpose in life, whether through competitive work or other routes, such as voluntary work. This is something a life-career counsellor could help stroke-survivors with at the appropriate transition stage for the individual, particularly as: “*there is growing recognition that RTW is not a discrete all-or-nothing event, but rather a process in which the individual prepares for and moves closer to, and engages in work”* (Wasiak et al., 2007, in Waddell, Burton and Kendall, 2008: 12).

Waddell, Burton and Kendall also add that: *"people with persistent or recurrent health problems are liable to further sickness absence, so what matters is sustained RTW".* Despite this 'growing recognition,' as I reported in my own rehabilitation story: "*everybody seemed to make it their business to question me about when I was going back, from casual acquaintances to the nurses at the doctors"* (Wilson, 2019: 13). Part of the reason for this is because RTW has been a much reported '*policy imperative'* within the National Health Service (NHS). This has led to harassment by the media and general public, which is both offensive and insensitive to stroke-survivors, unable to RTW, or to sustain a work position after returning too soon, especially in the context of the considerable commitment to 'work' the stroke-survivors interviewed made, but the policy, of course, is directed by the State (DWP).[29] As subsequently illustrated, this has led to SR being limited to individuals of working age and the evidence for provision being solely focussed on randomised control trials (RCTs), rather than also considering other qualitative research evidence (Waddell, Burton and Kendall, 2008: 10). Their review was commissioned by a task group representing the Government, employers, unions and insurers in conjunction with the Industrial Injuries Advisory Council and is heavily biased towards returning individuals to competitive work. Despite claiming to have conducted a review of the "*scientific evidence"* (Waddell, Burton and Kendall, 2008: 84), they state that the review: "*relied largely on randomised control trials, which are inappropriate or impractical for many clinical, scientific and policy questions, where other types of evidence may be equally valid"* (Johnston et al., 2006, in Waddell, Burton and Kendall, 2008:84). Confirmation of the '*policy imperative'* to focus on employment outcomes can be found on page ten of the review.

There is also some questionable methodology in relation to the 'scientific evidence', as I will subsequently illustrate. For example, despite an acknowledgement that provision for the *"long term sick must inevitably be multidisciplinary and designed specifically to meet complex needs"* (Waddell, Burton and Kendall, 2008: 51), "*Pathways to Work*" are credited with being "t*he most effective*

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[29] Department of Work and Pensions

example to date of such an intervention, with RTW rates of "7-9%". However, these rates are only "*estimated"* (Waddell, Burton and Kendall, 2008: 36) and they also contradict this claim by stating that *"there is lack of good evidence on effective interventions for recipients on benefits for more than one year"* (Waddell, Burton et al., 2008: 51). To put the figures being quoted into context for stroke-survivors, Radford et al. (2020:1) found that *"only one third of participants who were employed full-time at stroke onset were employed full-time at 12 months post-stroke".* This is despite *"two thirds RTW at some point in the 12 months following stroke".* As Radford et al. (2020:4) found, stroke-survivors are likely to be in receipt of benefits at some point following stroke, due to the "*dramatic impact of stroke on work status, working hours and income"* (Radford et al., 2020:1). This was highlighted by Brian, who changed the ending of his stroke story because he wanted to share the ordeal he had recently experienced going through an unsuccessful Personal Independence Payments' tribunal, which I explored further in the second interview:

> *"You are up against this… these hidden criteria that bear no… resemblance to the reality of the situation."*
>
> (Session 2, 55)

Returning to Waddell, Burton and Kendall's VR review (2008:52), it states that the rudimentary principle of VR *"is that everyone of working age*[30] *should have access to VR, at the appropriate level for their needs".* Interestingly, in the literature search for the review, and contrary to what my data showed, the retired were written off as 'failures' and excluded on that basis: *"ill-health retirement was excluded because this is an end point after rehabilitation has failed, and is complicated by social issues around retirement"* (Hayden et al., 1999, in Waddell, Burton and Kendall., 2008:85).

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[30] The review defined this as 16-65 years

My research challenges this exclusion as the data demonstrated that stroke-survivors remain actively committed to 'work' during retirement. This exclusion also contradicts the statement in their footnote (6) on P10, which states that:

> *"This review is about employment rather than work. Employment is typically a contractual relationship between the individual worker and an employer over time for renumeration as a socially acceptable means of earning a living. Work is not only 'a job' or paid employment, but includes unpaid or voluntary work, education and training, family responsibilities and caring."*
>
> (Waddell and Burton, 2006 in Waddell, Burton and Kendall, 2008:10)

While I would not argue with the distinction being made between work and employment, the last sentence in the above quotation suggests that a suitably broad definition of 'work' is being adopted in VR. However, the statement about employment being *"socially acceptable"* also strongly implies that other forms of 'work' are not '*socially acceptable*'. In another footnote (7) on the same page, which has clearly been added to meet the governments' RTW agenda, it claims that:

> *"Incapacity for work has a significant detrimental impact on the individual, his or her family, employers, the economy and society. Job retention, return to work and reintegration are therefore the most relevant and important (albeit not only) goals and outcome measures of vocational rehabilitation."*
>
> (Waddell and Aylward, 2005 in Waddell, Burton and Kendall, 2008:10)

This footnote clearly puts economic considerations over the needs of the individual being rehabilitated, whose opinions were not included in these policy documents and whose opinions are diminished as less relevant and important by virtue of Waddell and Aylward's judgement about what is “m*ost relevant and important*”. This is a good example of VR practitioners allowing stakeholders’ agendas to dominate healthcare, something Ellis-Hill, Payne and Ward (2008: 155) cautioned against.

Furthermore, Waddell, Burton and Kendall’s review (2008) excluded “*people with “severe medical conditions (e.g., neurological disease or blindness)”* (Waddell, Burton and Kendall, 2008:10), as they have “*different and specialised rehabilitation needs”* (BSRM, 2000, in Waddell, Burton and Kendall, 2008:10). However, I know from personal experience that stroke-survivors are being put through the Pathways to Work programme despite having *“different and specialised rehabilitation needs”.*

Also excluded from the review were people with “*severe mental illness*” (Waddell and Burton, 2008:10). This included *“personality disorder”* (Waddell and Burton, 2008:88), which one of the stroke-survivors interviewed was diagnosed with, and “*issues around disability discrimination because that is principally a social issue*” (Waddell, Burton and Kendall, 2008:88). My research demonstrated that three of the stroke-survivors interviewed perceived themselves to have been bullied or stigmatised because of their disabilities or impairments. Therefore, disability discrimination cannot be excluded from the RTW process. It must be given due consideration, especially as VR is designed for those with “*severe disabling illness or injury”,* the majority of whom *“will have some level of neurological impairment*” (BSRM, 2014: 2). By definition, severe disabling illness or injury can result in *“a complex range of impairments and disabilities, producing a mixture of physical, cognitive, emotional, social and behavioural difficulties”* (BSRM, 2014:2). Since stroke-survivors are subjected to Pathways to Work, then they should be included not excluded in this VR review. Furthermore, BSRM (2015: 6) states that: *“patients with category B*[31] *needs would typically be those who require… support to return to productive roles, such as work or parenting”.* It is worth noting that the reference to ‘productive roles’ includes parenting and is not confined to employment.

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[31] Patients with category B rehabilitation needs: “*have moderate to severe physical, cognitive and/or communication disabilities which may include mild-moderate behavioral problems…”* (BSRM, 2015:7). This is just one of the criteria defining category B needs and applied to all the stroke-survivors interviewed at certain stages of their recovery.

Further examination of the methodology behind the VR review also reveals what scientific evidence the review utilised: *“systematic reviews, extensive narrative reviews, reports and professional guidance was the primary focus, and individual studies were only selected if they added essential information not covered in the reviews”* (Waddell, Burton and Kendall, 2008:88).

The strength of evidence was also assessed using a system adapted by Waddell and Burton, 2006, (in Waddell, Burton and Kendall 2008:90). It therefore could be viewed as lacking impartiality. In relation to their exclusion criteria on social grounds, of significance is the fact that BSRM rehabilitation guidance (2021: 7) draws attention to the importance of VR teams working within a “*biopsychosocial model”,* as biopsychosocial factors can act as obstacles to an individual’s RTW (2021:7). My data also confirmed that this was the case.

BSRM rehabilitation guidance (2021:11) additionally acknowledges that “*the work environment has changed”* since the pandemic. In reality, it had changed years before then, although the pandemic perhaps brought that fact to a wider audience’s attention. This is why an alternative model of ‘career’ now needs to be embraced, something which SR, VR guidance and ‘*policy imperatives’* regarding employment have still to catch up with.

This led me to question VR definitions, which also had significant variations within them in relation to their intended audiences. For instance, BSRM (2021:11) define VR as: “*a process which enables persons with physical, cognitive and psychological impairments or health conditions to overcome obstacles to accessing, maintaining or returning to employment or other useful occupation****”.*** The latter statement resonates with a broad interpretation of life-career, more suitable for stroke-survivors than Waddell, Burton and Kendall’s (2008) definition: “*Whatever helps someone with a health problem to stay at, return to and remain in work: it is an idea or an approach as much as an intervention or a service”.* While at first appearance this seems flexible, in reality it prioritises the economy over serving the individual requiring support, as evidenced by the following statement:

"Being able to stay in work or RTW is an essential part of an individual's recovery from a disabling illness…. VR not only supports individuals, but it ensures work-place productivity and is good for the wider society, converting benefits recipients into tax payers." (BSRM, 2014:11)

This final remark once again reveals the economic agenda behind most VR, which is insensitive to people who may have paid taxes for many years, prior to becoming disabled, and who remain committed to 'work' in the long term, both of which applied to all the stroke-survivors interviewed. Moreover, as BSRM Brief Guidance stated (2021: 5): "*policy makers worry about the huge costs of health related benefits and these are increasing, but it can be argued that for a significant number of people work loss can be prevented by low cost VR services".* This is further substantiated by BSRM (2014: 3), which refers to the "specialist rehabilitation" needed for stroke-survivors: "*there is now a substantial body of trial-based evidence and other research to support both the effectiveness and cost-effectiveness of specialist rehabilitation".* BSRM (2021:03) also states:

> *"Services are needed for people in different socio-economic settings and cultural environments; with different lifestyles and educational backgrounds; with a wide spectrum of skills and occupations; and with a diverse range of injuries, illnesses and disabilities. Differences in any of these variables could affect both the processes and outcomes of VR."*

In other words, one size does not fit all, a person-centred approach is required. Pathways to Work fails in this respect, as it is generic and based on matching theory. While the simplicity of this may appeal to policy makers, it has limited utility in today's labour market since it assumes a degree of stability, whereas many occupational environments are now volatile and there is more pressure on individuals to adapt to ever changing circumstances, something which is extremely difficult for traumatised stroke-survivors. As Mitchell and Krumboltz (1996:263) explain: *"trying to place an evolving person into the changing work environment... is like trying to hit a butterfly with a boomerang".*

Osipow and Fitzgerald (1996) additionally highlight the failure of matching theory to address the issue of change in environments and individuals. Moreover, they draw attention to problems inherent with the theory's associated measures for gender but regard the most serious limitation to be its failure to explain the process of personality development and its role in vocational selection (Osipow and Fitzgerald, 1996:104).

As my data demonstrated that stroke-survivors are continually adjusting their self-concept, as they become more self-aware and transition through the recovery stages, Job Centre Plus' matching approach to career guidance should be deemed entirely inappropriate for their needs. Further,

NICE's recommendation (2023:68) to consider referring stroke-survivors who wished to resume work, to RTW programmes is based on a single study from South Africa, where occupational environments are quite different to the UK. The researchers themselves wisely point out that:

> "This *study was set in the economic and cultural capital of South Africa, and therefore the results cannot be generalised to other countries due to differences in labour laws and social security systems."*
>
> (Ntsiea et al., 2017:672)

NICE (2023) seem to have paid no heed to that crucial point as their recommendation seems to have been misguidedly based on the results of this randomised control trial in South Africa. Therefore, it is worth noting that NICE guideline (2023:2) is not mandatory.

Returning to the stroke-survivors' rehabilitation needs, in contrast, the GMC's Rehabilitation Medicine Curriculum define rehabilitation as: *"a process of assessment, treatment and management with ongoing evaluation by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living"* (BSRM, 2014:12). This is a far more ethical definition, with a suitable emphasis on growing the potential of the individual so that they might experience quality of life

(QoL). As such, it resonates with Super et al.'s (1976) definition of career and, which emphasises self-development, which was a focus for all the stroke-survivors interviewed. Adopting Super et al.'s (1976, in Chen 1998:438) broader definition of career would open up more flexible SR and VR approaches for both stroke-survivors and other people requiring rehabilitation and I therefore recommend it to SR and VR practitioners, and policy makers.

With that in mind, I also argue that a better emphasis for post-acute brain injury rehabilitation PABIR) would be on "*commitment to work*" (1998:438) which Super et al. correctly theorised as not confined to renumerated work and all the stroke-survivors' data verified. Moreover, this stance would genuinely focus on what is best for stroke-survivors. This need not be a more expensive approach either as BSRM Brief Guidance 2021:5 demonstrated.

Adopting this broader definition of career would facilitate a consensus on the definition of 'work' and resolve the issue of different countries and VR agencies interpreting work in different ways and thus rendering the RTW rates quoted in a plethora of studies unreliable data from which no conclusions should be drawn to inform policy and practice. Like neuropsychological testing, the results of RTW research should be interpreted with caution, not used as a stick to beat "*malingers*" (Shames et al: 1391) with.

Drawing on my own experience during that stage, I can confirm that the pressure to RTW started in hospital as Rehabilitation staff were working in a culture driven by RTW targets, rather than individual needs. Stroke-survivors' expectations and therefore hopes were raised at an early stage in the recovery process. The literature verifies this, as Radford et al (2022:1-2) confirm:

> *"Returning to work after a stroke is a major goal for stroke-survivors, contributing to social identity, emotional and financial wellbeing and conferring a sense of purpose and has benefits for the individual, the individual's family and the economy. Despite this, only half of working age stroke-survivors return to meaningful work, and they are two to three times more likely to be unemployed eight years after their stroke than the general population."*

The above quotation presents returning to work as a "*major goal for stroke-survivors*". I believe that opinion needs to be viewed in relation to the fact that SR and VR professionals confer themselves with *"expert status"* (Ellis-Hill, Payne and Ward, 2008: 151), and as they found, frequently set targets for stroke-survivors, irrespective of what stroke-survivors actually wanted.

It is also important to remember that social identities are *'co-created'* and while ever 'expert status' is assumed, in the context of stroke-survivors being '*malingerers'*, who are 'socially unacceptable' if they are not ready to immediately RTW or have a 'failed' RTW, stroke-survivors will continue to have low self-efficacy, which all the stroke-survivors reported. For example, Brian and Susan likened themselves to rubbish, Katie wanted to kill herself and Philip described himself as "a *vegetable*" in the early post stroke days (Session 1, 111). As Ellis-Hill, Payne and Ward (2008:157) suggest: *"practitioners can reduce the psychological burden of identity challenge by the creation of more supportive discursive relationships and services".*

In my mind, support should have the interests of the individual at the heart of it. According to BSRM (2021: 13) "*responsive and personal services"* are "*critical to the delivery of a successful VR service".* However, my own experience also confirmed that some rehabilitation staff set targets for stroke-survivors. In my case, these were sometimes past their sell-by date by the time they were set and crucially, as a former career professional, this practice went against the ethical code[32] I subscribed to when working with clients. Specifically in relation to impartiality and duty of care, regarding the importance of goal ownership. Consequently, I was very uncomfortable with this institutionalised practice. To further demonstrate how institutionalised goal setting by some rehabilitation practitioners is, I cite Radford et al.'s (2020:1) feasibility trial: ***"****RTW after stroke is a recovery indicator and rehabilitation goal***.** *Employment may be critical to QoL following stroke. People who do not RTW after stroke may be at increased risk of depression".*

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[32] The Institute of Career Guidance' code of ethics: https://www.thecdi.net/write/documents/ethical_principles.pdf

Contrary to the last point regarding depression, my data demonstrated that it was the stroke-survivors who were unable to maintain their RTW because they went back too quickly, who suffered breakdowns and/or depression. Stroke-survivors need to be given ‘work’ options and the facts about the “*return loop syndrome*” (Parente et al.,1991), so that they might make an informed choice about what is suitable for them at each stage of their recovery.

Interestingly, when approached by other providers of VR support, “*the doctor has a responsibility to work in the patient’s best interest with a team that may be external to the NHS*” (BSRM, 2021: 15).

In the spirit of Ellis-Hill, Ward and Payne’s (2008:155) point that *“rehabilitation belongs to the person, it is their process”,* I recommend early access to career counselling sessions, to help stroke-survivors reflect on their situation and have full awareness of the range of life-career options available to them post-stroke. This would help them be guided towards an informed decision about what is truly best for them at each stage of their recovery. I make this recommendation in the knowledge that the NHS “*does not meet the need for VR”,* (BSRM, 2021: 7), particularly in relation to people with long term neurological conditions (BSRM 2021: 17), so hope that my recommendations might be taken up as part of the rectification process. A recent and welcome development is the fact that the NHS long term plan (2024) now advocates for personalised care and rehabilitation, supporting the principles of self-management and laying the foundations for cultural change. However, the latter is unlikely to be an immediate or easy process, a point I return to later.

Despite pressure to RTW, currently propagated by the World Health Organisation (WHO) who acknowledge the need for *“universal rehabilitation coverage”* (2017: 1), but have failed to define ‘work’. This is ostensibly missing from the glossary (2017:35) and the fact that they continue to link rehabilitation with improving the economy further clarifies that the meaning of ‘work’ in healthcare is limited to paid work. Additionally, the recognition of developmental needs that disabled people might have are only mentioned in relation to children and even these are driven by economic concerns:

> *"Investment in rehabilitation increases human capacity by allowing people with a health condition to achieve and maintain optimal functioning, by improving their health and increasing their participation in life, such as in education and work, thus increasing their economic productivity. For children in particular, rehabilitation optimizes development, with far reaching implications for participation in education, community activities and in later years, work."*

This is contrary to what the data showed, that is, all of the stroke-survivors significantly developed their life- careers in 'retirement'. Perhaps because this phase of their lives provided them with time and a safe space for them to truly address the opportunities that their new lives presented, without the pressure to return to former work roles, which they all eventually accepted were lost to them, having experienced the accompanying strong emotions at that stage, although the impact of these lasted much longer, as Susan and Katie reported. This led to my next finding that retirement did not mean disengagement with 'work'. The stroke-survivors actually redefined the purpose of 'work' in their later life stages.

Re-imagining career: Retirement did not mean disengagement with 'work,' the purpose of 'work' was redefined

As the meaning of 'career' also varied at different stages of the transition process, SR and vocational support needs to reflect that fact and be accessible throughout the stroke-survivors' lives. Even though BSRM (2014: 6) recognised *"that the complexity of patient needs changes over time*", Waddell, Burton and Kendall's (2008) VR review fails to fully account for this by excluding both individuals 'working' in non-renumerated roles and in 'retirement'.

Before the transitions, all of the stroke-survivors experienced some form of chaos and slipped into an "*existential vacuum"* (Frankl, 1959-2004), 'crisis', or 'trauma', according to how each stroke-survivor conceptualised it.

All except Philip returned to renumerated work, but none of them were able to maintain this. Significantly, all of the stroke-survivors started the interview process with a traditional, hierarchical view of career, which was directly associated with renumerated work. For example, Brian reflected on how his drive for success came from his working-class parents before talking about how the job application process is designed to reflect ranked exam performance:

> *"I was in an environment through my school in which I was surrounded by very, very bright individuals. And I wasn't all that great at exams. I still associated higher intellect, erm, err, intelligence, with… exam performance. And everybody else does. You know, that's what you present, on your CV. I had, err, probably, a fairly negative view of myself as a consequence of that."*
>
> (Session 3, PhD opinion, 21-29)

However, by the end of the interview process, they had all embraced a multi-faceted life-career perspective, as evidenced by the roles they had started to accept and were juggling. These included non-renumerated positions, civic responsibilities, studying, avocational and familial roles. It was in regard to the juggling act of work-life balance, that Susan recognised the huge difference between her daughter's approach to career and her own (see '*CSM').*

It was only after accepting that their former work role was no longer a viable option, that the stroke-survivors were willing and able to explore other career options, and it was their willingness to experiment and be open to new opportunities that crucially allowed them to begin to learn about their differently-abled selves, and so the "cycle of 'failure'" proved to be temporary for them all. This was also the case for Philip, who at this stage returned to school, rather than paid work. Philip's new life-career directly equated with education at this stage, as it allowed him to realise his potential for development.

All of the stroke-survivors who were unable to sustain their former work roles, managed to break free of the cycle of 'failure' and through trialling opportunities, experimentation with rehabilitation strategies, and an energy of openness, they began to rebuild their life-careers during '*Becoming'.*

Notably, the process was lengthy, encompassing several years for them all, which has implications for service providers considering when the optimum time to support rehabilitation is. In short, readiness varied from individual to individual, reinforcing the need for a person-centred approach to rehabilitation. This was reflected in each stroke-survivors' novel approach to redefining their life-career by combining multiple roles to help them achieve a sense of purpose in their life-careers. In other words, they were embracing portfolio careers, which is the final finding.

Re-imagining career: embracing portfolio careers

As explained in '*Beyond*', all the stroke-survivors went through phases of greater or lesser proactivity during their transitioning work. Probably the most significant turning point for them all, was the movement from negative coping mechanisms, such as avoidance or expressions of anger, to positive coping mechanisms, like studying or volunteering. Sometimes proactivity was instigated by a change in circumstance. For example, Katie winning her court case and Philip finally attending a stroke networking event. At others, it occurred through happenstance, like Susan voluntarily caring for her friend leading to her becoming a paid carer when the direct payment system was introduced, or Brian hearing about the 'Roller Skating' stroke trial on the radio. All of these events proved to be catalysts to psychological transitions which in turn opened up further life-career opportunities for them all. Notably, none of their 'work' roles were renumerated roles at the appropriate levels for the stroke-survivors' experience and qualifications. However, in Susan's case, this led to the development of a portfolio career as her invigilation and carer roles were later augmented with a number of voluntary roles, which enhanced Susan's life-career satisfaction.

This leads me to question the narrow conception of 'work' and/or career used in SR policy and practice. It is also important to remember that volunteering or studying can be stepping stones to renumerated work, or can have intrinsic value in themselves. A range of non-renumerated positions were pivotal to the progression of all the stroke-survivors interviewed and they all developed portfolio careers, although only Susan showed an understanding of that.

Conclusion

These findings suggest that VR and SR programmes need to adopt a wider perspective of life-career that reflects stroke-survivors' interpretation of 'work'. Given the cyclical nature of their journeys, interventions need to be flexible enough to support those in transition.

In the next chapter, I return to the implications of the research for service providers and make some recommendations with the research findings in mind.

10: Recommendations and implications for stroke rehabilitation (SR) and vocational rehabilitation (VR)

As discussed in the literature review, the Stroke self-management programmes (SSMPs) that exist or are being trialled do not currently encompass life-career management, yet there is clearly a need for tailored support for stroke-survivors to be delivered at the most appropriate time for them. Given the complexity of the task, including self-employed career counsellors on rehabilitation teams may help to achieve this.

Radford et al.'s (2022:2) 'Retake' trial is a step in the right direction, in terms of a multi-agency approach towards rehabilitation and in acknowledging the need to support stroke-survivors' career progression. However, there are still some fundamental flaws in the trial design that my research highlighted. For instance, although *"work-related education*" is seen as part of renumerated work, that statement and the aim of the research "*to optimise work participation*" is restricting the life-career development of stroke-survivors to renumerated work and forgetting that education and the wider aspects of career can contribute to finding purpose in life, as it did for Philip in this study. The importance of these was also affirmed by the POISE study (Carcel et al., 2019:2) who noted that female stroke-survivors were frequently engaged in unpaid work before and after stroke. British Standards for Rehabilitation Services' (BSRM 2014:4) core standards for specialist rehabilitation verifies that caring and family responsibilities should be regarded as important because: "*a small but significant number of stroke patients, especially those of working age, require specialist rehabilitation to maximise their opportunities for return to independence and previous extended roles such as work, parenting etc".*

In addition, while the Early stroke specific vocation rehabilitation (ESSVR) logic model (Radford 2022:2) suggests that alternatives to *"current work"* will be explored where work "*is not feasible"* or "*cannot be sustained",* this forecloses the fact that many stroke-survivors may need to pursue interim steps, such as work shadowing, education or volunteering before attempting renumerated work; that is the pressure to return to renumerated work in the short term remains (Playford et al, 2011:7). As my data and World Health Organisation's (WHO's) rehabilitation rationale have demonstrated, this is the case, despite the fact that there is a lot of evidence to suggest this is a long term process for stroke-survivors (Kuluski et al., 2014). The latter means that stroke rehabilitation (SR) and vocational rehabilitation (VR) (needs to cater for stroke-survivors' needs over their whole lifetime, including their 'retirement' from paid work. Fortunately, this is now theoretically a possibility due to an amendment to NICE's 2023:15 guidance, which states that *"therapy should be provided for as little or as long as the person requires it and should be based on their needs, to ensure they get the most out of rehabilitation."* However, they also note that *"this could lead to a change in practice which may impact on resources, although they will be balanced out by long-term health benefits and potential care savings"* (NICE, 2023: 52). As NICE's guidance is not mandatory, only time will tell if this leads to service improvements, especially as ILASS (2023:6) also states that *"Stroke key worker capacity may be different depending on the model of service delivery"* and *"Other workforce roles (e.g. primary care practitioners) required to deliver aspects of the model will need to be locally defined."* Although this is well intended, there is a danger that this could lead to a continuation of the current 'piecemeal' approach to SR and VR.

An analysis of stroke specific VR provision by Sinclair, Radford, Grant and Terry (2014: 412) revealed the enormous range of service providers used in just one English county, in a helpful diagram and concerns about lack of training and awareness of best practice guidelines were also raised under the implications for rehabilitation. In addition, they reported that "*the lack of a sanctioned pathway results in disorganised and patchy provision of VR for stroke survivors"* (2014:409).

A common misconception in VR and SR, referred to in Culler et al.'s (2015) paper, and noted earlier, is that:

"*Most stroke-survivors have completed their education, have a clear career path, and may have been working for years"* (2011: 332). The assumption is that their 'career' maturity means they do not need life-career counselling. However, this stance fails to acknowledge the profound impact of the stroke on their self-awareness, despite the fact that Liaset et al. (2016:449) correctly state that *“brain injury can be linked to the key concept”.* Their meta synthesis demonstrated the importance of self-awareness in relation to RTW, and my data demonstrated that it is pivotal and therefore of greater importance than confidence and motivation, which are frequently cited in VR literature, for instance, Waddell, Burton et al. (2008: 51). My own study goes further in also relating self-awareness to sustaining paid work and the importance of utilising a broader conception of ‘work’ and ‘career’. It also recommends incorporating life-career self-management by using life-career counsellors as support for stroke-survivors in the life-long SR process. I now explain my vision of how that could work.

Type of intervention needed

The biographic narrative interpretative method (BNIM) methodology in this study was deliberately chosen because it approximates the first stage of the life-career counselling process, which involves listening to the client’s narrative. I have included a diagram of the stages of life-career counselling in figure 10.1, to clarify the purpose of that stage within the whole process.

It will be crucial to select career counsellors experienced in using a narrative approach that supports stroke-survivors’ enablement in society, rather than working with organisations like Job Centre Plus, who use an approach based on matching theory where advisors diagnose occupational fit in order to meet work related targets, as evidenced in BSRM 2021: 29.

Playford et al.’s (2011:39) recommendation that “*money should follow the individual so they can receive interventions from where they choose, be it NHS, Jobcentre plus, independent or voluntary sector*” supports the use of independent practitioners. While I welcome the idea that stroke-survivors should be funded to make choices, I think the timing of this funding is crucial. Expecting stroke-survivors recovering from the ‘trauma’ of a stroke to manage a budget and make informed choices would be a step too far for many in ‘*Before.*’ Stroke-survivors with cognitive disabilities could also find this particularly challenging as decision making can be impaired by stroke (Marinho et al., 2019). Furthermore, three of the stroke-survivors interviewed experienced mental health challenges during '*Before'* and so were not in a good position to make significant life decisions.

Timing intervention

In life-career management, it is considered unwise to take major life decisions in the immediate aftermath of a 'trauma'. However, I think stroke-survivors should receive some life-career counselling in the early days, to help give them and their families hope for the future. My recommendation would be that they should have access to an independent life-career counsellor, to listen to their story at the PABIR stage, before they begin to transition to their new normal. The life-career counsellor should listen to their hospital story and be tasked with conveying the message about the inadvisability of making life-career decisions straight after a stroke and provide reassurance for stroke-survivors and their families that the stroke-survivors will be supported in rebuilding their life-careers at appropriate points in their recovery.

Although Radford et al.'s (2022:9) approach is intended to provide intervention at the right stage, there is no opportunity for the stroke-survivors to be listened to. The process is still heavily dominated by rehabilitation 'experts,' leaving little to no inclusion of stroke-survivors' voices till the end of the intervention period, when the opportunity to participate in interviews is limited by the use of a topic guide. Listening to their hospital experience would acknowledge the sense in their experience and avoid them losing hope. As Frosh (2007:637) states: "*they would benefit from being able to speak their stories and have them reflected back in a way that enables them to be owned".* In short, they would feel empowered at an early stage and later receive the appropriate guidance needed to help them progress their life-careers when they have developed readiness[33].

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[33] Savickas (2005:49) perceived readiness to be a core part of career adaptability: "*a psychosocial construct that denotes an individual's* ***readiness*** *and resources for coping with vocational development tasks, occupational transitions and personal traumas".*

All of the stroke-survivors I interviewed chose to share their hospital experiences, although they were largely contextual to the research and so not all were included in the results. Nevertheless, most of the stroke-survivors commented on how valuable they found sharing their whole recovery story. Philip also attributed the way in which I had asked questions to being significant in helping his memory to return (see '*Beyond'*).

I now provide detail of what a life-career counselling session involves, drawing on my own experience and the Ali-Graham counselling approach to career guidance, which is used by the Association of Graduate Career Advisory Services (AGCAS) to train Higher Education (HE) career counsellors. I will then summarise the main differences between this and the BNIM interviewing approach.

Figure 10.1: The Life-career counselling approach to Career Guidance (a narrative approach)

(From Ali and Graham, 1996, adapted and redrawn by Carol Wilson, 2021). Source: Personal Collection.

As can be seen from Figure 10.1, this approach has four main stages, which I outline below:

CLARIFYING

During this phase, the stroke-survivor will be told what they can expect from the counselling process and the time frame for the interview. Confidentiality will also be explained, and the counsellor will begin to develop empathy. The counsellor will then invite the stroke-survivor to tell their story, and thereby identify any factors that are important to them, encouraging them to start where they like.

Hearing the stroke-survivors' story

Both life-career counselling and BNIM interviewing begin by encouraging the stroke-survivor to share their story. Both processes use active listening skills, (including observation of body language and listening to silence), paraphrasing and summarising. However, in life-career counselling a balance has to be struck between encouraging the telling of the story and focusing on important issues. In the BNIM research process, the first interview is used to listen to the stroke-survivors' story without interruption and subsequent interviews are used to explore aspects of the story in more detail. However, in life- career counselling, the counsellor would follow up by helping the stroke-survivor to separate the details of the story from the messages contained in it, as described next.

Making an initial assessment

As the stroke-survivor tells their story, the counsellor (she) would assess the 'issues' within it, checking she has fully understood by paraphrasing and summarising what the stroke-survivor has told her. She will be internally noting any beliefs and attitudes that might need challenging at a later stage in the counselling process. An important part of the initial assessment is to explore the stroke-survivors' self-awareness, the source and accuracy of their job knowledge, the extent of their decision making and the level and development of their transition skills. As mentioned in '*CSM*', the latter should include networking as well as traditional job application skills. The life-career counsellor's assessment of all these elements should facilitate the clarification of issues which require exploration. This is the point at which inconsistencies in what the stroke-survivor is saying, doing or believing could become apparent. The life-career counsellor's task is to record these internally in order to challenge and hopefully resolve them at a later stage.

EXPLORING

The life-career counsellor will agree with the stroke-survivor how they can realistically use the time available for one or a series of meetings. The life-career counsellor will then clarify expectations and identify the key issues and priorities, which may not necessarily have been expressed by the stroke-survivor, who may be encouraged to explore other options if, for example, their goals are unrealistic. Understanding the expectations each person has of the other, forms the basis of the contracting process, which is crucial to building trust for this and subsequent interviews. Summarising is key to contract forming as it helps the stroke-survivor see where and how the interview is progressing, and it is important that the stroke-survivor makes the contract their own. The life-career counsellor will model for the stroke-survivor, by clarifying the issues in precise language, encouraging the stroke-survivor to do the same.

Sometimes a key issue emerges late into the interview and the contract will need to be re-negotiated at that point, which will involve inserting a mini version of the counselling model (see figure 10.1) into the process. This is because the stroke-survivor may want to wait until the empathy is strong and trust and understanding are in place before raising a key issue. The life-career counsellor will also clarify and explore the newly introduced issue, evaluate its priority and help plan the action to deal with it within the interview process. This demonstrates that he/she understands the complexity of what the stroke-survivor has experienced before moving towards a revised contract, which the stroke-survivor will be actively involved in negotiating.

EVALUATING

Enabling the stroke-survivor to weigh up the pros and cons for each option

At this stage the life-career counsellor will draw the stroke-survivors' attention to the connections she/he has made between what has been said and what the stroke-survivor does and believes at various points during the interview. Any inconsistencies will be gently challenged, to enable the stroke-survivor to gain new insight about themselves. This requires higher level skills like immediacy, judicious information giving and other interpretative skills, as the life-career counsellor is conveying his/her interpretation of the issues involved for the stroke-survivor. This can enable them to see their world in a new, realistic and ultimately more rewarding way, which could prove a turning point for them. Throughout this stage, the life-career counsellor is laying the groundwork for action planning.

ACTION PLANNING

As the stroke-survivor explores each option with the life-career counsellor, they will become aware of knowledge gaps. This can limit their ability to evaluate the options, as could disabilities like cognitive impairment. The life-career counsellor will aid evaluation with strategies, such as challenging the source of opinions, which may be biased depending on their source. Different guidance tools may also be introduced to aid self or occupational knowledge, if required. This is the point at which stroke-survivors might potentially be guided towards work shadowing, work trials, training courses, volunteering and so forth. A key principle is that the stroke-survivor owns the action plan by being fully involved in its development, deciding which actions are appropriate and in what time frame.

The need to acquire more effective decision-making skills may become apparent as the level of self and job knowledge is revealed. Some indication will be gleaned by understanding how the stroke-survivor made decisions in the past. Previous difficulties could leave them feeling stuck, in which case the life-career counsellor will acknowledge the strength of their feelings and offer support. If they are not ready to come to terms with their feelings, for example fear, no amount of skilled challenging will move them forwards, and in fact risks the working relationship deteriorating and the stroke-survivor resisting the support being offered. Exploring the root cause of their feelings through an open question about them might be helpful and begin to resolve the issue. At a minimum, empathy will be retained in the relationship. It is important to bear in mind that while the life-career counsellor develops the process of the interview, the stroke-survivor dictates the pace as this is a person-centred intervention.

The life-career counsellor’s task is to help the stroke-survivor identify what needs to be done, to encourage them to develop a systematic plan of action, to introduce the concept of referral (to other SR/VR services), if necessary, and to complete the interview.

It is important to remember that life-career choice is a process and that the interview is an intervention to enable that process. Therefore, if a major issue arises part way through the interview, requiring the contract to be re-negotiated, the remaining time will be used to work on that issue, which becomes part of the overall development process. Action planning could then involve a referral to another practitioner, enabling the issue to be addressed in greater depth, before life-career decisions are made. The stroke-survivor might then simply identify their next step to meet with the professional they are referred to and undertake any required preparation. There is little point attempting to develop a long-term career strategy if, for example, the stroke-survivor is concerned with deteriorating family relationships or issues regarding receiving benefits or a pension. The stroke-survivor would then be encouraged to contact the life-career counsellor again when they are ready to move on.

The strategies described are drawn from my own life-career counselling experience, with reference to the Ali-Graham (1976) counselling approach to career guidance (Figure 10.1).

Each counsellor-client relationship is unique, and a skilled life-career counsellor will have learned through experience how to integrate counselling skills into the guidance model. Additionally, many have experience of working with disabled clients and those with mental health challenges.

The Ali-Graham career counselling model and approach has been used here to illustrate the fact that it is a narrative approach, which has the potential to focus on aspects of the stroke-survivors’ past, present and future that they consider important. I finish by highlighting further differences between the Ali-Graham model and approach and the BNIM interview method. I hope that the detailed interview format provided will allow all stakeholders to appreciate crucial differences between a narrative approach and the current Job Centre Plus matching approach. In particular, the way the stroke-survivor would be empowered to set their own goals in line with their readiness to progress, how the counsellor uses transparency and gentle challenging, to raise awareness of key issues and how referrals to other services would be made to facilitate a teamwork approach.

The process of gently probing the narrative and any associated emotions (latent or otherwise) is an important part of the first three stages of life-career counselling. The whole process is illustrated in Figure 10.1. However, the differences between BNIM interviewing and the life-career counselling process are the parameters of the interviewing process in research. With respect to expectations, the time frame for BNIM interviews and issues like confidentiality are set out through the information sheets, letters and consent forms in advance of the interviews, with reminders as appropriate during the interviewing process. In life-career counselling, these matters are addressed during the first (clarifying stage) of each interview and ongoingly, as required.

To allow trust and empathy to build between the stroke-survivor and myself, in the BNIM interview process sensitive matters were often shared or probed by myself, in the second or third interviews. For example, how the stroke had impacted on family relationships.

In BNIM the first interview promises non-interruption, in other words active listening, akin to the first stage of the Ali-Graham model. BNIM then continues with a focus on the stroke-survivors' words, which are used to structure successive interviews and facilitate clarification and exploration. Where appropriate, I used guidance skills, as described earlier, in the third interview session to enable me to clarify and fully explore the stroke-survivors' stories, by inviting them to provide further details/examples using the BNIM magic formula (see Appendix I). I was able to do this because the third session in BNIM is optional and structured in the way the interviewer chooses. The second and third interview sessions were when the stroke-survivor really opened up due to trust and empathy having built by that point.

The main differences between the two processes is that BNIM stops short of action planning, and therapy was not promised to the stroke-survivor, as it is a research process and so not designed to be therapeutic, although some of the stroke-survivors reported experiencing this. However, the BNIM interview process did facilitate stroke-survivor' reflection, as evidenced in earlier chapters.

Listening to the stroke-survivors' hospital experience and story of returning to their new normal shortly after leaving hospital would give stroke-survivors experience of life-careers counselling practices, which relatively few of them are likely to have had. They would then be better equipped to make informed choices and spend funding later, at a time when they had developed sufficient self-awareness and confidence, either to fully achieve their potential and/or embrace a wider conception of career. This would require independent life-career counsellors to be employed as part of SR/VR teams.

Ellis-Hill, Payne and Ward (2008:11) additionally noted that *"complex cultural changes"* were "*necessary for successful implementation*" of therapeutic practices that enable a more "*client-centred*" (2008:157) way of working. Radford et al. (2022) are now attempting to move in the right direction with the RAISE project, but as already discussed this needs to go further.

It is my sincere hope that my research helps to bridge the gap between recommendations and reality, by improving understanding of "*the discursive and material ways in which people approach life transitions following acquired disability"* (Ellis-Hill, Payne and Ward, 2008:157). I have also addressed the subsidiary aim of this research by suggesting how a narrative practice could be incorporated into a Stroke self-management programme. Since the Handbook to the NHS Constitution (2022) states that *"service improvement is dependent on feedback",* I now finish by summarising this study's recommendations and identify the individuals and organisations they are appropriate for:

Summary of recommendations in priority order

1. That the World Health organisation (WHO), British Standards for Rehabilitation Services (BSRM), National Institute for Care Excellence (NICE), Stroke Association (SA) and the

Vocational Rehabilitation Association (VRA) agree to adopt the same broad definition of life-career and the meaning of 'work' within a life-career. Unreliable RTW statistics and poor stroke-survivor' work retention rates will remain an issue forever whilst inter-agency guidelines continue to be written by the VRA, who represent the Department for Work and Pensions and therefore aim to "*maximise participation in the workforce*"[34]. This is why some Vocational Rehabilitation (VR) specialists are restricted by "*policy imperative*" (Radford et al., 2020:2). A suitably broad definition of life-career, which reflected the range of meanings the stroke-survivors in this study attached to 'work' and their life-careers at different transition points, was defined by Super as:

> *"The course of events which constitute a life; the sequence of occupations and other life roles which combine to express one's commitment to work in his or her total pattern of self-development; the series of renumerated and non-renumerated positions occupied by a person from adolescence through retirement, of which occupation is only one, includes work related roles such as those of student, employee, and pensioner together with complementary avocational, familial, and civic roles. Careers exist only as people pursue them; they are person centred."*
>
> (Super, 1976, in Chen, 1998:438)

2. That all SR/VR teams for stroke-survivors include independent life-career counsellors, trained in narrative methods.
3. That SR/VR teams utilise life-career counsellors to offer stroke-survivors lifelong support in their life-careers and that that the life-career counsellor be tasked with conveying the message to stroke-survivors and their families about the inadvisability of making life-career decisions straight after a stroke.

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[34] https://vrassociationuk.com/about/ (2023)

4. That stroke-survivors are individually funded to access that support when needed, once they return to their communities, as previously recommended by Playford et al.'s (2011:39) research.
5. That respective governments put sufficient funding in place to make recommendations 3,4 and 5 a realistic possibility, thereby supporting SR/VR Teams' ability to deliver lifelong services.
6. That "*narrowly conceived outcome measures*" (Watts, 2006:15) be abandoned in favour of addressing the needs identified by individual stroke-survivors in action planning with life-career counsellors.
7. That PABIR focuses on stroke-survivors' overall commitment to 'work', rather than a speedy RTW, with a life-career counselling session being offered to stroke-survivors before discharge, so that they can both share their hospital story and develop an understanding of the type of life-career support that they can access later in their communities.
8. That future qualitative research examines how incorporating a narrative based life-career intervention into SR/VR helps stroke-survivors move their life-careers forward.

11. Dissemination

Introduction

Dissemination will happen through conference attendance, academic journal publications, the publication of a book and by contributing my knowledge, expertise and the research findings to the development of a stroke self-management programme (SSMP). I have outlined the timeframe for these plans below:

Dissemination that has already occurred

The research was presented at the UK Stroke Forum in 2022 (see the e-poster produced for the forum in Appendix V) and as a consequence the abstract that was also produced for this forum was published in the International Journal of Stroke, 2023(18):103.

Short term plans

Further to this, additional publications in academic journals are planned. Three papers are currently in process. The first paper is about stroke-survivors' identity transitions and the plan is to publish that in Rehabilitation and Society, Disability and Society and/or Disability and Rehabilitation.

A second paper is planned to share the research findings with stroke-survivors. This could be potentially published in Stroke News and/ or the Different Strokes' newsletter.

The third paper is about the pluralistic methodology used in the study and the way that was tailored to stroke-survivors' needs. I am interested in getting that published in Health and/or the International Journal of Stroke.

Medium term plans

I would like to write and publish a book based on my thesis so that I can access a wide audience of stroke-survivors. In addition, I plan to create a web space or social media platform where my research can be accessed by stroke-survivors and I can refer them to charities who support the disabled.

Long term plans

I would most like to contribute my knowledge, expertise and research findings to the development of a SSMP and I would be particularly interested in talking to the Bridges Team about whether we could co-produce aspects of that.

Conclusion

My preferred route to dissemination, is to move beyond academic journals so that my research makes a real difference to stroke-survivors and SR/VR professionals across the world. With that in mind, I am interested in sharing my findings with charities that support the disabled and/or social enterprises. I have the Snowden Trust, Bridges and the Brain and Spine Foundation in mind for that.

However, publication in journals does set the agenda for future research, increasing the chance of that research examining whether incorporating a narrative based life-career intervention into SR/VR helps stroke-survivors move their life-careers forward (recommendation 8).

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12: Appendices

Appendix I: ethics process information

Ethics approval letter

17/07/2018

Dear Carol

PI: Carol Wilson
Title: How stroke survivors self-manage their transitions to an ordinary life after stroke
Ref: ERP1368

Thank you for submitting your application for review. As you are aware, the revisions that were made to your application were reviewed by a different Ethical Review Panel that reviewed your original application. The role of this panel therefore, was to ensure that the revisions stipulated by the original Ethical Review Panel had been completed. The Ethical Review Panel that reviewed the revisions are satisfied that this has been done, so I am pleased to inform you that your application has been approved by the Ethics Review Panel.

If the fieldwork goes beyond the date stated in your application, or there are any amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.governance@keele.ac.uk. This form is available via https://www.keele.ac.uk/raise/researchsupport/projectassurance/researchethics/

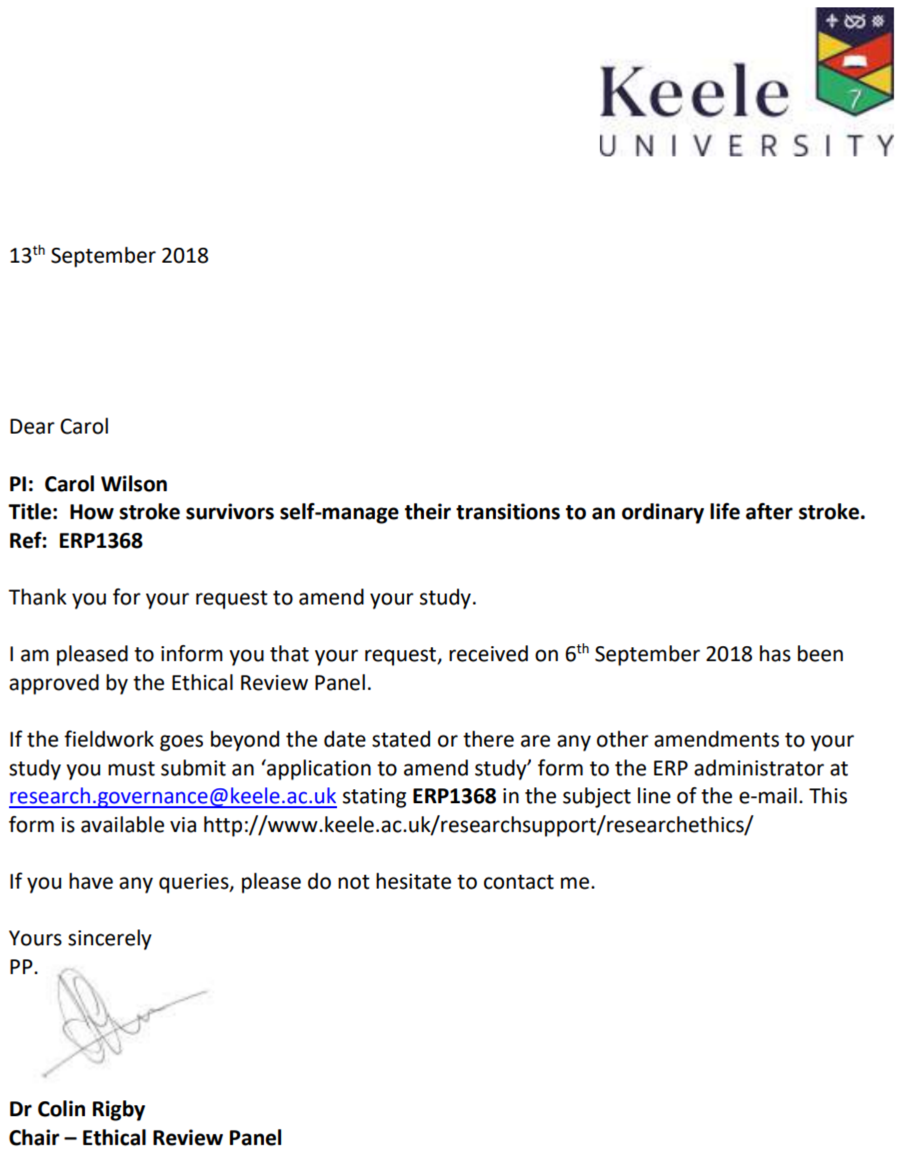
If you have any queries please do not hesitate to contact me, in writing, via the ERP administrator, at research.governance@keele.ac.uk stating **ERP1368** in the subject line of the e-mail.

Yours sincerely
PP.

R. Cunningham

Dr Colin Rigby
Chair – Ethical Review Panel

Ethical amendment approval letter



Keele
UNIVERSITY

13th September 2018

Dear Carol

PI: Carol Wilson
Title: How stroke survivors self-manage their transitions to an ordinary life after stroke.
Ref: ERP1368

Thank you for your request to amend your study.

I am pleased to inform you that your request, received on 6th September 2018 has been approved by the Ethical Review Panel.

If the fieldwork goes beyond the date stated or there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.governance@keele.ac.uk stating **ERP1368** 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.

Yours sincerely
PP.

Dr Colin Rigby
Chair – Ethical Review Panel

Consent form

CONSENT FORM.

Title of Project: How stroke survivors self-manage their transitions to an ordinary life after stroke.

Name a principal investigator: Mrs CT Wilson. E-mail: c.t.wilson@keele.ac.uk

Please tick box if you agree with the statement

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw my data from the study up to 4 weeks after Session 3. ☐

3. I agree to take part in the study. ☐

4. I understand that data collected about me during the study will be anonymized before it is submitted for publication. ☐

5. I agree to my story and subsequent interview/narrative sharing sessions being audio recorded. ☐

________________________	________________________	____________________________
Name of participant	Date	Signature
________________________	________________________	____________________________
Researcher	Date	Signature

Consent form (for use of quotes)

Keele
University

CONSENT FORM

(for use of quotes)

Title of Project: How stroke survivors self-manage their transitions to an ordinary life after stroke.

Name of principal investigator: Mrs CT Wilson.

Please tick box if you agree with the statement

I **agree** for any quotes to be used. ☐

________________________ ____________ ______________________________

Name of participant Date Signature

________________________ ____________ ______________________________

Researcher Date Signature

Keele
University

Information sheet

Study title: How stroke survivors self-manage their transitions to an ordinary life after stroke.

Aims of the research: to provide information about the ways in which people return to ordinary life after stroke. Stroke rehabilitation research (Ellis Hill et al., 2008) indicates that this is not well understood. The unmet needs of stroke survivors may also be identified during this research.

Invitation: You are being invited to consider taking part in the research study: How stroke survivors self-manage their transitions to an ordinary life after stroke.

The project is being undertaken by a stroke survivor, Mrs Carol Wilson, as part of a Professional Doctorate in Education, at Keele University.

Before you decide whether or not you wish to take part, it is important to understand why this research is being done and what it will involve. Please take time to read this information carefully and you are strongly encouraged to discuss it with people in your support network, such as family members or close friends. Please get in touch with me if there is anything that is unclear, or if you would like more information, by emailing: c.t.wilson@keele.ac.uk

Why have I been invited?

I am contacting stroke survivors, whom it has been suggested, by the stroke survivor interviewed for the research trial, might meet the following eligibility criteria:

- Major strokes survivors with both physical and cognitive impairments;
- male or female, aged between 31 and 65;
- able to speak and hear enough to share their story and answer questions about it;
- stroke survivors who have or had a professional/business role.

I am interested in hearing from stroke survivors who have experience of **one or more** of these categories:

- Returned to their former work role;
- changed career direction;
- taken the decision not to return to work;
- been forced into early retirement or redundancy.

Do I have to take part?

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for my records. These will be emailed to you well in advance of the first interview. You are free to withdraw your data from the study at any time up to four weeks after Session Three. You can also withdraw your participation in the narrative sharing/interview process, if you are feeling uncomfortable with it, or you could choose to take a break, if you feel that you are getting too tired.

What happens if I take part?

This will involve meeting Carol virtually, using a video conferencing facility called Google Meet. You will be asked to share what happened after your stroke, when you tried to return to an ordinary life. This will be over three sessions, the first of about 30-40 minutes. The second, after a break, will be longer - lasting up to 90 minutes, but again with breaks when required. A third session will be arranged for a four weeks later, lasting up to 90 minutes, with breaks when required. I will share transcripts of the first two sessions with you before this third session. The procedure is set out in more detail below. You will be able to talk to me each time in your own home. You will need either a computer or smart phone to use Google Meet, instructions are attached to this information sheet and should you have any technical queries please contact me in advance of the interview/s on c.t.wilson@keele.ac.uk and I will endeavour to resolve them.

If I take part, what do I have to do?

You will be asked to share your story with me. After a short tea/coffee break, I will then ask you some follow-up questions, to ensure that I understand your story.

After transcribing these first two sessions, I will then ask you some follow-up questions, to ensure that I fully understand your story. After transcribing these first two sessions, I may have some further questions. I will arrange a follow-on interview with you. This will be a few weeks after the first two sessions.

What are the benefits (if any) of taking part?

You will have an opportunity to express your views and think through your own position, in depth and possibly from a new viewpoint.

You will also be contributing to current stroke rehabilitation research which has the potential to influence and improve programmes of stroke rehabilitation and career management for stroke survivors.

What are the risks of taking part?

A potential risk for stroke survivors is fatigue. To minimise this, regular breaks will be taken. You will need to allow **6 ½ hours for the whole narrative sharing/interview process, although if you need more or longer breaks, this will take longer** (see below for outline of the suggested interview timescale). The process has been broken down into three separate sections, which will be scheduled around your needs. Within this time frame, I have allowed an hour for any questions you may have prior to the interview and afterwards.

Interview procedure:

Questions:

A chance to discuss what giving consent to be interviewed means and any practicalities with me (up to 30 mins)

Session 1: Your story

You have control over the timing of your story, within a **30 to 40-minute maximum** time frame. Carol will listen to this without interruption and you are free to decide where it begins and ends.

Session 2: Follow up Questions and Debriefing with tea/coffee (Suggested time – up to 90 minutes).

Re-visiting the past can bring uncomfortable emotions to the surface. However, you are free to take a break, or withdraw participation from the narrative sharing/interview process at any time, if you are feeling uncomfortable with it. You can also choose to withdraw your data from the study up to four weeks after Session three. I will check on your well-being before you leave and signpost you to a support service, if you feel in need of further support.

Session 3: further clarification.

This will be arranged through a further face-to-face meeting, **normally within four weeks after session 2**, once transcriptions have been completed. I will be in touch regarding timing, once I have completed the transcripts for sessions 1 and 2.

Where will the research take place?

The research will take place in your own home. It is a good idea to choose a quiet, pet free room and to make family members/carers aware of the interview times and politely ask them not to interrupt the process. They will have an opportunity to talk to you during the breaks, if needed. It would also be helpful to switch off your phone, so that you and Carol can fully concentrate.

How will information about me be used?

The data will be transcribed and used to form the basis of research into how stroke survivors manage their return to an ordinary life. The data will be used for the final research study.

Your details will be anonymised in all publications and presentations.

Who will have access to information about me?

Although you will be able to see Carol, she will only be audio recording the interviews, **not video recording.** The audio-recorded data and subsequent transcripts will be kept securely, on a password protected computer. Carol's supervisors will be given access, as part of your consent.

I will access transcripts through my secure home computer in order to use voice recognition software when I review and analyse the narrative.

I have to work within the confines of current legislation over such matters as privacy and confidentiality, data protection and human rights and so offers of confidentiality may sometimes be overridden by law. For example, in circumstances whereby I am made aware of future criminal activity, abuse, either to yourself or another, or suicidal tendencies. I must pass this information to the relevant authorities.

Who is funding and organising the research?

I am organising the research. I am partly self-funded and partly funded by the Snowdon Trust, a charity that assists disabled people to access vocational and academic courses in the UK by awarding grants: https://www.snowdontrust.org (Accessed 13.12.16.)

What if there is a problem?

If you have a concern about any aspect of the study, you may wish to speak to the researcher who will do their best to answer your questions. You should contact me on c.t.wilson@keele.ac.uk Alternatively, if you would prefer, you may contact Doctor Samantha Weston on s.k.weston@keele.ac.uk

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way you have been approached or treated during the course of the study please write to the Research Integrity Team, who are the universities contact for complaints regarding research at the following address:

Research Integrity Team
Directorate of Research, Innovation and Engagement
IC2 Building, Keele University, ST5 5NE

Email: research.governance@keele.ac.uk

Tel: 01782 733371

Contact for further information:

Mrs CT Wilson

Claus Moser Research Centre

Keele University

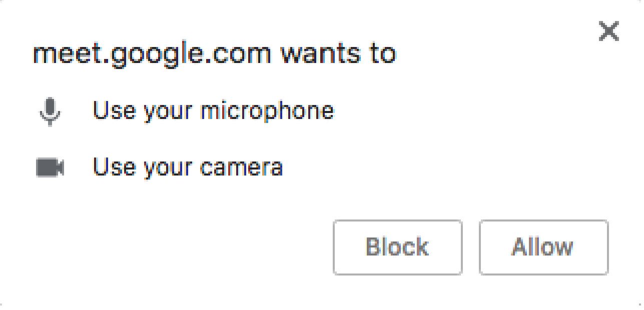
Keele, Newcastle ST5 5BG

Email: c.t.wilson@keele.ac.uk

Joining a Google Meet call

1. Open the URL provided for the interview (https://meet.google.com/xcz-etdu-ukc) at the agreed start time. It is recommended that you use Google Chrome and have a microphone or webcam to take part. If you are using a tablet or smartphone, using this URL will instruct you to download the Google Meet app.

2. It is likely that your web browser will ask permission to use your microphone and/or camera. Click **Allow**.

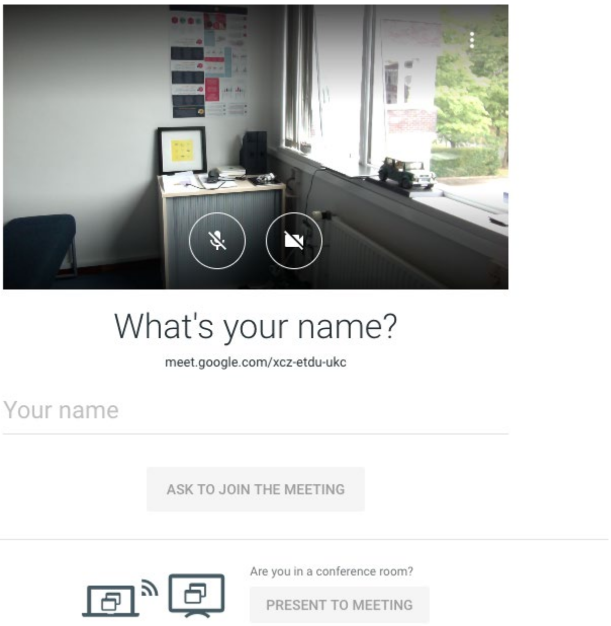


meet.google.com wants to

Use your microphone

Use your camera

3. If you are not signed in with a Google account, you will be asked to provide your name before pressing **Ask to Join the Meeting**.

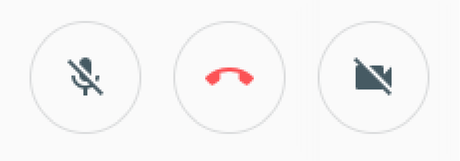


What's your name?

meet.google.com/xcz-etdu-ukc

Are you in a conference room?

4. Once the interviewer has accepted your request, you will join the Google Meet room. You can turn your microphone on or off or leave the call at any point by using the controls at the bottom of your browser window.



If you decide to withdraw from the discussion during the interview, please let the interviewer know prior to withdrawing, otherwise she will think you are having technical difficulties.

Appendix II: BNIM Sole Question aimed at inducing narrative (SQUIN) for first interview and BNIM magic formula

SQUIN

As you know I'm researching how stroke survivors manage to return to an ordinary life after stroke. Can you tell me about managing to return to an ordinary life after your stroke; all the events and experiences that were important to you. Begin wherever you like. Please take the time you need.

We've got 30-40 minutes. I'll tell you, if you are running out of time, but won't otherwise interrupt. I'll just takes some notes in case I have any further questions after you've finished telling me about it all. Ok. So, can you please tell me your story, all the events and experiences that were personally important to you? Start wherever you like.

Magic formula used by interviewer to compose questions in second and third BNIM interviews

You said… (words/phrase selected from previous interview).

Do you remember any particular time/situation/occasion/incident (select as appropriate) particularly strongly?

How it all happened?

Appendix III: case studies and final reduced table of themes

Summary of Brian's story

After a cycling accident on his way to work led to Brian having a hemiplegic stroke, he pushed himself to return to a new role he was promoted too just prior to his stroke. Due to the "*very, very ambitious environment that I worked in with very, very challenging targets to hit*" (Session 2, RTW pin, 47) and misinterpretation of his "*physical self and my response, in terms of my verbal activity, which was interpreted as this loss of intellect[pause] loss of ability and capacity*"(Session 2, RTW pin, 47) he was 'bullied' by his Principal and eventually suffered two emotional breakdowns, the second of which led to him being pushed into involuntary retirement.

At this stage he was uncertain about the future and lacking self-awareness about his condition but being a *"pragmatic activist"* (Changes pin, 101-106) he had a high level of opportunity awareness and the motivation to learn more about his condition in order to recover. Through taking up the opportunity to participate in a 'roller skating' trial, he began to learn more about his condition and the professional relationship he formed with a physiotherapist helped him to begin to recover psychologically. This led to further opportunities in stroke research and through his participation, he both developed a new understanding of the concept of career and honed his career self-management skills. In doing so, he made a number of transitions and learned to self-manage his own recovery. As a consequence, he created a new role for himself and developed ambition in retirement.

His key transitions are role transitions from a teacher, senior manager and father, who needed to work to support his sons, to a Stroke Ambassador and retired father, whose family are now settled with lives of their own. Through making these role transitions he became comfortable with the idea of living with future uncertainty and now finds the prospect "*exciting*" (Session 3, Q3, 67).

Themes	**Reference**	**Quote**
Transitions		
Future uncertainty	Session 1, 68	*"I didn't know what my future would hold".*
Future certainty	Session 3, Q3, 67	*"It's turned into something which is quite exciting".*
Mismanagement of recovery	Session 1, 106-109	*"I gradually increased my hours at work and by September[pause]2007, I'd actually got myself to full time".*
Self-management of recovery	RS Trial, 161-162	*"I started to [pause] self-assess myself. In terms of how I could control what was wrong with me, through that voluntary role".*
Allegations of incompetence	Session 2, RTW pin, 47	*"I think it was the interpretation of my [pause] physical self and my response, in terms of my verbal activity, which was interpreted as this loss of intellect [pause] loss of ability and capacity".*
Competence	Session 3, Q3, 49	*"Now I feel confident enough, and competent enough, in order to be able to contribute [pause] to those trials".*
Lacking awareness	Session 3, Holiday pin, line 53-55	*"It seemed to be [pause] all, as it had always been, with a little bit of, obviously err difference with me, not being able to be as quick as I used to be".*
Self-awareness	Session 2, RTW pin, 67-69	*"I was in this [pause] vicious circle: The worst I appeared to be physically and, in terms of my communication skills, the greater the isolation [pause]I had".*
Loss	Session 2 Hospital pin, 154-156	*"To be erm [pause] financially and emotionally erm [pause] secure and physically fit and healthy [pause]to be suddenly faced with all of that [pause] taken away. It was terrifying".*
Survivorship	Session 3, Q5, 32	*"You have to exclude everybody else and everything else, in order to achieve what you want to achieve".*

Freedom of choice (voluntary transitions)	Session 1, 267	*"I've got so many choices now; I don't know what to do with them".*
No choice (involuntary transition)	Session 1, 113	*"I was being pressurised to take early retirement on health ground, which I didn't want to do, because I was only 47".*
Identity: Teacher and Senior Manager	Session 1, 20	*"I was a teacher and senior manager at the sixth form college, Sheffield [pause] and I [pause] taught Biology, Psychology and [pause] Sport Science [pause] at 'A' level. And some other vocational courses at [pause] both higher and intermediate levels, erm [pause]".*
Identity: Stroke Ambassador	Session 1, 175-177	*"And by 2010, I'd applied to join the National Stroke Research Network and [pause] Lay Forum, which was headed up by Professor Helen Rogers in Newcastle. I was appointed to the Rehabilitation Clinical Studies group, erm in 2012, and that's when I suddenly started to be noticed on a national level, in terms of my capabilities".*
Understanding the concept of career pre-stroke	Session 3, PhD, 27	*"I still associated higher intellect, erm, err, intelligence, with [pause] exam performance. You know, that's what you present, on your CV".*
Developing a new understanding of career	Session 3, Changes pin, 136-137	*"And then, when I had to retire, I didn't really think, I'd be interested in a career per se".*
Career Self- management v		
Victim at work	Session 2, Hospital pin, 445	*"Now that was bullying behaviour, but I was so lacking in self-esteem and, confidence, I couldn't see it".*
EG. Decision making skills	Session 3, Changes pin, 141	*"I've now time, perhaps, to reappraise [pause] what I'd like to achieve".*
EG. Motivation	Session 2, RTW, 58-59	*I had three sons [pause] who were my motivation really".*

EG. Networking skills	Session 2, Hospital pin, 261-263	*"So, it's because of going to that seminar, at that time and that moment, that suddenly set off a ripple effect, which has carried on going to destinations I'd never have thought possible".*
EG. Opportunity aware	Session 1, 266	*"I'll just have to see if the right opportunity comes up".*
EG. Ambition	Session 1, 263-264	*"It's given me again, another [pause] ambition. I quite fancy being a patient representative, as a non-executive director[pause] on an NHS trust".*
EG. Self-awareness	Session 3, Changes pin, 101-106	*"As, I was going for more senior posts, I would have to have, psychometric assessments, and always came out as a pragmatic activist. Now, I actually understand [pause] more what that means".*
EG. Transition skills	Changes pin, 133	*"I'd learn more and could do more".*

Summary of Susan's story

Prior to her stroke, Susan was made redundant from her role as a Senior Manager in Housing Services. Her view of career is typical of that time:

> "*People stayed with their employers for 30/40 years [pause] whereas [pause] young people move around a lot. It's very different, isn't it*"?
>
> (Session 3, p2, 566)

As a committed Christian since her teens, she also saw her work as a vocation; that she had been *"privileged*" (Session 1, 32) to serve others and was engaged by a former colleague in Social Services after being made redundant from Housing Services. She described her new role in providing emergency housing as:

> "*Fairly relentless, day after day, and I think it has an impact on you as a person and your family life and relationships".*
>
> (Session 3, part 1, 148)

Six months later she had passed her probationary period and in the seventh month suffered a major stroke.

After a couple of weeks in hospital, she was transferred to a stroke unit where her recovery began. She was keen to make progress in order to return home in time to support her only daughter's transition to university. She described the transition to her home life as: "*When the hard work started"* (Session 3, p1, 138) and she also pushed herself to return to work before the colleague who had appointed her moved into the private sector.

Although she managed to return on a phased basis with IT and ergonomic support from her employer, in retrospect she realised she did this too quickly. She had not realised how stressful she would now find working in a busy office, where:

> "T*here was so much going on around me, that I found it really, really difficult to concentrate on [pause] the tasks I had to concentrate on*".
>
> (Session 1, 132-134)

After having to rescind her driving licence, she was chauffeured to meetings across the county by colleagues and she "*began to pick up the pieces*", gradually increasing her hours before things "*came to a head"* (Session 1, 138).

She had become very tired and on her way to a meeting suddenly experienced a panic attack, losing all sense of who she was and where she was going, despite the familiar surroundings. She subsequently experienced post stroke depression and went on sick leave. Although she once again tried to 'pick up the pieces,' she knew that she could not return to work because she could no longer rely on herself to do a good job: "*Somehow, I just knew that I couldn't*" (Session 1, 151-152) and she is understandably fearful of further ill health. Occupational Health assessed her and decided that she was too young to retire on ill health grounds. She was still under 50, so they believed that she might recover in time. While Susan accepted this and was grateful for the recovery she had made so far, it left her with an uncertain future. HR could not redeploy her, either within Social Services or the County Council. She described this as a "*blow beyond a blow*" (Session 1, 173) because "*the loss of my health was one thing, but the loss of my career; all that I valued at that time, what I saw as a vocation, the value of the work, my identity just "disappeared overnight*" (Session 1, 175). As a result, she felt worthless and when she realised that she was "f*inished*", she eventually began to look for jobs in the voluntary sector, on a substantially lower salary.

Her circumstances suddenly changed after Susan and her husband decided to take in a mutual friend with muscular dystrophy who was about to be discharged from hospital. As the friend was in a wheelchair, they moved home to accommodate her needs, making a number of personal sacrifices to do so within a tight timeframe. Initially she helped her friend with her ministry, as she had been exploring priesthood prior to her own stroke. In time, she became one of her friend's carers, managing her team of carers and attending to her needs on a part-time basis. This helped her to feel valued again. She also took on a seasonal invigilation role at a local university, through happenstance.

By the third interview, she had retired and felt that her career in housing had sort of been recognised by the fact that she is finally able to receive her pension at sixty. However, she justifiably remained angry at the way her former employer dismissed her without the opportunity to recognise her long service. However, she tried not to let this impact her life because she was wary of becoming consumed by anger, which she appreciated would be destructive for her.

She reflected that she had pieced together a new portfolio career that has left her feeling she still had a purpose in life. After being dismissed from her job, she looked for further opportunities to fulfil her Christian mission and so combined her happenstance roles with a voluntary role in the local library and also became Secretary at the stroke club (they supported her husband in the early post stroke days). As she let her past life go, she acknowledged that the 'psychological contract' with employers has changed and today: "*You are just a number*", but that it is possible to enjoy a career in 'retirement' as "*the shape*" (Session 2, 342) of it has now changed.

In summary, her excellent networks and strong sense of opportunity awareness, developed from her desire to find Christian missions and emotional support from her husband and friends, eventually enabled her to let go of her anger and move on with her life-career, which led to her adding several new Christian roles to a developing portfolio career: Spiritual Companion, mentor to spiritual companions and coordinator of Christian fellowship. As part of her new normal, she gradually resumed choir practice, yoga, walking and travelling. With the support of a friend, she was also eventually able to participate in Gilbert and Sullivan festivals once again. She loved the busyness of her life and through CBT learned to keep it in balance and manage her post-stroke fatigue and anxiety.

Themes	Reference	Quote
Transitions		
Involuntary transitions	*Involuntary* ” The redundancy in 2004 was horrendous”.	Session 1, line 51
	” I passed my probationary period without a day’s leave and then within the 7th month, Wham! In July 2005, I had a stroke. It was wow, life changing”.	Session 1, line 68-9
	“It was horrendous that I couldn’t take her and support her with that transition, that move to university”. (Loss of daughter)	Session 2, 144
	“But on the day, she went, it was like my insides being torn out, because erm, I should have been with her”.	Session 2, 152
	“So, we are now going through a real transition stage [pause] because Charles is home [pause] and I’ve been at home for ten years myself [pause] And it’s a big change”. (Husband’s retirement)	Session 2, 308-309
	“It’s so important, isn’t it, that you have that transition [pause] I never had that. I still haven’t had it”.	Session 2, 300-302
Voluntary transitions	“And then, the shape of my life changed when we invited a friend, who has muscular dystrophy, to come and share our home”.	Session 1, 271
	“Erm, ah, when I was; I was 60 in May, as that birthday	Session 1, 318-319

	approached, it was, it stuck, it represented for me, erm, such a, a momentous change to my situation because I was hitting this 60-age range and had access to my pension. And I was shocked by how it felt at the time, erm [pause]”	
	“There was this, this feeling that that was, at last that that was my contribution, to life; my working role was acknowledged, and it felt, it felt so, there was relief”.	Session 1, 331
	“A really important transition for me, was actually understanding how my new body and head post stroke was”.	Session 3, p2, 162
Not understanding her disabilities	“In terms of my energy levels, I just couldn’t see how I could combine that, and with the other parts of life that you have to get on with [pause] And do everything that was expected of me, by them, and probably more importantly by me”.	Session 3, p1, 207 & 209
Self-management of disabilities	“When you’re tired and something happens, your sense of perspective and ability to reason is distorted [pause] so I have to be careful of that”.	Session 2, 280-281
	“It’s tied up with a sense of value and this [pause] I’m not worth it, sort of thinking”.	Session 2, 283
	“It can be a debilitating, negative part of your characteristics [pause]when you push yourself too hard. It’s about recognising that”.	Session 2, 104
	“So, it’s about living this life of balance somehow”.	Session 3, p2, 164
Loss and suffering	“For a number of years, staff management responsibility, as well as the content of the job, working in some stressful situations, fires and emergencies, out of hours work I did as well”.	Session 3, p1,137

	"So, I think erm my health, my health, it took a toll on my health, without me, really realising that that was the case".	Session 3, p1, 138
	"I don't know if it was a panic attack, or how you would describe it, but I just, and it all sort of caved in on me".	Session 2, 196
	"And when you're down, down, down, it's very hard to come up from that baseline". (Post-stroke depression)	Session 1, 217
	"I was on the scrap heap".	Session 1, 180
	"Everybody always says to you 'What do you do for a living'? and I couldn't answer that question anymore".	Session 1, 185
	"I just knew that I felt like nobody, nowhere".	Session 1, 177
	"That for about 10 years plus, there was a, erm, oh, a resentment, a huge well of resentment in me, that I had been made to wait for something, erm, and I couldn't do anything about it". (Pension)	Session 3, 287
Surviving (Choice)	"And in the end my husband just said, 'you have to, you have to leave this, you have to move on with your life and not just think about what might have been".	Session 3, p1, 318
	"But it was a huge adjustment, huge"!	Session 3, p1, 320
Lack of choice	"I think I; I suppose I was fearful of what the impact might have on my health again". (RTW after post stroke depression)	Session 3, p1, 199
	"If I could have done anything about that I would have, there was no way that I wanted that to be how my working life ended".	Session 3, P1, 196
	"I think I missed the bus with that really, I think eh, yeah, I think [*pause]*. To be a priest in	Session 3, p1, 15-16

	this day it's, it's hard, its hard work and demanding and I don't, I think I'm at the wrong stage of my life now".	
Injustice (feeling devalued)	"It wasn't marked by anything, there was no card, no thank you, no collection, no leaving do, you know".	Session 2, 235
	"And it used to make me feel so angry and then you'd go down this ridiculous spiral of thinking, don't you"?	Session 2, 273
	"You know, he doesn't love me anymore and he's going to leave me on my own".	Session 2, 274
	"Where am I going to live"?	Session 2, 278
	"If I'd called him for his tea and I'd said, 'Your teas on the table' and he didn't come immediately [pause] I would get so upset with him. And say: 'this is all I can do".	Session 2, 268-270
Fulfilment (feeling valued)	"Not being measured s.., solely in terms of my working life and what I earned, you know, my career". (CBT)	Session 2, 260
	"I get referrals through the diocese of Lincoln so people in and around the area, and further afield, who want to talk with someone about their spiritual life, erm, their spiritual journey with God, or maybe their exploration of vocation".	Session 3, p1, 405
	"Err, and that was extraordinary because that really gave me a sense of purpose and a value".	Session 3, p2, 10
	"It's a voluntary role, it's not paid work, but that doesn't matter".	Session 3, p2, 11
Career		
Readiness	"It wasn't the content of the work, jobs, so much. It was more the expectations that, of any job, you know, that you attend regularly, you do a good job, you take your responsibilities seriously and I	Session 3, p1, 322- 323

	didn't think that I could do that".	
	"And I just didn't feel that I could take that risk, the risk of failing again, I think".	Session3, p1, 326
	"By perhaps trying again and failing and then that would do me even more harm".	Session 3, p1, 329
Motivation	"So, all of my adult life really, certainly as a student, and all my professional working life, I've been motivated strongly by my Christian values".	Session 3, p1, 113
	"I viewed it as a vocation. It's very, very recognised that Christians can have a sense of vocation in our working role".	Session 3, p1, 121
Networking skills	"It's mainly worship on a Sunday morning, but we also do things outside of that, like we have a group of non-students that meet together, oh, about once a month for fellowship and I, arrange that".	Session 3, p2, 127
	"And I was engaged by a former associate colleague of mine who worked for social services at Shropshire County Council".	Session 1, 58
Self-awareness	"I'm a very independent, sort of a strong-minded sort of a person and I'm not very good at letting others contribute to anything that I need".	
	"And that's a bit embarrassing you know, at the end of your working life to be dismissed for non-attendance, that's embarrassing".	Session 2, 422
Opportunity awareness (freedom of choice)		
	"I was desperate and eager, and any opportunity that I could have, I would take". (Rehabilitation)	Session 2, 69
	"I also do some, invigilation at Kingston university for exams and I enjoy doing that. It was really important to me, financially, for a few years, less	Session 2, 335-336

	so now I'm getting my pension".	
	"I sing in two choirs. I do amateur dramatics with my husband".	Session 2, 360-361
	"And we sing in the Gilbert and Sullivan festival once a year: fabulous"!	Session 2, 362
Decision making	"It was the, we, my husband and I were in full agreement, it wasn't just me, it was a full decision".	Session 2, 319
	"And that was in 2008 and we had to move house in order to accommodate her because she's in a wheelchair".	Session 2, 320
Changing concept of career	"So, I'm lucky that I've got this jigsaw of stuff, that's my life is now, all of which makes me feel good and makes me feel energised and well and the sense of value with that". (Portfolio career)	Session 3, p2, 112
	"I didn't plan it that way but that's how it's worked out". (Happenstance career)	Session 1, 277
	"So, I do a number of things, so, I don't feel retired. I can't say that I've retired because I haven't".	Session 2, 339-340

Summary of Katherine's (Katie's) story

After falling into a category 3 coma, following an aneurism, Katherine could not accept she has had a stroke, something she associated with being "*in a wheelchair and… sort of like grandad in the corner"* (Session 1, 23). She felt so estranged from her normal self, she adopted a new identity: Katie.

Through her battle to regain normality, she attempted to return to her work as a district judge and learned about the many barriers she now faced: "*everything now comes with an additional burden".* Despite an Access to Work assessment, the Ministry of Justice failed to fully meet her needs assessment and after a meeting with HR, in which she was put under pressure to return to work full-time, she had a breakdown, leading to her referral to the crisis team. She was subsequently forced to take early retirement, but her strong Christian faith prevented her from committing suicide. Parallel to her attempts to recover, she was fighting a legal battle against the consultant who failed to spot the aneurism which caused her stroke. This also took its toll on her health, which coupled with her emotional dysfunction, led to family estrangement.

After winning her court case, she was able to use her settlement to employ a brain injury case manager and personal assistant (PA), which led to her accepting her new life and feeling a little less overwhelmed.

Schlossberg et al. (1995) states that a transition is only a transition "if it *is* so *defined by the individual experiencing it*". Katie summarised her transitions as follows:

> "*I've had to go through transitions of not being able to work, transitions of trying to mend relationships with my children*".
>
> (Session 3, 534)

And:

> *"I have had to accept help, in the form of a PA; I had to accept the support of the brain injury case manager".*

(Session 3, 535)

And additionally:

> *"I have had to accept I need weekly treatment physically [pause] all this stuff I didn't have in my life before and, and to go with whatever rehab has been recommended and to go with whatever medication so yeah, I've had to have lots of different doctors assess me".*

(Session 3, 536)

It is only once she has been through these smaller transitions and the crisis of losing her career at the bar that she is ready to focus on Katie's career development. She began by undertaking a number of voluntary roles, including becoming a trustee of the Brain and Spine Foundation, and later began to consider what she would like her future to hold. She concluded:

> *"I think [pause] not wasting my experiences is important to me".*

(Session 3, 547)

As she explained:

> "All that stuff is very difficult, if I hadn't gone through those stages, I wouldn't have now been now able to sort of start to move on".

(Session 3, 537)

Themes	Reference	Quote
Transitions		
Becoming disabled	Session 2, 15	*"I did a course about disability discrimination on the day I was to become disabled".*
Regaining a degree of independence	Session 2, 100	*"I employed a brain injury case manager and one of the first things she wanted to put in place was to have a PA".*
Order/control	Session 2, 16-17	*"I had no idea anything was going on in my head and I came back and I prepared supper. And "I remember making little meatballs, which I lined up on the side".*
Disorder/Chaos	Session 2, 69	*"No, I think erm, my family have tried within their abilities, but it's never been quite enough for me, with my disabilities".*
Feeling frailer	Session 2, 262	*"I've had, in the last 12 months, 4 emergency hospital admissions, and that's not right, you know, I'm 53 [pause] that's what's happened and that's really hard".*
Regaining strength	Session 3, 537	*"All that stuff is very difficult, if I hadn't gone through those stages, I wouldn't have now been now able to sort of start to move on".*
Loss	Session 2, 49	*"Well I suppose, when I was medically retired, that was the final, sort of erm sword in the coffin, in terms of it being a death knell to my [pause] so, yeah I mean, August 17, I could no longer call myself a judge and that was a huge loss".*
	Session 3, 737	*"I just want to be happy, Carol. I don't know what happy is really".*
Surviving:	Session 3, 536	*"I have had to accept I need weekly treatment physically [pause] all this stuff I didn't have in my life before and, and to go with whatever*

		rehab has been recommended and to go with whatever medication so yeah, I've had to have lots of different doctors assess me".
Surviving by establishing a support network	Session 2, line 110	*"What we're trying to do now is establish some sort of routine for if I see the psychologist at a certain time each week, if I have a massage at a certain time each week, or if I see a neuro physio, whose very good at maintaining my level of pain and stopping it getting worse".*
Lack of choice	Session 3, 156	"I've, over the last 7 years, erm I've run away a lot and that is an example of when things get too much. I just have to get out".
Freedom of choice	Session 3, 708	"I hope by sharing my story I might be able to change other peoples' reaction and response to me as someone who has had a stroke and erm, just ensure that people have a degree of knowledge and education that they wouldn't otherwise have".
Lacking awareness of her disabilities	Session 3, 44	*"I thought I was going back to work and I thought I was going back to work full-time originally but that showed how little insight I had into how severe my stroke had been".*
Self-awareness	(Referring to her emotional dysregulation.) Session 3, 194	*"I think it's just the conflict in the family that it causes that is probably the issue".*
Loss of Katherine (old identity)	Session 2, 52	*"And it wasn't just because of its a status, it was because it was you know, part of my being".*
	Session 2, 54	*"I was a barrister for 18 years before I became a judge and [pause] because I was self-employed, it meant I took all the school holidays off, so I could be mum as well".*

Becoming Katie (new identity)	Session 2, 178	*"I've given speeches for them; I've spoken at the Neurological Alliance on primary care and I've spoken at the Royal Society of Medicine on my rehabilitation, so I think I'm helping".*
Identity transitions as demonstrated in her paintings	Session 2, 223	*"One is a picture of my pre-haemorrhage brain which was really bright and bold and busy and it's got all the stuff I did as a result of my brain on the first one and that describes Katherine".*
Identity transitions as demonstrated in her paintings	Session 2, 224	*"And then I had my haemorrhage brain which shows the night I had my haemorrhage and the torpedo-like aneurism and blood going through my brain and that's the night Katherine died".*
Identity transitions as demonstrated in her paintings	Session 2, 225	*"And then the third painting is of my post-haemorrhage brain, which is very gentle and pastel coloured and light and it's almost something that doesn't know what it is and that's when Katie was born".*
Trauma	Session 2, 22	*"And having said 'I don't feel too good,' I collapsed and that was it and I've got no memory then of the next few weeks till I came round".*
Understanding her condition/Therapy	Session 2, 221-222	*"When I was in rehab in Exeter, they wanted us to do a project that showed that we understood our brain injury. I just decided I was going to do some paintings and I've done 3 paintings".*
Career Self-management		
Victim at work		*"I just think that there was no understanding of my brain injury, there was no support, erm and human resources were diabolical and err, I, I was having to spend 2 or 3 hours a day on a phone to*

		Atos engineers, to try and get my computer equipment sorted whilst trying to do a highly intensive, erm and important job".
Decision making skills	Session 2, 22	*"I've exhibited them at the stroke conference, last year and I've also exhibited at the erm Museum of Art, at University College, London, as part of the Bloomsbury festival".*
Motivation	Session 3,548	*"Not wasting the talents I have, such as public speaking, and raising funds for charities, on that basis, [pause] it gives you a little sense of purpose back".*
Networking skills	Session 2, 177	*"I'm quite active in the sub-arachnoid haemorrhage Facebook group, in terms of just trying to provide some support for people who've had haemorrhages".*
Opportunity aware	Session 3, 763	*"I want to do a TED talk. About brain injury and about recovery and [pause] my life".*
Ambition	Session 3, 788	*"I still have an aspiration and I've just got to now, fulfil it and make sure I create a life that enables me to fulfil it".*
Self-aware	Session 2, 167	*"If I'd even gone back, you know a day or two a week, that would have been enough to stop me feeling this enormous sense of loss".*
Transition skills	Session 2, 175	*"I had to put together a proper application and went for an interview and became a trustee".*

Summary of Philip's story

Prior to his stroke, Philip was working as a licensed independent Financial Adviser, running his own financial services company. He was divorced, spent a lot of time on the road, ate badly and got little to no exercise. He was already working seven days a week when the financial services industry was transformed by Gordon Brown, becoming increasingly complicated from an administration point of view. The extra workload led him to experience a lot of stress and he ultimately had a very severe stroke. Afterwards, he described himself as "*just a vegetable*", (Session 1, 111) with no memory, hemianopia, aphasia and physical disabilities. His brain injury also left him so confused and terrified, that he was convinced that the hospital staff were trying to kill him and he threatened to escape. As a result, he was discharged into the care of his two younger sisters. He moved into Mary's farm to recover and his older sister, Katrina, provided "*respite care*" (Session 3, 241-2) at weekends.

Due to his memory loss, Philip lost all of his capabilities, his business and his ability to drive. He had to be "*looked after*" (Session 2, 468) as he had effectively reverted to childhood. His sister Mary became like a mother to him, teaching him to wash, shave, dress and eat healthily, alongside her own two sons. While living on the farm, he was encouraged by her to walk daily and his fitness gradually built up. He was eventually able to reduce his blood pressure medication, which he saw as a "*barrier to being functional*" (Session 1, 35). Philip credited that as being a significant turning point in his recovery, as he regained his interest in life from that point. Consequently, he agreed to go to a 'Living with Stroke' event, which he had had no previous interest in attending, another turning point for him. Once there, he networked with people from a range of different organisations and this enabled his life to open up more as the life-career opportunities he perceived consequently increased.

Even though his severe disabilities meant he was unable to engage with some of the contributors, like the Job Centre, he was effectively "*unemployable*," (Session 3, 129) he remained open to the limited opportunities on offer to him: "*If I thought I could do it, but I might be able to, I would still* *go"* (Session 2, 1023.) For example, he went back to school to relearn cooking skills, engaged in simple volunteering (putting letters in envelopes) and learned to use organisations like 'Age Concern' to delegate tasks to that had previously been a struggle for him and his family, such as managing his post. He also subsequently learned to utilise the staff at his local laundry to do his washing and ironing as he couldn't learn to work the machines that Social Services had attempted to teach him to use. Such was his tenacity, that he repeated an Adult Education course three times in an effort to progress to the next level, before realising that his need for repetition meant that he was wasting his time, which might be better utilised on other things he wanted to do.

As his independence developed, he was able to eventually go home, albeit still under the watchful eyes of his sisters, and learned to rely on his former friends to take him out.

Philip developed a close friendship with a teaching assistant at the school he attended and his friend Euan was instrumental in encouraging and assisting him with many of the IT systems Philip began to use. He was encouraged to enter a competition about overcoming adversity. Although, he didn't win, he used the information he had collated with Euan to build a website to help other stroke-survivors. He also trained as a stroke supporter and began volunteering on a stroke ward, initially with a buddy as he was still a danger to himself at this stage.

Once he began to understand how to manage his particular combination of disabilities, in "*ways that worked for me"* (Session 2, 1064-1066), Philip reluctantly accepted that he needed white stick training, which took four attempts. Afterwards he began to get out alone more, learning journeys repetitively with a friend at first and eventually successfully navigated the metro, after struggling with the local bus service. He also began to gradually expose himself to the busy places he struggled to cope with and to reengage with his former interests, such as adapting to watching the football in a local pub rather than attending a match. His friendship circle widened as a consequence and after seeing his new friend's reactions to his speech and memory difficulties, he devised systems to overcome these, effectively hiding his disabilities because he was tired of appearing *"dumb*" (Session

2, 1383). Despite repeatedly protesting that he wasn't "*bothered"* (Session 3, 157) by other people's impressions of him, his latent emotions surfaced over the course of the three interviews and he admitted to being *"frustrated"* (Session 2, 155-157), by both the initial void in his life (Session 3, 631) and other people's reactions (Session 3, 81-82), due to his intelligence and pre-stroke academic achievements.

Learning new things required a lot of repetition and Philip quickly realised that he would lose all his memories overnight. Nevertheless, he remained overwhelmingly positive and learned to begin each day by consulting his calendar and checking texts and emails, revisiting yesterday before tackling each new day. After realising he worked best in a morning, he coped with his fatigue by having two mornings a day, punctuated by sleep and a bath. If he forgot what he was doing /where he was, when he was out and about, he would use a computer at his local library to get up to speed. By relying on his "*daily set of things I do"* (Session 1, 8,) he was able to "*cope with, as near a normal life as possible"* (Session 1, 57). He also began to anticipate and problem solve potential difficulties like getting lost.

Once he had all that "*sorted,*" he started getting "*involved in other things*" (Session 3,62). For example, attending night school and serving as a governor for his local healthcare trust. The latter brought new challenges and he began to use text to speech software to manage his aphasia and he also quickly learned to present a business-like persona, hiding his continuing difficulties with considerable preparation ahead of meetings. However, he 'faked' "*competence*" by wearing a jacket and learned that by presenting the right persona he was able to take an "*active part*" (Session 3, 192), which "*gives me a, a good feeling"* (Session 3, 31-33).

Philip's strategies and willingness to prepare thoroughly enabled him to participate in this series of interviews, which had the unexpected consequence of helping him improve his reading and by the third interview he delightedly reported that he had evidence that demonstrated that he had started to recover his memory at last. His recognition of his transitions ("*turning points*") was limited by his inability to fully recall his past during the interviews, so I have supplemented them with additional ones that I have identified through analysis of the data, (which is why the data below is in a different format to the other stroke-survivors). Recognition was “very hard work but you’ve got to do it” (Session 3, 776) and his memory returning took so long that he’d stopped anticipating it: “*The thing that my consultant said to my sisters eventually it starts to do things but it will be very, very slow and it might not happen for a very long time. So, from going from something that my sisters were told, that I’d never believed, is actually happening”*! (Session 3, 847 & 851)

Final reduced table of themes for Philip all sessions

1. Transitions

Philip’s own interpretation of turning points: “*When I could do things*” (Session 3, 507)

“*Being in hospital or leaving hospital weren’t turning points, they were just my recovery and the turning points were things like me being able to take the next step, like go to school, like err, do simple volunteering for ‘Age Concern’”.* (Session 3, 509)

“So, when that, when that thing with ‘Age Concern’, when they took my mail, when my sisters came over, they were my sisters again and we’d go out, we’d go shopping or we’d go for a meal or whatever. That changed my life”. (Session 3, 498-500)

“*But the other things, there were some crucial ones, when my blood pressure had dropped, erm, so that was, my medication was reduced. After it, it takes a few months for the benefits to come through then I could start doing things and then I could start functioning and I did 5 things, no 6 things, that were important”*. (Session 3, 501-503)

“*Yeah, because I met 4 or 5 people and I did the 4 or 5 things, all in different directions that that, that were changing my life, so the turning point was that meeting or meeting those people”.* (Living with Stroke event) (Session 3, 545)

“But when it starts to happen, it isn’t 1,2,3,4, it’s 2,4,8,16,32,64,128, it’s exponential, so once your brain starts to work, it starts to work in lots of different directions at the same time. And my, getting involved in those 4 or 5 different things, was probably the first sign that that was the case”. (Session 3, 849-850)

“*Well, that was, I did the cookery class and that kick started my brain and I probably did that for 6 months or a year, or it might even be 18 months [pause] I was then offered a reading, well I was offered a one to one”.* (Session 3, 552 & 554)

“*Then after that, that must have been successful because they got me on the first level of err, the literacy and numeracy class, so that was a major move forward”.* (Session 3, 557)

“*They introduced me to Euan who was a teaching assistant and he and I did this ‘My Story’ and that became the basis of our website which we then did later”.* (Session 3, 570)

"*I got asked if I'd ever thought of being a governor, probably bumped into someone when I was doing the volunteering on the stroke ward".* (Session 3, 582)

"*The things that's surprising me is that by doing what we're doing has had a big, made a big difference because I couldn't have done what we're doing now, I couldn't have done it a year ago. And after the first interview, it might have been the first interview, I don't know, that I wanted to do my answers on my own*". (Session 3, 516-517)

"The information was there erm, but the thing that surprised me was that this, only this morning, Euan would normally read my emails to me because I'd done it with a combination of using my computer on the TV and my text-to-speech and I would do the emails to Euan or, or write them in a book in bold capitals". (His memory returning and being able to recognise it through preparing for the interviews) (Session 3, 520)

"*It's brought about things that neither of us knew because obviously I've got no memory and it wasn't stuff that Euan could find out and obviously the way you ask a supplementary question has brought about things that neither of us could remember".* (Session 3, 595)

"An example is the erm, photography class, I had no memory of doing the photography class until it came up in your notes so [pause]". (Session 3, 596)

"*So, I'm getting benefits from what we're doing".* (Session 3, 526)

<u>CW's additional identified transitions that Philp has yet to recognise</u>

<u>A journey from exclusion to inclusion</u>

Exclusion

"*When you have no memory, you have no answer".* (Session 3, 66)

"Well, it was dumb every time. It was just, it was something that was beginning to bother me". (Session 3, 81-82)

"*Then it, it was the looks on the faces of, you know, resignation, that they can't have a conversation with me, so I, I decided that [pause] I needed to find a way of just answering these daft questions. Because they're unimportant. But it was an important move forward".* (Session 3, 67-69)

Inclusion

"So, I developed a strategy, where I used to, what I did that day, or that week, I would look at my Google Calendar and I'd send myself texts and emails. And I would literally learn it and then when they asked a question, I could answer it and the difference, I just felt, great. And it, it's, in the early days, it's the nothing questions that are the most important, ones that you wouldn't remember anyway". (Session 3, 72-74)

"*You know, if you bump into somebody, err, you can have a quick conversation because I've done it every morning, it just makes life more enjoyable and less, less different to other people".* (Session 3, 671)

"*Erm, one thing I found out very quickly is, I seen, I found a way of dressing more formally by wearing a jacket, erm, attending the meetings [pause]".* (Session 3, 13)

"It's, it's the persona of what used to be the BBC news, not now, because it's all changed, but it was the fact that I actually took part". (Session 3, 46)

A journey from loss of control to empowered control

Loss of control

"*In the early days, I was just a vegetable".* (Session 1, 111)

"*My face had collapsed, my right arm didn't work, my right leg didn't work, couldn't see very well, couldn't see at all to begin with, I had speech problems".* (Session 2, 337)

"*And obviously the girls talked about it and decided I should live with the one who worked from home".* (Session 2, 733)

"*Even though she was my younger sister and err, of five years, it was like that's why I referred to her as 'she became my mum'. Because she had taught me to do things that your mum teaches you growing up as a child".* (Session 2, 474-476)

"*She had two young sons, so she just ended up with an extra son, just a very old one, but obviously occasionally it got quite difficult. How I've been told it's like toddlers, old people like me need to be watched all the time. Ha, ha".* (Session 3, 237-239)

"So, when it got too much, they would organise it between themselves, without including me in the deep conversations and Katrina would come and pick me up, but at the time it was just like a nice surprise. I didn't realise, till much later, that it was respite care". (Session 3, 241-2)

"*And so, I did nothing, which I, having an honours science degree from Middlesex University and not being able to read or understand things, is very frustrating. So, it was, it was a nothing time".* (Session 2, 155-7)

"You just function. I mean a lot of these things I've learned from other people later on". (Session 2, 212-213)

Empowered control

"*I have a daily set of things I do".* (Session 1, 8)

"Put the err, put the tablet on, and I look at my Google Calendar and my sent emails and look at what happened yesterday; look at my Google Calendar for what happened yesterday, look at my sent emails, and then look at my sent texts. That gives me an idea of what happened yesterday because I don't ever remember yesterday". (Session 1, 28-29)

"I follow that by looking at today's Google Calendar, at what I'm doing today, erm, today's received emails and today's received texts, and I'm just learning WhatsApp as well, so I look at my WhatsApp messages to see what's happening today. That's what I do before the start of every day, erm, to get me up to speed". (Session 1, 31-32)

"*Err, then to exercise, I managed to lower my blood pressure which meant they lowered my levels of my blood pressure medication [pause] which was a barrier to being functional".* (Session 1, 34-35)

"*Then I was able to get up to function and I went back to school, erm, to learn to read and write, to use a computer and all of that; all of which had to start from scratch".* (Session 1, 38)

“Erm and with more exercise and more learning, I could then cope with, as near a normal life as possible”. (Session 1, 57)

“*It was only when ‘Age Concern’, as it was then, started doing my post, all my correspondence, then whenever my sisters came over, it was to see me. It wasn’t a problem to sort out, so miraculously, as if there was a magic wand being waved, I got my sisters back and I lost two administrators who were struggling with the administration problems”.* (Session 2, 15-16)

“*You want something doing, get it done by a professional. Don’t stress the family, so I learned a very important lesson”.* (‘Age UK’ taking over his post) (Session 2, 269-271)

“*I was just determined, because you’ve got a choice when you’ve had a stroke, as you probably know. You can either stay as you are or move and move is hard, moving forward is very hard work but you’ve got to do it”*. (Session 3, 158-160)

“There are lots of possible futures depending on which forks in the road you take”. (Session 3, 776)

A mindset transition from perceived victim (loss) to surviving (lucky)

Loss (Perceived Victim)

“Yeah, I err, I lost all my memory from the whole of my life, erm so I lost a lot of abilities”. (Session 1, 3)

“*Erm I was Managing Director of my own financial services company”.* (Session 1, 139)

“*I used to have a fantastic memory”*. (Session 1, 142)

“*Most people don’t realise is that when you lose your ability to read, you actually lose your privacy. You can’t do anything about it until they’ve told you what it is and they’ve already read it”.* (Session 2, 41-45)

“*It’s very degrading... But there’s no other way around it “.* (Loss of privacy re. strangers opening his post) (Session 2, 46 & 48)

“*Sadly, the one that looked after me died about 7 years ago of cancer. So that was quite horrific because that was like losing your mam and your sister because she fulfilled both of those functions”.* (Session 1, 203)

“*I, I in my memory, I’ve always been like I am today. Erm I obviously wasn’t and I’ve come a long way but I have no appreciation of how far I’ve come”.* (Session 3, 366-68)

“*Well no, no matter what somebody tells you, it doesn’t bring back a memory. It is just a story that somebody’s told you and it could be about them, so there’s no emotional attachment”.* (Session 3, 382-384)

“*Well, I mean, you now know more about my life than I do and you now know as much as Euan. I’m the one who knows least about my life! Ha ha!”* (Session 3, 823-5)

Surviving ("Lucky")

"It's not upsetting because I don't remember being able to do it and that's one of the beauties of my life, all the things I can't do now, I don't remember doing in the first place. So, I've no sense of loss". (Session 3, 393-395)

"*Because I've met a lot of stroke patients who do remember what they can't [pause]. I mean I don't remember driving…. From that point of view, I'm quite lucky". (Session 3, 407-8 & 413)*

"And they have depression and they have terrible times and I've never had that". (Other SS) "I've been very lucky in that the beauty of my memory loss is that the bad things have gone, forever". (Session 3, 400-401)

"*And, at the end of the day, I'm living for today and hopefully for tomorrow so the past isn't very important".* (Session 3, 379)

"*He decided that we should set up a website which he would do with all of the information that I do, that I use erm, and obviously he had to research that because when you've got no memory, there's no story".* (Session 1, 116)

"*Erm and I've found what we've done quite therapeutic because when you have no memory, there's nothing to think about*". (Session 3, 818)

"*Err, the website was done over a period of years and updated all the time with information that we got, but this is the first review of my life that has ever been done. And I've found it fascinating"!* (Interviews with CW) (Session 3, 819 & 821)

"*I've got a relatively normal life now".* (Session 1, 113)

A journey from Loss (lack of choice) to Surviving (choice)

Loss (lack of choice)

"*Well the emotional side is heightened after a stroke".* (Session 2, 56)

"I just avoid situations where it's likely to happen, but I mean, I was at a recent funeral and I was devastated. It was a very close friend of mine and he was only I think, about 46. And I didn't know he had died until it was only the day before". (Session 2, 71-74)

"*I've never been able to stop getting upset".* (Session 2, 93)

"*Erm, so we were all with her when she died. She's the one that the website's dedicated to. Because without her, I wouldn't have existed. I'd probably be parked in an old people's home [Pause]".* (His sister: Mary) (Session 2, 488-493)

"I was 57 and I was in my early 60s before I could start to do things, before I could do things, I was literally of the age and the condition of somebody in an old folk's home". (Session 2, 500)

Surviving (choice)

"*When, obviously my, the thing I could do was walk. So, I used to walk a lot because that was part of my therapy, to get fit after my stroke".* (Session 2, 166-168)

"*And as I walked, I lost weight and as I lost weight, my blood pressure came down and then my blood pressure and medication was halved. And it was only when it was halved, in a few months later that the body would get used to the lower amount of perindopril that I actually started to think, and it was only then that I was able to do things*". (Session 2, 170-171)

"Err now, I don't know if it was the only 'Living with Stroke' letter I got, err, although I doubt it, but I eventually went to one. I was persuaded to go to one by my sister, by one of my sisters, err, and it was a sort of conference-type day". (Session 2, 225-227)

"*So, I went round and I was taken around, by somebody, I don't know who he was, but you know, they make sure that you are accompanied because obviously I had gone to this on my own".* (Session 2,236)

"It gave me my family back. It just changed my life". ('Age UK' doing his post) (Session 2, 249 & 265)

"*Erm, and then I got involved in education, but that wouldn't have been possible before".* (Session 2, 172)

"I've got a relatively normal life now". (Session 1, 113)

A journey from misunderstanding my disabilities and avoidance to understanding and accepting them

Misunderstanding and avoidance

"*With all of the work and the administration, and pressure and the fact that I wasn't doing any exercise, it all exploded".* (Session 1, 171)

"Ok, well I was at Mary's full time, it's just that I was quite difficult, erm, it was described to me as, I was like a rather old and awkward child because obviously when you are learning everything from scratch, erm, you don't fully understand things, so it was difficult for her". (Session 3, 234-6)

"When you don't like meeting people and you've got no memory, you avoid conversations". (Session 3, 244)

"*They would, because they visited me in hospital and they'd seen me improve, they would know the things that I struggled with. So, we'd avoid those, do the things that I like".* (Session 3, 273-4)

"*Erm, then we would go shopping or visiting somebody, which I didn't like, but sometimes we did and then she would finish by dropping me back at Mary's in the late afternoon*". (Session 3, 259)

"Well from what I was told, I didn't want to do anything. I didn't want, I would never leave the, I just wanted to watch telly, err, drink tea, watch telly, erm, have meals". (Session 2, 519- 520)

"But I think I went through a period when I was solving post problems by putting them in the bin". (Session 2, 291)

"I try and avoid things that will upset me because when I was volunteering on the stroke ward, if a stroke patient started to cry, I usually ended up joining them". (Session 2, 58)

"*I manage it and I don't run away from it*". (Emotional lability) (Session 2, 97)

"*I don't go to funerals of people I don't care about".* (Session 2, 102)

"I don't go to meetings that are pointless, you know, some of the councils and some of the local meetings [pause] all you're likely to do is go there and argue with people and never achieve anything". (Session 2 104-106)

"*And err banging my head against a brick wall, it's not something I've ever been fond of. So, I just avoid the situation".* (Session 2, 111-113)

"*I mean I try to avoid things that would stress me because that would put my blood pressure up and be dangerous for me health".* (Session 2, 786)

"*I go to restaurants and cafes and places like that, that have a comfortable, relaxed atmosphere. So, if it's frantic or something like that, I don't stay, I don't like it".* (Session 2, 789- 791)

"When I'm sat here talking to you, I can look in all directions and I can see everything. So, when people told me I was blind, I didn't believe them". (Session 2, 601-2)

"*The guy who organised my white cane and my white cane training, erm, when he came to do it, he said that several years before he had come to do it and he said it's the most polite way he's ever been chucked out of a house in his life! Because I said, I'm sorry but I'm not blind and I don't need your help".* (Session 2, 603-5)

***Understanding and / or accepting my disabilities* (self-awareness)**

"*I've got aphasia, which is a communication difficulty*". (Session 1, 21)

"So, they would, initially support me and walk me because I wasn't walking very well. Up and down the farm lane and then gradually as I got to be able to do it, and I was steadier, I used to do it on my own". (Session 2, 531-532)

"Erm and that was the start of my exercise regime and then everything started to function better. But that was still before my medication was reduced, so the functioning was physical rather than mental". (Session 2, 537-538)

"*It's the ideal place to be recovering from a stroke because they don't use a clock, they use a calendar and they do things by the season".* (Mary's farm) (Session 2, 544-546)

"*It took about 2 or 3 months after my, until the level of medication in my body had reduced. And then I started to feel brighter. And it was only then that I would agree to go to one of these err, meetings*". ('Living with Stroke' event) (Session 2, 308-311)

"I'm used to crying, it's not a problem. I know that it's therapeutic to do it, so [pause]". (Session 2, 82 & 84)

"It's, because I'm really passionate about what I believe in". (Managing emotional lability at meetings) (Session 2, 109)

"I don't avoid anything in my life". (Session 2, 115)

"Well, I don't worry about things I can't control". (Session 2, 781)

"Erm, so it's an advantage in one way because I don't have the baggage. But it's a disadvantage in the other way in that I don't realise how far I've come". (Memory loss) (Session 2, 375-377)

"*It's not upsetting because I don't remember being able to do it and that's one of the beauties of my life, all the things I can't do now, I don't remember doing in the first place. So, I've no sense of loss".* (Session 2, 393 & 395)

"I've been very lucky in that the beauty of my memory loss is that the bad things have gone, forever". (Session 2, 401)

"I didn't understand that I was blind. You see, hemianopia fools you". (Session 2, 152-3)

"And it was three years after, about three years after my stroke that it was made, I was made aware of the fact that my field of vision is only 50% of what's around. There are no gaps, there are no dark patches". (Session 2, 614-615)

"*I've got to be honest; I've never understood it, I've just accepted it*". (Session 2, 617)

"*When you've got vision problems, you always look straight ahead to make sure you don't fall. So, you are continually looking forward and down to make sure you don't trip on anything, there is nothing in your way. There isn't time to look around with your head. So, if I want to look around, I have to stand still and then look around and then start walking again. I can't do the two at the same time, in one go. So, before I had the white stick, it was a big problem because I was constantly walking into things that, I actually apologised to a lamp post before because I walked into it and then said sorry and kept going"*. (Session 2, 1333-1339)

"*I need a programme to start and finish when I'm watching it. I can't do the second episode when I don't remember the first*". (TV) (Session 3, 787-788)

"I could read out loud a paragraph but it wouldn't go in. It would just be mechanical reading of it". (Session 2, 931-932)

"I can't do the reading and the remembering because those two things seem to be separated. You just find out what works and what doesn't and adjust things accordingly". (Session 3, 839-841)

"Erm, I can only read and understand some phrases and short sentences which is why I use the text to speech on the tablet. Because it must go to a different bit of the brain because it allows me to process it". (Session 2, 933-935)

"Because the fact I used to run a company before I had a stroke, on a computer, was irrelevant". (Session 1, 53)

"I had to go to school for a while to try and learn to read, which never really worked". (Session 1, 53)

"But it wasn't a comfortable period, but I'm aware of the problems I had, which obviously got better with, the thing I didn't realise was the more you did it, the easier it got". (Session 3, 310)

"So, I started to get about more on my own, but I still have a problem now where I can't do an original journey on my own". (Session 1, 59)

"*I have to do it with a friend and I have to learn it and then, I can do it on my own, erm, if I do it on a repetitive, in a repetitive way"*. (Session 1, 60)

"*Actually, turning up for things at the right time in the right place is impossible, so I have a set of routines, which Euan's helped me to write out, or Euan's written out for me, of what I do every day because this helps my day's function".* (Session 1, 66)

"I just know when I'm tired and I'll have a, like we did. I'll go and have a cup of tea, go out of the room, into a different room because the change of room as well as the cup of tea, seems to reinforce the break, bring it back and do it again". (Managing fatigue) (Session 2, 1318-1322)

"I can't, I can't remember specifics, what I can remember are themes. Obviously, I have these meetings about once a month, so the repetition allows me to get the general theme". (Governor meetings) (Session 3, 9-11)

"Yeah. So, I've never been bothered about other people's opinions, my sister Mary used to say that I was my, my strongest critic. If it was good enough for me, it was good enough for everybody. My standards were higher than most people because I just felt I had to try that bit harder". (Session 3, 164-7)

A journey from loss of speech and appearing "dumb" to finding my voice through an advocate, to spotting and overcoming my mistakes, to speaking confidently

Loss of speech

"For a long time, I just didn't want to talk but once I'd learned to talk, talking to people never bothered me, strangers never bothered me". (Session 3, 157)

"*So, I would sit on the back on the right so that everybody was either in front of me or on the left, and apparently, I never talked for a long time*". (Stroke club) (Session 3, 362)

"Well, communicating, once I'd learned to talk, and I'd learned to talk normally, which took quite a long time because I slurred, when I could finally speak, because I slurred my words, I couldn't think of words". (Session 3, 155)

Dumb

"It is frustrating when people think you're a bit dumb". (Session 2, 1383)

Finding my voice through an advocate (Euan)

"Oh yeah, yeah, I don't have the up-to-date figures but I think the last time Euan checked the figures was probably a couple of weeks ago and I think whenever we do the figures, Euan updates the website and I think it was a hundred and, could be wrong, but I think it was something like 118,000; 115,800 or something like that, which is astonishing... The main one they seem to look at is my story, because that has, the reason, the reason we did it on my development…. We've done the, my story in chronological order of my recovery and it allows [pause] the families to pinpoint the area that they are at and give them tips on how to develop and improve and apparently that's, that's made a fantastic difference to a lot of people". (Session 2, 1506 & 1509)

Spotting and overcoming my mistakes

"*And I developed a strategy where whenever I was talking to anybody, err, normally I tried to avoid it, but I used to watch their eyes, and watch their faces*". (Session 3, 307)

"When I said something and their eyes opened, I used to ask them what I'd said and obviously it's as if your brain and your mouth are not connected at times. But they would tell me what I'd said and I would try and correct what I'd said to answer the question in the first place". (Session 3, 308-9)

"*Well, you learn those things, well, when you've got no memory, people tell you but they have to tell you over and over again. Then eventually it sinks in so [pause] it's the way the expressions on their faces were, quite shocked, so you need to know what you've said".* (Session 3, 313-6)

Speaking confidently

"*And then, as my speech probably improved and I got more confident, the old joke was that now they can't shut me up"!* (Session 3, 364)

"*And I found that I could hold certain amounts of information, for that day, and it meant that I went into the meetings fully prepared, which was very rewarding, knowing that you could take part".* (Governor meetings) (Session 3, 415)

<u>A journey from incompetence through faking competence to achieving a degree of competence</u>

Incompetence

"*But obviously as I was, err, a bit incompetent, I did it buddy style with a friend of mine, he used to meet me and take me there, we did it as a couple".* (Volunteering on stroke ward) (Session 3, 209)

"*When you've got no memory, you're a bit wary about your speech because it's not that competent".* (Session 3, 256)

"*Err, that, at that stage, we didn't know that it was unlikely I would ever learn to read competently".*

(One to one reading sessions from going back to school) (Session 3, 559)

Faking Competence

"I'm using the negative things of my memory to develop a system that works". (Session 3, 428)

Achieving a degree of competence

"Erm, for the first time this morning, I actually read them to Euan. I have never been able to do that, up until now, so that was quite a, that was fresh out of the blue that one because even Euan and I both realised after I started doing it, because neither of us were expecting it, I just started doing it".

(Answers to interview questions) (Session 3, 522-523)

"*It's brought about things that neither of us knew because obviously I've got no memory and it wasn't stuff that Euan could find out and obviously the way you ask a supplementary question has brought about things that neither of us could remember*". (Session 3, 598)

"In the course, well, in the early part before we started this, the things were improving, in the course of this, I got a lot more competent, in terms of I couldn't have written out my answers on my own and given them to Euan". (Session 3, 812)

<u>A journey from lack of purpose to normality.</u>

Lack of purpose

"*Well, I went through three, probably, roughly three years, give or take six months, of an educational vacuum. I couldn't do anything".* (Session 3, 120-123)

"But there were other things that I couldn't, there were sort of volunteering things but well, I couldn't volunteer because I was a danger to myself". (Session 3, 132-134)

Moving towards a 'normal' life

"*Yeah, well, basically I used to 'Age Concern', I used to go to the café with friends and then on my own, and they, I don't know the sequence, but they did my post, but I did some simple volunteering, like filling envelopes and things, but they did my post".* (Session 3, 385)

"*So, there was the volunteering on the stroke ward, and then I was, I put my name forward to be a governor and I was elected, and it went on from there"*. (Session 3, 407)

"*I wanted to be a governor of 'Nottinghamshire healthcare' which was, to me was like a follow-on, a sort of step up from being a stroke support volunteer".* (Session 3, 411)

"*It was like everything started to open out and there was a major difference".* (After 'Living with Stroke' event) (Session 3, 623)

"Yes, yeh, that kick started my brain". (Cookery course for disabled) (Session 3, 149)

"Erm, it's when you're learning everything, there's a limit to what you can learn, but some of the meetings were once a week, some of them were once a fortnight. With a bit of organisation from somebody else, I could fit them all in, but I wanted to do them all". (Activities he was introduced to by 'Living with Stroke' organisations) (Session 3, 216-217)

"*The stroke club was more about I needed to do it to improve. It wasn't, whilst we were very friendly, it wasn't for enjoyment, it was part of my therapy to move on".* (Session 3, 346-7)

"Erm, that was more like work, more like my job at the time, to get past, to the next stage, whereas at about five years later, I was at the stage where I could go and watch a football match and then meet friends and well, find friends, through discussion watching a football match. That enabled me to carry on with the next bit of my journey". (Session 3, 348-9)

<u>A journey from being unable to make decisions to considered decision making</u>

Inability to make decisions/impulsivity

"*Erm and she stopped me buying what's it called, what's the popular thing now, hot tubs. Which was a lunatic thing to do, but she managed to convince me not to have one"!* ("She" is his sister: Katrina) (Session 3, 249 & 252)

Considered decision making

"*Well, I decided that because preparing for meetings and having sensible conversations and things like that, I was forced to separate what I wanted to do, like different classes, like the digital photography, which was never going to work".* (Session 3, 447)

"*But I realised if I just stuck to those, because that was going to involve a lot of time, from my point of view".* (Session 3, 450)

"Now, if you do the course three times and you still can't remember anything, you realise if it's something you're interested in, and it still doesn't work, you can't do things like that and alongside this I had an interest in increasing my involvement in the Trust and then I got the opportunity to put myself down for election for a public governor". (Session 3, 449)

<u>A journey from hard work to pleasure</u>

Hard work

"*And I carried on with all, I can't remember if it was 4 or 5, but I carried on with all of those 4 or 5 doing different things, because now I could [pause]I had a lot to learn but it was just, it was just, it was hard work".* (Activities following the 'Living with Stroke' event) (Session 3, 137-9)

"It doesn't just happen; you've got to put the time in". (Session 3, 140)

Pleasure

"*Erm, and it allowed me to sort of, when they came over, we would have lots of talking and I would take them for meals, you know, buy their lunch, or we would take turns buying lunch, or whatever. So, it was back to pleasure with the family".* (Relieving his sisters' workload by using 'Age Concern' to do his post) (Session 3, 36-7)

An identity transition from Stroke Survivor to 'Living with Stroke' committee member

"*Erm, when my blood pressure tablet medication was dropped, I found that I could do more, I was able to walk about more, able to recognise people, because all that was just a blur. Eh, so eventually, I had been to a living with stroke group and met somebody, [pause] and I went as a stroke survivor".* (Session 3, 124-127)

"I'm involved from the organising front and basically what we do is we all, we invite stroke survivors and their families, or carers, to an event". ('Living with Stroke' event) (Session 3, 196)

A journey from a pointless life to "*a good feeling*" (fulfilment) and recognition of my progress

A pointless life

"*Days were just the same and pointless. It was a struggle to get through the day, very tiring".* (Session 3, 195-6)

"And for a long time, I was just treading water and functioning". (Session 3, 631)

Moving towards fulfilment ("a good feeling")

"*Yes, yeah that's when all of my different parts of work and education, I say work, its unpaid. All my different parts of work and education started from that point"*. ('Living with Stroke' event) (Session 3, 222-224)

"*And the thing about surviving a really serious stroke is you need to enjoy life".* (Session 3, 629)

"*It gave me my family back"*. (Session 3, 249)

"I was able, I was able to function. I wasn't yet able to learn. It took about 2 or 3 months after my, until the level of medication in my body had reduced. And then I started to feel brighter". (Once blood pressure medication was reduced) (Session 3, 306-8)

"My reason for "being alive" (his purpose) and recognition of my progress

"*Erm, so and you get a really good feeling when you've actually help someone. Definitely, concentrating on helping somebody else is the greatest therapy in the world".* ('Living with Stroke' Committee) (Session 3, 345 & 349)

"And, the feeling of having helped somebody, because in a lot of cases, you're not talking to the stroke patient because if they are like, if they are like the way that I was told that I was like, I didn't understand much. Families could see light at the end of the tunnel". (Session 3, 350-352)

"So, actually talking to somebody and saying I know I was like that and this is what I'm like today".

(Session 2, 363)

2. Career development skills

Building a Portfolio career

"It takes me all day to prepare for that meeting at night and so, I wanted to do that and so, but at that time I was only doing one thing a day. Now I'm doing a lot more a day". (Session 3, 453-455)

"I don't like sitting in the house. It seems a waste of time". (Session 3, 471-473)

"*Enjoying it the most I can, doing as much as I can of all the things that I like doing, all the things that help other people, because that's part of my new career".* (Session 3, 781)

"*Yeah, yeah, well it is, I don't get paid for it but that's my job".* (Session 3, 803)

"*Yeah, it's what I do, it's my reason for being alive*". (Session 3, 808)

"*I do it to the best of my ability but if some of those were taken away, then they would have to be replaced, whether replaced with volunteering or enjoyment, or travelling, because obviously while I've had a duff knee, travelling's not been a possibility and that's one thing I've not explored".* (Session 3, 805)

Changing concept of career

"Anyway, my working day or my leisure day, the two things are the same; get up in the morning, put the computer on [pause]". (Session 1, 26)

"*To be honest, some of them are never going to work. So, the NHS needs to look at it differently with the Department of Works and Pensions, or whatever they call the [pause]. All they are interested in is, is we need to get back to work. Even though there's not going to be any jobs. With all these redundancies and with the retail market collapsing, we've got to look at things differently so [pause]".* ("Them" are the stroke-survivors he supports) *(*Session 3, 957-965)

Readiness

"*But it also, you got to interact with other people. Erm, then you got to learn how not to talk when everybody else is talking and things like that".* (Learning social skills at school) (Session 2, 881-2)

"*I didn't realise it wasn't possible as much as I wanted it to when I started, but [pause] Those are the things that in life that you deal with [pause]*". (Session 3, 187-9)

"*And slowly over probably, I'm guessing 6 months, maybe a year, my brain started to function".* *(*Session 1, 51)

"*So, the school which was Nuneaton. School in, err Nottingham, which is where I live, they put me on a one-to-one course about reading, writing, using a computer and from there I progressed to a computer course, to learn how to use a computer".* (Session 1, 52)

"*So, I learned how to do that and then, got to do more of a function of real life".* (Session 1, 56)

"Erm and with more exercise and more learning, I could then cope with, as near a normal life as possible". (Session 1, 57)

"Erm, so once I'd got all of that sorted, I then started getting involved in other things". (Session 1, 62)

"*So, I think that's probably where I got my strategy from, if I don't like something I need to do, I do it until I no longer find it distressing, just keep going until it goes away".* (Session 2, 833)

"*And it was only then that I would agree to go to one of these err, meetings. And then I met loads of people who have changed my life over the following years [pause]".* (Session 3, 311-313)

"*It's only when you've got to a certain stage you can actually relax and start, as I did, I started going err, to watch football and go for meals, that sort of thing"*. (Session 3, 632)

"*You'd do them to see if you did, because obviously a lot of people I know, through being a stroke supporter, is, a lot of peoples' tastes change and personalities change after they've had a stroke, so I needed to find out if things I used to enjoy, I still enjoy".* (Session 3, 638)

"*Yeah. I always, I don't know if I've always done it but since my stroke, if I need to do something, and I find it very stressful, as long as the need to do it is greater than the stress of doing it, I can generally do it enough times and then eventually the fear dissipates, no longer exists".* (Session 2, 835)

"*Everything's a struggle. And to begin with, you've got to do it quite a few times before you're comfortable with it".* (Session 3, 655)

"*But then you start to expand what you do [pause] but you do a lot of that, and life becomes more enjoyable, but it's been a stage-by-stage process".* (Session 3, 659-660)

Motivation

*"I went through years of just being alive. And whilst I don't remember them, it does seem pointless". (*Session 2, 1181-1182)

"Like most things, if things bother me, or I can't do them. I either don't do them again, or if I want to do them again, I find a strategy that will allow me to do them again, comfortably". (Session 3, 86-87)

"It, it was, in the family, education was really part of my life, you know education and training for the jobs I did. So, it was always very frustrating that I couldn't do anything. So, I wanted to correct that, if it was possible". (Session 3, 182-186)

"It was an unknown, but it was something I was desperate to do". (Going back to school)

(Session 2, 856)

"*Oh yeah, I used to look, apparently, I used to look forward to it [pause]. Bearing in mind that was the only thing I was doing at the time".* (School) (Session 2, 908-9)

"It seems daft having two meals the same in the same day. But when you are trying to train a memory, you do what you can". (Session 2, 916-7)

"But, I did miss it that year, so I was determined to get re-elected. I got re-elected and then I've just been re-elected again". (Missed year as a governor) (Session 2, 1268-9)

"*By being around and being involved if there's any open days or things like that [pause]. When you are not elected, if you go to them when you're not elected, it shows that you are serious. So, I would* *go there as a member of the public and talk to people and you get a reputation for wanting to be involved, even though you're not officially involved"*. (Session 2, 1292-1298)

Self-awareness

"There are five learning styles, I believe, one of which is kinaesthetic, which is the one I have, which is being shown how to do something". (Session 1, 42)

"Leisure things, I still have to put them on my calendar, and I still have to have it in my phone if I'm going to meet someone because there is no way I'm going to remember". (Session 1, 106)

"*It just looks like normal life, to them it was unimportant. To me it was a major way forward. But obviously I've improved a lot since".* (Conversation with football pals) (Session 3, 90-96)

"*And then obviously I went to bed that night, slept and the next morning it was all gone, as if I could fill the glass and it was empty, so then I could fill it again the next day, which was quite a nice way of running your life*". (Session 3, 416)

"*No, as if I had a, I felt as if I had a limited amount of memory and overfilling it just used to confuse me".* (Session 3, 420)

"*So, I could bring two things to it. I could tell them about what is possible, you can't tell them they are going to recover because they may not [pause]but you can say well I was like that, and this is what I'm like now. So, the visual presentation was as important as the words*". (Volunteering on stroke ward) (Session 3, 330-341)

"*I did the same photography; no I did the same computer course three times. But that's, I can only learn at the pace that my brain can cope with".* (Session 2, 978 & 985)

"You are finding out about yourself all the time. You're learning what works and what doesn't". (Session 2, 999-1000)

"My difficulties from what I can gather, obviously I've never discussed it with other people, but they seem to be specific to me. A combination of the memory, the sight, and you know that, I know it's the combination of those two things that, I've found ways that work for me". (Session 2, 1064-1066)

"So, we had to collect all this information erm, and then over time, people who I've met, they've told me about things that I didn't know. And I've sent a text to Euan or an email to Euan and then we've looked into it and if it's been worth going on the website, we've added [pause] so it has sort of grown a little at a time". (Session 2, 1491)

Problem solving

"*Erm, then because I've got no memory, to be able to cope with the average day, I needed some strategies, which I worked out".* (Session 1, 7)

"*Erm, I do exercise classes and stuff like that, so I needed a way to organise things because when you've got no memory, and you have difficulty reading [pause]".* (Session 1, 64)

"I switch on my computer err my computer is connected to a large screen TV, and I use a keyboard and a mouse. I also have text-to-speech on a 10-inch tablet". (Session 1, lines 13 -14)

"I find the text-to-speech seems to go to a different part of the brain which makes it easier to understand". (Session 1, 23)

“Reading the minutes is the most difficult thing and things like that, and the agendas, so I have them on my large screen TV and I play them on my text-to-speech tablet”. (Session 1, 74)

“And in the day of the meeting, and the meetings are usually at teatime, so over and over again, I will err, play and follow on the computer screen, on my TV with my mouse, all of the information, over and over again”. (Session 1, 75)

“*And I use a Google Calendar with different colours; it’s not, it’s not colour coded, but just so as I can see different days and different things on the same day. That allows me to do several things on the* same day. I couldn’t do that before I started using that system”. (Session 1, 93-94)

“*I couldn’t cope with the memory but err, I have it on my computer at home and then when I go into Nottingham, or somewhere similar, West Bridgford, I go in the library and I use their computers to look at my calendar and look at my notes and things like that“.* (Session 1, 95)

“*So, it acts as a refresher, erm, I use technology to do my shopping, which is obviously an important part of my life because I like to cook my own food. But obviously I can’t remember what to buy so I make a list on my phone and on the computer and I will go; my friend, one of my pals, takes me to the supermarket when I’m buying my shopping*”. (Session 1, 96 & 98)

Networking (to develop living capital)

“*The local launderette, I used to, the council, I think it’s social services who used to take me there and try to teach me how to use a washing machine, which never worked. And one of the ladies in the launderette said we can do it for you”*. (Session 1, 184-5)

“It’s, if I want to do it, those are the things I’ve got to do every day. It’s just a routine that works, otherwise I can’t take part”. (Session 2, 1309-1310)

“And I met quite a few people who were then going to help me move on. And there were 4 or 5, I mean there were a lot more, but they couldn’t help me with what, because some of them were like the job centre which, well, they were never going to help me because I was unemployable”. (Session 3, 129-130)

“*Err, learning, trying to remember them, there was the going to school, erm, with ‘Leisure Choices’, there was ‘Age UK’, who were doing simple volunteering, because obviously my eyesight then was, hadn’t settled down, so it was a bit random”.* (Organisations that had helped him at ‘Living with Stroke’ event) (Session 3, 202)

“*There was err, Harriet from ‘Nottinghamshire Healthcare,’ and she got me involved in visiting the stroke ward and being a peer supporter”.* (Session 3, 208)

“*I can’t remember what the fourth one was, oh, ‘Stroke Nottingham South’, I went to ‘Stroke Nottingham South’”.* (Session 3, 212)

“*Erm, so literally it was a few people that I could, that I could benefit from and that, that changed the course of my life”.* (Session 3,135)

“*Well, without people, there was nothing happening, nothing. It was the ‘Living with Stroke’ that actually got my brain working in different directions”.* (Session 3, 614 +618)

“*And then I met loads of people who have changed my life over the following year [pause]. Which is why I’m on the ‘Living with Stroke’ committee for the luck, because it was so crucial”.* (Session 2, 313-314)

"Erm, he involved a lot of people in it, so it was erm, the one thing the website had to be was it was basically for people who had strokes. Erm, and the eh, the chairman of my stroke group, erm, Donald, his *daughter was a speech and language therapist in stroke and she made, she chose the colour, the basic colours, the font size, the font type, all of which were aphasia friendly, for people who had reading difficulties and learning difficulties, it made it easier*". (Building the website with Euan) (Session 2, 1481-1485)

Opportunity awareness

"Until I had a stroke, I had no interaction with the health service and in fact until I had a stroke, I don't think I went to the doctors but erm, so this is, something completely new to me". (Session 1, 84)

"Obviously I wanted to learn how to use a computer. Erm, so I did that at 'Age Concern' for quite a number of years and also a friend of mine from long ago erm, was volunteering there as well as a volunteer teacher [pause] so, I used to go to his, I used to go and do learning a computer next to him". (Session 2, 956-960)

"*And I probably laughed because the concept of me doing a website eh, for someone who can't, or couldn't at that time read, or use computers, was quite funny. And I said yeah, and we went on from there".* (Opportunity to build a website for other stroke-survivors) (Session 2, 1479-80)

"And I'm just, finding it astonishing that I've helped so many people in so many different places, none of whom I've ever met". (Session 2, 1492)

"If I thought I couldn't do it, but I might be able to, I would still go". (Session 2, 1023)

"*The photography course, I couldn't understand it because they were doing a different thing every week. So, I did it because it was nice meeting different people and doing different things".* (Session 2, 971 & 975)

"*I was looking for somewhere else to learn".* (Adult education courses after school) (Session 2, 1033)

"*I might as well go out while its, while I can*". (Session 3, 479)

"So, thought about lots of theoretical futures has never interested me because all or most of them, are not relevant anyway. I spend all the time doing the best I can and getting the most out of what I'm doing every single day". (Session 3, 609-612)

"*Yeah, I'm exploring them in the present, going forward*". (Session 3, 625 & 627)

"*I can only cope with one thing at a time. I can only concentrate on what I'm doing today".* (Session 3, 772-3)

"If something works, I'll make a note of it, expand on it, if something doesn't work, if it's going to, for something like a restaurant and the meal was rubbish, then I'll put in my phone: don't ever go there again". (Session 3, 684)

"*And obviously if things change, like if I'm not allowed to be the governor again, I'll have to find other things to do so and that's not a choice, that's something that either will happen or not happen and whatever it is, that's fine. I don't worry about things I can't control"*. (Session 3, 796-798)

"If that was taken away from me, then I'd have to find something else, I like to be busy". (Session 3, 801)

"Unfortunately, I've damaged ligaments and tendons in my right knee about [pause]18 months or 2 years ago so I'm not able to walk safely all the time and I think, after going on the stroke ward to volunteer on crutches, much to the annoyance of the people on the ward"! (Session 3,705-707)

"*I promised her that I wouldn't go back until I'm cleared by my doctor but I do miss it, but I made a promise and it would be foolish, because they would be liable for any accident that I had".* (Session 3, 714)

"*It's been a naturally growing thing but this would be a major change so Euan would be the guy in charge of doing that [pause] we just bounce them off each other".* (Building his website) (Session 3, 752-756)

"*So, onwards and upwards as they say"*! (Session 3, 879)

Decision making skills

Inability to make decisions

"To be honest, at that stage, they'd read through my letters and they would decide, if necessary, by talking to my sisters, what to do. Because I was unable to make decisions". (Session 2, 243-4)

Developing the ability to make decisions

"Erm, and apparently, I'd told my sisters, after they looked after me, the one thing I wanted to do when I got back to as near as possible a normal life, was to help people who have been in my situation". (Session 2, 1452)

Volunteering

"*So, me standing there talking and looking reasonably ok was a great lift for the families because they could see what was possible. You can't ever promise somebody they'll recover, but you can say well I was like that, and this is what I'm like now. So, the visual presentation was as important as the words. And I've probably, over the period seen 500 families, along with my colleagues, because I've been doing it for over 7 years".* ('Living with Stroke' events) (Session 2, 338-344)

"*And a lot of families, erm, it's one of our passions and I know a lot about it*". ('Living with Stroke' Committee) (Session 3, 322)

"Definitely, concentrating on helping somebody else is the greatest therapy in the world. And [pause]the feeling of having helped somebody, because in a lot of cases, you're not talking to the stroke patient because if they are like, if they are like the way that I was told that I was like, I didn't understand much". (Session 2, 349-350)

"*I never remember what I was like previously. So, actually talking to somebody and saying I know I was like that and this is what I'm like today, it gives you an idea of how far you've come".* (Session 2, 363)

Transition skills

"And you do an election statement which obviously Euan processed mine for me about the things

I believe and I wanted to do". (Session 2, 1258)

Appendix IV: Master table of themes

Major theme 1: TRANSITIONS

'Before' loss of previous identity/role)

Katie: Believes Katherine (her former self) has died and adopts a new, softer identity: Katie.

Brian: Nostalgic about his former life and keen to emphasise that he has no co-morbidities. His stroke was caused by an accident. Immediately after the stroke, he felt 'terrified' by everything he had lost.

Philip: Frustrated by his new 'incompetent' identity.

Susan: Loss of career meant loss of her identity as it was anchored to her 'vocation.'

Katie: "So, it wasn't me, I just… knew Katherine wasn't there anymore". Session 3, 302

Brian: "To be …financially and emotionally… secure and physically fit and healthy… to be suddenly faced with all that taken away. It was terrifying". Session 2 Hospital pin, 154-6

Philip: "*And so, I did nothing, having an honours degree from Middlesex University and not being able to read or understand things, is very frustrating. So, it was a nothing time".* (Session 2, 155-7)

Susan: "*Everybody always says to you 'What do you do for a living?' and I couldn't answer that question anymore".* (Session 1, 185)

'Becoming' (lack of purpose/fulfilment)

Philip: Before he was able to restart his education, he was in a limbo state: 'treading water' (Session 3, 631). His use of the word vacuum, in the quotation below, suggests he was in an existential vacuum.

Susan: After losing her career and identity, Susan no longer knows who she is and where she fits in life.

Katie: Fixated with Katherine's death, she uses it as a metaphor to signify the enormous loss her career at the bar was for her.

Brian: The metaphor of 'running on empty' signifies how low on energy/unable to cope he was at the start of the new term. This could have signalled depression, but it actually led to him having a breakdown.

Philip: "*Well, I went through three [pause] years, give or take six months, of an educational vacuum, I couldn't do anything".* (Session 3, 123)

Susan: "*I just knew that I felt like nobody, nowhere*". (Session 1, 177)

Katie: "*When I was medically retired, that was the final, sort of erm sword in the coffin, in terms of it being a death knell [pause] August 17, I could no longer call myself a judge and that was a huge loss".* (Session 2, 49)

Brian: "*I was certainly running on empty*". (Holiday pin, 104)

'Beyond' (established in new role/identity/fulfilment)

Philip: Has 'upgraded' from 'simple' volunteering roles to greater challenges, which are more akin to his pre-stroke identity as a financial adviser. As a governor of an NHS trust, he adopts a business-like persona by dressing accordingly, to be taken seriously at formal meetings.

Susan: Now in receipt of her pension, Susan is financially stable and content with the range of paid and voluntary activities she undertakes. Her Christian community has offered several networking opportunities which she has embraced with gusto as they have helped to confirm her continuing value as a person, one of which is her role as a Spiritual Companion.

Brian: His involvement in Stroke research trials has renewed his sense of ambition. Brian is recognisable as a stroke ambassador on a national level as his networking abilities are starting to pay dividends.

Katie: Has now transferred her work skills to public speaking opportunities, to raise funds for charity. The charity work she now engages in has helped her find a new sense of purpose so she feels she is not entirely wasting her talents. She describes her sense of purpose as 'little' because it doesn't give her the same degree of fulfilment that her role as a district judge did.

Brian: "*And by 2010. I'd applied to join the National Stroke Research Network and [pause] lay forum [pause]. I was appointed to the Rehabilitation Clinical Studies group, erm in 2012, and that's when I suddenly started to be noticed on a national level, in terms of my capabilities."* (stroke ambassador) (Session 1, 175-177)

Philip: *"I found a way of dressing more formally by wearing a jacket attending the meetings [pause], it's the persona of what used to be the BBC news".* (Session 3, 13-46)

Susan: *"It's a voluntary role, it's not paid work but that doesn't matter".* (Spiritual Companion) (Session 3, part 2, 11)

Katie: "*Not wasting the talents I have, such as public speaking and raising funds for charity [pause] it gives a little sense of purpose back".* (Session 3, 548)

Future uncertainty to certainty to living with change

Future uncertainty

Brian: After his numerous losses, the future feels frighteningly uncertain to Brian.

Philip: Overcomes his fear and discomfort with the unknown because he is 'desperate' to return to school, to make progress with his recovery.

Brian: "I didn't know what my future would hold" Session 1, 68

Philip: *"It was an unknown, but it was something I was desperate to do".* (Session 2, 856)

Future certainty

Brian: Now he has begun to open up new opportunities for himself, Brian is able to perceive the 'excitement' they offer, rather than fear the unknown.

Philip: Reflects that the future you attain is made possible by the choices you make.

Susan: Finally receiving her pension at 60 was a rite of passage that marked her transition into retirement. She particularly values this after being denied an ill health retirement and her departure form work went unmarked.

Brian: *"It's turned into something which is quite exciting".* (Session 3, Q3,67)

Philip: *"There are lots of possible futures depending on which forks in the road you take".* (Session3, 776)

Susan: *"I was sixty [pause] it represented to me such a momentous change [pause] I had access to my pension [pause]. At last, that was my contribution, to life; my working role was acknowledged".* (Session 1, 331)

Living with change

Philip: After injuring his knee, he is temporarily unable to continue with volunteering on the stroke ward. He now understands that change can be both good and bad and reflects that if he is not elected as governor again, he will have to seek out new opportunities because it is important to him that he stays 'busy.'

Susan: Although she did not plan to have a career in retirement, the 'jigsaw' of paid and unpaid roles she now participates in, means she has unconsciously created one through happenstance.

Brian: Has so many career options now, he is spoilt for choice.

Philip: "*If that was taken away from me, then I'd have to find something else, I like to be busy".*

(Session 3, 801)

Susan: "*I didn't plan it that way but that's how it's worked out*". (Portfolio career) (Session 1, 277)

Brian: "*I've got so many choices now; I don't know what to do with them".* (Session 1, 267)

Devalued to valued

Susan: Felt the loss of a rite of passage when she was forced to leave her long career in housing management.

Katie: Questions whether she is still loveable now she is so 'different' to her former self.

Brian: Reflecting on the fact that it is only with hindsight, that he has realised that his return to work was an achievement, even though he was unable to sustain his teaching career.

Feeling devalued ('Before' and 'Becoming)

"**Susan:** It wasn't marked by anything, there was no card, no thank you, no collection, no leaving do" Session 2, 273.

"**Katie:** I think…because of the way I am now, … I'm almost paranoid that... I'm not good enough and

"I'm so different, why would anyone love me"? (Session 3, 206)

Brian: "*Getting back to work [pause] I didn't appreciate [pause]what an achievement it was [pause] because I was unsuccessful in maintaining it [pause]I just saw it as yet another failure".* (Q1 22-26)

Valued ('Beyond')

Susan: Becoming a Spiritual Companion has helped her to value herself again and given her life a new purpose.

Brian: Now recognises that the changes that a stroke brings can also offer positive opportunities. Consequently, he has recovered his sense of ambition.

Philip: 'Astonished' by the impact that the website he built with Euan, to help other stroke-survivors, has had. He regularly monitors the number of visitors and other statistics like country of origin.

Katie: Recognised that as she has decided upon her future ambitions (writing a book about her life and filming it), she now needs to make them happen.

Finding a new purpose

Brian: *"I have ambition again, as a consequence of being involved in stroke research".* (PhD Pin, 46)

Susan: "*And that was extraordinary because that really gave me a sense of purpose and value".* (Becoming a Spiritual Companion) (Session 3, part 2, 10)

Katie: "*I still have an aspiration and I've just got to now, fulfil it and make sure I create a life that enables me to fulfil it".* (Session 3, 788)

Philip: "*And I'm just finding it astonishing that I've helped so many people in different places, none of whom I've ever met".* (Session 2, 1492)

Perceived victim/excluded to lucky/included

Perceived victim/excluded ('Before' and 'Becoming')

Brian: With hindsight, Brian recognised that he was 'bullied' by the senior management team at his school. For example, the Principal ripped up his development plan.

Katie: Felt 'bullied' by her Human Resources Department, who 'pressurised' her to return to full-time work, even though she didn't have appropriate IT support in place to meet her needs.

Susan: Unable to get an ill-health pension because her employer believed that she would recover from her stroke over time. She was so frustrated by the injustice of this, that she found it extremely difficult to move on with her life, during the ten-year period she had to wait until she reached state pension age.

Philip: He was perceived as 'dumb' by his pals in the pub every time he joined them to watch a match. This was starting to 'bother' him. The latent emotion he eventually shared led to him developing his 'system' so that his memory loss and aphasia were less apparent, leading to him being accepted into the group.

Susan: "For about 10 years plus, there was a…. resentment, a huge well of resentment in me, that I had been made to wait for something… and I couldn't do anything about it". (Pension) (Session 3, 287).

Brian: "Now that was bullying behaviour, but I was so lacking in self-esteem and confidence I couldn't see it". (Session 2, Hospital pin, 445)

Philip: "*Well, it was dumb every time. It was just, it was something that was beginning to bother me"*. *(*Session 3, 81-82)

Katie: "*Bullying me to return to work in just 3 months, when I hadn't had [pause] a proper stab at it, with the support I should have had"*. (Session 3, 90)

Perceived Victim (excluded) to Survivor (lucky and included)

Survivor (lucky/included: 'Beyond')

Katie: Feels fortunate that her daughter was with her when she had a stroke, so was able to summon assistance. A GCS of 3 indicates that she was brain dead. This is where the idea that Katherine had died originated (see identity theme).

Brian: Made a downward comparison, feels 'lucky' because he didn't have depression, unlike other stroke-survivors he knows. He acknowledged being 'fed up,' but chose to 'occupy' himself, to take away that feeling.

Susan: Feels lucky because the portfolio career she has now established has restored her self-belief and helped her to feel valued and motivated.

Philip: Is now a committee member, involved in organising the 'Living with Stroke' event

Katie: "T*hankfully with my daughter by my side, Otherwise I would have died because I fell immediately into a coma with a GCS of 3 and literally [pause]"*. (Session 1, 21)

Brian: "*I've been really lucky that I've never suffered from depression"*. (Session 2, Pin on radio + choice, 84)

Susan: "*So, I'm lucky that I've got this jigsaw of stuff, that my life is now, all of which makes me feel good and makes me feel energised and well and the sense of value with that".* (Portfolio career) (Session 3, part 2, 112)

Philip: "*I'm on the Living with Stroke committee for luck, because it was so crucial".* (Session 2 ,1485)

Loss of control to empowered control

Loss of control

Philip: Was so child-like in the early days post- stroke, that his sister became like a second mum to him as she had to teach him everything he needed to learn ‘from scratch.’ For example, washing, shaving, how to eat and drink healthily.

Susan: Used a visceral simile, to describe being unable to accompany her daughter as she started university. She had to rely on her ex-husband to take her as she had just got out of hospital herself.

Brian: The allegations of ‘incompetence’ meant that he was forced into premature early retirement by the senior management team at his sixth form college. He was told that if he didn’t apply, the college would apply for “a competency, a grievance against me”. (Session 1, 115)

Katie: Recognised how much her family tried to help her, but that it wasn’t enough for her with her disabilities and the subsequent needs she had.

Philip: “Even though she was my younger sister [pause] I referred to her as ‘she became my mum.’ Because she taught me to do things that your mum teaches you growing up as a child”. (Session 2, 474-476)

Susan: *“It was horrendous that I couldn’t take her and support her with that transition [pause] on the day she went, it was like my insides being torn out [pause]. I should have been with her”.* (Session 2, 144 & 152)

Brian: *“I was being pressurised to take early retirement on health grounds, which I didn’t want to do because I was only 47”.* (Session 1, 113)

Katie: *“I think my family have tried within their abilities, but it’s never been quite good enough for me, with my disabilities”.* (Session 2, 69)

Empowered control (voluntary transition)

Philip: The ‘strategies’ he uses to compensate for his memory loss.

Susan: The first step to her happenstance career developing was inviting her disabled friend to live with her and her husband.

Katie: After winning her court case, was able to employ a brain injury case manager, who helped her realise she needed a personal assistant, to help her manage her disabilities.

Brian: What he learned from participating in stroke trials and working with stroke-survivors, helped him to learn about his own condition and make more progress with his recovery.

Philip: “*Put the tablet on and I look at my Google Calendar and my sent emails [pause] and then [pause] my sent texts [pause]. That gives me an idea of what happened yesterday because I don’t ever remember yesterday*”. (Session 1, 28-29)

Susan: *“And then the shape of my life changed when we invited a friend, who has muscular dystrophy, to come and share our home”.* (Session 1, 271)

Katie: “*I employed a brain injury case manager and one of the first things she wanted to put in place was to have a PA”.* (Session 2, 100)

Brian: "I started to [pause] self-assess myself. In terms of how I could control what was wrong with me, through that voluntary role" (RS Trial, 161-162)

Major theme two: CAREER SELF-MANAGEMENT

Readiness

Susan: The difficulties she faced applying for other jobs after she was 'let go' from her job as a housing manager.

Philip: Had to re-learn social skills when he went back to school.

Katie: Her brain injury case manager has helped her to establish a new daily routine, that is meaningful for her.

Susan: "*It wasn't the content of the work, jobs, so much. It was more the expectations that, of any job [pause] that you attend regularly, you do a good job, you take your responsibilities seriously and I didn't think I could do that".* (Session 3, part 1, 322-323)

Philip: "*But it also, you got to interact with other people [pause]. Then you got to learn how not to talk when everybody else is talking and things like that".* (Session 2, 881-2)

Katie: "*For what we're trying to do now is establish some sort of routine for if I see the psychologist at a certain time each week, if I have a massage at a certain time each week, or if I see a neuro physio, whose very good at maintaining my level of pain and stop it getting worse".* (Session 2, 110)

Brian: "*It's given me again, another [pause] ambition. I quite fancy being a patient representative, as a nonexecutive director [pause] on an NHS trust".* (Session 1, 263-4)

Self-awareness

Katie: Reflecting that returning to work on a part-time basis would have alleviated some of the suffering she felt at the loss of her career at the bar.

Brian: Explaining that his work as a stroke ambassador has helped him to understand the label that the psychometric assessments had derived for him.

Philip: Explaining that recovery post-stroke involves you developing a better understanding of your disabilities over time, which is an ongoing process.

Susan: Sharing a post-stroke recognition that she now needs to accept help from others, as well as providing it, something she finds hard.

Katie: "*If I'd even gone back you know, a day or two a week, that would have been enough to stop me feeling this enormous sense of loss".* (Session 2, 167)

Brian: "*As I was going for more senior posts, I would have to have psychometric assessments and always came out as a pragmatic activist. Now, I actually understand [pause] more what that means".* (Session 3, Changes pin, 101-106)

Philip: "*You are finding out about yourself all the time. You're learning what works and what doesn't".* (Session 2, 999-1000)

Susan: *"I'm a very independent, sort of a strong-minded sort of a person and I'm not very good at letting others contribute to anything that I need".* (Session 2, 254)

<u>Opportunity awareness (open to finding a new purpose)</u>

Brian: Hoping for an opportunity to fulfil his ambition to become a non-executive director of a hospital trust.

Katie: Explaining she has now exhibited the paintings that she originally did in stroke therapy.

Susan: Her willingness in hospital to engage with as much physio as she could.

Philip: Open to trying out college courses, despite his learning difficulties.

Brian: *"I'll just have to see if the right opportunity comes up".* (Session 1, 266)

Katie: "*I've exhibited them at the stroke conference, last year and I've also exhibited at the [pause] Bloomsbury Festival".* (Session 2, 224)

Susan: "*I was desperate and eager and any opportunity I could have, I would take".* (Rehabilitation) (Session 2, 69)

Philip: "*If I thought I couldn't do it, but I might be able to, I would still go*". (Session 2, 1023)

<u>Decision making skills</u>

Susan: Taking in their friend Margaret, involved having to move house because she was in a wheelchair.

Philip: Learned about his motivation to help others from his sisters.

Katie: Her ambition to do a TED talk about her life.

Brian: Reflecting that he is now at a turning point in his life and so needs to consider his next career move.

Susan: *"And that was in 2008 and we had to move house to accommodate her because she was in a wheelchair".* (Session 2, 320)

Philip: "*Apparently, I'd told my sisters, after they looked after me, the one thing I wanted to do when I got back to as near as possible a normal life, was to help people who've been in my situation". (*Session 2, 1452)

Katie: *"I want to do a TED talk about brain injury and about recovery and [pause] my life".* (Session 3, 763)

Brian: "*It's now time, perhaps, to reappraise [pause] what I'd like to achieve*". (Session 3, Changes pin, 141)

Transition skills

Katie: Formally applied and was interviewed for her position as trustee of the Brain and Spine Foundation, prior to becoming a trustee.

Susan: Her involvement in the Christian community at Kingston University**.**

Philip: Reiterating the value of the networking opportunities that the 'Living with Stroke' event offered him.

Brian: Started to see the benefits of networking after attending a seminar on the results of the CLOTS 1 trial, where he met the chair of the Stroke Research Network.

5. Transition skills (Include Networking as data showed that was important for the stroke-survivors)

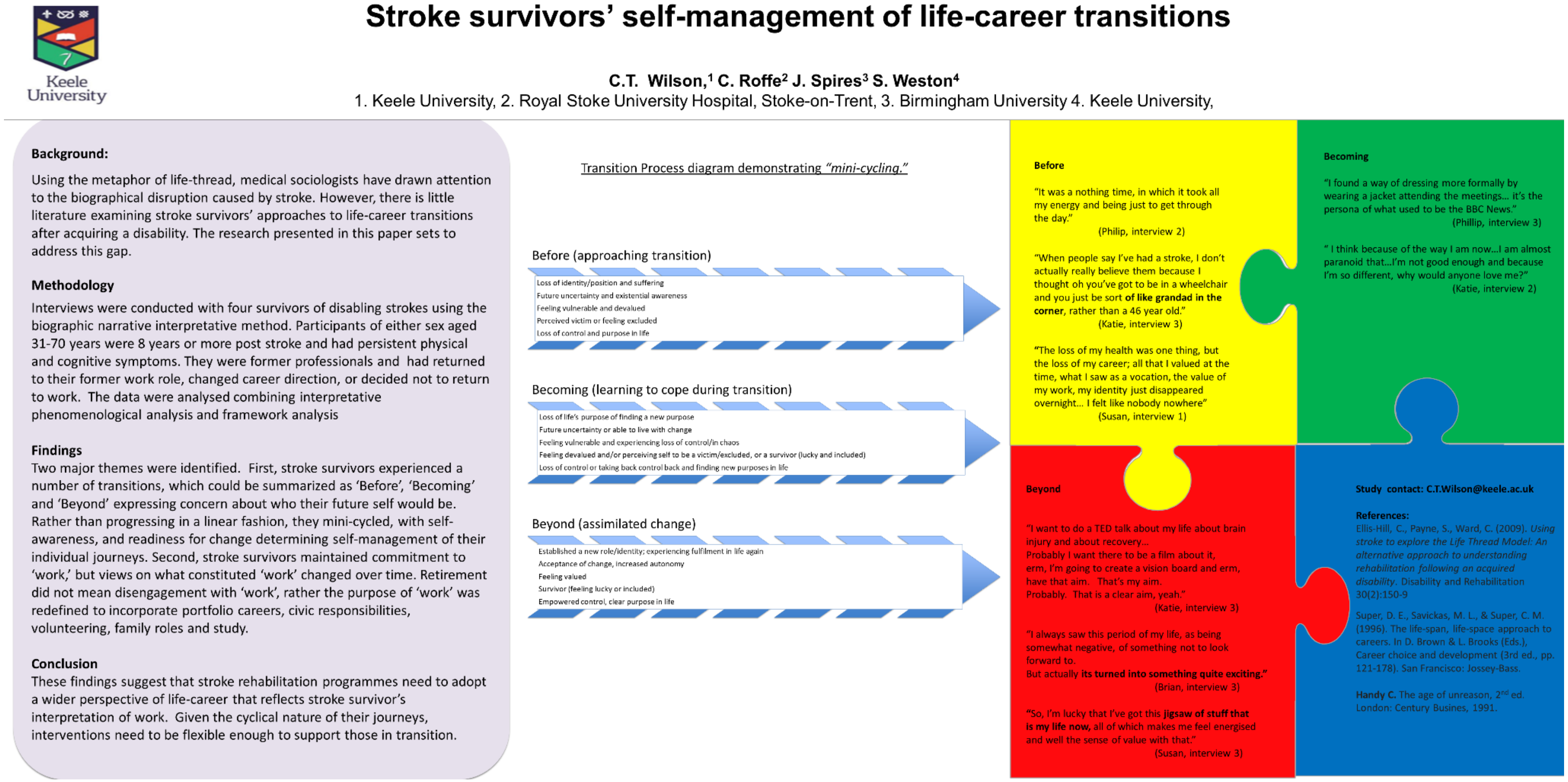
Katie: *"I had to put together a proper application and went for an interview and became a trustee". (Brain and Spine Foundation).* (Session 2, 175)

Susan: "I*t's mainly worship on a Sunday morning, but we also do things outside of that, like we have a group of non-students that meet together, oh about once a month for fellowship and I, arrange that".* (Session 3, part 2, 127)

Philip: *"And then I met loads of people who have changed my life over the following years".* ('Living with Stroke' event) (Session 2, 1481)

Brian: "*So, it's because of going to that seminar, at that time and that moment, that suddenly set off a ripple effect".* (Session 2, Hospital pin, 261-263)

Appendix V: e-poster for UK Stroke Forum, 2022.



Stroke survivors’ self-management of life-career transitions

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Background:

Using the metaphor of life-thread, medical sociologists have drawn attention to the biographical disruption caused by stroke. However, there is little literature examining stroke survivors’ approaches to life-career transitions after acquiring a disability. The research presented in this paper sets to address this gap.

Methodology

Interviews were conducted with four survivors of disabling strokes using the biographic narrative interpretative method. Participants of either sex aged 31-70 years were 8 years or more post stroke and had persistent physical and cognitive symptoms. They were former professionals and had returned to their former work role, changed career direction, or decided not to return to work. The data were analysed combining interpretative phenomenological analysis and framework analysis

Findings

Two major themes were identified. First, stroke survivors experienced a number of transitions, which could be summarized as ‘Before’, ‘Becoming’ and ‘Beyond’ expressing concern about who their future self would be. Rather than progressing in a linear fashion, they mini-cycled, with self-awareness, and readiness for change determining self-management of their individual journeys. Second, stroke survivors maintained commitment to ‘work,’ but views on what constituted ‘work’ changed over time. Retirement did not mean disengagement with ‘work’, rather the purpose of ‘work’ was redefined to incorporate portfolio careers, civic responsibilities, volunteering, family roles and study.

Conclusion

These findings suggest that stroke rehabilitation programmes need to adopt a wider perspective of life-career that reflects stroke survivor’s interpretation of work. Given the cyclical nature of their journeys, interventions need to be flexible enough to support those in transition.

Transition Process diagram demonstrating *“mini-cycling.”*

Before (approaching transition)

Loss of identity/position and suffering
Future uncertainty and existential awareness
Feeling vulnerable and devalued
Perceived victim or feeling excluded
Loss of control and purpose in life

Becoming (learning to cope during transition)

Loss of life’s purpose of finding a new purpose
Future uncertainty or able to live with change
Feeling vulnerable and experiencing loss of control/in chaos
Feeling devalued and/or perceiving self to be a victim/excluded, or a survivor (lucky and included)
Loss of control or taking back control back and finding new purposes in life

Beyond (assimilated change)

Established a new role/identity; experiencing fulfilment in life again
Acceptance of change, increased autonomy
Feeling valued
Survivor (feeling lucky or included)
Empowered control, clear purpose in life

Before

“It was a nothing time, in which it took all my energy and being just to get through the day.”
(Philip, interview 2)

“When people say I’ve had a stroke, I don’t actually really believe them because I thought oh you’ve got to be in a wheelchair and you just be sort **of like grandad in the corner**, rather than a 46 year old.”
(Katie, interview 3)

“The loss of my health was one thing, but the loss of my career; all that I valued at the time, what I saw as a vocation, the value of my work, my identity just disappeared overnight… I felt like nobody nowhere”
(Susan, interview 1)

Becoming

“I found a way of dressing more formally by wearing a jacket attending the meetings… it’s the persona of what used to be the BBC News.”
(Phillip, interview 3)

“ I think because of the way I am now…I am almost paranoid that…I’m not good enough and because I’m so different, why would anyone love me?”
(Katie, interview 2)

Beyond

“I want to do a TED talk about my life about brain injury and about recovery…
Probably I want there to be a film about it,
erm, I’m going to create a vision board and erm,
have that aim. That’s my aim.
Probably. That is a clear aim, yeah.”
(Katie, interview 3)

“I always saw this period of my life, as being somewhat negative, of something not to look forward to.
But actually **its turned into something quite exciting.”**
(Brian, interview 3)

“So, I’m lucky that I’ve got this **jigsaw of stuff that is my life now,** all of which makes me feel energised and well the sense of value with that.”
(Susan, interview 3)

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