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**Understanding self-harm behaviour
in older adults: a systematic review
and qualitative study**

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Abstract

Two worldwide challenges served as a drive for this research: the reality of an ageing population and the identified need of supporting people who self-harm. Addressing self-harm has been increasingly prioritised due to its social, economic and health impact. Despite lower rates of self-harm in older adults compared to younger populations, this behaviour has shown to have wider repercussions in later life. However, key research questions amongst this age group remain unanswered. The aim of this thesis was to increase the understanding of self-harm in older adults. Specifically, I addressed i) motivations to self-harm behaviour in older adults; ii) barriers and facilitators to access to care; iii) role of the different sources of support.

To address the aim of the thesis I start by introducing the research and policy context as well as key definitions and rationale for the study in Chapter 1. In Chapter 2, I provide an introduction to key terms and an overview of characteristics of self-harm. In Chapter 3, I introduce the literature on the characteristics of self-harm behaviour in the older adult population through the conduct of a systematic review. After reviewing the absence of current literature exploring motivations and access to care in older adults who self-harm, in Chapter 4, I present the methodology of the qualitative research exploring self-harm in older adults, framed within a critical realist perspective. In Chapter 5, I introduce the specific methods used. A qualitative approach was taken to answer the research questions, using semi-structured interviews with two participant groups recruited from community settings: older adults disclosing self-harm behaviour, and third sector workers with experience supporting older adults who self-harm. Follow-up interviews were offered to older adults. Data were analysed using thematic analysis with constant comparison methods. A Patient and Public Involvement and Engagement (PPIE) group contributed to the development and conduct of the research.

Findings are presented in Chapters 6 and 7 where I summarise the findings from 24 interviews conducted with 16 participants included in this research (9 older adults and 7 support workers). Narratives from older adults and support workers follow a life-course perspective where self-harm was described as occurring throughout the years as a response to the accumulated life experiences of older adults. Self-harm was described by participants as a response to dealing with different accumulated stressors experienced throughout the life-course of older adults: i) adverse childhood events; ii) interpersonal problems; iii) health problems; iv) loss and loneliness. Motivations to self-harm varied within a suicidal spectrum of no suicidal intent to high levels of suicidal intent, where self-harm served different functions to older adults throughout their lives. More specific motivations to self-harm were provided and described as 'a cry for help', a strategy to cope or to regain control. Participants described older adults often feeling shame due to self-harm.

Chapter 7 explores barriers and facilitators to access to care, describing the process of help-seeking behaviour experienced by older adults. Participants described older adults often living with their self-harm undisclosed due to the shame and stigma experienced, this may result in delayed help-seeking. Furthermore, older adults were described as not identifying their self-harm behaviour as needing a medical consultation, delaying further access to care. When the decision to seek help was made, older adults used different sources of support, ranging from the formal sector (health services, social care and third sector) to the informal sector (family, peers, faith and internet). Barriers and facilitators to access to care were described by participants, ranging from external to internal factors as well as structural barriers and facilitators.

Lastly, in Chapter 8 I contextualise the findings with current literature. Strengths and limitations to the study are provided as well as description of the impact of PPIE involvement. Research and policy implications resulting from this research are summarised, highlighting implications for the healthcare, education, social care and third sectors.

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List of Abbreviations

CPN: Community Psychiatric Nurse

DALYs: Disability Life Adjusted Years

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition

ED: Emergency Departments

GP: General Practitioner

IAPT: Improving Access to Psychological Therapies

ICD-10: International Classification of Diseases, Tenth Revision

LGBT: Lesbian, Gay, Bisexual and Transgender

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health Research

NSSI: Non-suicidal Self-injury

PPIE: Patient and Public Involvement and Engagement

PTSD: Post-traumatic Stress Disorder

UK: United Kingdom

USA: United States of America

WHO: World Health Organization

YLD: Years Lived with Disability

YLL: Years of Life Lost

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CHAPTER 1: INTRODUCTION

1.1 Introduction

This thesis is an exploration of self-harm behaviour in older adults. Throughout the chapters that follow, I detail why, how, when and what was conducted for me to explore in-depth self-harm behaviour in older adults. First, I start by giving the definition of terms and concepts used throughout, introducing the area of study within a policy and research context, state the underlying reasons for the need of this study, provide the research questions, objectives and overall aim of this thesis. Secondly, I provide a background chapter presenting the main characteristics of self-harm, epidemiology, impact to society, functions, amongst others. Thirdly, I present a systematic review of the literature of self-harm in later life, focusing on characteristics, methods, prevalence and risk factors of the mentioned. Fourthly, I describe the qualitative methodology followed by the selected methods. Fifth, in Chapters 6 and 7 I present the findings, followed by discussion of the findings with reference to prior research, implications and areas for future research.

1.1.1 Definition of terms and concepts

Throughout this thesis, I regularly use the terms self-harm and older adults. Prior to presenting the rationale for this thesis, clarification of the definition of constructs of self-harm and older adults is needed to orientate the reader with regards to the meaning attributed to the two mentioned concepts.

Self-harm

There is a vast array of terms and definitions used to refer to self-harm behaviour across the academic literature. Maintaining consistency to one single terminology with a clearly stated definition is imperative to carry out and deliver research and findings. For the purpose of this thesis, the definition as adopted by the National Institute for Health and Care Excellence (NICE) guidelines was used to refer to self-harm. NICE defines self-harm as “any act of self-poisoning or self-injury carried out by a person, irrespective of their motivation” (NICE, 2011).

Typical presentations of self-harm include self-poisoning with medication and self-injury by cutting (NICE, 2011).

Whilst certain behaviours such as excessive consumption of alcohol or drugs, mismanagement of physical health conditions, overeating, or starvation may be seen as harmful behaviours to oneself, this thesis did not include such behaviours to refer to self-harm. This was done to maintain consistent with one single, universal definition and have a clear construction of meaning of self-harm. Limitations to adhering to one single definition and not including a broader definition are acknowledged and discussed in Chapter 8.

The terms mental health and mental disorders are also used throughout this thesis. Mental health, defined by the World Health Organization (WHO) (2004) as “a state of wellbeing in which the individual realises his/her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his/her community” is the term adopted in this research when making reference to mental health. As the WHO (2004) further comments, mental health is not merely the absence of a mental disorder, but rather a state of wellbeing. Also used throughout this thesis is the term mental disorder, used to refer to the broad range of different health conditions (e.g. depression, schizophrenia, personality disorders) that are “generally characterised by some combination of abnormal thoughts, emotions, behaviour and relationship with others” (WHO, 2018). Other terms used to refer to the above described include mental health conditions, mental illness, psychiatric disorders. However, the term used throughout this thesis is mental disorders.

Older adults

As with the definition of self-harm, there is a lack of agreement across the literature when defining older adults. For the purpose of this research, the lower age range used for older adults is the one used by the WHO, which defines older adults as any person aged 60 years or older (WHO, 2015).

Both definitions used throughout this study, self-harm and older adults, were discussed and agreed with the Patient and Public Involvement and Engagement (PPIE) group that contributed to the research as is further summarised in sections 3.4, 5.3, 6.6, 7.5 and 8.3.

1.2 Rationale for the study

Prior to the introduction of the specific area of research, I present the main areas that drove the conduction of this thesis. I start by stating the policy and research context, introducing the need for exploring mental health, including self-harm behaviour, and older adults, followed by the importance and relevance of conducting health research in collaboration with patients and the public. Lastly, taking into consideration all elements together, I provide the rationale for the conduction of this thesis.

1.2.1 Policy context

i. Mental health

It is estimated that one out of three people will suffer from a mental disorder during their lifetime (Steel et al., 2014). Non-communicable diseases (NCDs), including mental disorders, have been on the rise and approximately two of every three deaths are caused by NCDs worldwide (Lozano et al., 2013). Alongside mortality, the impact NCDs have on society can be calculated through the estimation of morbidity through disability life adjusted years (DALYs) (WHO, 2008). Years of life lost (YLL) and years lived with disability (YLD) are the two measures that combined estimate both mortality and morbidity in DALYs (WHO, 2008). Results from the Global Burden of Disease study show mental disorders to be one of the groups of diseases to cause most burden to society, with 21.2% of YLDs and 7.1% of DALYs (Vos et al., 2015). These figures ranked mental disorders as the highest group of conditions to cause YLDs and fifth overall in terms of Global Burden of Disease (Institute for Health Metrics and Evaluation, 2013).

Vigo and collaborators argue that the results from the Global Burden of Disease are an underestimation of the impact of mental disorders given that this study failed to consider

suicide and self-harm in their cluster of mental disorders and instead were classified under injuries (Vigo, Thornicroft & Atun, 2016). Self-harm behaviour and suicide contribute significantly to the Global Burden of Disease, with an estimated 880,000 deaths due to suicide in 2010 alone (Lozano et al., 2013). A caveat to this estimate is that this is most likely an underestimation of the actual number of occurring self-harm episodes and suicides due to the stigma and even legal implications behind these behaviours amongst certain societies (Thornicroft, Rose, Kassam & Sartorius, 2007; WHO, 2012a). Self-harm behaviour has a significant economic and social impact on society, including loss of productivity caused from absence to the workforce, as well as associated direct medical costs (Naghavi, 2019; O'Dea & Tucker, 2005). Although self-harm is a behaviour and not a diagnosed mental disorder, it is linked to mental disorders and the burden arising from them (Hawton, Saunders, Topiwala & Haw, 2013). Evidence suggests self-harm to be the most important risk factor for suicide and is also common amongst many mental disorders (APA, 2013; Hawton, Zahl & Weatherall, 2003). Increasingly, governments worldwide, alongside the WHO have called for action to reduce the number of suicides and self-harm due to the irreparable consequences they have to society (Department of Health, 2017; NICE, 2011; O'Dea & Tucker, 2005; WHO, 2012a).

Consequences of untreated mental disorders entail economic, human and social costs to society (Romeo, McCrone & Thornicroft, 2017). Self-harm is often a symptom or behaviour of people diagnosed with certain mental disorders, contributing to this impact. Untreated mental disorders take out a substantial toll of a nation's economy, with figures showing £105.2 billion annually in the United Kingdom (UK) (Department of Health, 2011). However, this can be easily prevented as cost-effective interventions have been identified for multiple mental disorders, including self-harm behaviour (Barrett et al., 2005; Byford et al., 2003; Knapp, 2000; Knapp et al., 2006; Park et al., 2018). Governments worldwide have prioritised mental health given the described adverse effects. In the UK, the 2011 cross-government strategy and policy '*No Health without Mental Health*' called for action to improve mental wellbeing, seeing mental

health as an inseparable part of overall wellbeing, with similar policies following in more recent years (Department of Health, 2011; NHS, 2016a & 2019).

Amongst older adults, addressing mental health in later life has been identified as a priority according to the UK's Department of Health (2005) not only because of the low service provision and access to care from this significant part of the population, but also due to the comorbid conditions and frail health in older adults (NHS, 2016b).

All of the above mentioned puts the present study into context with regards to the overarching mental health policy context. There is both a need and recognition of addressing mental disorders, including self-harm behaviour.

ii. Ageing

The world's population is ageing, presenting both challenges and opportunities for societies. Specifically, in the UK, the population is rapidly ageing, with over 15 million people being 60 years or older (ONS, 2017). There are different terminologies used to refer to those aged 60 and older including older adults, elderly, late adulthood, later life, senior citizens, pensioners, retired, amongst others. Each term holds different meanings and values amongst societies, some holding negative connotations. Older adult is the term used in this thesis to refer to the WHO's definition of those adults aged 60 and older. Further description and clarification of what it means to study this population is made below in order to fully comprehend the implications of the study of later life.

Improving healthcare in older populations is a priority worldwide and, in the UK, (NHS, 2016b; WHO, 2015). Medical and technological advances have increased life expectancy worldwide, as well as creating changes in age distribution, resulting in ageing societies (WHO, 2015). Despite populations worldwide growing older, they are also facing increased morbidity and disability (Atun, 2015; Bloom, 2011; Lozano et al., 2013; Vos et al., 2015). This changing age distribution has implications for societal, political, cultural, economic, educational and health settings.

Drawing on principles put forward in social gerontology, this thesis adopted a life-course perspective to the study of ageing (Dannefer & Phillipson, 2010). When studying older adults, social gerontology stresses the importance of seeing the study of life in a life-course perspective, where gerontology and older people are one part of it (Dannefer & Phillipson, 2010). As defined by Hutchison (2010, p. xxii), a life-course perspective “looks at how chronological age, relationships, common life transition and social change shape people’s lives from birth to death”. Environmental and personal factors also shape and influence the experience of people’s lives. These factors include culture, family and social structures for the former and biological and psychological factors for the latter. The decisions, cumulated practices and experiences of individuals throughout their entire life result in ageing. Therefore, a life-course perspective, that recognises later life as being dynamic and part of cumulated life practices and experiences, was adhered to in this study to comprehend and put into context the different social, political, historical and educational aspects of ageing.

1.2.2 Research context

Alongside the presentation of the policy context which drives this thesis, it is important to highlight the research context which this study is situated in. Health research contributes to a fundamental part of research conducted worldwide, with a significant amount of resources, funded by governments, charities and the private sector, spent on health research (NIH, 2017; Scienceogram UK, 2017). Health research has indeed transformed the world, with changing population patterns and overall increased quality of life, as the WHO highlights (WHO, 2015). Not only has health research increased over the past decades, but also its applicability and overall quality (WHO, 2012b).

Increased patient and public involvement in health research and service delivery, also known as Patient and Public Involvement and Engagement, has been cited as one of the reasons for increased quality and applicability of health research (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). The concept of PPIE emerged over 40 years ago, with the Alma Ata Declaration stating both the duty and right of the public being involved in health

research and service planning (WHO, 1978). Since then, PPIE in health research has increased significantly, with the most recent systematic review reporting over 13,000 studies published between 1995 and 2002 including PPIE in their research (Brett et al., 2014).

Over the past years, PPIE has had a significant impact to both health services and planning, as well as health research (Crawford et al., 2002; Domecq et al., 2014; Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012) (see Figure 1.1). For service planning, a systematic review exploring PPIE’s impact on health services found that PPIE can result in improvement of health services planning and development, influence the attitudes of service users and providers and aid information development and dissemination (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). This impact goes beyond the described development of health services, but it also starts a shift in responsibility from a traditional health model where patients are merely spectators of their health and wellbeing, to a collaborative and proactive healthcare model (Seedhouse, 2008).

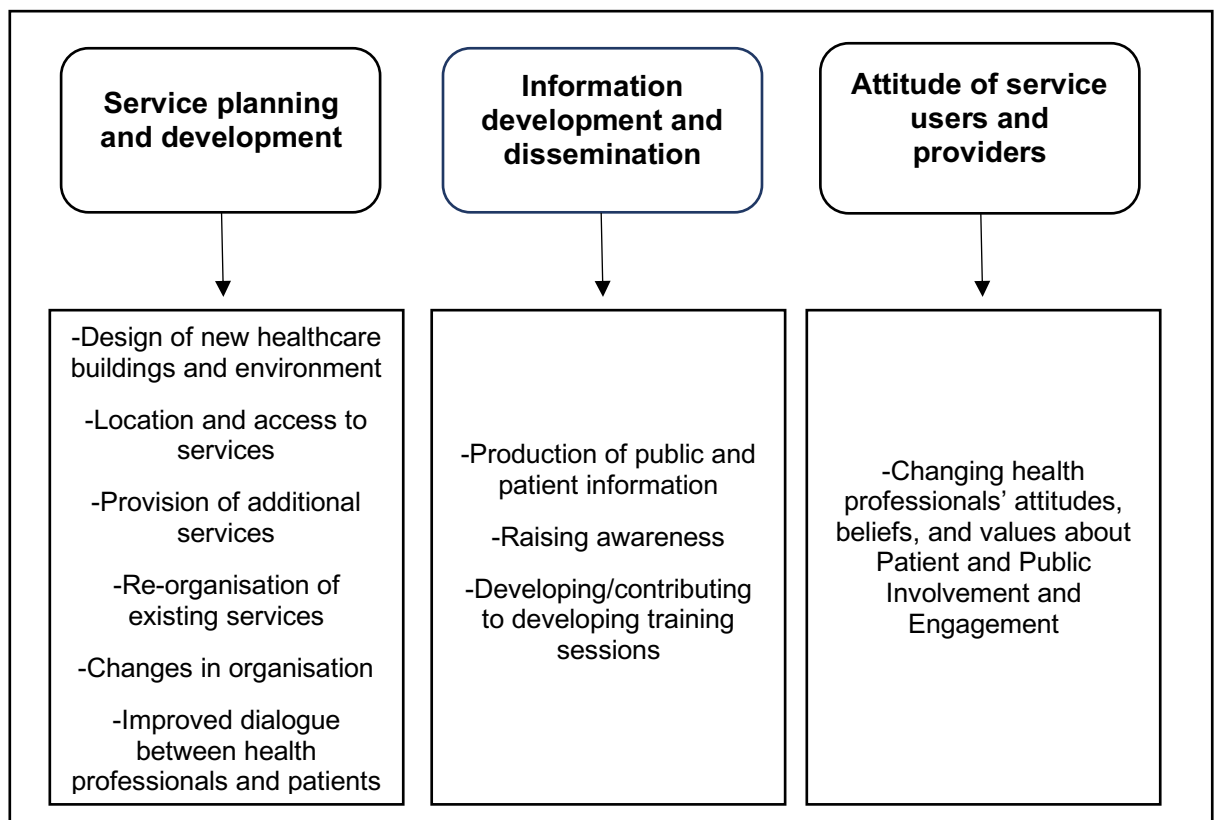


Figure 1. 1 Impact of PPIE in health services adapted from Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012

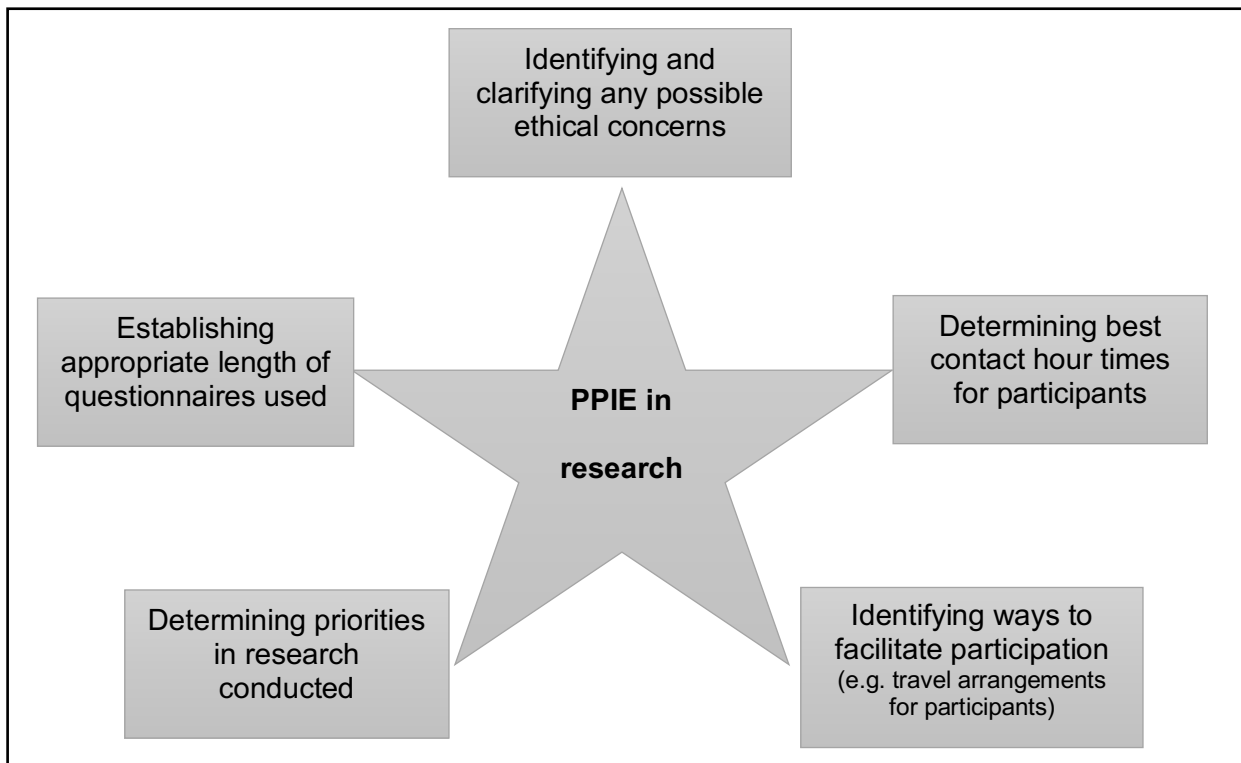


Figure 1. 2 Examples of benefits of including PPIE consultation in research

Furthermore, as a result of the importance of including the public's perspective in health research conducted, the majority of research funding bodies worldwide, request PPIE in the research being funded. Benefits of including the public's perspective in health research have been identified previously (Domecq et al., 2014) and summarised in Figure 1.2. Despite the possible pitfalls that may occur when incorporating PPIE in health research (highlighted in Figure 1.3), PPIE gives researchers the opportunity to transcend in their study findings and take advantage of the benefit of involving the public in research.

This thesis takes the described context forward by conducting its research in collaboration with a PPIE group as a fundamental pillar in the research conducted as highlighted in future chapters. As part of previous research conducted on the epidemiology of self-harm in primary care (Carr et al., 2016), a PPIE group was set up by one of the study's co-authors and PhD supervisor (CCG). Members from that PPIE identified the need to research self-harm in older adults as this was not covered in the study. In particular, the group highlighted the importance of exploring motivations for self-harm in this age group. After this

meeting had been held, I commenced my PhD and reconvened a new PPIE group that would be present during all aspects of the research. PPIE members for my PhD had to be older adults (60 years or older) with a history of self-harm behaviour, carers of older adults with self-harm behaviour, or support workers with experience supporting older adults with self-harm behaviour. Eligible members from the PPIE group from the Carr and collaborators study (2016) were invited to be join the newly formed PPIE group. Local third sector groups were also contacted in order to invite potential members to join the PPIE group convened for the PhD.

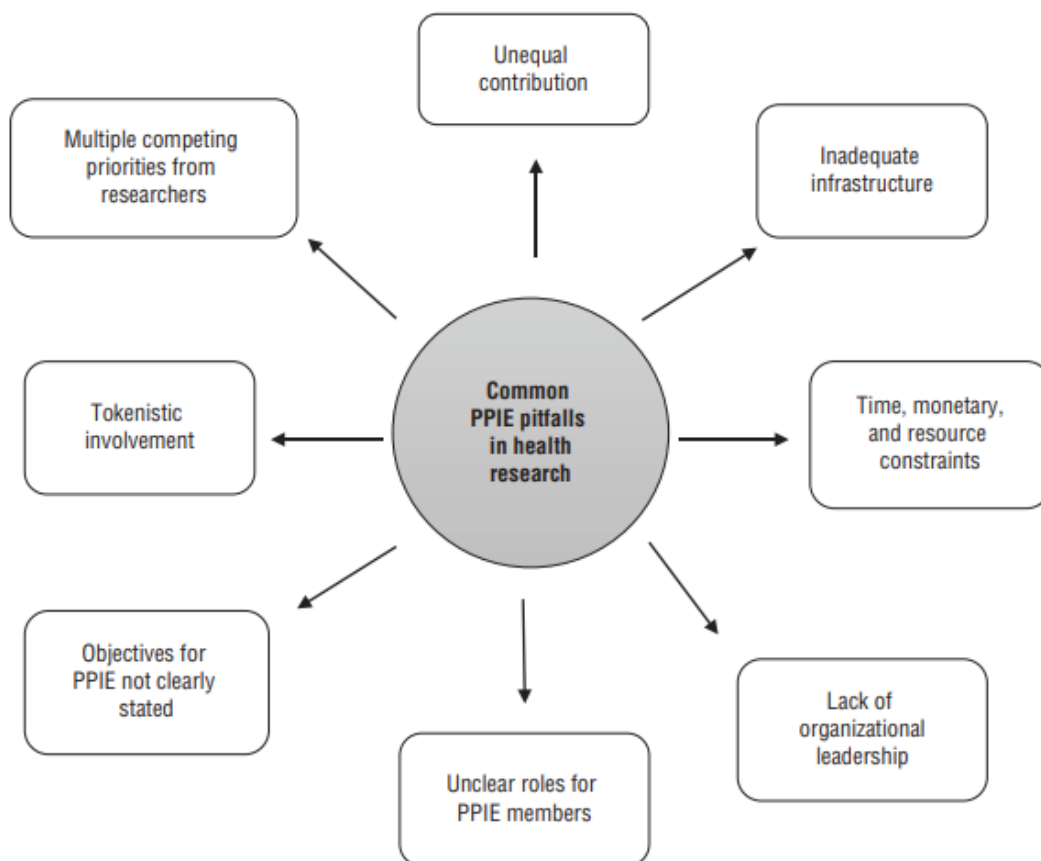


Figure 1. 3 Common pitfalls of PPIE in health research (from Troya, Bartlam & Chew-Graham, 2018)

Moreover, as will be presented throughout this thesis, patient involvement in my research did not solely consist on one-off consultations with the public but was rather regular

and robust involvement. Such involvement allowed taking PPIE one step forward to co-production of research and outputs, as is further presented in subsequent chapters.

1.2.3 Overall rationale

The previously presented research and policy context highlight two underlying priorities that drive this research: the reality of a worldwide ageing population and the identified need of supporting people with self-harm behaviour. Also driving this research is the importance of researching self-harm in older adults, which the PPIE group highlighted. In the UK, self-harm has been increasingly prioritised by research and health authorities due to its social, economic and health impact on the general population (NICE, 2011). With an estimated 220,000 emergency department (ED) presentations of self-harm per year in England and an estimated cost of £162 million per year for medical and psychiatric care of self-harm patients, self-harm prevention is a national priority (Hawton et al., 2007; Tsiachristas et al., 2017).

Despite rates of self-harm in later life not being as high compared to other populations (Brown, Comtois & Linehan, 2002; Brown & Beail, 2009; Haw et al., 2005a; Hawton, Rodham, Evans & Weatherall, 2002; Snow, 2002), self-harm in older adults is a major public health concern due to its close link with suicide and increasing resource costs (Logan, Crosby & Ryan, 2007). Although not necessarily linked with suicide, self-harm in older adults most closely predicts suicide and is 67 (secondary care settings) and 145 (primary care settings) times more likely in older adults (Morgan et al., 2018; Murphy et al., 2012). Suicide rates in older adults are one of the highest worldwide (De Leo et al., 2001; WHO, 2012a). Moreover, self-harm rates in older adults have been increasing over the past decades, showing different patterns, methods and motivations compared to other populations (Geulayov et al., 2016). It is, thus, important to further explore self-harm behaviour in older adults.

Understanding motivations to self-harm behaviour is important as this may improve service delivery and support offered to individuals with self-harm behaviour. Motivations to self-harm in older adults may be different compared to younger populations and therefore tailored

treatment and support can be offered depending on the age group. Older adults who self-harm have a higher suicidal intent compared to middle aged adults according to a prospective cohort study from North West England that collected data for 10 years (1997 to 2007) (Oude et al., 2011). The study also reported that self-harm in older adults is more closely related to feelings of hopelessness and increased physical illness, so interventions and responses need to be tailored to account for these factors (Oude et al., 2011). Despite the study being based in a very specific sample (secondary care settings: such as ED), it illustrates trends and patterns of self-harm in the two different age groups of middle-aged and older adults.

It is important to learn what type of support people who self-harm access in order to provide adequate funding and support. However, no previous research has explored access to care in older adults with self-harm behaviour.

No systematic review of the literature has been conducted to explore self-harm in older adults, highlighting the need of summarising and critically appraising evidence. Furthermore, existing literature exploring self-harm in older adults is mostly limited to quantitative designs, focusing on estimating prevalence rates, and predominantly based in secondary care settings. However, older adults are in frequent contact with community settings such as primary care and the third sector, so further information is needed from this setting (Abendstern, Hughes, Jasper, Sutcliffe, & Challis, 2018). Accounts of lived experiences are essential to understanding complex behaviours such as self-harm behaviour (Bantjes & Swartz, 2019; Hjelmeland & Knizek, 2010). A qualitative methodology can allow for the exploration of self-harm behaviour in older adults. No research has focused on exploring the motivations of older adults who self-harm, or the type of care older adults who self-harm access when seeking support. Both the public and academics have identified the need of researching self-harm behaviour in older adults. The dearth of research in the area highlights a gap in the literature that must be addressed. There is a need to understand individuals' perspectives on self-harm in older adults to further support this population.

1.3 Investigation approach and research questions

The aim of this thesis is to increase the understanding of self-harm behaviour in older adults (60 years or older). The study addresses the following research questions:

- What are the perceived motivations of self-harm behaviour in older adults?
- What are the barriers and facilitators of access to care and support for older adults who self-harm?
- What are the potential roles, if any, of family, friends, third sector support groups and primary care professionals, in supporting older adults who self-harm?

Objectives

- To explore what underlies self-harm behaviour and what can help a person avoid this behaviour
- To identify the facilitators and barriers of access to care of older adults who self-harm
- To explore the role, if any, of the different sources of support involved in supporting or hindering older adults who self-harm
- To develop service and policy recommendations for the population of older adults who self-harm.

Through the stated research questions, objectives and aim, I explore in this thesis the perspectives of older adults with self-harm behaviour, as well as third sector support workers offering support to older people with self-harm behaviour.

CHAPTER 2: BACKGROUND

2.1 Introduction

In this chapter, I provide an in-depth exploration of self-harm, giving readers a historical perspective of the development of the terminology used, rates of self-harm amongst populations (both clinical and community) and different methods used to self-harm. I then present the association of self-harm with other conditions such as suicide and certain mental illnesses. The perspectives of four schools of thought explaining functions of self-harm is then presented. The clinical management and prevention of self-harm repetition is addressed, as well as literature around clinicians' attitudes towards people who self-harm. The different opportunities to accessing care is presented, including the social, health and third sector. Finally, in this chapter I conclude by presenting the impact self-harm has, including percentages from the global burden of disease, as well as the economic strain on society.

2.2 Self-harm overview

2.2.1 Terminology of self-harm

As mentioned in Chapter 1, within the existing academic literature, there are a variety of terms used to refer to self-harm: parasuicide (Kreitman, Philip, Greer & Bagley, 1969; Platt, Hawton, Kreitman, Fagg & Foster, 1988), deliberate self-harm (Chan, Draper & Banerjee, 2007; Hawton, Rodham, Evans & Weatherall, 2002), non-fatal self-harm (Geuyalov et al., 2016), suicidal behaviour (Fassberg et al., 2012), self-injury (Bosman & van Meijel, 2008), self-poisoning (Gjelsvik, Heyerdahl, Holmes, Lunn, & Hawton, 2016), non-suicidal self-injury (Selby, Bender, Gordon, Nock & Joiner, 2012) and self-harm (Hawton et al., 2016a, Taylor, Hawton, Fortune & Kapur, 2009). This range of terminology has taken away consistency, applicability and generalisability of research in the area, as well as hindering implementation of available evidence in practice and policy. The core difference between each term used varies but is mostly based on suicidal intent and/or method of self-harm. However, suicidal intent is not always easy to obtain, given that intentions behind the act are often not clear from

individuals, with self-harm holding several functions (Freedenthal, 2007). In a recent study reviewing the self-harm classification system, it was found that deliberate self-harm and self-harm are terms commonly used in the UK, while self-injury and self-mutilation are most typically found in the United States (Buresova, 2016). In an attempt to fully comprehend the different terminology used in the academic literature, a brief overview of the terms used are presented.

One of the earliest written reports of self-harm date back to the early 13th Century, when first descriptions of self-harm were described by Christian writers (Chaney, 2017). Despite self-harm behaviour continuing being described throughout the different periods (Figure 2.1), it was only during mid-late 19th century that self-harm was codified and classified as a behaviour amongst early asylum psychiatry (Chaney, 2017). Over the years, not only have different terminologies been used to refer to self-harm, but additionally, other conceptualisations of self-harm have been considered to further understand self-harm.

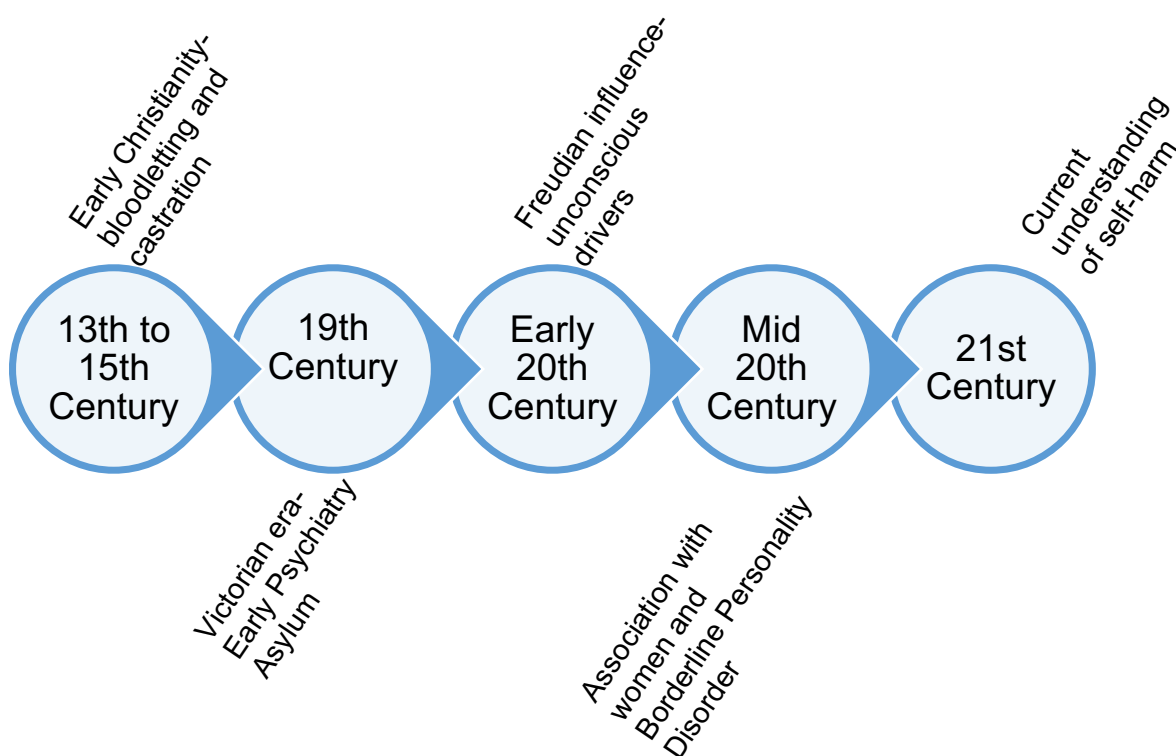


Figure 2. 1 Development of the term self-harm through history

Psychoanalytic researchers Emerson and Menninger were amongst the first authors to describe self-destructive behaviour during the early first half of the 20th century, referring to such behaviour as self-mutilation (Emerson, 1913; Menninger, 1935). Kreitman (1969) followed by defining and using the term parasuicide to refer to all suicide attempts and self-harm behaviour that does not result in death. The term 'parasuicide' continued to be used during the last century, referring to non-fatal deliberate self-harm or non-fatal act in which an individual deliberately causes self-injury and or takes a substance in excess of any prescribed or generally recognised therapeutic dosage (Platt, Hawton, Kreitman, Fagg & Foster, 1988).

Due to increasing knowledge and the realisation of how parasuicide may misguide the audience by including an exclusive focus on suicidal intention, the term deliberate self-harm started to be used in the last decade of the 20th century. Simultaneously used, maintaining to the term used by previous psychoanalysts, Favazza started to research and conceptualise self-harm under the name of self-mutilation during the end of the 20th century (Favazza & Rosenthal, 1990). The American psychiatrist has since then continued to research the field, changing the terminology used, starting with self-mutilation to self-injurious behaviour (Favazza, 2007) and non-suicidal self-injury (Favazza, 2011).

'Deliberate self-harm' was a term used to refer to intentional self-poisoning or self-injury, irrespective of the apparent purpose, an almost identical definition when compared to the one used by the NICE (2011) (Hawton, Rodham, Evans & Weatherall, 2002). However, due to the pejorative connotation that the prefix 'deliberate' has, as well as the belief that a person could refrain from self-harm behaviour (Allen, 2007), the term was modified to self-harm, eliminating the word 'deliberate'.

It is worth noting which behaviours are and are not considered self-harm is to an extent reliant on prevailing social and cultural acceptable norms (Allen, 2007). Without taking away from clearly evident behaviours of self-harm which have the explicit intention to harm oneself, there are other behaviours which are dependent on existing cultural norms. Body piercing could be seen as self-harm behaviour, but it is not due to the cultural acceptability within a

group of individuals (Favazza, 2011). As part of his examination of the relationship between culture and psychiatry, specifically self-harm, Favazza (2011) noted that body piercing could be seen as self-inflicting harmful behaviour but very much varies on culture, context and time.

As presented in Chapter 1, self-harm as defined by NICE (2011) is the selected meaning used in this thesis. However, as just reviewed there have been different terminologies used throughout the years used to refer to self-harm. What must also be taken into consideration prior to reviewing the literature is that there are still heterogeneous definitions, terms and meanings used to refer to self-harm by researchers and clinicians worldwide.

2.2.2 Methods of self-harm

The WHO (2016a) classifies self-harm according to the different methods used through the ICD-10: International Classification of Diseases (Table 2.1). It is important to have worldwide common terminology and coding to refer to self-harm as it gives a universal classification and recognition of this type of behaviour amongst clinicians and other professionals. Nevertheless, a more comprehensive overview of the different type of self-harm methods is also presented.

i. Self-poisoning

As stated in NICE's definition of self-harm, self-poisoning is one of the presentations of self-harm. According to NICE (2011), self-poisoning refers to the intentional self-administration of more than the prescribed dose of any drug or medication that aims to harm the patient, though not necessarily results in death. Many studies show that more than half of self-harm hospital presentations are due to self-poisoning, with rates as high as 90% (Gunnell, Bennewith, Peters, House & Hawton, 2005; Hawton & Harriss, 2006; Horrocks, Hughes, Martin, House & Owens, 2005; O'Loughlin & Sherwood, 2005). Therefore, evidence suggests that self-poisoning may lead to increased contact with secondary settings such as ED. This reflects what others have found regarding people who self-poison being more likely to obtain help compared to those who self-injure given the management and treatment needed resulting from the self-harm episode (Hawton, Rodham, Evans & Weatherall, 2002; Meltzer, 2002).

Table 2. 1 ICD 10 classification for self-harm (WHO, 2016a)

<i>ICD 10 classification for self-harm</i>	
X60	Intentional self-poisoning by and exposure to non-opioid analgesics, antipyretics and antirheumatics
X61	Intentional self-poisoning by and exposure to antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs, not elsewhere classified
X62	Intentional self-poisoning by and exposure to narcotics and psychodysleptics (hallucinogens), not elsewhere classified
X63	Intentional self-poisoning by and exposure to other drugs acting on the autonomic nervous system
X64	Intentional self-poisoning by and exposure to other and unspecified drugs, medicaments and biological substances
X65	Intentional self-poisoning by and exposure to alcohol
X66	Intentional self-poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours
X67	Intentional self-poisoning by and exposure to other gases and vapours
X68	Intentional self-poisoning by and exposure to pesticides
X69	Intentional self-poisoning by and exposure to other and unspecified chemicals and noxious substances
X70	Intentional self-harm by hanging, strangulation and suffocation
X71	Intentional self-harm by drowning and submersion
X72	Intentional self-harm by handgun discharge
X73	Intentional self-harm by rifle, shotgun and larger firearm discharge
X74	Intentional self-harm by other and unspecified firearm and gun discharge
X75	Intentional self-harm by explosive material
X76	Intentional self-harm by smoke, fire and flames
X77	Intentional self-harm by steam, hot vapours and hot objects
X78	Intentional self-harm by sharp object
X79	Intentional self-harm by blunt object
X80	Intentional self-harm by jumping from a high place
X81	Intentional self-harm by jumping or lying in front of moving object
X82	Intentional self-harm by crashing of motor vehicle
X83	Intentional self-harm by other specified means
X84	Intentional self-harm by unspecified means

However, it is important to note that these studies were based in secondary care settings such as ED, where only a fraction of individuals with certain self-harm characteristics present. Commonly, self-poisoning has been associated with increased suicidal intent, however self-harm methods vary amongst individuals who self-harm, as well as motivations, not following a single pattern (Lilley et al., 2008; NICE, 2011; Sutton, 2007). Numerous studies have attempted to establish the relationship between method of self-harm and suicidal intent which is further explored in section 2.2.4.

ii. Self-injury

Self-injury is defined as the intentional and direct act of injuring one's body tissue with or without suicidal intent (NICE, 2011). This includes cutting, stabbing, burning, hitting, or excessive rubbing. The terminology just defined is not the same as the recently developed term of NSSI or non-suicidal self-injury, which is used to refer to the act of self-injury that excludes suicidal intention (APA, 2013; Nock, 2009; Zetterqvist, 2015). Despite the American Psychiatric Association's newly appointed terminology of NSSI, the present study maintains to the term of self-injury used to include both suicidal and non-suicidal intention, as evidence of a new diagnosis is premature due to the lack of evidence across the wide-ranging population of those who self-harm (Kapur, Cooper, O'Connor & Hawton, 2013). This will also maintain consistency with the overarching definition of self-harm given by NICE (2011). Studies amongst specific populations, such as imprisoned (Lohner & Conrad, 2006), psychiatric inpatients (Taiminen, Kallio-Soukainen, Nokso-Koivisto, Kaljonen & Helenius, 1998), teenagers (Hawton, Rodham, Evans & Weatherall, 2002), people with Borderline Personality Disorder (BPD) (Soloff, Lis, Kelly, Cornelius & Ulrich, 1994) and intellectual disabilities (Brown & Beail, 2009), present evidence of prevalent cases of self-injury as a method of self-harm. In addition, trends and characteristics of those who self-injure can be very distinct to those who self-poison. Evidence from a multicentre cohort study conducted with emergency department self-harm presentations showed that hospital-presenting patients who self-injure are more likely to have self-harmed previously and have had contact with mental health services,

however, they are less likely to receive a psychosocial assessment or be admitted to hospital after an episode of self-harm (Lilley et al., 2008). Other studies in the area resonate the previously stated findings, having confirmed them (Arensman et al., 2018; Harriss, Hawton & Zahl, 2005; Horrocks, Price, House & Owens, 2003; Mitchel & Cameron, 2018). Patients who self-injure are not being adequately supported when presenting to hospital settings, following lack of appropriate of care and support, hindering their wellbeing (Lilley et al., 2008).

iii. Other self-harm methods

Despite NICE guidelines (2011) not mentioning other methods of self-harm as part of the criteria, there are other methods people use to harm themselves. As was seen earlier, self-harm through self-poisoning and self-injury are the most common with overdose of medication (both prescribed and over the counter), as well as inducing cuts, burns, hanging, asphyxiation and jumping. However, excluded from the definition used in this study is self-harm through, mismanagement of physical health conditions, starvation, overconsumption of alcohol or other drugs, or body piercing (NICE, 2011). Indirect self-harm, which includes self-neglect, refusing to take essential medication, eat, or drink, is also referred by some researchers (Draper, Brodaty & Low, 2002; Wand, Peisah, Draper & Brodaty, 2018a). However, as mentioned earlier, NICE's (2011) definition of self-harm was adhered to in this thesis, therefore indirect self-harm was excluded.

2.2.3 Epidemiology

As was noted in section 2.2.1, there is a wide terminology used worldwide to refer to self-harm. The different range of terms used makes it difficult to synthesise information of self-harm across populations. This is why some of the studies used to report on epidemiological rates will have a specific term to refer to self-harm and a narrow/precise definition of self-harm (e.g. attempted suicide or NSSI).

Without including non-suicidal self-harm, the WHO (2016b) estimates that there are 16 million suicide attempts per year. This is most likely an underestimation, as the calculation is

based on hospital presentations as well as excluding self-harm without suicidal intent. However, a significant proportion of people self-harm and manage their behaviour at home, without receiving any medical or psychological attention (Royal College of Psychiatrists, 2010). This has been noted by Geulayov and collaborators (2017) study in self-harm in adolescents where they estimated that for every 370 adolescents presenting with self-harm to hospital, 3,900 adolescents reported self-harm in the community. Section 2.2.10 further explores the role of stigma, however stigma associated with self-harm makes it hard to estimate the exact number of occurrences amongst the general population (Law, Rostill-Brookes & Goodman, 2009). Multiple studies have reviewed epidemiological rates of self-harm, with more evidence in certain groups as this type of behaviour is seen more prevalent in them as is now presented (Bhui, McKenzie & Rasul, 2007; Carr et al., 2016; Hawton, Rodham, Evans & Weatherall, 2002; King et al., 2008; Klonsky & Moyer, 2008; Swannell, Martin, Page, Hasking & St John, 2014).

In England, the prevalence of self-reported non-suicidal self-harm has increased according to a recent study conducted by McManus and collaborators (2019a). This study of a cross-sectional design compared self-reported non suicidal self-harm in adults aged 16-74 in 2000 and then again in 2014 (McManus et al., 2019a). Although this study only captured self-reported non-suicidal self-harm, it is one of the first to report self-harm in community settings (McManus et al., 2019a). Moreover, a meta-analysis on self-harm in non-clinical samples was conducted by Swannell and collaborators (2014). A compilation of all the published literature around NSSI was performed to estimate prevalence rates amongst the general population (Swannell, Martin, Page, Hasking & St John, 2014). Results of 119 studies meeting inclusion criteria showed extremely heterogeneous rates, varying from 1.5% to 54.8% in adolescents (Swannell, Martin, Page, Hasking & St John, 2014). Overall, after pooling data from the included studies, prevalence rates of NSSI amongst non-clinical samples showed 17.2% amongst adolescents, 13.4% in young adults and 5.5% among adults (Swannell, Martin, Page, Hasking & St John, 2014). This review did have limitations such as possible sources of

bias from the different included studies, as well as factors such as socio-economic status, sexual orientation and ethnicity, not being accounted for. Also, despite this review's very specific inclusion criteria for self-harm (limited to non-suicidal self-injury), it is the only review which has collected data on non-clinical samples and gives an overview of prevalence rates amongst community populations. Prevalence rates are most likely higher if the broader definition of self-harm used in this study was to be used, as this also includes other methods of self-harm as well as including behaviour regardless the suicidal intention.

People presenting to primary care centres such as attendances to General Practitioners (GPs) are another relevant group to consider when considering people who self-harm, especially in the UK as over 98% of people are registered with a GP (Carr et al., 2016). Carr and collaborators (2016) reviewed epidemiological rates of self-harm in a UK primary care cohort aged 16-64 throughout a 13-year period. Using data from the Clinical Practice Research Datalink (CPRD), the largest population based primary care database in the world (Herrett et al., 2015), Carr and collaborators (2016) presented epidemiological rates of self-harm amongst the primary care attending population. After carefully selecting a representative sample with regards to age range, gender, socioeconomic status and country, Carr and collaborators (2016) found that overall women had higher incident rates of self-harm compared to men (17.9 and 12.3 per 10,000 respectively). In addition, self-harm presentations were increasing annually across all groups, but slightly higher in younger age groups (Carr et al., 2016). Higher risk of self-harm was found in populations living in deprived areas (Carr et al., 2016). This study was however limited by the method self-harm was identified through: clinical read codes documented by GPs in patient records. With this method of recording data, multiple participants may have been missed out due to inconsistent reporting by GPs or undisclosed cases of self-harm. Additionally, Carr and collaborators study (2016) did not include older adults in their population, limiting the included sample.

Multiple studies have reviewed self-harm rates in adolescents, as this has been an increasing concern amongst this population group (Geulayov et al., 2017; RCP, 2010;

Swannell, Martin, Page, Hasking & St John, 2014). Hawton and collaborators (2002), reviewed the epidemiology of self-harm in teenagers in England through the administration of a self-report anonymous survey in schools. A total of 41 schools were included in the study with over 6000 pupils surveyed and an 80% response rate (Hawton, Rodham, Evans & Weatherall, 2002). 6.9% of the participants had reported an episode of self-harm within the last year, 8.6% had self-harmed previous to one year and 13.2% a history of self-harm in their life (Hawton, Rodham, Evans & Weatherall, 2002). Females had higher rates of self-harm compared to males (11.2% vs. 3.2%) and over 54% of those who self-harmed had done it multiple times (Hawton, Rodham, Evans & Weatherall, 2002). Only 12.6% of those who had self-harmed within the last year had presented to hospital following their self-harm episode (Hawton, Rodham, Evans & Weatherall, 2002). This study had certain limitations such as the method self-harm was recorded: self-report. Although self-report may be more anonymous compared to clinical presentations of self-harm, under-reporting could still be present as the wish to not disclose or accept the behaviour may be present. Furthermore, participants were 15 to 16 years old, capturing only a small age group of teenagers. Nevertheless, this study confirms that self-harm in adolescence is a concern which is underestimated in the majority of studies which are hospital based. As was previously mentioned, Geulayov and collaborators (2017) estimated incidence of self-harm in English adolescents presenting to hospital settings as well as amongst the community. For every self-harm hospital presentation, there are more than 10 community occurring self-harm episodes (Geulayov et al., 2017). This study also found increased females reporting self-harm in the community when compared to males (Geulayov et al., 2017). Despite this study being conducted in one country using data from five hospital databases and school surveys, it is one of the first in its kind as the estimate of community occurring self-harm was offered and therefore could be compared to hospital self-harm presentations.

Self-harm in midlife, people aged 40-59, is also increasing, particularly amongst men (Clements et al., 2019). In a recent study exploring self-harm related hospital attendances in

three major English hospitals, a quarter of the total presentations were done by people aged 40 to 59. Furthermore, incidence rates increased over time in men, as well as employment, alcohol use, housing and financial problems at a time of austerity being more common (Clements et al., 2019). Despite this study reporting exclusively hospital related self-harm, it shows that self-harm in midlife is a concern.

Older adults are another population with increasing self-harm rates over the past decades, with different patterns, methods and motivations compared to other populations (Geulayov et al., 2016; Morgan et al., 2018; Oude et al., 2011). The results of a systematic review of self-harm rates and overall characteristics in older adults is presented in Chapter 3 but it is worth noting that previous research on self-harm amongst the older adult population shows increased suicidal risk (Morgan et al., 2018).

Populations undergoing economic hardship have also reported higher self-harm rates according to studies conducted in Ireland (Corcoran, Griffin, Arensman, Fitzgerald & Perry, 2015), England (Barr, Taylor-Robinson, Scott-Samuel, McKee & Stuckler, 2012; Carr et al., 2016; Hawton et al., 2016b), Greece (Kentikelenis et al., 2011), Italy (De Vogli, Marmot & Stuckler, 2012) and the United States (USA) (Reeves et al., 2012). People from deprived areas are less likely to be referred to specialist mental healthcare, limiting care and support to people who self-harm from these areas (Carr et al., 2016; Morgan et al., 2017). The impact of recent economic recessions on populations has been explored with regard to self-harm, in addition to the more commonly explored suicide links (Hawton et al., 2016b; Reeves et al., 2012). In addition to increased suicide in times of economic hardship, studies suggest increased self-harm rates amongst populations, with higher rates found in women (Corcoran, Griffin, Arensman, Fitzgerald & Perry, 2015; Hawton et al., 2016b; Reeves et al., 2012). A further relationship between unemployment, vulnerability and hopelessness has also been reported amongst those who self-harm experiencing economic hardship according to a recent qualitative study (Barnes et al., 2016). As highlighted by Chandler (2019) socioeconomic inequalities indeed have an impact on individuals' wellbeing and self-harm behaviour.

As for ethnic background, multiple authors have reviewed epidemiological rates across different groups (Bhui, McKenzie & Rasul, 2007; Goddard, Subotsky & Fombonne, 1996; Jablonska, Lindberg, Lindblad & Hjern, 2009; Turnbull et al., 2015). In a systematic review conducted in the UK, self-harm rates were higher in ethnic minorities, specifically South Asian women (Bhui, McKenzie & Rasul, 2007). Bhui and collaborators' (2007) systematic review did find a lack of studies reporting self-harm and other ethnic groups such as people of Caribbean and African groups. The methodological quality of the studies included in the systematic review must also be noted as over half of the studies were ranked as low quality (Bhui, McKenzie & Rasul, 2007). Complementing the findings from the systematic review, Cooper and collaborators (2010) explored self-harm amongst ethnic minorities in a three-city cohort in the UK. This study found that young black females aged 16 to 34 had higher self-harm rates across the three cities, followed by South Asian women in some of the cities but not all (Cooper et al., 2010). Despite higher rates of self-harm in black and minority ethnic groups, these groups were less likely to receive psychiatric assessment after presenting to hospital, highlighting a serious service provision need (Cooper et al., 2010). A national Swedish cohort was prospectively studied by Jablonska and collaborators (2009) for nearly three decades, to explore the relationship between self-harm and ethnicity as well as socioeconomic status. Findings from this study showed that people from an ethnic minority background, with both parents being born outside of Sweden, had higher self-harm rates compared to the rest of the population (Jablonska, Lindberg, Lindblad & Hjern, 2009). Socioeconomic status was also closely related to higher self-harm rates, with lower socioeconomic status having higher self-harm rates (Jablonska, Lindberg, Lindblad & Hjern, 2009). These studies reflect previous evidence from Chew-Graham and collaborators (2002), who qualitatively explored self-harm in South Asian women. This study suggested that contributing factors including social adaptation and adjustment to a new culture and environment, may lead women from this group to self-harm. The risk of increased self-harm amongst ethnic minorities and people from a different country of origin was also found in an Israeli prospective cohort study, showing increased risk amongst older adults born outside of Israel (Briskman et al., 2017).

Previous negative and traumatic childhood experiences such as sexual abuse can also lead to self-harm as has been noted by multiple authors (Cleare et al., 2018; Gladstone et al., 2004; Liu, Scopelliti, Pittman & Zamora, 2018; Noll, Horowitz, Bonanno, Trickett & Putnam, 2003; Romans, Martin, Anderson, Herbison & Mullen, 1995; Weierich & Nock, 2008). Childhood maltreatment including neglect, sexual abuse, physical and emotional abuse, has been shown to have a relationship with future adult occurring self-harm behaviour. Liu and collaborators' (2018) systematic review evaluated current evidence on childhood maltreatment and future self-harm finding a medium effect size relationship amongst the two, with no reported publication bias. With a total of 71 included studies, this meta-analysis contributes to the accumulating evidence of the relationship between self-harm and all forms of childhood maltreatment (including sexual abuse) with the exception of emotional neglect (Liu, Scopelliti, Pittman & Zamora, 2018). Limitations of the systematic review included most of the studies being retrospective recalls of childhood maltreatment rather than prospective, opening the possibility to imprecise estimations and recall of childhood maltreatment. This review was focused on non-suicidal self-harm exclusively, meaning that other forms of self-harm which include suicidal intent were excluded. Despite the mentioned limitations, Liu and collaborators (2018) provide compelling evidence for the relationship of childhood maltreatment and future adult self-harm.

The relationship between sexual orientation and self-harm has been explored multiple times, as higher rates have been reported amongst the Lesbian, Gay, Bisexual, Transsexual (LGBT) community (King et al., 2008; Liu & Mustanski, 2012; Skegg, Nada-Raja, Dickson, Paul & Williams, 2003). King and collaborators (2008) conducted a systematic review of prevalence rates of self-harm in the LGBT community in people aged 12 and over, finding self-harm, suicide attempts and suicidal ideation significantly higher amongst LGBT compared to the general population. Suicide attempts and self-harm with higher suicidal intent was higher than other types of self-harm amongst this group (King et al., 2008). The authors also explored the relationship between mental disorders in the LGBT community, finding higher rates in this

group, particularly depression, anxiety, alcohol and substance misuse. These findings introduce the relationship of comorbidity between mental disorders and self-harm, which is further explored in section 2.2.5. However, this systematic review does highlight the lack of robust methodological quality in the included studies as well as the low prevalence of the LGBT community in studies, affecting representativeness of the group. Additionally, the included studies had heterogeneous definitions and methods of recording sexual orientation, limiting the generalisability of results in the LGBT community. Although the relationship between self-harm, suicide attempts and mental illness was noted, the relationship these had amongst each other could have been further explored (e.g. self-harm prior to mental illness or mental illness causing self-harm).

Whilst not everyone who engages in self-harm behaviour will have a mental disorder, certain mental disorders have as a key feature for diagnosis criteria, self-harm behaviour (APA, 2013; Skegg, 2005). This will be further reviewed in section 2.2.5, but overall epidemiological rates of self-harm in populations with mental illness are higher compared to those who do not have any (Haw, Hawton, Houston & Townsend, 2001; Haw et al., 2005a; Hawton, Sutton, Haw, Sinclair & Harriss, 2005; Skegg, 2005). A recent report from the Oxford Monitoring System of self-harm, the longest data registry on self-harm behaviour collecting self-harm presentations at a local hospital, found that over a 10-year period the percentage of psychiatric disorders was of 17.2% and 17.5% in males and females respectively (Hawton et al., 2015a).

The literature suggests depressive disorders as most often associated with self-harm presentations, with rates ranging from half to two-thirds of the total population presenting with self-harm episodes (Geuyalov et al., 2011; Haw, Hawton, Houston & Townsend, 2001; Hawton et al., 2015a; Murphy et al., 2012). There is a caveat with these estimations as the methods chosen to measure depression varied from clinical impressions and diagnosis to structured questionnaires. Nevertheless, it gives an estimate of the elevated presence of depression amongst those who self-harm, which is confirmed by NICE guidelines (2011) which sees depression as a major risk factor for self-harm.

Haw and collaborators (2001) studied a representative sample of 150 people presenting with self-harm in an Oxford hospital and found that nearly half (45.9%) had a personality disorder. Personality disorder was diagnosed using PAS, the Personality Assessment Schedule (Tyrer, Alexander & Ferguson, 1988), together with an ICD-10 diagnosis in 78% of the sample that went to a follow-up interview (Haw, Hawton, Houston & Townsend, 2001). BPD, now known as Emotionally Unstable Personality Disorder (EUPD) has been further explored by multiple authors as it is a population with a high rate of self-harm (Brown, Comtois & Linehan, 2002; Chapman, Specht & Cellucci, 2005; Sansone, Wiederman & Sansone, 1998). One of the diagnostic criteria for BPD is presence self-harm behaviour (APA, 2013). Again, the motivations for and functions of, self-harm amongst this population can be quite distinct to others, with lower suicidal intent reported amongst those with BPD (Brown, Comtois & Linehan, 2002; Sansone, Wiederman & Sansone, 1998; Sansone, Sellborn & Songer, 2018).

Suicide is an increasing problem amongst patients under psychiatric services, especially those with schizophrenia (De Hert & Peuskens, 2000), representing up to 13% of deaths of patients with schizophrenia (Haw et al., 2005a). A systematic review showed that self-harm amongst patients with schizophrenia most closely predicts suicide (Haw et al., 2005a), i.e. not only is self-harm prevalent amongst this population, but also more lethal. The systematic review did show however a paucity in the literature with regard to schizophrenia and self-harm, as well as identifying limited study designs and in-patient populations. This means the included studies are not representative of the whole population of patients with schizophrenia who self-harm, as well as not being able to further estimate relationship between self-harm and schizophrenia as certain study designs may allow to do so.

Self-harm amongst people with eating disorders has also been commonly reported and explored by various authors (Favazza, DeRosear & Conterio, 1989; Paul, Schroeter, Dahme, & Nutzinger, 2002; Sansone & Levitt, 2002; Troya, 2015). Some researchers report self-harm and eating disorders as equivalent (Favazza, DeRosear & Conterio, 1989; Miller, 1994),

classifying eating disorders as a manifestation of self-harm behaviour. Findings are inconclusive with regard to which eating disorder has highest rates of self-harm, with some authors (Sansone & Levitt, 2002) reporting higher rates amongst those with bulimia and others amongst those with EDNOS (eating disorder not otherwise specified) (Paul, Schroeter, Dahme, & Nutzinger, 2002) or anorexia (Favazza, DeRosear & Conterio, 1989). Nevertheless, the existing literature reports high prevalence of self-harm amongst populations with eating disorders (Sansone & Levitt, 2002). Some authors have even hypothesised a relationship between self-harm and eating disorders as a new diagnostic criterion. Favazza and collaborators (1989) further explored the association amongst eating disorders and self-harm, proposing a new diagnosis of 'deliberate self-harm syndrome', as one manifestation by impulse control disorder. However, since evidence was not strong enough to take this forward, this syndrome was not further explored. Despite this, the distinctive nature of self-harm amongst this population highlights once again the different avenues and functions self-harm has amongst varying groups.

The presented epidemiological rates highlight the need of addressing self-harm worldwide. Despite the previously mentioned limitations of each of the studies conducted with different population groups, these reports give an overall picture of the groups which are most at risk of self-harm. The gathered evidence highlights the need of addressing self-harm not only generally but also separately, as the functions, motivations and role self-harm has in each of these groups seems to differ. This not only requires a different understanding and comprehension of self-harm for each group, but also different approaches and methods of treatment to be able to give effective and cost-effective care. These epidemiological rates are also important to have into consideration to further comprehend self-harm and appreciate it does not occur in a vacuum, but it is closely intertwined amongst both social and biological factors as has been previously highlighted.

2.2.4 Association of self-harm with suicide

Self-harm is the major risk factor for suicide, therefore a strong link exists between self-harm and suicide. The association between self-harm and suicide has been widely researched amongst self-harm and suicide academics (Cooper et al., 2005; deCatanzaro, 1981; Harriss, Hawton & Zahl, 2005; Hawton, Zahl & Weatherall, 2003). There are some researchers that argue that some self-harm behaviours are exclusively restrained from suicidal intent and can even be used to prevent future suicide, referring to this as non-suicidal self-injury (Butler & Malone, 2013). The latest edition of the American Psychiatric Association (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) has a new classification for NSSI, stating it to be “any act within the last year of intentional self-inflicted damage to the surface of one’s body of a sort likely to induce bleeding, bruising, or pain, with the expectation that the injury will lead only to minor or moderate physical harm and absence of suicidal intent” (APA, 2013). This definition given by the APA makes a clear distinction with regard to suicidal intent and NSSI, with no association or relationship amongst suicidal intent and NSSI. Another proposed category for self-harm given in the latest DSM edition is suicidal behaviour disorder which is a suicide attempt within the last 24 months that does not meet the criteria for NSSI (APA, 2013).

While the APA and other researchers make a distinction between self-harm and suicidal intent having two different criteria and definitions, other researchers and organisations like the WHO (2016b), classify self-harm as part of suicidal behaviour, meaning that to a certain extent suicidal intention may be present (Refer to Figure 2.2). While there are still ongoing debates (Kapur, Cooper, O’Connor & Hawton, 2013) of whether or not NSSI should have a separate diagnosis and classification to self-harm, further research, particularly on experiences and motivations behind self-harm behaviour is needed to understand the association with suicide or not. Additionally, as some authors have started to do (Haw et al., 2008; Hawton, Saunders & O’Connor, 2012) further understanding could be reached when researching on specific populations that self-harm rather than on the general self-harm population as patterns and experiences may be different.



* Proportions illustrated in this diagram stem from international research findings; however, these proportions may vary between countries and regions.

** While increased accuracy and uniformity of information is needed at all levels, the focus of this manual is on suicide attempts and self-harm presenting to general hospitals.

Figure 2. 2 Extent of suicidal behaviour (Reprinted with permission from Practice manual for establishing and maintaining surveillance systems for suicide attempts and self-harm, WHO, pg. 8., Copyright, 2016b)

Furthermore, the association between suicidal intent and method of self-harm has been explored by multiple authors (Gjelsvik, Heyerdahl, Holmes, Lunn, & Hawton, 2016; Hamdi, Amin & Mattar, 1991; Harriss, Hawton & Zahl, 2005; Haw, Casey, Holmes & Hawton, 2015). However, evidence is contradictory and inconclusive about the link between the two with some research (Haw, Casey, Holmes & Hawton, 2015) finding suicidal intent higher with self-

poisoning when compared to self-injury and other research (Hamdi, Amin & Mattar, 1991) finding higher suicidal intent amongst patients who self-injure as opposed to self-poison. Only more recently, a longitudinal study provided evidence that suicidal intent and lethality amongst those who self-poison should be considered as two different dimensions of self-harm because of the lack of association amongst them (Gjelsvik, Heyerdahl, Holmes, Lunn, & Hawton, 2016). With these contradictory findings, evidence seems to suggest suicidal intent and method of self-harm is not as simple to make an association and establish a relationship, but instead each individual case should be assessed independently with no one common rule for all.

2.2.5 Self-harm and mental disorders

Self-harm has seen to be more prevalent amongst certain mental disorders which are summarised in Figure 2.3. However, it must be highlighted, that not everyone that engages in self-harm behaviour has a mental disorder as self-harm is a behaviour, not an illness.

Depression and other depressive disorders have a relationship with self-harm as well as suicidal behaviour as stated by the DSM V (APA, 2013). This due to one of the key characteristics of the illness, which may drive the person towards hopelessness and engaging or planning suicidal behaviour. Other studies amongst different populations have also found that there can be presence of depression in patients who self-harm (Dennis, Wakefield, Molloy, Andrews & Friedman, 2005; Ennis, Barnes, Kennedy & Trachtenberg, 1989; Hamer, Sanjeev, Butterworth & Barczak, 1991).

Anxiety disorders such as panic disorder, post-traumatic stress disorder (PTSD), generalised anxiety, amongst others and may also commonly have self-harm presentations. Specifically, in PTSD, research has shown more frequent self-harm presentations amongst those with complex PTSD (Dyer et al., 2009). In specific groups like teenagers, O'Connor and collaborators (2010) described groups with acute stress were more likely to self-harm and have higher anxiety levels. Additionally, psychiatric patients presenting with deliberate self-harm also scored higher anxiety levels (Hamer, Sanjeev, Butterworth & Barczak, 1991).

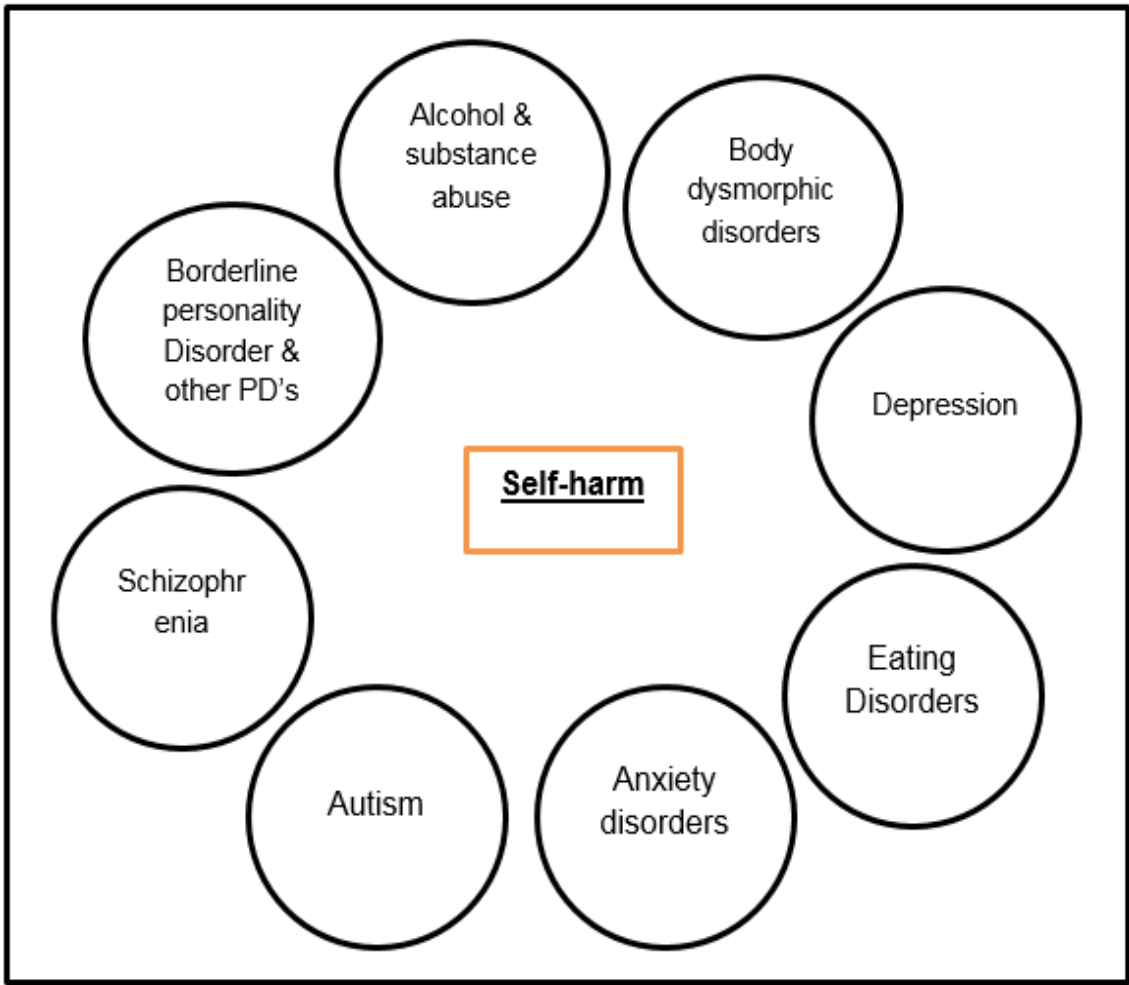


Figure 2. 3 Association of self-harm with mental disorders

Self-harm in populations with body dysmorphia and other obsessive-compulsive related disorders as classified by the DSM V can be frequently found (APA, 2013). Again, because of the nature of these disorders, people who are diagnosed with them engage in self-harm behaviour presenting with elevated anxiety levels (APA, 2013; Neziroglu & Kaplan, 1995).

As was presented in section 2.2.3, self-harm is also commonly found in those with eating disorders (bulimia or anorexia) (APA, 2013; Favazza, DeRosear & Conterio, 1989; Paul, Schroeter, Dahme, & Nutzinger, 2002; Sansone & Levitt, 2002; Troya, 2015). Some authors (Favazza, DeRosear & Conterio, 1989) consider eating disorders a self-harm behaviour as refraining oneself from eating or self-inducing vomit. Although these may be similar, the key

difference lays in self-harm being classified as a behaviour and not a mental disorder like eating disorders with different motivations for each. Nevertheless, the association amongst those with eating disorders and self-harm has been previously explored showing a close link amongst the two.

Studies suggest that neurodevelopmental disorders such as autism can be associated with self-harm behaviour (Duerden et al., 2012; Fee & Matson, 1992; Karim & Baines, 2016; Matson & LoVullo, 2008; Weiss, 2003). Due to the nature of autism and the common symptomatology of repetitive behaviours, it is common to find self-harm amongst this population.

People diagnosed with schizophrenia also often present with self-harm as previously mentioned (Caldwell & Gottesman, 1992; Drake, Gates, Cotton & Whitaker, 1985; Haw et al., 2005a; Reid, 1998). Additionally, self-harm amongst this population has a higher risk factor for suicide compared to other populations (Haw et al., 2005a).

Self-harm has been reported in other Cluster B personality disorders such as histrionic and narcissistic personality disorders, as well as EUPD. Once again, due to the nature of this mental disorder of pervasive nature in personal and social situations, self-harm is likely to be found (APA, 2013; Tantam & Whittaker, 1992).

Amongst populations with alcohol and other drug misuse, self-harm is commonly found (Haw et al., 2005b). The role impulsivity and addiction have towards drug misuse and self-harm has been suggested as strong according to some research (Victor, Glenn & Klonsky, 2012; Welch & Fairburn, 1996).

As just reviewed, self-harm may present itself amongst varying populations with mental disorder. However, its functions and motives are not the same across the different groups. Additionally, not everyone who self-harms has a mental disorder. Multiple people without a mental disorder self-harm and do so for different functions as is described in sections 2.2.6 and 2.2.7.

2.2.6 Functions of self-harm

Section 2.2.3 set the scene for overall self-harm rates and presence within different groups and populations. However, the literature was limited to exploring the possible functions this behaviour may have in people who self-harm. Self-harm holds different functions depending on the individual as well as the chosen perspective to examine this behaviour. Within psychology, there are different schools of thought which explain the different functions self-harm may have in the individual. These may vary from very medical perspectives to more social ones. The main schools of thought with their perspective of self-harm functions are further explored with a hope of gaining a more in depth understanding of the subject and hypothesis the different functions self-harm may have in an individual. Also provided in this section is the sociological perspective to understanding the functions of self-harm.

i. Psychodynamic perspective

The psychodynamic perspective is enrooted and surges from Freud's psychoanalysis (Freud, Strachey, & Freud, 2001). Alongside other authors that based their theories from Freud's psychoanalysis like Jung and Erikson amongst others, the psychodynamic perspective incorporates all of these different psychoanalytic theories to study and explain human behaviour. Psychodynamics' underlying principle is that all human behaviour is driven by the unconscious, which is forced to repress many of its desires because of them being unacceptable to the conscious state of mind; as a result of this conflict arises when both forces clash (Gabbard, 2014). One of the main criticisms made to the psychodynamic perspective is the lack of evidence corroborating its theory. The unconscious and its repressed desires, which psychodynamics bases its perspective on, have no experimental evidence, making it unpopular amongst many in the scientific community. Nevertheless, researchers from the field have started to address this with increasing experimental studies carried out in the last decade (Gabbard, 2014).

Taking psychodynamics' perspective into self-harm, psychodynamic views self-harm as a behaviour that occurs due to the conflict of unexpressed unconscious desires and/or presence

of death wishes (Gabbard, 2014; Ghijsens, Lowyck & Vermote, 2010). The individual that self-harms expresses this conflict through harming themselves, a maladaptive response to this conflict, which in other individuals would be expressed through defence mechanisms such as repression or sublimation (Gabbard, 2014). In order to treat this behaviour, the underlying mechanisms which lead to self-harm must be identified (Ghijsens, Lowyck & Vermote, 2010). These could either be self-destructive behaviour with a wish to end one's life manifested through self-harm, or self-harm expressed as a coping mechanism which serves as affect regulation to the individual dealing with conflict (Gabbard, 2014; Ghijsens, Lowyck & Vermote, 2010). Whatever the case may be, self-harm conceptualised through psychodynamic theory states its function as the expression of unconscious desires which are not able to be expressed due to the conflict caused with a conscious state of mind. Recent evidence suggests psychodynamic therapy having short-term effectiveness in reducing self-harm behaviour according to an analysis of 12 trials included in a meta-analysis (Briggs et al., 2019).

ii. Cognitive-behavioural perspective

This perspective is rooted from Cognitive Behavioural Therapy (CBT), developed by Aaron Beck in the second half of the 20th century. CBT's core principal and therapeutic approach is based on modifying maladaptive or dysfunctional thoughts and behaviours through present-orientated therapy (Beck, 2011). By choosing to focus on present concerns of an individual, Beck was revolutionary in the field of psychology as up until the mid-sixties the majority of therapies focused on reviewing past behaviours like the then leading psychoanalysis did. Through different methods of identification of maladaptive behaviours and forms of coping with them, Beck's CBT quickly gained popularity amongst the field of psychology as a promise of eliminating unwanted behaviour was given to patients and clinicians within a short time period. Increasing empirical support has continued to be found for CBT, making it one of the most popular type of psychological therapies to this date.

The perspective CBT has towards self-harm is like any other type of maladaptive behaviour. Instead of focusing on what past events or why self-harm is being caused, CBT

views self-harm as an unwanted dysfunctional behaviour caused by maladaptive thoughts such as cognitive deficiencies and distortions which can be dealt with through modification of behaviour as well as thought (Beck, 2011). Nevertheless, some authors hypothesise self-harm may be caused from previous unpleasant experiences and serves as a function of avoidance of these (Slee, Arensman, Garnefski & Spinhoven, 2007). This is why emotional regulation as described by Linehan (1993) and Rudd and collaborators (2001) plays an essential role in those who self-harm, as it allows for emotions and thoughts to be released and expressed in non-maladaptive behaviours. In conclusion, serving a function of avoidance of previous unwanted thoughts or, self-harm as seen by CBT experts is a behaviour which can be modified throughout the different existing techniques. Lastly, regarding CBT psychotherapies, evidence suggests this to be the strongest psychotherapies for reducing self-harm (Hawton et al., 2016a).

iii. Neurobiological perspective

Neurobiology, a sub-discipline from neuroscience and biology, studies the nervous system and its cells to research human behaviour (Groschwitz & Plener, 2012). Through the study and understanding of cell functioning, morphology and organisation, neurobiology attempts to explain behaviour as something influenced by internal factors instead of external ones. This can be done by studies involving neuroimaging and neurotransmitters, as these allow to research from a neurobiological perspective. Neurobiology is important in mental health research as with a further understanding of the functioning of the nervous system, effective pharmacological treatment can be identified (Groschwitz & Plener, 2012).

According to this perspective, self-harm is caused by any sort of deficit or neurobiological alteration (Groschwitz & Plener, 2012; Maletic et al., 2007; Van Heeringen & Mann, 2014). In a review of the current literature Groschwitz and Plener (2012) identified the neurobiological aspects which were common amongst individual that self-harmed. The findings are still inconclusive in many aspects as there were contradictory results amongst the studies, warranting further research. Nevertheless, certain neurobiological aspects of self-harm were

clearly identified: a) insufficient stress response; b) serotonergic genes such as THP and 5-HTTLPR amongst certain groups; c) altered physiological reactivity; d) reduced cortisol secretion and endogenous opioids (Groschwitz & Plener, 2012).

Additionally, a meta-analysis conducted by O'Connor and collaborators (2015), reviewed the evidence on cortisol levels and suicidal behaviour. Given the increasing evidence on the association of suicidal behaviour and the hypothalamic-pituitary-adrenal (HPA) axis, axis which is activated when we perceive stress and release cortisol, a review of the evidence was done by O'Connor and collaborators (2015). This review found evidence to support that HPA axis activity which produced increased cortisol levels had an association with suicidal behaviour including suicidal attempts in samples younger than 40 (O'Connor et al., 2015). However, in people over 40, an association was found with reduced cortisol levels and increased suicidal behaviour (O'Connor et al., 2015). Overall, O'Connor and collaborators (2015) provided evidence for the association of cortisol levels and suicidal behaviour, but the way this association is positive or negative depends on age, something which is still unclear to researchers in the area. However, more recently, research suggests lower cortisol levels and lower response to stress is associated with suicidal behaviour in adults (Melham et al., 2016; O'Connor et al., 2017).

Van Heeringen & Mann (2014) review of the neurobiology suicide literature mirrored some of the previously mentioned results. Two main areas of neurobiology were found to have an influence on suicidal behaviour in individuals: serotonin neurotransmitter system and the stress-response hypothalamic-pituitary-adrenal axis (Van Heeringen & Mann, 2014). The behavioural manifestations of the altered neurobiology of the mentioned elements include altered mood control, impaired problem solving, pessimism, emotional pain, reactive aggressive traits, suicidal ideation and suicidal behaviour (Van Heeringen & Mann, 2014). The authors did highlight the influence of environmental factors such as adverse childhood events, which in combination with genetic predisposition may lead to altered neurobiology leading to suicidal behaviour.

Regardless of the role the different neurobiological aspects may have on individuals, self-harm's function to individuals according to the neurobiological perspective varies from stress response to altered physiological reactivity.

iv. Sociobiological perspective

Developed nearly half a century ago, sociobiology made significant contributions to suicidal behaviour and self-harm when first developed in the eighties (deCatanzaro, 1981). Sociobiology is influenced by both sociology and biology, being developed by Wilson, taking into principles of biology and animal behaviour (Wilson, 1975). Wilson (1978) defined sociobiology as the "systematic study of the biological basis of all forms of social behaviour, including sexual and parental, in all kinds of organisms, including men".

With regard to self-harm, sociobiology takes into account the historical and cross-cultural perspective, as well as biology and social ecology. Cultural determinants to self-harm are important to comprehend this behaviour amongst individuals as they are heavily influenced by this. Additionally, sociobiology takes into consideration the influence of learning theory through conditioning and reinforcement of the behaviour, physiological factors such as abnormalities in pain avoidance and environmental stimuli such as stress and social isolation (deCatanzaro, 1981). Overall, within the theoretical framework of sociobiology, this perspective views self-harm's function as an adaptive behaviour that avoids the individual from dying by suicide. Sociobiology makes a clear distinction amongst suicide and suicide attempts and self-harm, as the first serve the purpose of ending one's life and stopping gene propagation to future generations, while the latter is adaptive as it allows the individual that deals with different environmental and physiological factors to continue without ending one's life.

v. Sociological perspective

Sociology, the study of human relationships, society, culture, and social interactions (Marshall & Scott, 2009) provides a different understanding to the functions of self-harm. From a sociological perspective, self-harm cannot be conceptualised with an exclusive

focus on the individual, as other perspectives would argue. Instead, sociology proposes that the different factors, including the social and cultural context of the individual should also be considered and prioritised when conceptualising and explaining self-harm behaviour. However, the majority of existing research focuses on psychological explanations to self-harm and is dominated by hospital-presenting populations (Abrutyn & Mueller, 2019; Chandler, Myers & Platt, 2011). By taking a sociological perspective to self-harm, researchers can take a step back from the assumed notion that self-harm is a pathological behaviour or a symptom of a mental illness. Instead, seeking to critically explore the individual's environment, social relationships, culture and social context, allows for a more in-depth understanding of self-harm behaviour. The meanings and functions attributed to self-harm will inevitably vary, as these will be unique to the social context of the individual. Different aspects such as social isolation, deprivation, influence of social media, amongst other social factors can be further explored to understand the function of self-harm from a sociological perspective.

2.2.7 Motivations of self-harm

Earliest explanations for self-harm dated from Before Christ up to the middle ages, state self-harm motivations being for spiritual and religious purposes, highlighting the importance of cultural contexts and meanings (Chaney, 2017). In the 16th and 17th century, bloodletting was a common form of self-harm. Although accounts report blood-letting serving medical purpose according to the individual engaging in such behaviour (Chaney, 2017). However, medical practitioners of the time did not see this behaviour as serving any medical purpose, hence it being regarded as self-harm behaviour. Moving on to the mid-19th century, self-harm motivations started to be much more related to psychiatry and mental disorders, as this was the era where mental asylums became popular in western Europe and multiple self-harm presentations were observed (Chaney, 2017). Psychiatrists and others working with the population, tried to understand the complexity of self-harm motivations, which were explained in the Victorian era as: a) physiological explanations based on absence of pain in individuals

who self-harm; b) socio-environmental understanding due to mixed environmental factors as well as a potential mental disorders (Chaney, 2017). Moving into the early 20th century, self-harm motivations were strongly influenced by psychoanalysis, seeing self-harm as an unconscious death wish from the person (Chaney, 2017). From the mid-late 20th century until now, self-harm motivations have been explained by different varying personal and environmental influencing factors amongst individuals, such as presence of mental disorders to vulnerability caused by socio environmental factors, amongst others.

According to the most recent publication on self-harm and suicide from the WHO (2016b), there are four motivations for this type of behaviour: suicidal intent, cry for help, cry of pain and ambivalence. In addition to the WHO's motivations for self-harm, the literature gives alternative perspectives to explain self-harm motivations.

Multiple studies exploring self-harm motivations have been carried out, these varying from literature reviews to research studies amongst specific populations assessing this by either qualitative or quantitative measures (Brown et al., 2002; Brown & Beail, 2009; Edmondson, Brennan & House, 2016; Idenfors, Kullgren & Renberg, 2015; Klonsky, 2007; Rodham, Hawton & Evans, 2004; Suyemoto, 1998). The populations which have been the focus of research studies vary but have mostly consisted on those with more prevalent self-harm such as individuals with personality disorders (Brown et al., 2002), adolescents (Idenfors, Kullgren & Renberg, 2015; Rodham, Hawton & Evans, 2004) and imprisoned populations (Brown & Beail, 2009). Motivations for other populations (e.g. older adults) with less prevalent self-harm are mostly absent, resulting in current evidence of self-harm motivations being limited to certain groups.

Several authors have attempted to build frameworks for understanding self-harm motivations through reviews of the literature (Klonsky, 2007; Suyemoto, 1998). The most recent systematic review conducted exploring motivations for self-harm (Edmondson, Brennan & House, 2016) identified 152 studies. An initial framework for self-harm motivations based on a previously conducted review by Klonsky (2007), was further developed with the data from

the 152 studies in Edmondson’s review (See Figure 2.4). Motivations for self-harm were divided into three broad categories: a) responding to distress; b) self-harm as a positive experience; and c) defining the self (Edmondson, Brennan & House, 2016). As can be seen in Figure 2.4, these three main categories are subsequently divided further into 15 subcategories.

Responding to distress	Self-harm as a positive experience	Defining the self
<ul style="list-style-type: none"> • Affect regulation & distress management • Interpersonal influence • Punishment • Averting suicide • Dissociation management 	<ul style="list-style-type: none"> • Gratification • Sensation seeking • Experimenting • Protection: self and others • Developing a sense of personal mastery 	<ul style="list-style-type: none"> • Defining boundaries • Responding to sexuality • Validation • Self as belonging or fitting in • Having a personal language

Figure 2. 4 Self-harm motivations adapted from Edmondson, Brennan & House, 2016

i. Responding to distress

Perhaps one of the most commonly explored motivations is self-harm as a response to distress, which has been hypothesised frequently (Chaney, 2017; Klonsky, 2007). As Edmondson and collaborators (2016) identified, affect regulation and distress management, interpersonal influence, punishment, avoiding suicide and dissociation management were the common themes found for the category of responding to distress as a self-harm motivation. Distress caused by either a wish to avoid suicide, managing body dissociation, seeking to influence others, or emotional regulation from negative or unwanted feelings, was dealt through self-harm, being amongst the most common motivations for self-harm.

ii. Self-harm as a positive experience

Other motivations for self-harm which are reported by those engaging in such behaviour include gratification, sensation seeking, experimenting, protection of self and others and the

development of a personal sense of mastery (Edmondson, Brennan & House, 2016). Unlike the different category of self-harm motivations, this section consists of those engaging in self-harm behaviour to gain a positive experience from the behaviour.

iii. Defining the self

Another category which was found across studies reviewing self-harm motivations was self-harm which aided in defining the self (Edmondson, Brennan & House, 2016). Through defining or exploring personal boundaries, a response to sexuality, validation, belonging or fitting in a group and having a personal language, individuals expressed self-harm as a behaviour that enabled the defining of the self.

iv. Other motives for self-harm

Other existing motivations for self-harm include making political statements (e.g. hunger-strikes), sadomasochistic sexual practices and acting out psychotic explanations (Edmondson, Brennan & House, 2016). However, as the nature and frequency of these are different compared to the three main categorisations, these were not included in the conceptualisation model of self-harm motivations. This may be considered a limitation to the way self-harm motivations were conceptualised.

2.2.8 Management and prevention of self-harm repetition

Within the UK setting, despite NICE guidelines (2011) of self-harm management stating that a thorough assessment should be made in all patients who have self-harmed or are at risk of self-harming, the reality of other competing priorities does not allow for this to happen in everyday practice (Bennewith, Gunnell, Peters, Hawton & House, 2004; Cooper, Murphy, Jordan & Mackway-Jones, 2008; Gunnell, Bennewith, Peters, House & Hawton, 2005). Additionally, as has been previously mentioned, self-harm behaviour has a close relationship with suicide, as it is one of the major predictors or risk factors for suicide (Zahl & Hawton, 2004). Several authors (Chew-Graham et al., 2019; Crawford & Wessely, 1998; Hetrick,

Robinson, Spittal & Carter, 2016) have already described the importance of initial management of a person following self-harm to avoid further repetition of self-harm behaviour.

NICE guidelines (2011) state that every self-harm presentation should receive person-centred care, risk assessment of further self-harm repetition and suicidal behaviour through dialogue and overall assessment if further health (including psychiatric) services are needed. Additionally, careful consideration should be taken with vulnerable groups including children and older adults as stated by NICE (2011). With appropriate identification, management and treatment of self-harm, prevention of repetition of such behaviour and even suicide can be reached.

Furthermore, the WHO (2016b) has recommendations based on evidence-based findings on how to manage and prevent self-harm, however this is with a predominant focus to hospital-treated self-harm and self-harm linked with suicidal intent (refer to Figure 2.5). These recommendations are mostly based on reducing access to means, as well appropriate management and treatment for self-harm in non-specialised settings (WHO, 2010). Once again, the importance of managing self-harm as soon as an episode is presented and even previously with prevention programmes is highlighted. This adds to the literature on the value of appropriate management and prevention programmes for self-harm. Section 2.2.12 further explores access to care and support for people who self-harm.

Lastly, regarding most recent evidence provided to assess the effectiveness of interventions to reduce self-harm, these can be divided into psychosocial interventions and pharmacological treatments. For the first, based on results from a systematic review assessing 29 trials, strongest evidence is provided for CBT psychotherapies and problem-based therapies to reduce self-harm behaviour (Hawton et al., 2016a). Although pharmacological treatments are often provided to those who self-harm, most recent evidence shows no association between the different medications (newer generation antidepressants, mood stabilisers, or antipsychotics) and reduction of self-harm, suggesting further studies are

needed to assess the effectiveness of pharmacological treatments for self-harm (Hawton et al., 2015b).

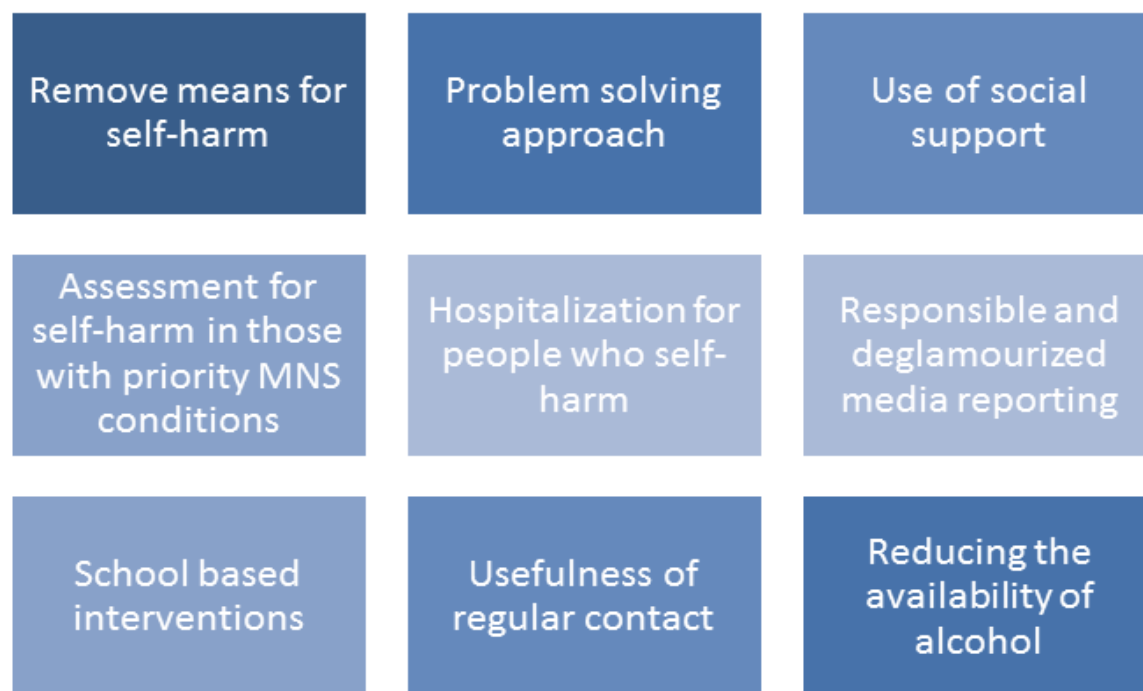


Figure 2. 5 WHO's evidence-based recommendations for management of self-harm and suicide in non-specialised settings adapted from WHO, 2010

2.2.9 Assessing self-harm

There is no one single standardised tool used to measure risk of self-harm repetition and suicide risk. These vary from clinicians' impression, to questionnaires given to a person asking why they have engaged in such behaviour. In addition, there are different scales used to measure different aspects of self-harm, such as intent (Beck, Kovacs & Weissman, 1979), risk of repetition (Quinlivan et al., 2016) and overall prevalence (Borschmann, Hogg, Phillips & Moran, 2012). Currently, the accuracy of these risk assessment tools is poor, as is further described below (Quinlivan et al., 2016 & 2017; Steeg et al., 2018; Woodford et al., 2019)

Contributing to the evidence of assessing self-harm through clinicians' impression, Woodford and collaborators (2019) conducted a systematic review of the literature exploring unstructured clinician assessments of future risk of self-harm. This was done in hospital treated

populations presenting with self-harm and identified as having high rates of subsequent self-harm (Woodford et al., 2019). Through statistical calculations of accuracy such as specificity and sensitivity, results from the review showed close to 70% of all cases of future self-harm misclassified as low risk by clinicians (Woodford et al., 2019). This has further treatment and management implications as those with high risk for self-harm repetition will not be assigned to receive treatment and after-care management aimed at reducing self-harm (Woodford et al., 2019). Factors such as confounding by indication (e.g. patients receiving effective after-care treatment after being allocated to high-risk category) may have influenced the estimation of results but were mostly addressed with risk of bias rating conducted in the analysis stage of the review. Nevertheless, results from this study show that unstructured clinician assessments of future risk of self-harm are not currently reliable.

A recent systematic review exploring the diagnostic accuracy of risk scales for repeated self-harm found that these vary widely amongst results provided (Quinlivan et al., 2016). Of the eight included scales, none of them had a good diagnostic accuracy when measuring validity, positive and negative predictive values, sensitivity and specificity (Quinlivan et al., 2016). Findings from this study also showed that despite multiple existing tools used to measure self-harm risk, their validity is very low and show overall negative results when used across population (Quinlivan et al., 2016). This was also confirmed by Quinlivan and collaborators (2017), in an English multicentre cohort study that showed poor performance in use of risk scales when assessing future self-harm in adults aged 18 and over. Sampling bias due to patients refusing to participate may have influenced the results, but these were in line with the previous review of the literature showing low accuracy in risk scales (Quinlivan et al., 2016). NICE guidelines (2011) warn against the utilisation of these tools and instead suggest a thorough assessment to patients should be made.

In addition, Swannell and collaborators (2014) systematic review on prevalence rates of NSSI in non-clinical samples found that one of the main reasons for the heterogeneity in results found was due to methodological measurement issues used amongst the over 100

included studies. Over 5% variance between study heterogeneity was found due to the response format of questionnaires or tools administered to measure self-harm (Swannell, Martin, Page, Hasking & St John, 2014). Anonymity, incentive for participation, response format, number of self-harm measures identified, and research focus were amongst the top reasons for the variation in response rates (Swannell, Martin, Page, Hasking & St John, 2014).

Overall, evidence shows that assessment of self-harm through risk scales and other tools are inaccurate. Likewise, clinicians' assessment of future self-harm has also been found to be poor. This indicates that current self-harm assessment tools are not completely accurate, demonstrating the complexity of self-harm behaviour which cannot be entirely understood only with such assessment tools. Instead, until evidence demonstrates the contrary, self-harm should be further assessed with the different involving aspects of this behaviour including mental and physical health as well as a wider social and external perspective.

2.2.10 Clinicians' attitudes towards people who self-harm

There is increasing evidence regarding clinicians' attitudes, as well as knowledge, towards people who self-harm due to the significant impact it has on both people who self-harm as well as attending staff (Crawford, Geraghty, Street & Simonoff, 2003; Friedman et al., 2006; McAllister, Creedy, Moyle & Farrugia, 2002; McCann, Clark, McConnachie & Harvey, 2006; Saunders, Hawton, Fortune & Farrell, 2012; Taylor, Hawton, Fortune & Kapur, 2009). The impact of clinicians' attitudes towards people who self-harm may influence on future help-seeking for support from people who self-harm, which is high due to repetition rates in the mentioned group.

Saunders and collaborators (2012) conducted a systematic review which aimed to review staffs' attitudes and knowledge towards people who self-harm. Results from this review showed that general hospital staff had negative views of people who self-harm while psychiatric staff had fewer negative views of the mentioned group (Saunders, Hawton, Fortune & Farrell, 2012). Additionally, nursing staff had fewer negative views compared to attending

doctors (Saunders, Hawton, Fortune & Farrell, 2012). Frustration, helplessness, feelings of waste of resources and hostility towards people who self-harm were common attitudes reported in the review (Saunders, Hawton, Fortune & Farrell, 2012). The study also reviewed the impact of training staff on knowledge of self-harm, with results showing that with increased knowledge of the behaviour, a more positive and understanding view towards people who self-harm was achieved (Saunders, Hawton, Fortune & Farrell, 2012). Taylor and collaborators (2009) systematic review on attitudes towards clinical services by people who self-harm is congruent with Saunders and collaborators' findings, as people who self-harm tend to have negative views towards clinical services and staff as well as poor communication and lack of knowledge.

The importance of staff attitudes and knowledge towards people who self-harm cannot be overstated, as repetition rates are high in those who self-harm, making attendance and encounters with staff treating those who self-harm common. Additionally, evidence suggests patients' future consulting behaviour is very much influenced by previous experiences and consultations, having an effect on whether people seek for help in the future or not (Pilgrim, Pescosolido & Rogers, 2011). This concept, known as recursivity, refers to the interdependency between an individual's experiences of health services and his/her future actions in regard to health and help seeking (Pilgrim, Pescosolido & Rogers, 2011). As was seen in section 2.2.8, appropriate management and treatment of people presenting with self-harm is pivotal, as it not only allows the person to receive the needed treatment, but additionally can prevent self-harm repetition and suicide. In order to achieve this appropriate management and treatment, negative attitudes towards people who self-harm are an impediment which need to be attended to. As Saunders and collaborators (2012) review described, with appropriate training and increased knowledge given to staff treating people who self-harm, staff attitudes can be modified.

The role of stigma

Goffman's (1963) seminal work on stigma has revolutionised medical sociology, aiding with the understanding and conceptualisation of stigmatising behaviours towards and amongst individuals with chronic illness. Stigma, as defined by Goffman (1963), is used to refer to discrediting attributes that are incongruent to stereotypes of how individuals should act. According to Goffman (1963), individuals possess a virtual social identity as well as an actual social identity and stigma occurs when there is a discrepancy amongst the two (Nettleton, 2006). Virtual social identity is the stereotyped attributions we make daily, while actual social identity are the attributes individuals do in fact have (Goffman, 1963; Nettleton, 2006). Goffman (1963) also identified discrediting and discreditable stigma; discrediting is visible or known stigma (e.g. self-harm scars) while the latter is not immediately apparent: can be managed, hidden, can become discrediting if people find out. Further exploring stigma amongst individuals with chronic illness, Scambler (1989) identified two types of stigma: discredited and enacted stigma (Scambler & Hopkins, 1986). According to Scambler (1989) enacted stigma is the discrimination towards people from the perceptions of others, while felt stigma is the feelings of shame that comes along with the fear of enacted stigma (Nettleton, 2006; Scambler & Hopkins, 1986). This means that there is 'self-stigma' from individuals with a certain medical condition in addition to the stigma caused by others negative views. Due to the social meaning certain medical conditions may have, some will be more or less stigmatised when compared to others. Self-harm has historically been known as a stigmatised behaviour given its deviation from established and agreed social norms (Chaney, 2017; Taylor & Ibañez, 2015). This is why many individuals who self-harm may try to keep their self-harm hidden and not openly seek for help or care for their self-harm as discussed in section 2.2.12. Attitudes clinicians' and other members of the health sector and even society have may impact help-seeking behaviour from individuals who self-harm as was previously described. Therefore, it is important to note the social meaning self-harm has amongst society, with the contributing role of stigma ever-present.

2.2.11 Impact of self-harm

After having presented the epidemiology of self-harm amongst different populations, the literature's stand is unequivocal, there is a worldwide need to address self-harm. Furthermore, calculated self-harm rates are more than likely underestimated, because in addition to the attached stigma of self-harm and accessing support, the majority of epidemiological studies are based from hospital presentations, rather than primary or community settings. Therefore, there are considerably greater expected rates of self-harm, as the calculated numbers only reflect a limited part of the population that engages in self-harm.

As the policy context described in Chapter 1, the burden of mental disorders worldwide is high. Prevention and adequately timed treatment is crucial for mental disorders to avoid unnecessary costs of untreated mental disorders. Self-harm can be one of the early outward manifestations of mental disorders as well as evidence of a mental health crisis (Department of Health, 2014). Therefore, identification and treatment is imperative. This is needed not only as an economic imperative which will be presented posteriorly but is also both an ethical and moral argument due to the personal toll and impact self-harm has to those experiencing it as well as those surrounding them. This moral and ethical argument should be taken into consideration as much as the economic imperative, as governments and authorities worldwide should continue to address worldwide needed issues.

i. Global burden of disease

As was seen in Chapter 1, the Global burden of disease study reviews worldwide estimates of costs due to major illness' and conditions through years of life lost (YLL) and years lived with disability (YLD). Being the second leading cause of death due to injury and the principle contributor to DALYs caused by injury, self-harm has a significant worldwide impact and burden on society. According to the latest Global burden of disease study (2010), self-harm presentations have increased by 32% compared to 1990's estimate (Lozano et al., 2013). The burden this has to society is high, with close to 900,000 deaths due to self-harm in 2010 (Lozano et al., 2013). Additionally, this is most likely an underestimation as many cases of self-

harm are not reported due to the attached stigma and religious and social attitudes towards self-harm. Nevertheless, self-harm's burden worldwide is estimated as one of the highest for the injury group it is in and even higher in regions like Eastern Europe and Southeast Asia (Haagsma et al., 2016).

ii. Economic impact

With an increasingly growing worldwide population living within a resource limited environment, there is the necessity of creating health services which are cost-effective if health inequality is wished to be avoided. In order to know how to best allocate scarce limited resources within health settings, economic evaluations are the best alternative to calculate the most cost-effective way of distribution (Drummond, Sculpher, Claxton, Stoddart & Torrance, 2015). Estimating economic costs of any health condition always comes with the caveat of speculation and impreciseness due to the inherent nature of a fluctuating social market and resources (Drummond, Sculpher, Claxton, Stoddart & Torrance, 2015). However, these estimations are needed to attempt economic prediction and avoid potential economic losses.

Costs of self-harm, as any other health area, can be divided into direct and indirect costs. In the case of self-harm, direct costs would be the resources being spent on actively treating people seeking support after self-harm, varying from ED staff salary to the cost of the hospital building's rent. Also, any direct treatment given to those who self-harm, like any medication or psychotherapy would be included in direct costs. As for indirect costs, the days the individual spends going to hospital or sick days at home due to the self-harm behaviour, accumulating days' loss of productivity, would be indirect costs. In addition, any family member or caregiver that are affected by having to invest any resource or time attending the person who self-harms would be costed in.

The cost of suicide has been previously reported and explored, estimating alarming figures due to the loss of production and resource costs: an average \$1.3 million lost for every completed suicide (Kennelly, 2007; Shepard, Gurewich, Lwin, Reed & Silverman, 2016; Yang

& Lester, 2007). As described previously, self-harm is one of the major risk factors for suicide (Murphy et al., 2012), therefore costs due to suicide could be prevented with self-harm prevention. Self-harm behaviour should therefore be taken into consideration for a proportion of the estimated cost of suicide worldwide.

Additionally, self-harm should be costed separately as this behaviour is not always linked to suicide with many making use of it throughout their lives without any suicidal intent or attempt as was presented in sections 2.2.4 and 2.2.7. The cost of self-harm has received less attention despite its chronicity and continuous cost to society. Several authors worldwide have attempted to calculate the economic costs of self-harm (Florence, Haegerich, Simon, Zhou & Luo, 2015; Gurewich, Lwin, Reed & Silverman, 2016; Tsiachristas et al., 2017). As is with suicide, costs of self-harm are due to indirect costs such as productivity losses that are a result of the person being unable to attend work and direct costs such as medical treatment. For direct costs, Tsiachristas and collaborators (2017) estimated a proportion of these when calculating costs for medical and psychiatric care of self-harm in England. Only being a proportion of direct costs of self-harm in England, Tsiachristas and collaborators (2017) estimated £162 million per year in England for medical and psychiatric care of self-harm patients in England. Similarly, Florence and collaborators (2015) estimated the costs of ED treated self-harm in the USA, calculating \$289.7 billion in 2013 for both medical and work loss costs. These two studies are based on partial estimates by seeing one specific medical department such as ED. However, self-harm may also occur outside these settings, making these studies just a proportion of the costs of self-harm. Additionally, due to the stigma self-harm still has, under-reporting must also be acknowledged and recalculated as Shepard and collaborators (2016) have done, with an over 50% increase in the total costs of self-harm. Lastly, much self-harm goes untreated, as not all individuals will access care or support, and will engage in such behaviour in order 'to cope'. Such coping function to self-harm may allow some people to continue in the workplace, however the emotional, interpersonal, and health impact of this behaviour will remain.

Self-harm not only has a cost to the individual and close network, it has also a cost to society which must be accounted for, being a significant economic cost to health and social services, amongst others.

2.2.12 Access to care and support

People who self-harm may receive care and support from different avenues such as the health, social and third sector. Additionally, more informal groups such as family, friends, community and religious groups, may also offer care and support to people who self-harm. This is often due to self-harm being a stigmatised behaviour, therefore individuals choose to contact informal groups instead of the alternative of the social sector (Long, 2018). However, help-seeking may be complex amongst individuals who self-harm and many may have delayed access to care or not access support and care for their self-harm given the stigma that is attached to self-harm (Long, 2018). Being a complex entity, which involves more than one influencing factor towards this behaviour, people who self-harm may have diverse identified aspects which may need to be seen from the different supporting sectors. The different roles and further information regarding the support given to the mentioned population is presented. This section is predominantly focused on access to care and support from a UK setting given the setting of the PhD.

i. Informal sector: family, friends and others

Informal help-seeking for supporting self-harm behaviours is commonly reported amongst those who self-harm (NICE, 2011; Skegg, 2005; Wu, Stewart, Huang, Prince & Liu, 2011). Accompanying many hospital self-harm presentations are family members and/or friends. Highlighting the importance of support given by family and friends, Wu and collaborators (2011) identified the essential role this informal sector has in people who self-harm, in many cases even preventing such behaviour. Other informal support systems such as religious or community groups have also supported people with mental disorders, being a possible avenue for support to people who self-harm (Nooney & Woodrum, 2002).

ii. Health sector

There are different types of healthcare systems across the world, varying from private and out of pocket payments to universal and free of charge systems. United Nation's Sustainable Development Goal (SDG) 3 states universal health coverage in all its members by 2030, highlighting the importance of free healthcare to citizens across the world and equity (United Nations, 2015). While some countries like Canada and the UK do offer universal health coverage, the out of pocket model is commonly seen in low- and middle-income countries, where there are not enough resources or the needed infrastructure for universal health coverage (Asante, Price, Hayen, Jan & Wiseman, 2016). Within the UK, the NHS (National Health Service) fulfils the role of offering universal healthcare to its citizens since 1948, through the different NHS governments (e.g. NHS England) (Webster, 2002). Funding for the NHS comes from National Insurance contributions and taxation. Besides providing universal healthcare, the NHS also is the commissioner of healthcare services, meaning it manages the process of planning, monitoring and agreeing services. Healthcare within the UK is firstly provided through primary care, which manages the patients and the health condition, with patients being referred to secondary care and specialised care when indicated. Unlike other healthcare systems, the NHS includes mental health services as part of its universal healthcare provision. Mental healthcare is usually provided in primary care by GPs, or in some cases referrals to secondary care. IAPT or Improving Access to Psychological Therapies, is an initiative that funds mental health support to patients delivered within primary care. For preventative measures and disease control, Public Health England also has an important role in healthcare and self-management of health conditions and improvement. Within primary care, the different healthcare providers include GPs, pharmacists and nurses. In contrast, secondary care settings offer healthcare delivery through psychiatrists, community psychiatric nurses (CPN), psychologists, social workers, occupational therapists and other mental health nurses. Furthermore, secondary care settings can be hospital-based or within the community (e.g. Community Mental Health Teams based in GP surgeries), although mostly hospital-based.

The health sector with its different services including primary and secondary care settings, offer a range of care and support to people who self-harm including pharmacological and psychological interventions. According to NICE (2011) guidelines on self-harm longer term management, a person presenting with self-harm and risk of repetition should be referred for assessment to community mental health services with increased priority to more vulnerable groups with high levels of distress. As well as treating people following self-harm, healthcare professionals are expected to monitor physical health of patients as they may often present with comorbidities in addition to the physical consequences of self-harm (NICE, 2011). Additionally, in the case of treatment from both primary and secondary care settings, NICE (2011) suggests good and up to date communication between both. Treatment through secondary care settings are mostly formed by mental health services and hospital-settings. In these settings, healthcare professionals should carry out a comprehensive psychosocial assessment to evaluate the treatment pathway according to current guidance (NICE, 2011). Special recommendations for older adults and children and teenagers are made, stating specialised practitioners with mental health training in the specific age group should be offering this service.

For longer term management of people who self-harm, risk management and care plans should be offered (NICE, 2011). This service should be provided by specialist mental health services. These services, however, vary according to locality, as demand and funding is very dependent on the context. Also, harm reduction and identification of alternative coping strategies need to be a priority for longer term management. As for those with associated mental disorders, these conditions must be taken into account when treating people who self-harm and any associated medication/intervention.

Lastly, NICE (2011) guideline state as one of the recommendations to practitioners, the importance of being aware of other avenues of access to care and support for people who self-harm such as from the social and third sector. This way, a broad range of options for care and support can be offered, treating the different needs of each individual. With this

recommendation, NICE highlights the importance and role of other groups outside of the health sector as a more complex and wider approach to healthcare is often needed.

iii. Social care sector

Being a behaviour and not an illness, self-harm has a range of different aspects which need to be considered when managing this behaviour; therefore, care and support regarding self-harm are likely to involve other sectors as well as the healthcare sector.

There are a range of social care services that are regulated by local councils as well as by the government in the UK. The social care system promotes independence for individuals who are in need. The services offered to support individuals with different needs include housing, employment, welfare benefits, education, disability, childcare, amongst others.

People with self-harm behaviour often access care and support from the social care sector as their self-harming behaviour is not an exclusive health condition but also involves social aspects such as housing, disability, employment, amongst others. Subsequently, making access to social services common amongst people who self-harm. As seen by Sinclair and collaborators (2011) and Byford and collaborators (2003), social service resource use and access to care include adult placements, group homes, nursing homes, residential rehabilitation for alcohol misuse, contact with social workers and counsellors, day centres and contact with the police and criminal justice system.

The services offered by the social care sector to people who self-harm help alleviate the burden on the healthcare system which cannot exclusively manage this behaviour. As seen in section 2.2.7, self-harm holds a variety of functions and motivations to individuals who engage in such behaviour, involving different influencing aspects including social and health related. The importance of giving comprehensive support to people who self-harm, including all aspects involved in their self-harm is essential to avoid repetition as well as fatal repetition, something which is emphasised by NICE guidelines (2011).

With the assistance from the social care sector, individuals who self-harm can achieve independence as well as manage the different involving aspects of their behaviour. Nevertheless, access to social services may not always be an option for all people who self-harm since they may not qualify to receive such services or due to shortages in resources. Public health plays an important role in social care services as well as in the NHS as was previously mentioned. Through preventative measures as educational campaigns, health promotion, reduction of health inequalities and overall health improvement, the Departments of Health office of Public Health can alleviate some of the resource use from the social care sector.

iv. Third sector

The third sector is defined as “a range of organisations that are neither public sector nor private sector that include voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutual and co-operatives” (National Audit Office, 2010). A more comprehensive definition of the third sector can be found in Chapter 5, section 5.2.4. Within and outside the UK, the third sector offers a range of services and support to people in need, especially those with mental health problems, including self-harm.

Qualitative studies on experiences of access to care and support from people who self-harm repeatedly state frequent access to third sector groups (McManus et al., 2019b; Okolie, Dennis, Thomas & John, 2017; Rowe et al., 2014; Taylor, Hawton, Fortune & Kapur, 2009). Experiences through these groups are perceived more positively when compared to health services for people who self-harm (McManus et al., 2019b; Okolie, Dennis, Thomas & John, 2017; Rowe et al., 2014; Taylor, Hawton, Fortune & Kapur, 2009). Consequently, access to care and support from third sector organisations is popular amongst people who self-harm. However, due to these organisations being dependent on donations and contracts which are commissioned on a short-term basis, they are variably available to people who self-harm.

2.3 Conclusions

Self-harm is a concern worldwide due to its prevalence and potential cost to society. Setting the stage for subsequent chapters, this chapter provides a comprehensive understanding of the different involving factors around self-harm, including methods, motivations, epidemiology, association with suicide and mental disorders, cost, management and access to care and support. The importance of supporting populations who self-harm, as well as the common difficulties encountered was highlighted. Additionally, there are certain groups which are more vulnerable to self-harm and its detrimental effects as discussed previously. There were certain factors lacking in the included reports of evidence, such as a further exploration in more vulnerable groups, including motivations for self-harm. These are important to further explore as with increased understanding of self-harm within specific groups, adequate service provision and prevention measures can be identified.

This chapter has presented a review of the literature regarding self-harm. It was mostly set in a UK based context with the existing policies, resources and available guidelines. The impact of self-harm on society, as well as the individual, is evident, particularly amongst certain groups, such as older adults, warranting further exploration. Chapter 3 further explores self-harm in the population of older adults.

CHAPTER 3: SYSTEMATIC REVIEW

3.1 Introduction

The aim of this chapter is to present a systematic review of the literature of the characteristics of self-harm in older adults, conducted in collaboration with the PPIE group. Self-harm rates, methods and clinical characteristics in older adults are presented. The methods used to conduct the systematic review are described. After results of included articles are described and analysed, strengths and limitations of the review are summarised as well as implications for research and clinical practice. Finally, areas for future research in the field are highlighted. The below described systematic review is fully reported and published in *The British Journal of Psychiatry*, see Troya et al., 2019a.

3.2 Background to review

The importance of systematically examining current evidence with regard to a subject is important so that health professionals, researchers, stakeholders and patients can access up to date information. For instance, researchers may choose to shift their focus to a specific area that has been highlighted as needing more research, while stakeholders may choose to invest their resources in certain interventions for specific groups that have proved to be more cost-efficient and accessible.

Previous systematic reviews have presented the evidence of self-harm characteristics in certain populations such as adolescents (Webb, 2002), people with a diagnosis of schizophrenia (Hawton, Sutton, Haw, Sinclair & Harriss, 2005), LGBT community (King et al., 2008), non-clinical populations (Swannell, Martin, Page, Hasking & St John, 2014), ethnic minorities (Bhui, McKenzie & Rasul, 2007), amongst others. In the case of self-harm in older adults, no systematic review of the evidence has been done despite the highlighted need of further understanding self-harm in later life. The latest collection of evidence in the subject was done over 10 years ago, when Chan and collaborators performed a literature review on self-harm in older adults (Chan, Draper & Banerjee, 2007). However, still lacking is a

methodologically robust systematic review. A synthesis of available evidence regarding self-harm in older adults is essential to understand, identify and offer more effective and adequate health service provision to this population.

3.3 Systematic review question, aim and objectives

This systematic review aimed to describe the characteristics of self-harm in older adults (aged 60 years or older) including clinical characteristics, risk factors, methods, rates and lived experiences, to increase understanding behind self-harm in later life.

It does so by summarising and appraising the evidence regarding older adults who self-harm answering the following question: What are the main characteristics of older adults who self-harm regarding rates, risk factors, methods and clinical characteristics?

Specific objectives of this review were to:

- i. Describe the characteristics of older adults who self-harm, including clinical characteristics and lived experiences with self-ham
- ii. Estimate rates of self-harm behaviour in older adults
- iii. Identify and describe the different risk factors for self-harm in older adults

3.4 Systematic review methods

The conduct of the systematic review was supported by a six-person review team. In addition to the Principal Reviewer (Isabela Troya), the review team consisted of the academic supervisors and two PhD students.

This review was conducted and reported in accordance with established systematic review guidance. An a priori protocol was established and registered on PROSPERO, an international prospective register of systematic reviews (CRD42017057505). All members of the review team agreed with the submitted protocol. An amendment was made to this protocol to update the quality assessment toolkit used.

3.4.1 Data sources and searches

The search strategy was developed and performed after having consulted an experienced information specialist (Dr. Nadia Corp). Databases were searched with keywords “self-harm” and “older adults” (See Appendix 1 for complete search strategy specific for each database). Databases selected to perform the search were chosen after having considered populations and subject to be explored. Interface EBSCO was used to perform the search in databases AgeLine, CINAHL and PsycINFO. While MedLine was searched using OVID interface. Web of Science database was also searched for relevant studies. Searches in the different databases were performed from inception to February 28, 2018. Additionally, hand-searching of reference lists of included studies was carried out to identify other potentially relevant grey literature. No language restrictions were applied.

3.4.2 Study selection

After having carried out the searches in the different databases, relevant articles were imported to RefWorks, a bibliographic management program. Title and abstract screening were performed independently by two reviewers (IT and fellow PhD student, Kay Polidano) to ensure consistency. In the title screening stage, articles were rejected if a study title was not relevant to the review topic. In the abstract screening stage, studies were rejected if inclusion criteria were not met; reasons for exclusion were recorded. The total number of searches and studies included and excluded can be found in Figure 3.1 in section 3.5. Studies were included in the review if they met all the eligibility criteria as established a priori within the protocol and further described in the following section. In addition to title, abstracts and the final set of included studies being independently reviewed and agreed by two reviewers (IT and KP), a randomly selected sample (20% of the selected studies) were further reviewed by the rest of the review team (CCG, BB and OB) to ensure consistency and validate the selection process. Team discussion until consensus is reached was used to resolve disagreements in case of discrepancies following study selection.

3.4.3 Eligibility criteria for including studies in review

Population: Studies examining older adult populations (aged 60 years or older) with presence of at least one self-harm episode as defined by NICE guidelines (2011).

Exposure: Self-harm determined by clinical presentation, self-report, or reports from family, carers, or health practitioners regardless of suicidal or non-suicidal intent.

Outcomes of interest: Studies reporting at least one clinical characteristic (e.g. self-harm rates, methods and repetitions) and/or lived experiences (defined as an individual's representation and understanding of a particular experience) with self-harm were included (Given, 2008).

Setting: This review focused on studies done in both clinical and community samples.

Study design: Observational studies with or without comparison groups were included in the review. Both clinical and community samples were included. This systematic review aimed to include the following study designs.

- Cross-sectional studies
- Cohort studies: retrospective and prospective
- Case control studies
- Qualitative studies

The questions being assessed in this review could be answered with different study designs. While questions regarding risk factors are more suitable with prospective cohort studies, estimating prevalence rates could be answered with cross-sectional surveys. This is why, a different range of study designs were included to answer review questions.

Articles that met the above described criteria were included in the systematic review, regardless of the date of publication. This was done to avoid any form of selection bias which may arise from choosing to exclude articles with certain date range.

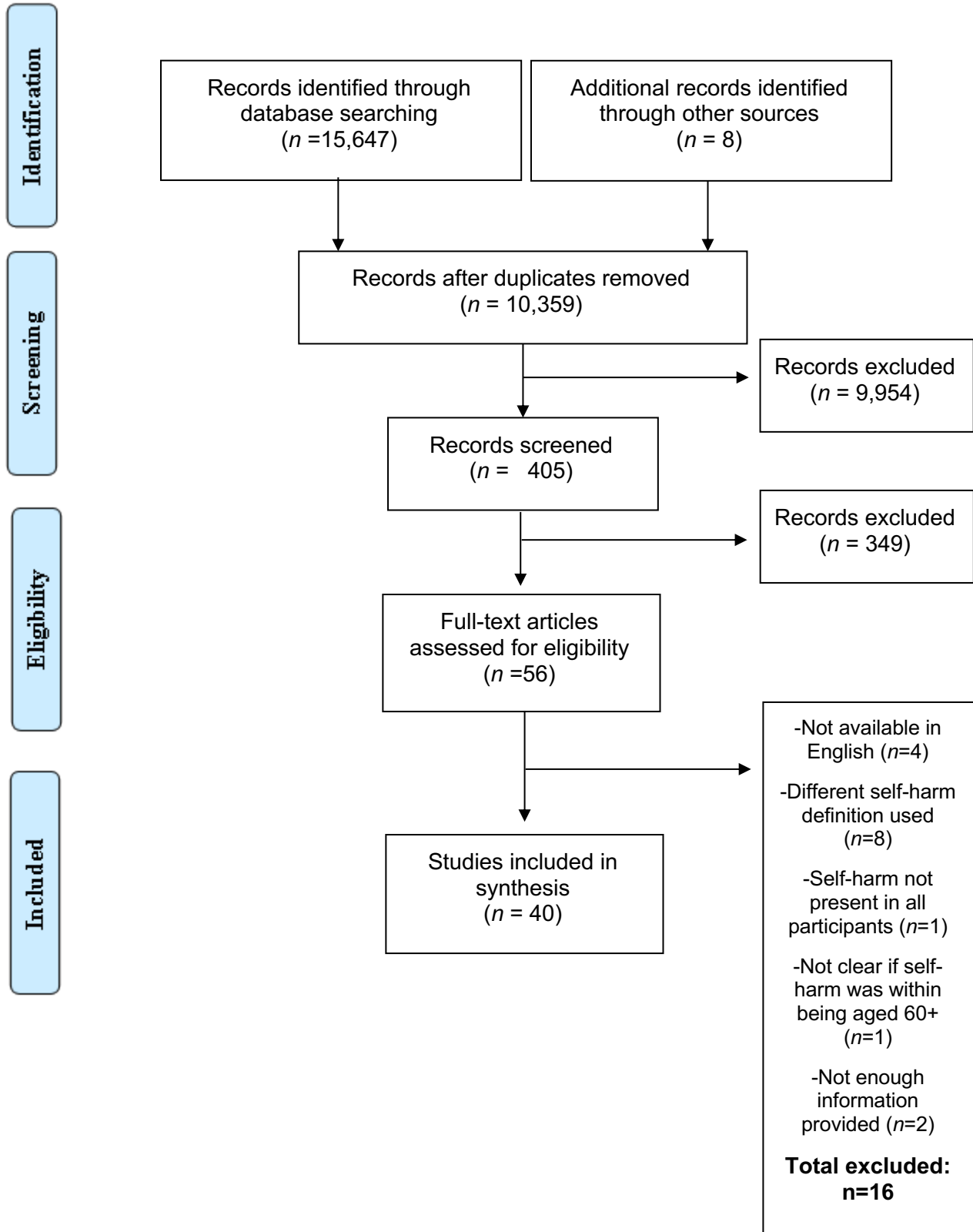


Figure 3. 1 PRISMA flow diagram

3.4.4 Exclusion criteria

Criteria for exclusion is as follows:

- studies which could not be interpreted with respects to language
- studies where only an abstract was retrieved and no full-text was available
- systematic reviews
- letters or editorials; case reports or case series
- studies where the population was exclusive to a specific disease or condition (e.g. borderline personality disorder or imprisoned population)
- studies done exclusively in cognitively impaired populations (e.g. advanced dementia or Alzheimer's disease). Cognitive impairment was defined as: "...deficits or impairment in cognitive function. The term may describe deficits in global intellectual performance but may also refer to deficits in specific cognitive domains including memory, language, attention, perception, reasoning and executive function. Cognitive impairment can be found in various patient groups, including but not restricted to, patients with dementia, individuals with autism, Down syndrome (DS) and traumatic brain injury (TBI)." (Defrin et al., 2015).

3.4.5 Data extraction and data synthesis

Data were extracted by one reviewer (IT) using a pre-tested customised data extraction form and independently checked for completion, accuracy and consistency by a second reviewer (KP or Erin McCloskey, fellow PhD student). Data were extracted on the clinical characteristics of self-harm and lived experiences of the study participants. More specifically, data were extracted regarding population characteristics (e.g. age, gender, marital status, living situation and ethnicity), characteristics of self-harm including methods and rates and outcomes (e.g. risk factors, clinical characteristics, contact with health services, motivations and stressors for self-harm). Extracted data items are listed on Table 3.1. In instances of missing or incomplete quantitative data (i.e. lack of crude estimates or measures of variability for estimates of self-harm), additional information was requested through contacting primary

study authors. A random effects meta-analysis of quantitative self-harm data was planned but could not be performed due to inherent heterogeneity of data from primary studies and non-response to/provision of required information from study authors.

Table 3. 1 Data extraction

Elements extracted from data

Study characteristics, terminology used, setting, study aim, study design, study length (follow-up), quality assessment, participants (presentations), gender, age, living situation, ethnicity, marital status, self-harm method, risk factors, rates (per 100,00), percentage of patients admitted for self-harm, previous self-harm, previous psychiatric history, depression diagnosis, use of antidepressants, current psychiatric treatment, physical illness, self-harm repetition (time), death (suicide), suicidal intention, stressors, contact with GP prior to episode, alcohol or drug use at SH episode, history of psychiatric consultation, psychiatric assessment after episode, qualitative findings, motivations for self-harm, cost, other, findings

A narrative synthesis approach was used to synthesise studies, based on guidance from Popay and collaborators (2006). Evidence was synthesised in a systematic way, ensuring an unbiased research collection and synthesis. In this guidance (Popay et al., 2006), different tools for synthesising data are described and used in the present review (Refer to Figure 3.2). Guidance followed from Popay and collaborators (2006) was used to synthesise the quantitative evidence from the review.

For the qualitative studies included in the review, steps for thematic synthesis were followed to synthesise the evidence (Thomas & Harden, 2008): a) line by line coding of findings; b) organisation of codes into descriptive themes; c) generating analytical themes. The first two stages consist on summarising the presented evidence, while the last stage entails an interpretation of the summarised findings within the broader context (Thomas & Harden, 2008). A descriptive analysis of quantitative data alongside a thematic synthesis of qualitative data was performed and narratively synthesised together. Thematic analysis was conducted by one

reviewer (IT) and then checked for completion, accuracy and consistency of identified themes by a second reviewer (EM).

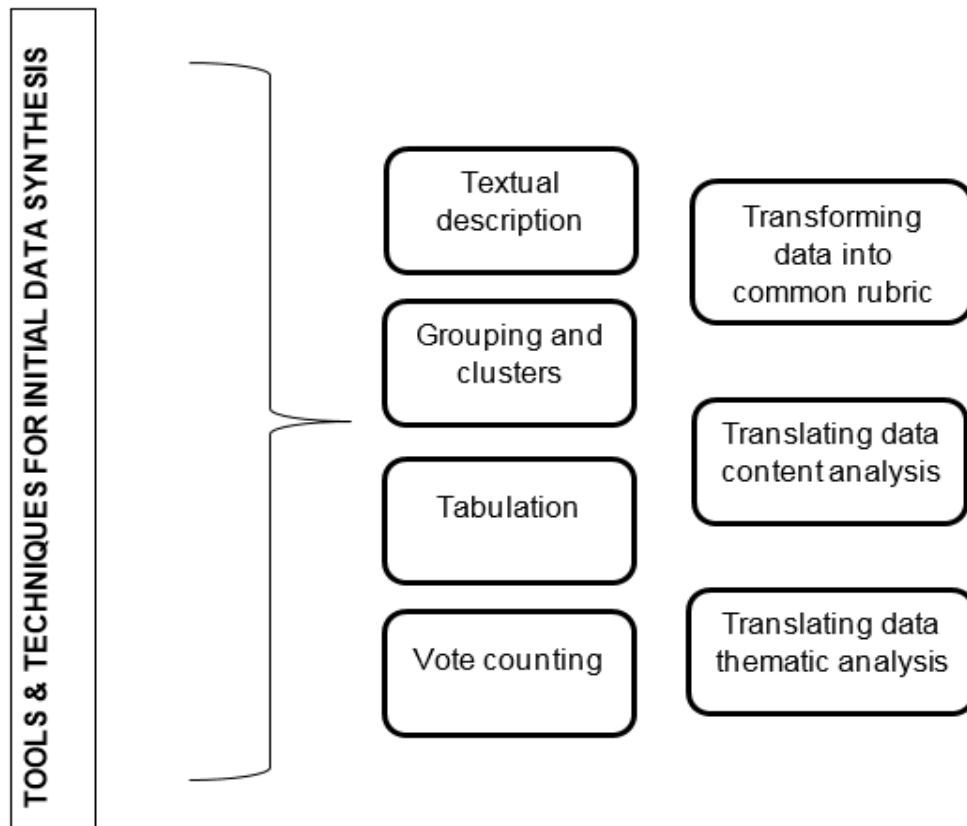


Figure 3. 2 Tools and techniques for initial data synthesis (Popay et al., 2006)

3.4.6 Methodological quality

To ensure methodological quality of included studies, a quality assessment was performed by two of the reviewers independently to ensure consistency. Disagreements regarding methodological quality of the included studies was resolved through discussion until consensus was reached.

Since the study designs included for the systematic review were more than one, multiple quality assessment toolkits were used. The NIH's (National Institute of Health) toolkit was used to appraise methodological quality of observational and cohort studies, as well as the one for case-control studies (NIH, 2018). In order to assess the quality of qualitative studies the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist was used

(CASP, 2018). NIH's toolkits and the CASP checklist were chosen after taking into consideration the robustness of the questions assessed and approachable and concise way of addressing methodological properties of each study. However, the potential limitations of the use of these types of toolkits are acknowledged in section 3.6.2.

The toolkits consisted on a series of questions on study design and methodological quality. For each question, instructions and guidance were provided to take into consideration when reviewing the methodological quality of an article. Three possible quality assessment ratings could be given: poor, moderate and good. Results section (3.5) gives further detail of how each study was rated according to the quality assessment toolkits used.

Summary of findings for each risk factor for self-harm repetition was completed. A modified version of the GRADE rating system (www.gradeworkinggroup.org/) was used to assess the overall quality of evidence considering: strength of association for each risk factor, methodological quality/design of the studies, consistency, directedness, precision, size and (where possible) dose-response gradient of the estimates of effects across the evidence base. Evidence was graded as very low, low, moderate and high, similar to a GRADE rating system.

3.4.7 Patient and Public Involvement and Engagement (PPIE)

The review was conducted in collaboration with the established PPIE group. The PPIE group was consulted four times at different stages of the review, including refining the review question, specification of study eligibility criteria, outcomes, interpretation and dissemination of findings. Regarding dissemination of findings, the PPIE group collaborated in the creation of an information leaflet summarising findings from the systematic review which has been widely distributed across networks, including the National Suicide Prevention Alliance (see Appendix 2). The group also contributed to developing the diagrammatic representation of the relationship between the various risk factors for self-harm among older people (see Results section: Influencing factors for self-harm). Findings based on lived experiences and current literature were discussed to reach consensus during PPIE meetings. These discussions were

then considered when interpreting results from the review. Inclusion of the PPIE group was considered essential to ensure the study outcomes were mapped pragmatically to patient-centred outcomes.

3.5 Results

A total of 15,647 unique citations were identified, with eight additional studies included through additional searches by reference checking. Subsequent to removal of duplicate citations and non-relevant studies at the titles screening stage, 405 abstracts were screened and a total of 56 full-text articles were assessed for inclusion. Forty studies met full eligibility criteria and were included. The flow of studies through the review process is presented in Figure 3.1. The main characteristics of the included studies are summarised in Table 3.2.

3.5.1 Description of studies

Study setting and designs

The 40 included studies were predominantly cross-sectional study designs ($n=21$), followed by cohort studies ($n=14$), three qualitative studies and two case-control studies.

All of the studies were written in English. The majority of them were conducted in countries where the main language was English ($n=21$). Fourteen of the studies were conducted in the UK. Four studies originated from Australia (Draper, 1994; Lawrence, Almeida, Hulse, Jablensky & Holman, 2000; Pillans, Page, Ilango, Kashchuk & Isbister, 2017; Ticehurst et al., 2002), two studies were carried out in New Zealand (Cheung et al., 2017; de Beer, Murtagh & Cheung, 2015) and two studies were done in the USA (Carter & Reymann, 2014; Logan, Crosby & Ryan, 2007). Seventeen studies were from non-English speaking countries which included China (Zhang et al., 2017), Taiwan (Yang, Tsai, Chang & Hwang, 2001), Korea (Kim et al., 2011; Kim, 2014), Hong Kong (Chiu, Lam, Pang, Leung & Wong, 1996; Tsoh et al., 2005), Japan (Takahashi, 1995), Turkey (Gokcelli et al., 2017), Israel (Briskman et al., 2017), Belgium (Bonnewyn et al., 2014), France (Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006), Sweden (Van Orden et al., 2015; Wiktorsson, Runeson, Skoog, Ostling & Waern, 2010),

Iran (Gheshlaghi & Salehi, 2012), Greece (Gavrielatos, Komitopoulos, Kanellos, Varsamis & Kogeorgos, 2006) and Brazil (Armond et al., 2017). The remaining two studies were conducted within a European setting, being multi-centre studies, therefore included both English and non-English speaking settings (De Leo et al., 2001 & 2002).

The majority of the included studies were hospital-based ($n=34$), mostly ED and psychiatry departments, with the exception of two studies, one conducted in a plastic surgery department (Packer, Hussain, Shah & Srinivasan, 2012) and the remaining within a poison's unit (Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987). The remaining six studies were conducted in different healthcare facilities ($n=2$) (e.g. general hospitals, private doctors and GPs) (De Leo et al., 2001 & 2002), community mental health services ($n=2$) (Crocker, Clare & Evans, 2006; Kim, 2014), a national household survey (Zhang et al., 2017) and a national surveillance system which includes both presentations from hospitals and primary care (Armond et al., 2017).

Length of each study was reported in all but three studies (Bonnewyn et al., 2014; Crocker, Clare & Evans, 2006; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007). Study length varied from eight months to 26 years, with Kim's (2014) qualitative study having a length of eight months, to 26 years with Pillans and collaborators (2017) cross-sectional study. Follow-up was reported in all of the 13 cohort studies, with follow-up varying from one to 23 years.

Data from participants was obtained through different methods in the included studies. These varied from hospital databases, clinical interviews with assessment and diagnosis made by health professionals and various scales. All but one study were based on self-harm presentations as determined by clinical presentation. The remaining study was based on self-reported self-harm (Zhang et al., 2017).

Table 3. 2 Characteristics of included studies

Study ID	Study design	Quality assessment	Study setting	Study length (follow-up)	Participants (presentations)	Age range	Self-harm method (frequency)	Self-harm repetition (time)	Death (suicide)	Influencing Factors for self-harm	Motivations for self-harm
Armond 2017 Brazil	Cross-sectional	Moderate	Hospital & community based	1 year	93 (93)	60-90+	Self-poison: 39 Self-injury: 0 Other: 54	NA	NA	Low education level and socio-economic status	NR
Bonnewyn 2014 Belgium	Qualitative	Moderate	Hospital-based (Psychiatry)	NR	8 (8)	66-85	NR	NA	NA	Loss, death of spouse or family, conflict with family, physical illness, physical disability, insomnia, loneliness, loss of control	Death of a spouse or family member, conflict with family member, physical illness/disability, loneliness, loss of control
Briskman 2017 Israel	Cross-sectional	Moderate	Hospital-based (ED)	8 years	187 (187)	65-95	Self-poison: 177 Self-injury: 10 Other: 0	NA	NA	NR	NR
Carter 2014 USA	Cross-sectional	High	Hospital-based (ED)	1 year	4,915 (4,915)	65-85+	Self-poison: 3,077 Self-injury: 595 Other: 1,243	NA	NA	Alcohol and drug use	NR
Cheung 2017 New Zealand	Cohort	High	Hospital-based (ED)	3 years (1 year)	339 (339)	65-96	Self-poison: 233 Self-injury: 31 Other: 37 Multiple: 38	50/339 (1 year)	7 (7)	Perceived physical illness, family discord, bereavement, financial trouble, partner separation	NR
Chiu 1996 Hong Kong	Cohort	Poor	Hospital-based (Psychiatry)	2.5 years (1.5 years)	55 (55)	65-91	Self-poison: 15 Self-injury: 40	5/55 (1.5 years)	16 (3)	NR	NR
Crocker 2006 UK	Qualitative	High	Community-based	NR	15 (15)	65-91	Self-poison: 14 Self-injury: 0 Other: 1	NA	NA	Social isolation, loss of social status, physical illness and loss of mobility, loneliness, ageing perceived as burdensome	Become invisible to others, regaining control
De Beer 2015 New Zealand	Cohort	Moderate	Hospital-based (ED)	3 years (1 year)	52 (52)	65-80+	Self-poison: 34 Self-injury: 8 Other: 7 Multiple: 3	7/52 (1 year)	5/52 (0)	Physical illness, pain, family discord, changed relationship, bereavement, financial or legal difficulties	NR

Study ID	Study design	Quality assessment	Study setting	Study length (follow-up)	Participants (presentations)	Age range	Self-harm method (frequency)	Self-harm repetition (time)	Death (suicide)	Influencing Factors for self-harm	Motivations for self-harm
De Leo 2001 Europe	Cross-sectional	Moderate	Hospital & community based	5 years	1,518 (1,734)	65-82	Self-poison: 1,196 Self-injury: 191 Other: 347	NA	NA	NR	NR
De Leo 2002 Europe	Cross-sectional	Moderate	Hospital & community based	3 years (1 year)	63 (63)	60 and over ¹	Self-poison: 50 Self-injury: 3 Other: 4 Multiple: 6	15/63 (1 year)	8 (8)	Bereavement of father, poor mental health and poor social assistance. Financial problems	Relational difficulties, desire to manifest desperation to others, or mental illness
Dennis 2007 UK	Cross-sectional	Moderate	Hospital-based (Psychiatry)	NR	76 (76)	65-92	Self-poison: 43 Self-injury: 9 Other: 4 Multiple: 20	NA	NA	Isolated lifestyle, life events and difficulties, bereavement, health problems	Gain relief from an unbearable state of mind, escape, make others understand how desperate they were, influence others, seek help, make others feel sorry
Draper 1994 Australia	Cross-sectional	Moderate	Hospital-based (Psychiatry)	6.5 years	69 (69)	65-85+	Self-poison: 52 Self-injury: 13 Multiple: 4	NA	NA	Social isolation, family issues, marital issues, death, accommodation issues, financial problems	NR
Gavrielatos 2006 Greece	Cross-sectional	Moderate	Hospital-based (ED)	3.5 years	44 (44)	65-91	Self-poison: 44 Self-injury: 0 Other: 0	NR	NR	Domestic stress (e.g. health or financial issues), stress of chronic illness	NR
Gheshlaghi 2012 Iran	Cross-sectional	Poor	Hospital-based (ED)	1 year	43 (43)	65-83	Self-poison: 43 Self-injury: 0 Other: 0	NA	3 (3)	NR	NR
Gokcelli 2017 Turkey	Cross-sectional	Moderate	Hospital-based (ED)	9 years	63 (63)	60-91	Self-poison: 56 Self-injury: 3 Other: 4	NA	NA	NR	NR
Hawton 2006 UK	Cohort	Moderate	Hospital-based (Psychiatry and ED)	23 years (23 years)	730 (730)	60-85+	Self-poison: 647 Self-injury: 62 Multiple: 21	112/730 (23 years)	432 (30)	Physical illness, social isolation, relationship problems, bereavement, housing problems, alcohol misuse, financial worries	NR

Study ID	Study design	Quality assessment	Study setting	Study length (follow-up)	Participants (presentations)	Age range	Self-harm method (frequency)	Self-harm repetition (time)	Death (suicide)	Influencing Factors for self-harm	Motivations for self-harm
Hepple 1997 UK	Cohort	Moderate	Hospital-based (Psychiatry)	3 years (2-5 years)	100 (100)	65-94	Self-poison: 87 Self-injury: 2 Other: 11	28/100 (2-5 years)	42 (7)	Isolation, friction with family, bereavement, physical and psychiatric problems	NR
Kim 2011 Korea	Cross-sectional	High	Hospital-based (ED)	2 years	57 (57)	65-81	Self-poison: 57 Self-injury: 0 Other: 0	NA	NA	NR	Interpersonal conflict, economic problems, physical illness
Kim 2014 Korea	Qualitative	Moderate	Community-based	8 months	35 (35)	64-89	NR	NA	NA	Financial problems, domestic violence, illness, childhood events, violence, grief, mental illness	Feelings of helplessness, despair, dependence and isolation
Lamprecht 2005 UK	Cohort	High	Hospital-based (Psychiatry)	3 years (1-2 years)	82 (99)	65-82	Self-poison: 90 Self-injury: 5 Other: 4	15/82 (1-2 years)	NR	Pain and debilitating illness	NR
Lawrence 2000 Australia	Cohort	Moderate	Hospital-based	15 years	1,368 (1,596)	60-80+	NR	NA	NA	NR	NR
Lebret 2006 France	Cohort	High	Hospital-based (Psychiatry)	7 years (3 years)	59 (59)	61-85	Self-poison: 31 Self-injury: 9 Other: 12 Multiple: 7	8/59 (3 years)	17 (3)	Physical illness, loneliness, relationship conflict	Physical illness, interpersonal problems, social isolation/loneliness
Liu 2009 Taiwan	Case-control	Moderate	Hospital-based (ED)	20 months	43 (43)	61-90	Self-poison: 21 Self-injury: 12 Other: 10	NA	NA	Health conditions, finances, interpersonal relations, affinity relations, parent-child relations	Depression, family conflict, long-term physical illness, financial burden
Logan 2007 USA	Cross-sectional	Moderate	Hospital-based (ED)	1 year	5,710 (5,710)	65 and over ¹	Self-poison: 3,425 Self-injury: 1,062 Other: 1,223	NA	NA	NR	NR
Murphy 2012 UK	Cohort	High	Hospital-based (ED)	8 years (1-8 years)	1,177 (1,177)	60-97	Self-poison: 1,031 Self-injury: 107 Other: 39	196/1,177 (1 year)	24 (24)	Relationship problems, bereavement, physical and/or mental health problems, alcohol problems	NR
Nowers 1993 UK	Cohort	High	Hospital-based (ED)	7 years (5 years)	88 (88)	65-90	Self-poison: 85 Self-injury: 2 Other: 1	17/88 (1 year)	26 (5)	NR	NR

Study ID	Study design	Quality assessment	Study setting	Study length (follow-up)	Participants (presentations)	Age range	Self-harm method (frequency)	Self-harm repetition (time)	Death (suicide)	Influencing Factors for self-harm	Motivations for self-harm
Packer 2012 UK	Cross-sectional	Moderate	Hospital-based (Plastic surgery)	5 years	10 (10)	60-80+	Self-poison: 0 Self-injury: 10 Other: 0	NA	NA	NR	NR
Pierce 1987 UK	Cohort	Moderate	Hospital-based (ED)	13 years (1-12 years)	145 (145)	65-92	Self-poison: 138 Self-injury: 7 Other: 0	12/145 (1-12 years)	4 (4)	Physical illness, housing or financial stress, pain	NR
Pierce 1996 UK	Cohort	Moderate	Hospital-based (ED)	20 years (1-19 years)	39 (89)	60-87	Self-poison: 78 Self-injury: 6 Other: 5	39/39 (50 months)	18 (2)	NR	NR
Pillans 2017 Australia	Cross-sectional	High	Hospital-based	26 years	626 (626)	65-97	Self-poison: 500 Self-injury: 126	NA	24 (NR)	NR	NR
Ruths 2005 UK	Cohort	Moderate	Hospital-based (ED)	2 years (2 years)	43 (43)	65-95	Self-poison: 36 Self-injury: 7 Other: 0	8/43 (2 years)	18 (0)	Chronic pain, terminal illness	NR
Shah 2009 UK	Cross-sectional	Moderate	Hospital-based	9 years	44,310 (44,310)	60-75+	Self-poison: 41,298 Self-injury: 2,635 Other: 377	NA	NA	NR	NR
Takahashi 1995 Japan	Cross-sectional	Moderate	Hospital-based (Psychiatry)	10 years	50 (50)	65-89	Self-poison: 21 Self-injury: 13 Other: 5 Multiple: 11	NA	NA	NR	NR
Ticehurst 2002 Australia	Cross-sectional	Moderate	Hospital-based	7.5 years	110 (110)	65 and over ¹	Self-poison: 110 Self-injury: 0 Other: 0	NA	6 (NR)	NR	NR
Tsoh 2005 Hong Kong	Case-control	Moderate	Hospital-based (Psychiatry)	15 months	66 (66)	65-82	NR	NA	NA	Psychiatric and physical morbidities, family discord	NR
Van Orden 2015 Sweden	Cohort	Moderate	Hospital-based (ED)	3 years (12 months)	101 (101)	70-91	Self-poison: 73 Self-injury: 13 Other: 15	6 (12 months)	2 (2)	Social problems, perceived burdensomeness, psychological problems, physical problems	Escape, functioning and autonomy, psychological problems, somatic problems and pain, perceived burden, social problems, lack of meaning
Wiktorsson 2010 Sweden	Cross-sectional	Moderate	Hospital-based (ED)	3 years	103 (103)	70-91	NR	NA	NA	Hopelessness, loneliness, low education	NR

Study ID	Study design	Quality assessment	Study setting	Study length (follow-up)	Participants (presentations)	Age range	Self-harm method (frequency)	Self-harm repetition (time)	Death (suicide)	Influencing Factors for self-harm	Motivations for self-harm
Wynne 1987 UK	Cross-sectional	Moderate	Hospital-based (Poisons unit)	4.5 years	45 (45)	65 and over ¹	Self-poison: 45 Self-injury: 0 Other: 0	NA	NA	Physical: pain, severe illness, disability, terminal illness. Social: relationship, housing, financial problems. Psychiatric: depression, personality disorder, alcohol problems	Physical: pain, severe illness, disability, terminal illness. Social: relationship problems, housing, financial problems. Psychiatric: depression, personality disorder, alcohol problems
Yang 2001 Taiwan	Cross-sectional	Moderate	Hospital-based (Psychiatry)	6 years	55 (55)	65-84	Self-poison: 20 Self-injury: 21 Other: 14	NA	NA	Psychosocial problems, family problems, interpersonal problems, adjustment problems and physical illness	Psychosocial problems, family problems, interpersonal problems, adjustment problems, physical illness
Zhang 2017 China	Cross-sectional	High	Community-based	6 months	63 (63)	60-112	NR	NA	NA	Having no caregivers, psychological problems	NR

*NR= Not Reported

*NA= Not Applicable

¹ Paper did not report upper range limit

Quality assessment

Included studies were mostly of moderate ($n=28$) to high ($n=10$) methodological quality. Two studies were assessed as having poor quality. Table 3.3 provides an overview of the quality assessment of studies, while Figure 3.3 highlights areas with higher or lower risk assessment. Risk assessment of studies was determined by grouping and rating the different methodological quality assessments of studies. High-risk ratings were given to studies where the quality assessment element was not reported at par with recommended criteria as determined by the appraisal toolkit, while low-risk when this was reported at par to standards. Overall, participation rate, study population and research question, repeated exposure, timeframe, defined outcomes and inclusion criteria were consistently assessed as having lower risk assessment across studies ($\geq 80\%$), while loss to follow-up and measurement and adjustment of confounding variables were rated as having higher risk across studies ($\geq 60\%$). Blinding of assessors and estimate of sample size were rated as having an unclear risk assessment across studies given the included study designs ($\geq 60\%$).

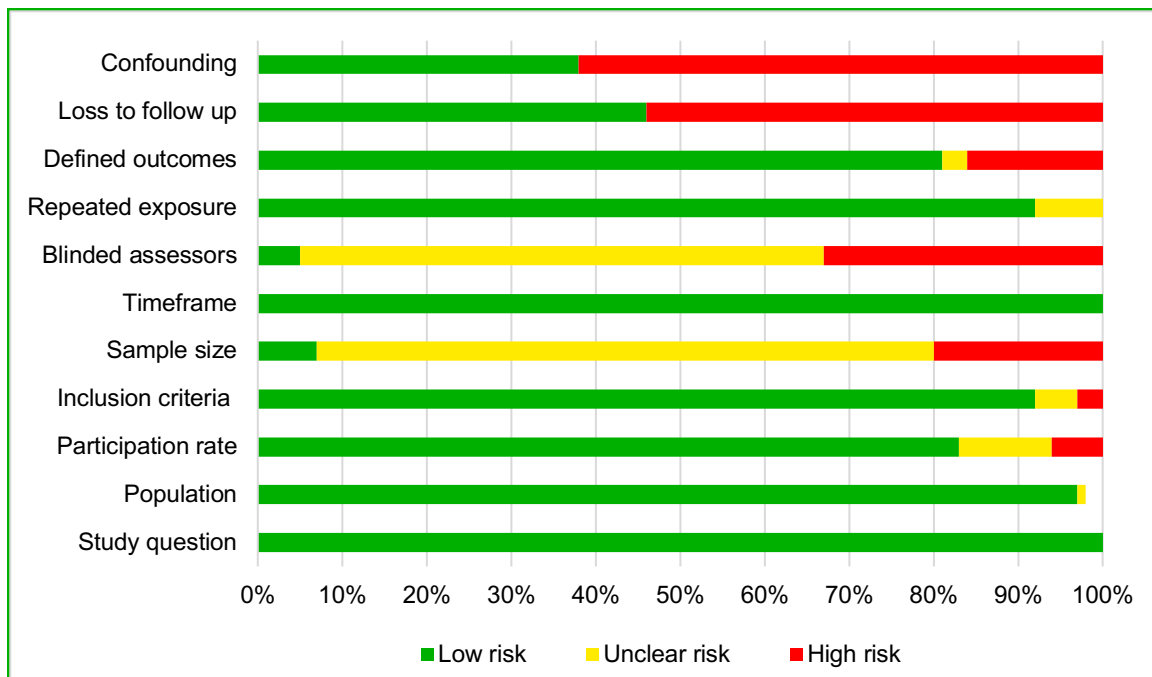


Figure 3. 3 Risk assessment of studies

Table 3. 3 Quality assessment of included studies

	Study question	Population	Participation rate	Inclusion criteria	Sample size	Timeframe	Blinded assessors	Repeated exposure	Defined outcomes	Loss to follow-up	Confounding
Armond et al 2017	✓	✓	-	✓	-	-	?	-	✓	-	x
Briskman et al 2017	✓	✓	-	✓	-	-	x	-	✓	-	x
Carter et al 2014	✓	✓	-	✓	-	-	?	-	✓	-	x
Cheung et al 2017	✓	✓	?	✓	?	✓	?	✓	✓	✓	✓
Chiu et al 1996	✓	✓	✓	x	?	✓	x	✓	?	x	x
De Beer et al 2015	✓	✓	✓	✓	✓	✓	?	✓	✓	x	x
De Leo et al 2001	✓	✓	-	?	-	-	x	-	✓	-	x
De Leo et al 2002	✓	✓	✓	?	x	✓	x	✓	✓	x	x
Dennis et al 2007	✓	x	-	✓	-	-	?	-	✓	-	✓
Draper 1994	✓	✓	-	✓	-	-	x	-	x	-	x
Gavrielatos et al 2006	✓	✓	-	✓	-	-	x	-	✓	-	x
Gheshlaghi et al 2012	✓	✓	-	✓	-	-	?	-	✓	-	x
Hawton et al 2006	✓	✓	✓	✓	?	✓	✓	?	x	✓	✓
Hepple et al 1997	✓	✓	✓	✓	?	✓	x	✓	✓	x	x
Gokcelli et al 2017	✓	✓	-	✓	-	-	x	-	x	-	x
Kim et al 2011	✓	✓	-	✓	-	-	?	-	✓	-	x
Lawrence et al 2000	✓	✓	-	✓	-	-	?	-	✓	-	✓
Lamprecht et al 2005	✓	✓	✓	✓	?	✓	?	✓	✓	✓	✓
Lebret et al 2006	✓	✓	✓	✓	?	✓	x	✓	✓	✓	✓
Liu et al 2009	✓	✓	✓	✓	x	-	?	-	✓	-	✓
Logan et al 2007	✓	✓	-	✓	-	-	?	-	✓	-	x
Murphy et al 2012	✓	✓	✓	✓	?	✓	?	✓	✓	✓	✓
Nowers 1993	✓	✓	✓	✓	?	✓	?	✓	✓	✓	✓
Packer et al 2012	✓	✓	-	✓	-	-	?	-	✓	-	x
Pierce 1987	✓	✓	✓	✓	?	✓	x	✓	✓	x	x
Pierce 1996	✓	✓	✓	✓	?	✓	?	✓	✓	x	x
Pillans et al 2017	✓	✓	-	✓	-	-	?	-	✓	-	✓
Ruths et al 2005	✓	✓	✓	✓	?	✓	?	✓	✓	x	x
Shah 2009	✓	✓	-	✓	-	-	?	-	✓	-	x
Takahashi et al 1995	✓	✓	-	✓	-	-	x	-	x	-	x
Ticehurst et al 2002	✓	✓	-	✓	-	-	?	-	x	-	✓
Tsoh et al 2005	✓	✓	x	✓	x	-	?	-	✓	-	✓
Van Orden et al 2015	✓	✓	✓	✓	-	✓	?	✓	✓	✓	✓
Wiktorsson et al 2010	✓	✓	-	✓	-	-	?	-	x	-	✓
Wynne et al 1987	✓	✓	-	✓	-	-	?	-	✓	-	x
Yang et al 2001	✓	✓	?	✓	-	-	x	-	✓	-	x
Zhang et al 2017	✓	✓	✓	✓	-	-	✓	-	✓	-	✓

	Study question	Methodology	Research design	Recruitment	Data collection	Relationship researcher	Ethical considerations	Data analysis	Findings	Research value
Bonnewyn et al 2014	✓	✓	✓	✓	✓	?	✓	✓	✓	?
Crocker et al 2006	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Kim 2014	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

✓ **Reported:** element reported appropriately in study

x **Not reported:** element not mentioned in study

? **Cannot determine** lack of clarity to assess if element was reported

- **Not applicable:** due to study design, element not applicable to report

3.5.2 Socio-demographic characteristics

Age

Age of participants ranged from 60 to 112 years. Nine studies (Armond et al., 2017; Carter & Reymann, 2014; Chiu, Lam, Pang, Leung & Wong, 1996; De Leo et al., 2001; Draper, 1994; Gokcelli et al., 2017; Nowers, 1993; Shah, 2009; Zhang et al., 2017) made a classification of individuals according to age range ($n=51,174$). Of those that did, 60% ($n=31,072$) of participants were aged 60 to 74 years old. This shows that the majority of participants were 'young' older adults.

Gender

All but three studies ($n=17,377$) reported participants' gender (Lawrence, Almeida, Hulse, Jablensky & Holman, 2000; Liu & Chiu, 2009; Shah, 2009). Of the studies that did, over half (57%; $n=9,903$) were women and 43% ($n=7,474$) were men.

Ethnicity

Eleven studies classified participants according to ethnicity ($n=6,573$), with the majority of participants being White: 68.1% ($n=4,479$) and 13.3% ($n=875$) of another ethnicity (Black, Asian, Hispanic, or Maori) (Armond et al., 2017; Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; Crocker, Clare & Evans, 2006; de Beer, Murtagh & Cheung, 2015; Lamprecht, Pakrasi, Gash & Swann, 2005; Logan, Crosby & Ryan, 2007; Liu & Chiu, 2009; Tsoh et al., 2005; Yang, Tsai, Chang & Hwang, 2001; Zhang et al., 2017). The remaining 18.6% ($n=1,219$) participants' ethnicity was unknown.

Marital status

27 studies reported the marital status of their participants ($n=4,161$) (Bonnewyn et al., 2014; Briskman et al., 2017; Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; Crocker, Clare & Evans, 2006; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2001 & 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gavrielatos, Komitopoulos, Kanellos, Varsamis & Kogeorgos, 2006; Gokcelli et al., 2017; Hawton & Harriss,

2006; Hepple & Quinton, 1997; Kim et al., 2011; Kim, 2014; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Liu & Chiu, 2009; Nowers, 1993; Pierce, 1987; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Ticehurst et al., 2002; Tsoh et al., 2005; Wiktorsson, Runeson, Skoog, Ostling & Waern, 2010; Yang, Tsai, Chang & Hwang, 2001). Of these, half were not married (51%, $n=2,121$); 38% ($n=1,582$) were married and the marital status of the remaining 11% ($n=461$) was unknown.

Living situation

Over half of the studies ($n=3,103$) reported participants' living situation either living with family or in care (53.5%; $n=1,658$), followed by 40% ($n=1,241$) living alone at the time of the self-harm event (Bonnewyn et al., 2014; Briskman et al., 2017; Cheung et al., 2017; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2001 & 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gheshlaghi & Salehi, 2012; Gokcelli et al., 2017; Kim, 2014; Lamprecht, Pakrasi, Gash & Swann, 2005; Liu & Chiu, 2009; Murphy et al., 2012; Nowers, 1993; Packer, Hussain, Shah & Srinivasan, 2012; Pierce 1987 & 1996; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Tsoh et al., 2005; Wiktorsson, Runeson, Skoog, Ostling & Waern, 2010; Zhang et al., 2017). The remaining of participants' living situation was unknown (6.5%; $n=203$).

3.5.3 Overall findings

Self-harm rates

Overall, there were 63,266 self-harm presentations involving a total of 62,755 older adult participants. Of the 40 included studies, seven (Carter & Reymann, 2014; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2001; Logan, Crosby & Ryan, 2007; Murphy et al., 2012; Pierce, 1987; Ruths, Tobiansky & Blanchard, 2005), presented overall estimates of self-harm rates per population ($n=13,776$). Yearly rates per 100,000 habitants varied from 19.3 to 65 as shown in Table 3.4.

Methods

Of the 40 included studies, 34 ($n=61,395$) reported self-harm methods. Table 3.2 includes a summary of the reported methods, with the majority of self-harm presentations being self-poisoning (86.1%; $n=52,866$) which included overdose of medication or ingestion of toxic substances. Self-injury through lacerations or burning of skin was 8.1% ($n=5,002$). Other methods included hanging, gunshots, car fumes, jumping in front of cars and immolation (5.6%; $n=3,417$). The remaining 0.2% ($n=110$) of the total participants used multiple methods to self-harm. Settings of the majority of studies reporting self-harm methods were hospital-based, with the exception of four studies (Armond et al., 2017; Crocker, Clare & Evans, 2006; De Leo et al., 2001 & 2002) that also reported community-based data. However, similar trends regarding self-harm methods used were reported across the different study settings.

Table 3. 4 Yearly self-harm rates per 100.000 habitants

Study	Study setting	Population size	Yearly rates per 100,000 habitants	Confidence Intervals (CI)
Logan et al., 2007	Hospital-based (ED) USA	$n=5,710$	19.3	95% CI: 13.9-24.8
De Beer et al., 2015	Hospital-based (ED) New Zealand	$n=52$	32.7*	Not provided
Pierce, 1987	Hospital-based (ED) UK	$n=145$	46*	Not provided
Ruths et al., 2005	Hospital-based (ED) UK	$n=43$	47.3*	Not provided
De Leo et al., 2001	Hospital & community-based Multi-site study conducted in 13 European countries	$n=1,734$	61.43	Not provided
Carter et al., 2014	Hospital-based (ED) USA	$n=4,915$	63	95% CI (61.2-64.8)
Murphy et al., 2012	Hospital-based (ED) UK	$n=1,177$	65	Not provided

*Small population size ($n<200$)

Associated clinical characteristics

Previous history of self-harm

Thirty studies reported previous history of self-harm ($n=6,033$) (Briskman et al, 2017; Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; Crocker, Clare & Evans, 2006; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2001 & 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gavrielatos, Komitopoulos, Kanellos, Varsamis & Kogeorgos, 2006; Gokcelli et al., 2017; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Kim et al., 2011; Kim, 2014; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebet, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Liu & Chiu, 2009; Murphy et al., 2012; Nowers, 1993; Packer, Hussain, Shah & Srinivasan, 2012; Pierce 1987 & 1996; Pillans, Page, Ilango, Kashchuk & Isbister, 2017; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Tsoh et al., 2005; Wiktorsson, Runeson, Skoog, Ostling & Waern, 2010; Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987; Yang, Tsai, Chang & Hwang, 2001). Nearly one third of participants (29.4%; $n=1,774$) had a previous history of self-harm.

Previous psychiatric history

Thirty studies reported participants' previous psychiatric history ($n=10,976$), including alcohol and substance misuse, schizophrenia and personality disorder, with 30% of participants having previous psychiatric history ($n=3,279$) (Bonnewyn et al., 2014; Briskman et al, 2017; Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; Crocker, Clare & Evans, 2006; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2001 & 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gavrielatos, Komitopoulos, Kanellos, Varsamis & Kogeorgos, 2006; Gheshlaghi & Salehi, 2012; Gokcelli et al., 2017; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Kim et al., 2011; Lamprecht, Pakrasi, Gash & Swann, 2005; Logan, Crosby & Ryan, 2007; Murphy et al., 2012; Nowers, 1993; Packer, Hussain, Shah & Srinivasan, 2012; Pierce 1987 & 1996; Pillans, Page, Ilango, Kashchuk & Isbister, 2017; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Wiktorsson, Runeson, Skoog, Ostling & Waern, 2010; Yang, Tsai, Chang & Hwang, 2001; Zhang et al., 2017).

Depression was the most commonly reported psychiatric diagnosis ($n=7,893$) across the 29 studies reporting depression. Specifically, 68.5% ($n=5,414$) had a diagnosis of depression.

Physical illness

Twenty-five studies reported comorbid physical illness among older adults who self-harm ($n=4,211$) (Bonnewyn et al., 2014; Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gheshlaghi & Salehi, 2012; Gokcelli et al., 2017; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Kim et al., 2011; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Liu & Chiu, 2009; Murphy et al., 2012; Nowers, 1993; Pierce 1987 & 1996; Pillans, Page, Ilango, Kashchuk & Isbister, 2017; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Tsoh et al., 2005; Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987; Yang, Tsai, Chang & Hwang, 2001). Chronic physical illness (including cardiovascular disease, diabetes, musculoskeletal disorders, neurological problems) was common among participants, with 40% having a comorbid condition ($n=1,666$).

Medication

Seven studies reported medication use of participants ($n=689$) (Cheung et al., 2017; de Beer, Murtagh & Cheung, 2015; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Gavrielatos, Komitopoulos, Kanellos, Varsamis & Kogeorgos, 2006; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Ruths, Tobiansky & Blanchard, 2005). Nearly half of the participants from these studies (42.4%; $n=292$) were prescribed antidepressants at the moment of the self-harm episode.

Alcohol use

Eleven studies ($n=13,326$) reported on alcohol use (Armond et al., 2017; Carter & Reymann, 2014; Cheung et al., 2017; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Hawton & Harriss, 2006; Logan, Crosby & Ryan, 2007; Murphy et al., 2012; Nowers, 1993;

Ruths, Tobiansky & Blanchard, 2005; Ticehurst et al., 2002; Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987). Of those studies that did, 16% ($n=2,131$) of participants presenting with self-harm had consumed alcohol at the time of the episode.

Self-harm repetition and completed suicide

Fourteen studies reported self-harm repetition ($n=3,065$) (Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2002; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Murphy et al., 2012; Nowers, 1993; Pierce 1987 & 1996; Ruths, Tobiansky & Blanchard, 2005; Van Orden et al., 2015). The time measurement period varied vastly from one to 23 years and 17% ($n=518$) of the older adult population that self-harmed repeated this behaviour during the study period.

Those 16 studies that reported death of participants following self-harm ($n=3,883$) reflected this variation in follow-up time: up to 17% ($n=653$) had died during the time of the studies (Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2002; Gheshlaghi & Salehi, 2012; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Murphy et al., 2012; Nowers, 1993; Pierce 1987 & 1996; Pillans, Page, Ilango, Kashchuk & Isbister, 2017; Ruths, Tobiansky & Blanchard, 2005; Ticehurst et al., 2002; Van Orden et al., 2015). Not all of these studies specified causes of death, but in those which did ($n=2,939$), 3.3% ($n=98$) died by suicide (Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; De Leo et al., 2002; Gheshlaghi & Salehi, 2012; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Murphy et al., 2012; Nowers, 1993; Pierce 1987 & 1996; Van Orden et al., 2015). As summarised in Table 3.2, the studies reporting self-harm repetition and completed suicide were all based in hospital settings.

Contact with health services

Contact with different health services ranging from primary care to specialised care was reported. Primary care settings, consisting of visits to primary care or GPs, were one of the frequently reported contacts with health services. For more specialised healthcare settings which need referral from the primary care sector, psychiatric services were also used.

Primary Care: Three studies ($n=208$) reported participants having previous contact with primary care services prior to the self-harm episode (Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Lamprecht, Pakrasi, Gash & Swann, 2005; Takahashi et al., 1995). 28.84% ($n=60$) had seen their GP one week prior to self-harming. Dennis and collaborators (2007) and Lamprecht and collaborators (2005) estimated 62% ($n=98$) had been in contact with primary care one month prior to the self-harm episode. Additionally, Cheung and collaborators (2017) reported 47% of participants ($n=339$) had a non-psychiatric hospital admission in the last year.

Psychiatric services: Twenty-nine studies reported previous use of psychiatric services ($n=5,054$) (Briskman et al, 2017; Cheung et al., 2017; Chiu, Lam, Pang, Leung & Wong, 1996; Crocker, Clare & Evans, 2006; de Beer, Murtagh & Cheung, 2015; De Leo et al., 2001 & 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gavrielatos, Komitopoulos, Kanellos, Varsamis & Kogeorgos, 2006; Gokcelli et al., 2017; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Kim et al., 2011; Kim, 2014; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Murphy et al., 2012; Nowers, 1993; Packer, Hussain, Shah & Srinivasan, 2012; Pierce 1987 & 1996; Pillans, Page, Ilango, Kashchuk & Isbister, 2017; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Tsoh et al., 2005; Wiktorsson, Runeson, Skoog, Ostling & Waern, 2010; Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987; Yang, Tsai, Chang & Hwang, 2001). Of these studies, 41.3% ($n=2,086$) of participants had previously attended services and/or received treatment prior to the self-harm episode. In contrast, only seven studies ($n=2,493$) reported participants receiving psychiatric treatment at the moment of the episode (28.2%; $n=703$) episode (Cheung et al., 2017; de Beer, Murtagh & Cheung, 2015; Dennis, Wakefield,

Molloy, Andrews & Friedman, 2007; Gheshlaghi & Salehi, 2012; Hawton & Harriss, 2006; Lamprecht, Pakrasi, Gash & Swann, 2005; Murphy et al., 2012).

Follow-up

Twenty-three studies ($n=8,398$) reported 52.4% ($n=4,403$) of participants having received a psychiatric assessment immediately after the self-harm episode (Bonnewyn et al., 2014; Briskman et al., 2017; Carter & Reymann, 2014; Chiu, Lam, Pang, Leung & Wong, 1996; Cheung et al., 2017; de Beer, Murtagh & Cheung, 2015; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Gheshlaghi & Salehi, 2012; Hawton & Harriss, 2006; Lamprecht, Pakrasi, Gash & Swann, 2005; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Liu & Chiu, 2009; Murphy et al., 2012; Packer, Hussain, Shah & Srinivasan, 2012; Pierce 1987 & 1996; Ruths, Tobiansky & Blanchard, 2005; Takahashi et al., 1995; Ticehurst et al., 2002; Tsoh et al., 2005; Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987; Yang, Tsai, Chang & Hwang, 2001). Across the studies, there was no further follow-up or indication whether this assessment led to any treatment or prevention of repeated self-harm.

Suicidal intention

Nine studies ($n=972$) reported suicidal intention of participants with a total of 73.45% ($n=714$) of participants declaring suicidal intent (Cheung et al., 2017; Crocker, Clare & Evans, 2006; de Beer, Murtagh & Cheung, 2015; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Draper, 1994; Hawton & Harriss, 2006; Hepple & Quinton, 1997; Lamprecht, Pakrasi, Gash & Swann, 2005; Nowers, 1993). A variety of tools to assess suicidal intention were used, varying from interviewer's assessment to questionnaires such as the Beck suicidal intent score.

Risk factors for self-harm repetition

Of the 40 included studies, nine calculated risk factors for self-harm repetition ($n=2,646$). Risk factors for self-harm repetition, summarised below are grouped according to socio-demographic, clinical, or other factors. Table 3.5 provides a summary of findings per group for the identified risk factors for self-harm repetition.

Table 3. 5 Summary of findings on risk factors for self-harm repetition in older adults

Risk Factors for self-harm repetition in older adults					
		Evidence base	Strength association	Strength of evidence (GRADE)*	Comments
Socio-demographic factors	Female gender	3 studies n= 858	Significant value p<0.05 using χ^2 estimates p=0.014 ²¹ , 0.01 ⁴⁹	⊕⊕ Low	Uncertainty due to incomplete estimates presented in 2 of the studies
	Single, living alone and younger age (60-74 y/o)	1 study n= 1,177	p<0.05 a) Single: HR= 1.5, CI 1.0-2.1 b) Living alone: HR= 1.5, 95% CI 1.0-2.3 c) Younger age (60-74 y/o): Multivariate HR= 1.8, 95% CI 1.2-2.8	⊕⊕⊕ Moderate	Evidence limited to one study, but strong association provided and large sample size
	No caregiver	1 study n= 63	OR= 1.82, 95% CI 1.04-3.33	⊕⊕ Low	Strong association provided but limited evidence with one study and small sample size.
	Self-harm history	2 studies n= 1,240	Significant value p<0.05 Multivariate HR ²³ = 1.9, 95% CI 1.4-2.8 Adjusted OR ⁵³ = 32.9, 95% CI 3.2-339.37	⊕⊕⊕ Moderate	Mixed evidence for strength of association amongst studies. Stronger association found in study with increased number of participants
Clinical factors	Psychiatric history	2 studies n= 169	χ^2 = 5.61; p<0.05 ³⁷	⊕ Very Low	Uncertainty due to incomplete estimates presented
	Depression diagnosis	4 studies n= 272	Adjusted OR ⁵³ = 59.2, 95% CI 6.4-546.6 OR ⁵⁵ = 8.38, 95% CI 2.27-30.93 OR ⁵⁶ = 5.19, 95% CI 2.92-9.22 χ^2 =4.98; p<0.05 ³⁷	⊕⊕ Low	Despite multiple studies included, small sample size. Mixed evidence regarding strength of association, particularly imprecision of overall estimates.
	Previous and current psychiatric treatment	3 studies n= 1,616	p<0.05 Multivariate HR ²³ = 1.8, 95% CI 1.2-2.7 OR ³¹ = 2.73, 95% CI 1.20-6.25 χ^2 = 4.59 ³⁷	⊕⊕⊕ Moderate	Strong association with estimates provided. Large sample size and multiple studies included
	Arthritis diagnosis	1 study n= 66	Adjusted OR= 22.6, 95% CI 3.2-157.3	⊕ Very Low	Low association provided with large imprecision in estimates. Limited evidence from only 1 study.
Other factors	Time (12 months)	1 study n= 730	p=0.042	⊕⊕ Low	Limited evidence from one study but large sample size
	Alcohol and drug use	2 studies n= 1,516	p<0.05 HR ²³ = 1.9, 95% CI 1.5-5.1 OR ³¹ = 3.87, 95% CI 1.35-11.12	⊕⊕ Low	Large sample size but inconsistency due to mixed results in strength of association among studies
	Poorer function of self-care ⁺	2 studies n= 129	Adjusted OR ⁵³ = 0.3, 95% CI 0.1-0.7 OR ⁵⁶ = 0.83, 95% CI 0.76-0.92	⊕⊕ Low	Limited evidence with small sample size. Validity of tool used unknown

χ^2 : chi-square; HR: Hazards Ratio; CI: Confidence Interval; OR: Odds Ratio

*Modified GRADE system used to assess overall quality of risk factors. Elements used to assess evidence: risk of bias, inconsistency, indirectness, imprecision, large effect (strength of association) and dose-response gradient

Quality of evidence across studies:

⊕⊕⊕⊕ High= Further research is very unlikely to change our confidence in the estimate of effect

⊕⊕⊕ Moderate= Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate

⊕⊕ Low= Further research is likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate

⊕ Very low= Any estimate of effect is very uncertain

+ Measured using the Lawton Instrumental Activities of Daily Living Scale (IADL)

Sociodemographic characteristics

Three studies found female gender to be a risk factor for self-harm repetition (Draper, 1994; Hawton & Harriss, 2006; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006). Not being married or partnered, living alone and younger age (being 60-74 years old) were also found to be risk factors for self-harm repetition (Murphy et al., 2012). Not having a caregiver was found to be a risk factor (Zhang et al., 2017).

Clinical characteristics

Previous episode of self-harm was found to be a risk factor for self-harm repetition (Murphy et al., 2012; Tsoh et al., 2005). Three studies found that those with previous psychiatric history were also more likely to repeat self-harm (Draper, 1994; Hepple and Quinton, 1999; Tsoh et al., 2005). Four studies identified that people with a depression diagnosis were more likely to repeat self-harm (Hepple & Quinton, 1999; Liu & Chiu, 2009; Tsoh et al., 2005; Zhang et al., 2017). In this review, both previous and current psychiatric treatment was found to be a risk factor for self-harm repetition as reported in three of the included studies (Cheung et al., 2017; Hepple & Quinton, 1999; Murphy et al., 2012). Finally, Tsoh and collaborators (2005) also identified a diagnosis of arthritis as a risk factor for self-harm.

Other

Time was also found to be a determinant of self-harm repetition. Hawton and Harriss (2006) found that older adults were most likely to repeat self-harm within 12 months of the first episode. Two studies found alcohol and drug use as a risk factor for self-harm repetition (Cheung et al., 2017; Murphy et al., 2012). Poorer function of self-care was also found to be a risk factor for self-harm repetition (Tsoh et al., 2005; Zhang et al., 2017).

Motivations for self-harm

Eleven studies ($n=551$; less than 1% of the total participants) presented motivations for self-harm with broader explanations besides suicidal intent (Bonnewyn et al., 2014; Crocker,

Clare & Evans, 2006; De Leo et al., 2002; Dennis, Wakefield, Molloy, Andrews & Friedman, 2007; Kim et al., 2011; Kim, 2014; Lebret, Perret-Vaille, Mulliez, Gerbaud & Jalenques, 2006; Liu & Chiu, 2009; Wynne, Bateman, Hassanyeh, Rawlins & Woodhouse, 1987; Van Orden et al., 2015; Yang, Tsai, Chang & Hwang, 2001). The identified motivations emerged from both qualitative and quantitative studies and were based on self-reported motivations. Table 3.2 provides further detail of the identified motivations for self-harm which included relationship problems, physical and psychiatric illness, financial worries, regaining control, bereavement, isolation, helplessness, amongst others.

Qualitative findings

Three qualitative studies explored the experiences of self-harm in older adults (Bonnewyn et al., 2014; Crocker, Clare & Evans, 2006; Kim, 2014). Participants were similar with regards to sociodemographic characteristics: majority were 'young' older adults (60-74 years old) and female. Contrastingly, study settings and country of origin were diverse, including psychiatric departments (Bonnewyn et al., 2014), local mental health services (Crocker, Clare & Evans, 2006; Kim, 2014) and older adults community groups (Kim, 2014). In comparison to the quantitative studies included in this review, participants from the qualitative studies also shared similar sociodemographic characteristics. Despite the broad definition of self-harm included in this review, the focus of the qualitative studies was in self-harm with suicidal intent exclusively, as all studies classified the act of self-harm as a suicide attempt. There were no qualitative studies which were classified as self-harm. Three major themes were identified: loss of control contributing to suicide attempt, increased loneliness and isolation and ageing perceived as 'burdensome' and affecting daily living. Other individual themes such as dependency on tranquilisers (Kim, 2014), were identified separately in some of the studies but overall the three main themes were commonly narrated in all of the included qualitative studies. Table 3.6 illustrates the three major themes with direct quotes provided from the studies.

Table 3. 6 Main themes identified from qualitative studies

<i>Major themes</i>			
	Bonnewyn et al., 2014	Crocker et al., 2006	Kim, 2014
Loss of control leading to suicide attempt	<p>"I was very tired. Completely exhausted. I did not see a way out anymore. I was tired doing the dishes, I was tired making up my bed. Tired, tired, always tired. But then again, I had almost not slept for months and months on end. I never slept during night time. My eyes hurt so much, I could simply not close them anymore."</p> <p>(Female participant 1)</p>	<p>"Once I retired, I had no further aim and had nothing to get up for. I didn't know what to do with my day. [...]. My partner said, 'Just take that day as it comes, read the paper, go out and get the paper, do the chores ...' and I thought 'Oh god, all unconstructive things'."</p> <p>(Male participant 1)</p>	<p>"I've tried twice to kill myself. It is not as easy to commit suicide as people think. I know it is a sin to do it, but I can't change my mind about ending this painful life. It's always stuck in my mind. I eat a lot of sugary foods and I do not take insulin because I think I have lived long enough."</p> <p>(Female participant 5)</p>
Increased loneliness and isolation	<p>"6 months after my husband passed away, I really started to realize that I'm on my own now. The children, they came in and I was troubled by something, I wanted to talk about it, but I could not."</p> <p>(Female participant 2)</p>	<p>"When it got to the second stage [prior to attempt] it felt like that again, vanishing, you know, and I thought I can't go on my own. And it's funny that because I've always been a loner."</p> <p>(Female participant 3)</p>	<p>"I opened my eyes after three days. I was lying down in my room. No one knew what I had done. That was really sad and embarrassing. I felt terrible because no one cared about me."</p> <p>(Female participant 6)</p>
Ageing perceived as burdensome and affecting daily living	<p>"It felt as if I could no longer cope. My greatest fear was that I would no longer be able to do the things which I was able to: looking after the grandchildren, everything related to housekeeping. I'm no longer able to do that and that is my biggest fear: that I won't be able to do that in the future. I can't do anything anymore, nothing works out; I'm no longer of use. I can no longer do the things which I used to do before anyway."</p> <p>(Female participant 1)</p>	<p>"Oh yes, I've been independent since I was born, let's put it that way. I never really depended on anybody or relied on anybody. I was very, very independent. I was a very feminine person, very sexy".</p> <p>(Female participant 4)</p>	<p>"They [doctors] have been telling me I need surgery since last year. But why should I? To live longer? I don't have the money anyway. It would have been great if I had just died. This is more painful."</p> <p>(Male participant 2)</p>

Loss of control contributing to the suicide attempt was a major theme mentioned in two of the included studies (Bonnewyn et al., 2014; Crocker, Clare & Evans, 2006). Loss of control due to both physical and mental health problems was described by older adult participants that

felt overwhelmed, exhausted and feeling unable to continue living (Bonnewyn et al., 2014). Loss of control was also perceived to be caused by not only health related losses, but also mobility, social status and support losses (Crocker, Clare & Evans, 2006). Once again, these losses led to feelings of helplessness where older adults felt they no longer could continue living (Bonnewyn et al., 2014; Crocker, Clare & Evans, 2006). Despite not identifying as loss of control, Kim (2014) identified deteriorating physical health and additional hardship as contributing to the suicidal attempt and worsened health and wellbeing. Despair and feelings of helplessness was also reported amongst older adults that had attempted to end their lives (Kim, 2014).

Older adults mentioned increased feelings of loneliness and isolation, this was a major theme reported in all qualitative studies (Bonnewyn et al., 2014; Crocker, Clare & Evans, 2006; Kim, 2014). Feelings of loss often led participants feeling lonely and isolated from others (Bonnewyn et al., 2014; Crocker, Clare & Evans, 2006). Participants also described having increased feelings of loneliness and isolation after the self-harm event given that family members regarded the episode as shameful and older adults were isolated (Kim, 2014).

Participants described ageing perceived as 'burdensome' and affecting daily living (Crocker, Clare & Evans, 2006; Kim, 2014). Growing older was deemed to be a struggle and described with negative stereotypes of age and overall ageist views by older adults (Crocker, Clare & Evans, 2006). Regret and opportunities missed was also narrated by participants which intensified the felt internal struggle which contributed to the suicidal attempt (Crocker, Clare & Evans, 2006). Finally, participants described as feeling too old, leading them to their suicidal attempt to end the perceived pain of old age (Kim, 2014).

Influencing factors for self-harm in older adults

A thematic analysis of the influencing factors for self-harm in older adults is summarised in Figure 3.4, from the data presented from both quantitative and qualitative studies. Influencing factors range from internal (e.g. age, gender) to external factors (e.g. financial

worries, low education), showing the complex relationship between these factors throughout the presented layers. Figure 3.4 highlights the potential risk for self-harm and shows that not one single factor independently influences self-harm in older adults. The themes are interconnected and layered across different individual, societal and healthcare settings and are represented diagrammatically in Figure 3.4.

3.5.4 Summary of findings

Overall, based on moderate quality evidence, previous history of self-harm, previous and current psychiatric treatment and socio-demographic factors (single, living alone, younger older adults aged 60-74 years old) were found to be significant risk factors for self-harm repetition (Table 3.5). Others, such as alcohol/drug use, female gender, psychiatric history and a diagnosis of musculoskeletal conditions such as arthritis were also associated with self-harm repetition but the overall quality of evidence for these factors ranged from low to very low.

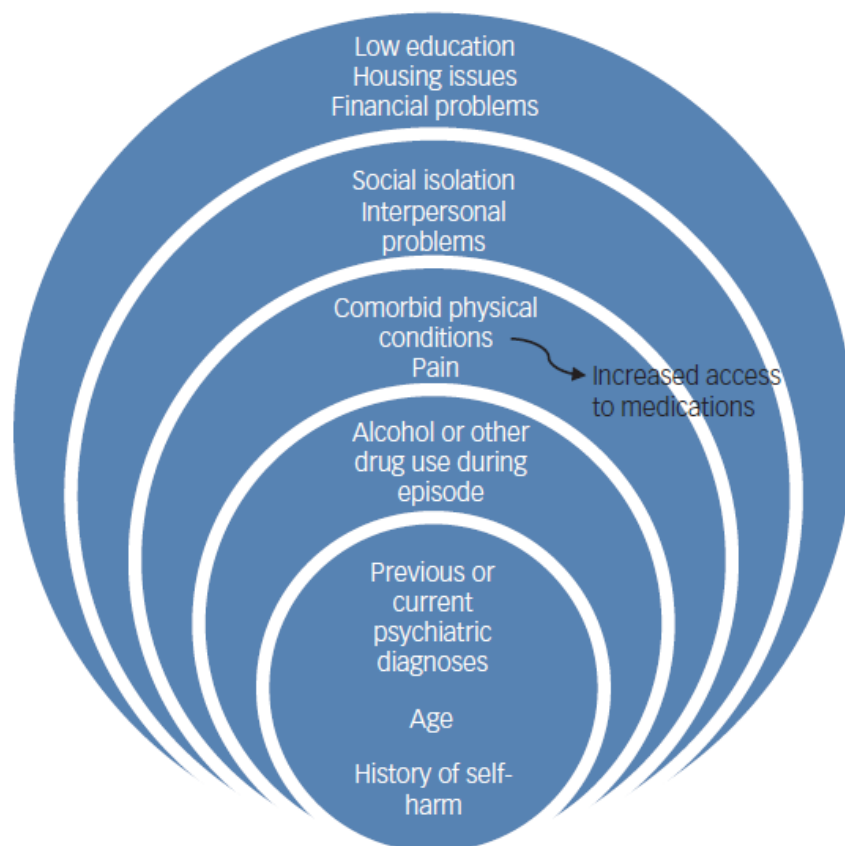


Figure 3. 4 Influencing factors in self-harm in older adults (from Troya et al., 2019a)

3.6 Discussion

This review presents current evidence regarding the characteristics of self-harm in older adults. Findings from this systematic review highlight self-harm in later life as having distinct characteristics to younger populations that should be explored to improve management and care for this age group. Despite sharing some characteristics of self-harm with younger populations (e.g. higher percentage in women, those with psychiatric history and those with a previous episode(s) of self-harm), there is an increased risk of repetition and suicide in older adults (Hawton, Rodham, Evans & Weatherall, 2002; Morgan et al., 2017). Previous history of self-harm, previous and current psychiatric treatment and socio-demographic factors including being single, living alone and being a younger older adult (60-74 years old) were more strongly associated with self-harm repetition.

Ranging from 19 to 65 yearly self-harm episodes per 100,000 people, findings from this review suggest prevalence rates to be lower compared to those reported in the literature of younger populations (Swannell, Martin, Page, Hasking & St John, 2014). However, the identified prevalence rates are to be taken with caution given that they are based on only seven studies which reported such findings, representing less than 5% of the total population of the systematic review. Furthermore, three of these studies have sample sizes of less than 200 participants, meaning their estimated rates must be taken with caution when calculating yearly self-harm rates per 100,000 people (de Beer, Murtagh & Cheung, 2015; Pierce, 1987; Ruths, Tobiansky & Blanchard, 2005). There were also variant rates amongst the studies with only one study identifying yearly rates of less than 20 per 100,000 people, with the rest of studies having nearly double the number of rates. Variance in rates could be attributed to the study design setting and different healthcare system which reported non-suicidal self-injury as opposed to other presentations of self-harm (e.g. attempted suicide) as reported in the other studies. Furthermore, even with variant and lower prevalence rates compared to younger populations, the impact these presentations have on individuals and health services are significant. Hospitalisation is longer in older adults who self-harm and medical complications

more likely, resulting in increased resource expenditure (Corso, Mercy, Simon, Finkelstein & Miller, 2007; Logan, Crosby & Ryan, 2007). Additionally, accuracy of self-harm estimates may not be completely representative given that the majority of the studies were based in hospital settings and do not consider other presentations of self-harm which may not result in hospital attendance. With an increasingly ageing population, it is important to acknowledge this possible under-representation of self-harm presentations in older adults. Older adults who self-harm are at 67 times higher risk of suicide compared to younger populations (Murphy et al., 2012). This is congruent with worldwide epidemiological literature which states suicide rates in later life are one of the highest globally (Bertolote & Fleischmann, 2015; Shah, 2007).

The use of self-poisoning as a method is distinctive compared to other populations. One reason for this may be increased access to medication due to comorbid conditions that require prescribed medications. Nearly one third of the older adults were being prescribed antidepressants, giving them increased access to tablets for use in overdose. Data from the UK's Office for National Statistics highlights that over one third of self-poisoning deaths were due to antidepressant overdose in 2014 (ONS, 2016).

Findings suggest that older adults who self-harm report feelings of isolation, loneliness and loss of control. Ageing and reaching later life were perceived as "burdensome" by older adults, which contributed to their self-harm episode. However, these experiences were limited to the context of self-harm with exclusive suicidal intent.

3.6.1 Considerations for interpretation of findings

There are three main factors to consider when interpreting findings from this review. First, different terminologies were used across studies to refer to acts of self-harm, reflecting the on-going heterogeneity of meanings inherent in the concept. For instance, definitions of self-harm in the literature included non-suicidal self-injury, deliberate self-harm and attempted suicide. Most of the included studies ($n=29$) classified self-harm as attempted suicide, i.e. as holding an exclusive suicidal intent, which is not always the case.

Second, the design and reporting of many of the included studies did not allow for a comprehensive capture and statistical synthesis of all predefined outcomes (e.g. risk factors for repeated self-harm) as set out by the review. For instance, over half of the included studies were descriptive observational studies (e.g. cross-sectional) which mainly report disease distribution among populations, to see whether a disease or condition is present or not (Hennekens, Buring & Mayrent, 1987). This means that factors such as potential confounders and direction of causality between exposure and outcome could not always be determined for all the older adult population. However, the availability of analytic study designs ($n=14$ cohort studies) allowed more detailed exploration of the factors that influence self-harm in older adults. This is a strength for the evidence presented in this review as the inclusion of varied study designs ensured no evidence was lost and all available evidence is used to inform future research and practice.

Lastly, findings from this review are limited to data presented from included studies, which were predominantly based on self-harm presentations to hospital settings ($n=34$). For instance, the yearly self-harm rates presented in this review were mostly based on studies conducted in hospital settings, as opposed to population or community-based data. Not all self-harm episodes result in hospital presentations, therefore other self-harm episodes (e.g. in the community) may not have been comprehensively captured in this review. Therefore, appropriate consideration must be taken when interpreting results from this review to ensure not generalising to the wider populations.

3.6.2 Strengths and limitations

This is the first review to systematically synthesise and appraise information regarding self-harm in older adults from both quantitative and qualitative studies. Reporting qualitative findings is of great importance to researchers and clinicians in the field, offering further explanation of self-harm in older adults. A further strength of this review is its emphasis on the inclusion of PPIE perspectives at all stages. An example of the PPIE group's involvement in the review is the contribution to the development of Figure 3.4, which was achieved by

discussing the identified stressors with the PPIE group. As the National Institute for Health Research (NIHR) national advisory group INVOLVE (2012) states, this makes reviews more relevant and likely to be addressing the needs of patients.

The conclusions of this review should be viewed with caution due to two factors. The majority of included studies were similar with regard to study setting, reporting self-harm in hospital settings rather than in the community. In addition to study selection by two independent pair of reviewers, the search strategy was both sensitive and comprehensive, minimising the chances that any study might have been missed. Easier access to hospital patient records in the older adults' population compared to conducting community-based research may explain the limited number of community-based studies. Another reason for the majority of evidence being predominantly from hospital settings may be the high level of stigma attached to self-harm, resulting in resistance to help-seeking and/or accessing primary care services (McAllister, 2003). Given the different settings and other factors influencing recording of self-harm, findings from the review may not be generalisable to the whole population of older adults that self-harm, but mostly limited to a population of older adults attending hospital settings. Secondly, evidence presented in systematic reviews is dependent on the inherent methodological quality of included studies. Despite quality assessment of the studies across domains being mostly moderate and low risk of bias, the assessments highlighted certain areas of high-risk of bias, including confounding, blinding of assessors and loss to follow-up. The low-quality rating of these areas is important to take into consideration when analysing the overall literature on self-harm in older adults. Lastly, despite the quality assessment toolkits which are robust, concise, and widely used amongst researchers, the use of such toolkits may have its limitations. In particular with qualitative research, where previous authors have suggested the use of such toolkits as counterproductive and limiting (Barbour, 2001).

3.6.3 Comparison with previous literature

This review offers an update from previous reviews and explores factors not covered in previous work, such as self-harm repetition and motivations for self-harm (Chan, Draper &

Banerjee, 2007; Draper, 1996). In contrast to other studies, findings examined were specifically around older populations and included additional study designs, i.e. both quantitative and qualitative studies. Other conducted reviews assessing qualitative evidence may not be directly comparable to the present review given their inclusion of both direct and indirect self-harm (Wand et al., 2018a). This review adhered to NICE guidelines definition of self-harm and view direct self-harm as distinct to indirect self-harm, therefore this review focused on direct self-harm only.

Furthermore, in younger populations, there is empirical evidence which provides an explanation for under-estimation of self-harm presentations (Geulayov et al., 2018). According to the Iceberg Model there are three layers of self-harm presentations, with only two of them being overt and on the tip and surface of the iceberg: fatal self-harm (i.e. suicides) and hospital or clinical presentations of self-harm (Geulayov et al., 2018). However, the last and largest layer of the Iceberg Model is self-harm presentations in the community, which are mostly hidden given the lack of visibility. Considering the Iceberg Model of self-harm reported in younger populations, it is likely that findings from this review can be translated to the Iceberg Model in older populations, once again highlighting the hidden element of self-harm and most likely underestimation of self-harm as found in this review.

3.6.4 Implications for research and clinical practice

Research

Further work is needed to identify appropriate resources and clear referral pathways to enable clinicians to support older people who self-harm. Future research may wish to focus on populations of older adults engaging in self-harm within community settings so there is a more comprehensive capture and understanding of self-harm in older adults. Given that many people who self-harm will be managed in primary care, there is a need for further research in primary care and community settings. Research exploring the different motivations for self-harm (suicidal or non-suicidal) would aid in clarifying the heterogeneous terminology used to refer to self-harm and further understand experiences of self-harm in later life. Lastly, data

reporting standards within the psychiatric literature will benefit from careful consideration. Due to inadequate reporting/incomplete data provision across included studies, this review was unable to pool together findings in a meta-analysis. The agreement and compliance to high-reporting standards should be a priority for researchers within the mental health field.

Clinical practice

Findings are in line with NICE guidelines (2004, 2011) recommendation of identifying and managing older adults who self-harm differently than younger populations, due to the increased risk of repetition and suicide in this population. Health professionals may have the potential to intervene and prevent self-harm in older adults as frequent contact with health services was reported. This would be an important public health concern to be addressed regarding self-harm repetition, subsequent suicide and premature death (Carr et al., 2017). Avoiding self-harm in older adults could then also reduce the increased resources being spent on post-episode treatment. Additionally, as increased access to means of self-harm (medication for comorbid physical conditions) is more common in older adults, adequate measures must be taken by clinicians prescribing to safeguard patients who might be at risk of self-harm. There is a need for adequate resources and clear referral pathways for healthcare professionals to enable them to support older people who self-harm.

Based on the findings of this review, a model of influencing factors for self-harm in older adults was developed (Figure 3.4). These are important to be taken into consideration when assessing an older adult in health or social services, to see whether they could be at risk of self-harm. As other researchers in the field have already highlighted (De Leo, 2017) the model, highlights the fact that adequate treatment and service provision for self-harm in later life is not limited to health services, but also social services and the informal sector. However, this model should not be used as a comprehensive list for assessing self-harm, as there can be other influencing factors not identified from the evidence presented in this review.

3.7 Conclusions

This chapter presented a systematic review of the literature regarding self-harm in older adults and found that self-harm in older adults has distinct characteristics, including increased suicide risk and self-harm repetition. Areas for future research such as community-based studies, as well as the need of qualitative studies have also been highlighted in the chapter. Given the absence of community-based qualitative studies exploring self-harm behaviour in older adults, the qualitative research conducted as part of this PhD aimed to address this gap in knowledge. In the following chapters I present the methodology and methods used in the qualitative study which explores motivations and access to care of older adults with self-harm behaviour.

CHAPTER 4: METHODOLOGY

4.1 Introduction

The aim of this chapter is to outline the methodological approach of my qualitative study. I start with a brief overview of the study's overarching aim and research questions. Then, the research paradigm is presented, covering my ontological, epistemological and methodological stance. The selected methods and interconnectedness with the overall methodology is then presented. I then continue to present how methodological rigour has been sought and applied throughout the study including reflexivity, followed by a description and role of PPIE in this PhD. Finally, ethical considerations of the study are presented. Overall, this chapter presents the justification of the methodological approach as well as starting to build a link with the methods to be presented in the next chapter: data generation using in-depth semi-structured interviews.

4.2 Research questions and aim

Research questions arose from identifying a gap in the literature as presented in earlier chapters and from discussion in a previous PPIE group meeting. The study aim and research questions, which were co-constructed with the PPIE group (further discussed in section 4.5), were as follows.

The overall aim of the thesis is to increase the understanding of self-harm behaviour in older adults (60 years or older).

Research questions:

- What are the perceived motivations of self-harm behaviour in older adults?
- What are the barriers and facilitators of access to care and support for older adults who self-harm?
- What are the potential roles of family, friends, third sector support groups and primary care professionals, in supporting older adults who self-harm?

4.3 Research paradigm

Being aware of one's research paradigm (epistemology, theoretical perspective and methodology) when conducting research is not only best practice as Carter and Little (2007) describe, but also an obligation researchers have when attempting to expand knowledge or meaning. The importance of considering how my research paradigm influences the research cannot be overstated as it not only leads the way towards conducting the study, but also governs the selected methodological approach. It is as important to acknowledge as the nature of the research question itself, as it is both what creates and guides the taken approach.

My views regarding research paradigm are aligned with Crotty's (1998), who argues that there are four main elements which need to be considered when conducting research: epistemology, theoretical perspective, methodology and methods. Unlike other authors, Crotty (1998) does not include ontology, the study of being, in his main elements of research as he argues it is covered throughout the entire research process. Regardless of where different authors place ontology within the research process, it is present. These elements enable researchers to both identify and clarify the proposed study's methods and methodology, as well as provide a justification for the chosen methods (Crotty, 1998). All of the four elements are closely linked together to one another, informing each other as can be seen in Figure 4.1.

Selecting and reflecting on appropriate methodology congruent with the chosen research methods and the epistemological position of the researcher, is fundamental to its delivery and success (Jackson, 2013). In addition, research questions being addressed must work in tandem and are drivers of the methods chosen. Given the exploratory nature of the research questions, a qualitative methodology and methods were chosen as most appropriate. In section 4.3.1, I describe the qualitative methodology while Chapter 5 further details the used methods.

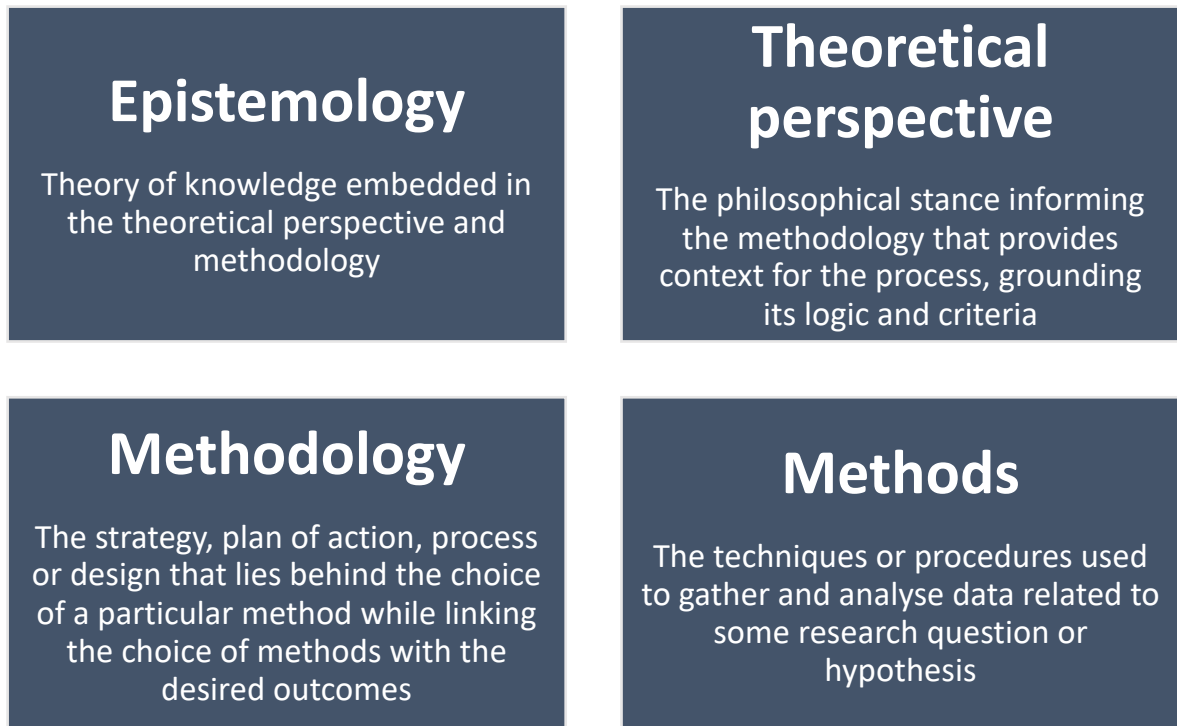


Figure 4. 1 Key research elements (Crotty, 1998)

4.3.1 Qualitative methodology

One can attempt to understand the world and seek knowledge through a range of ontological and epistemological positions within a spectrum of positivism and interpretivism. In one extreme, classic positivism states that there is one single external reality that we have access to, therefore truth is to be attained by experimental models of testing hypothesis and controlling for possible causal factors when analysing findings (Collins, 2010). In this position, it is argued that researchers conducting a study have an independent and objective role when involved, with no effect of them over the results of the study. On the other hand, classic interpretivists would argue that there is no single external reality nor direct access to the real world, therefore seeking knowledge is subjective to the context and the researcher's position, which will inevitably influence the results, as well as the phenomenon under study (Collins, 2010; Neuman, 2000). Positivism has been the predominant position taken by the scientific community in the past centuries, with much of the focus of researchers being on obtaining one answer through an objective comprehension of the world (Kuhn, 1975). However, this started

to change in the last century, with scientists questioning the validity and appropriateness of the classic positivistic position, realising that there can be different research questions to be addressed and therefore alternative ways of seeking and obtaining knowledge.

Qualitative methodology has been mostly associated with the interpretivist position, as its predominant interest is in the subjective meaning of the group under study and seeks to answer context specific questions, going particularly in-depth with the studied phenomenon (Creswell, 2007). Increasingly interpretivist views have started to be associated with qualitative methodologies.

4.3.2 Philosophical underpinning: critical realism

Clarifying the philosophical underpinning is fundamental when conducting research to have a clear view as of where the research stands, to avoid a superficial understanding in the subject of study (Clark, Lissel & Davis, 2008). Since positivist and interpretivist positions were first conceptualised, there has been development and additional alternatives of understanding the world which have emerged in the last century. Critical realism is one of the positions that has emerged after further elaboration of classic positivist and interpretivist views. Critical realism can be found somewhere in between the positivist and interpretivist spectrum. From an ontological position, critical realism acknowledges that there is a single reality and view of the world, however it argues that there can be multiple interpretations and understanding of this reality.

Critical realism is a relatively young philosophical position that dates back to the mid-late twentieth century (Archer, Bhaskar, Collier, Lawson & Norrie, 2013; Bhaskar, 1978). British philosopher Roy Bhaskar first developed this approach in the seventies, looking for a way to understand reality in a comprehensive way that fell outside of classic positions of the time (Bhaskar, 1978). Critical realism's distinctive features, that are also assumed by myself, are:

- i) reality is differentiated and stratified;
- ii) causal mechanisms: social structures are activity dependent;

iii) knowledge has both intransitive and transitive aspects to it.

Therefore the different characteristics of reality and how the world is viewed and understood were also taken into this research project. As well as there being one single reality, this reality can only be imperfectly comprehended by humans due to our limited understanding and the nature of an intractable phenomenon (Guba & Lincoln, 1994). Nevertheless there being a single reality and existence of objective knowledge, this will be dependent on the social context as this provides an influence on how reality and knowledge is assimilated- see Figure 4.2 (Archer, Bhaskar, Collier, Lawson & Norrie, 2013; Bhaskar, 1978; Guba & Lincoln, 1994; Pilgrim, 2014 & 2019).

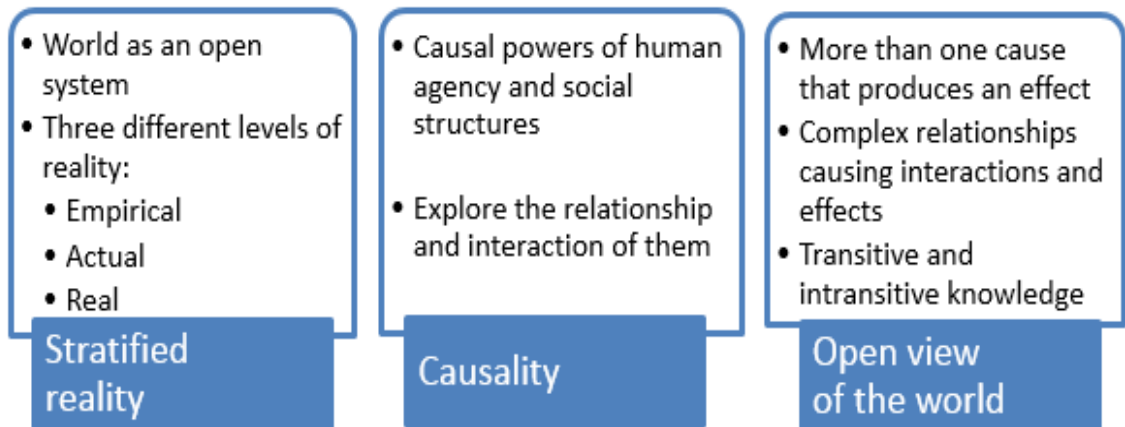


Figure 4. 2 Main characteristics of critical realism (Fletcher, 2017)

Instead of taking part of radical dichotomies like other classic philosophical positions, critical realism poses itself parallel to attempt to comprehend reality (Archer, Bhaskar, Collier, Lawson & Norrie, 2013). Despite there being other philosophical positions that I could have adhered to, after careful consideration, reading and self-reflection, critical realism was the chosen one which mostly fits with my ontological and epistemological position, as well as research design and questions. Not only is this position in alignment with my views and understanding of the world, but is also congruent with my way of understanding and conceptualising the phenomenon under study: self-harm behaviour. With a critical realist

perspective, one can see the reality of the occurrence of self-harm behaviour and at the same time understand and take into consideration that each person's experience and context will vary, giving a valuable justification to the qualitative enquiry of the posed research question. Given that I sought to explore participants' understanding and experiences of self-harm behaviour, appreciating both their narrated accounts and social contexts, following a critical realist perspective allowed me to do so.

Moreover, critical realism has been widely explored in other health research areas such as nursing and midwifery, as it can offer a holistic exploration of health research and its complexity (Clark, Lissel & Davis, 2008; Walsh & Evans, 2014). Health research also poses itself in a midway position regarding interpretivist and positivist views, as illness is commonly conceptualised in a biomedical model (typically positivist), while understanding experiences and meaning these illnesses have to the individual lay in a more interpretivist spectrum like the biopsychosocial model (Engel 1977; Rogers & Pilgrim, 2014; Wade & Halligan, 2017). Engel (1977) was amongst the first to dispute the traditional biomedical model in mental health; arguing it did not provide a comprehensive account for the numerous factors (e.g. psychological, social) involved when conceptualising, understanding and treating mental disorders. Furthermore, the biomedical model fails to see the person as a whole, focusing on the body as isolated from other characteristics of an individual. Within mental health, the importance of individuals' understanding and experiences of the condition are essential, something that the biomedical models fails to cover. Also, the existence of different influencing factors common in mental health such as biological, psychosocial and environmental traits can be conceptualised through a critical realist view. Critical realism meets both the subjective (individuals experiences and understanding) and objective (the reality of the presence of self-harm behaviour) parts of mental health, being comprehensive when carrying out mental health research. Nevertheless, the possible limitations critical realism may have, especially within a mental health project, are acknowledged in Figure 4.3 and considered throughout this doctoral study.

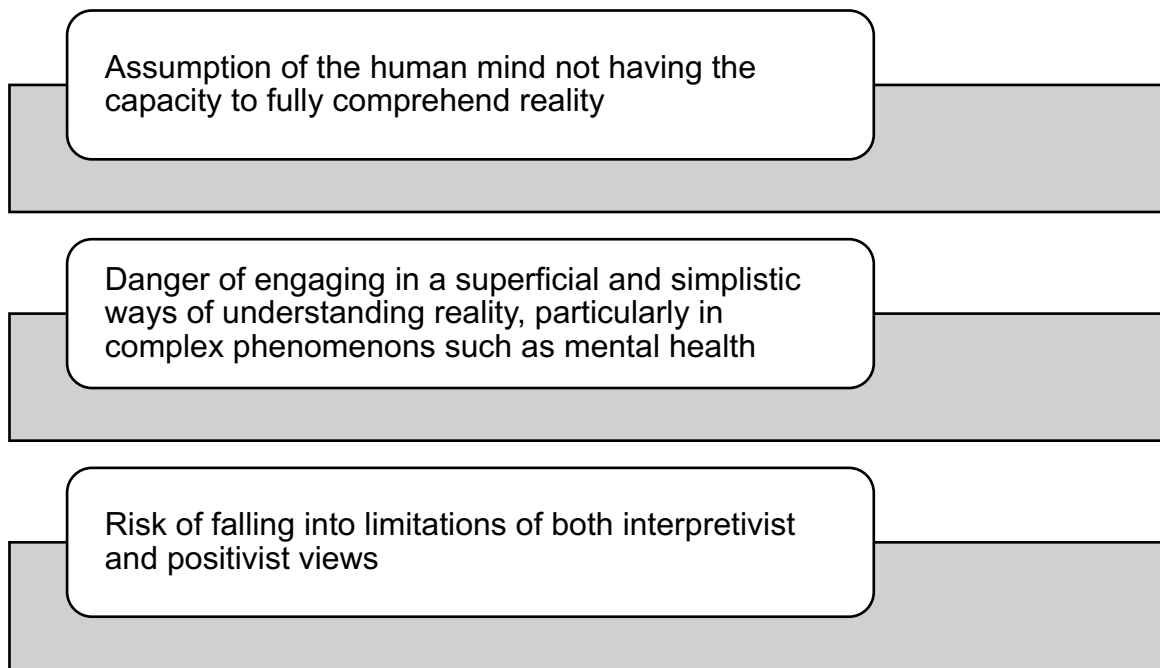


Figure 4. 3 Limitations of critical realism

4.3.3 Methodology meets methods

As further described in Chapter 5, the selected methods for this doctoral study are individual in-depth semi-structured interviews (Green & Thorogood, 2010; Kvale & Brinkman, 2008; Mason, 2017). I selected and deemed this method as most appropriate with regard to answering the research questions and overall aim of the study, being that they are exploratory and allow for an in-depth exploration of self-harm. Semi-structured interviews were used as opposed to unstructured or structured ones as semi-structured interviews allow there to be both flexibility and focus in the research area. Topic guides, composed of open-ended questions and prompts, permit semi-structured interviews to have some structure but with flexibility and openness to explore the reserach questions in-depth with participants (Mason, 2017).

The mentioned methods are congruent with the theoretical perspective, as the views of the two different participant groups. Through in-depth, semi-structured interviews, the research questions of the study can be answered, as well as with the additional follow-up interview offered to older adults which is further explained in Chapter 5.

In line with my theoretical perspective, the use of in-depth semi-structured interviews, which are used as a tool for eliciting a response and data from participants, follows a realist perspective, where my main interest and focus is on what is being said, this being the content of the interview (Elliott, 2005). Despite the value of constructivist approaches focusing on how interviews are being conducted and how meaning is being constructed, the overall aim and research questions of this PhD followed a different perspective, prioritising overall meaning and content of interviews.

i. Data analysis

Data analysis in qualitative research is the process of systematically arranging, searching and condensing collected data to understand the area of study (Miles, Huberman & Saldana, 2013). According to Miles, Huberman and Saldana (2013), data analysis can be summarised in three main steps: data condensation, data display and conclusion drawing or verification. Within qualitative research, there are different methods used to analyse data. Regardless of the method, analysing qualitative data entails going beyond describing what has been reported initially; data is instead transformed into something with further detail and meaning (Dey, 2003). Data analysis in qualitative research is an iterative process, which has as key elements description, classification and connection of the research area (Dey, 2003). But prior to this process, organisation and condensation of the data is essential to be able to interpret and analyse the data (Mason, 2017; Miles, Huberman & Saldana, 2013). Data is first displayed and then described taking into consideration the event, intentions, process and context (Dey, 2003; Miles, Huberman & Saldana, 2013). Following describing, is a classification of the data according to the different themes or concepts, requiring an interpretation and explanation from the researcher (Dey, 2003). Lastly, interconnecting concepts with each other is the final step when analysing qualitative data which entails conclusion drawing or verification of the analysed results (Dey, 2003; Miles, Huberman & Saldana, 2013).

The different methods used to analyse qualitative data not only vary with regard to the techniques used, but also the overall theoretical perspective which guides data analysis. Thematic analysis using a framework approach and constant comparison was the selected analysis method for the data set as it goes in concordance with the research project's aims and purpose of an identified a priori issue with a predetermined sample population (Srivastava & Thomson, 2009). It is also a suitable analysis method for the identified research questions which are classified as contextual and diagnostic according to Spencer and Ritchie (2002), meaning that they are used to identify the form and nature of what exists and reasons for what exists (e.g. experiences of self-harm in later life). Unlike other methods of qualitative data analysis, thematic analysis has no specific theoretical, epistemological or philosophical approach, making it flexible to the researcher's stance and research project's questions (Nowell, Norris, White, & Moules, 2017). Being adaptable to the researcher's position, thematic analysis worked with the aforementioned research paradigm including my understanding and conceptualisation of the study, as well as theoretical perspective.

Conventional qualitative analysis is mostly guided by taking an inductive approach, meaning that categories and themes emerge from the data set instead of the existence of influence from the researcher or previous literature. However, thematic analysis following a framework approach acknowledges that data being collected and analysed is and can be influenced by the researcher's interpretation and previous knowledge of the subject, taking a step back from the purely inductive approach (Gale, Heath, Cameron, Rashid & Redwood, 2013; Green & Thorogood, 2010; Nowell, Norris, White, & Moules, 2017; Srivastava and Hopwood, 2009). Therefore, rather than being a purely inductive approach, thematic analysis following a framework approach sits on the spectrum of the inductive-deductive continuum, being guided by what the data set is communicating, as well as acknowledging the possible influence the researcher's experience and interpretation of the data set has (Smith & Firth, 2011).

Additionally, as further described in Chapter 5, constant comparison techniques were also used when analysing the data set. Typically seen within grounded theory (Glaser & Strauss, 2017), constant comparison methods are used to interpret and compare codes throughout the data set. Grounded theory was originally created to generate theory from qualitative data sets (Glaser & Strauss, 2017). However, the constant comparison method used in grounded theory was designed with the purpose of provisional testing rather than discovering theory or hypothesis (Glaser & Strauss, 2017). Therefore, similar to thematic analysis following a framework approach, the constant comparison method from grounded theory sits within the inductive and deductive spectrum.

Thematic analysis is one of the most common methods of analysing qualitative data in health research (Green & Thorogood, 2010). Thematic analysis following a framework approach, using constant comparison methods, is dynamic, systematic and comprehensive when analysing qualitative data (Gale, Heath, Cameron, Rashid & Redwood, 2013; Srivastava & Thomson, 2009). Following this approach, where data analysis is flexible with regard of when to start analysing the data, data transcription and analysis started after the first interview was completed (Srivastava & Thomson, 2009). Chapter 5 further describes how the data generated by semi-structured interviews were analysed using thematic analysis with a framework approach and constant comparative methods.

4.4 Methodological rigour

Methodological rigour defined as the “design elements that support strong causal attributions and analytical generalisation” (Quinn, 2002), has been argued to be one of the fundamental and most important aspects when carrying out research (Giorgi, 2000). Within qualitative research, many have rejected the usefulness and applicability of methodological rigour as it does not go in congruence with interpretivist conceptualisations that are common (Denzin & Lincoln, 2011). Nevertheless, the value of methodological rigour when correctly applied to qualitative research has been increasingly recognised amongst researchers as it can enhance the overall methodological process (Tobin & Begley, 2004).

Rigour, regardless of the paradigm, is concerned with demonstrating competence and integrity. Within qualitative research, this can be reached without falling into positivist approaches as some authors have feared (Aroni et al., 2001; Tobin & Begley, 2004). Through methodological rigour, qualitative research can be recognised to have the valuable scientific process it entails, as many have previously argued it lacks rigour and scientific credibility (Tobin & Begley, 2004). Elements commonly used to demonstrate rigour in quantitative research such as generalisability and validity, are not applicable in qualitative research. Instead, with qualitative research, methodological rigour can be demonstrated throughout the entire research process with reflexivity, transparency, triangulation and credibility (Lincoln & Guba, 1985; Tobin & Begley, 2004). In an attempt to provide trustworthiness and methodological rigour in qualitative studies, Lincoln and Guba (1985) elaborated a list of key characteristics summarised in Table 4.1. The four main characteristics identified by Lincoln and Guba (1985) were addressed throughout this doctoral study, making use of some of the described techniques which are further described.

Table 4. 1 Methodological rigour in research (adapted from Lincoln & Guba, 1985)

	Definition	Used techniques
Credibility	Confidence in the truth of findings	Persistent observation, prolonged engagement, triangulation, checking with participants, debriefing with supervisory team
Transferability	Findings applicable in other contexts	Detailed account of experiences
Dependability	Consistent, repeatable findings	Inquiry audit: interpretation from supervisory team
Confirmability	Degree of neutrality or extent to which findings are influenced by researcher	Reflexivity, triangulation, transparent description of research steps
Involved throughout entire research process (from data collection to interpretation)		

4.4.2 Researcher's positionality

Not only was the research conducted guided by the mentioned theoretical, epistemological and ontological stance, it was also influenced by my academic and clinical background. My background is in Clinical Psychology and Global Mental Health. As a Clinical Psychologist who trained and practised in Ecuador, the training I received focused on both a biomedical model with combined social and environmental aspects that had as an aim to promote mental health wellbeing and understanding of human behaviour: following Engel's (1977) biopsychosocial model. My clinical background and learnt views of mental health and human behaviour very much had an influence on the way I conducted my PhD, this being reflected in the focus of the areas considered in my reviews of the literature and overall conceptualisation and understanding of self-harm. Additionally, my previous experience in self-harm research (Troya, 2015) allowed me to further comprehend and conceptualise self-harm.

My background in global mental health enabled me to obtain skills and knowledge on critically evaluating mental health research and developing programmes and policies across different resource settings to target mental health inequality. It widened my perspective to take into consideration other external cultural aspects that may influence participants' views and experiences. This background made me reflect on my position as a international researcher in the UK, studying self-harm in a predominantly British and Western population. The added challenge of researching, navigating and attempting to understand a national health system foreign to mine was also identified early during the research process, which made me take a critical view of my understanding of the research and policy context.

Prior to this PhD, my experience conducting research using qualitative methods was limited. This was compensated with extensive reviews of the literature with regard to this methodology, as well as attending several modules on qualitative research.

Additionally, influence from my academic supervisors, conformed by an academic General Practitioner, a critical gerontologist, a medical sociologist and a research physiotherapist must also be taken into account, as feedback from them did help guide and

steer the research being conducted. In addition, my PhD was also influenced and guided by the environment it was conducted in: a research institute of primary care and health sciences. Being part of this research institute entails adherence and acceptance of certain perspectives and assumptions due to the nature of the department, which promotes mental health delivery, management and treatment in primary care. The research conducted and focus given would have not been the same if it was conducted elsewhere, for instance at an institute of social science or sociological research. The culture of the research institute, did have an influence in the researcher and study being conducted with regard to the focus taken.

Additionally, as Mishler (1991) would argue, researchers bring their different cultures, experiences, values and levels of understanding when conducting and analysing qualitative data. Being a 26-year-old woman, foreign to the UK, with different cultural views and English as second language, were personal characteristics that I noted early on and acknowledged as having an inevitable influence of my understanding of the subject of study. As is further described in the next sub-section, maintaining a reflexive account was essential to follow a clear understanding of the subject.

Reflecting on section 4.4.1, there are several assumptions that I brought into this PhD. First, I believe that if we increase the understanding of self-harm in later life, specifically reasons for self-harm, we can increase awareness of the phenomenon in this life stage and start building and working towards reduction of stigma, better healthcare services, more cost-effective treatments, better support for family and carers and overall improved quality and reduced burden to older adults who self-harm. Additionally, I assumed participants will be willing and have the capacity to truthfully and openly communicating their views of self-harm. With this, I also assume communication will not be a barrier with participants, but instead an enabler for me to further comprehend their experiences and views of self-harm. Another assumption comes from the chosen participant groups included in the study, as I am assuming third sector support workers will have enough insight to respond to the prompts about self-

harm motivations in older adults, despite them not experiencing them but only having worked with people that have.

4.4.3 Reflexivity

Reflexivity defined as “an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process”, is fundamental in qualitative research (Robert Wood Johnson Foundation, 2008a). I am well aware of the role researchers have in studies, as this may have an impact and influence results. This is even more evident in qualitative methodology, where an exploration of views and understanding of the individual’s views is sought. That is why it is paramount to be reflexive throughout the entire process of the research project, from data collection to interpretation of the results, as well as with previous stages such as focus of research questions and review of literature. Therefore the importance of stating my background and previous research experience as done in the previous section is essential.

Chaney (2019) argues that researchers involved in self-harm and mental health research indeed require to be transparent and reflexive of their personal accounts and identity when conducting self-harm research. However, there are other elements which are also crucial to maintain a transparent and reflexive research process, such as being critical and reflexive when conducting research, challenging one’s own assumptions. In the previous section, I stated the identified assumptions I had when commencing this research. In what follows, I provide further information on how I aimed to be critical and reflexive throughout the research process.

Like previously described, both my clinical and academic background resulted in my interest in self-harm. Additionally, adding to my interest and experience of mental health problems in later life, I had a family member that experienced this. Because of these experiences, I was aware of the importance of being reflexive, as the possibility of influencing subsequent themes and findings based on my previous experience was present. This is why

throughout the entire duration of the study, I ensured to be clear when including themes and findings as described by participants. This was achieved by keeping a reflexive diary where I took notes of my impressions and thoughts throughout data collection and analysis, as well as checking findings and meanings with my supervisory team. Failing to note or acknowledge previous experiences and assumptions can be detrimental when attempting to build an understanding of the phenomenon being studied. Nevertheless, being an absolute objective and neutral researcher was not attainable or sought due to the inevitable influence of researcher's presence, this being acknowledged and reduced through reflexivity.

4.4.4 Triangulation

The use of multiple sources of data to produce understanding within a research study is known as triangulation (Robert Wood Johnson Foundation, 2008b). In qualitative research, triangulation aids to reach a more in-depth and comprehensive understanding of the research area. This technique can be used in different sections of the research process. In the case of this doctoral study, triangulation of sources and analyst triangulation were used as further described in Chapter 5. Triangulation of sources meant that there was no single participant group when collecting data. Third sector workers and older adults were both invited to take part of the research project, gaining different perspectives and experiences from the two groups. Additionally, inviting participants to take part in a second interview allowed comparison of the data collected in different points in time. On the other hand, analyst triangulation was also applied when the supervisory team was involved in the data analysis of a sample of the interviews. This allowed to take into account the perspectives of more than one researcher, with different backgrounds and views. Through these triangulation techniques, a more in-depth understanding of self-harm in older adults was reached, as well as maintaining methodological rigour. With the use of the described techniques throughout the entire research process, methodological rigour and consistency was established in this doctoral study. Prior to presenting ethical considerations, section 4.5 describes the role PPIE had in this PhD.

4.5 Patient and Public Involvement and Engagement

PPIE has an impact in health research within the UK and internationally as summarised in Chapter 1. Within this doctoral study, PPIE has been involved since its inception when it was first conceptualised and continued to do so throughout the entire duration. As can be seen in Figure 4.4, the research questions and overall focus of the PhD arose from a PPIE meeting. The group identified the need of researching self-harm in older adults as the carried out study did not include older populations (Carr et al., 2016). Since then, a newly convened PPIE group collaborated and participated in this PhD as described in Figure 4.4.

PPIE has been reported to be particularly important in mental health research (Ennis & Wykes, 2013). Mental health has attached with it stigma, therefore many patients are often afraid to ask for help or voice their concerns, affecting participatory research from this group. It is a particularly vulnerable population that can and is easily not represented, or involved in health research. However, in the last few years, the NHS and collaborating health research leaders have noticed this concerning issue and have addressed it by increasing the public's involvement in mental health research (NHS, 2014). Ennis and Wykes' (2013) longitudinal study assessed all the Mental Health Research Network studies in the UK to see if patient public involvement had any impact on mental health research and found that PPIE in mental health research was associated with study success with regards to recruitment. Despite the limitations of basing these findings and conclusions from a single database (Mental Health Research Network), Ennis and Wykes (2013) provide evidence for the potential of studies improvement through patient involvement.

Being classified as a vulnerable population (older people who self-harm) given the heightened risk, PPIE is particularly important in this study to ensure relevant research is conducted with high ethical standards. Given the evidence of the importance of PPIE in mental health research and how it has already been previously involved in developing the research question being addressed, working in collaboration with PPIE has been of great aid for the present research project. In alignment with my ontological and epistemological position, the

importance of participants and PPIE's input as co-constructors of knowledge is a fundamental pillar of the research endeavour. Chapter 5 further describes the impact and involvement PPIE had in the methods of this research, while this section has given an overview of the importance of involving the public in health research.

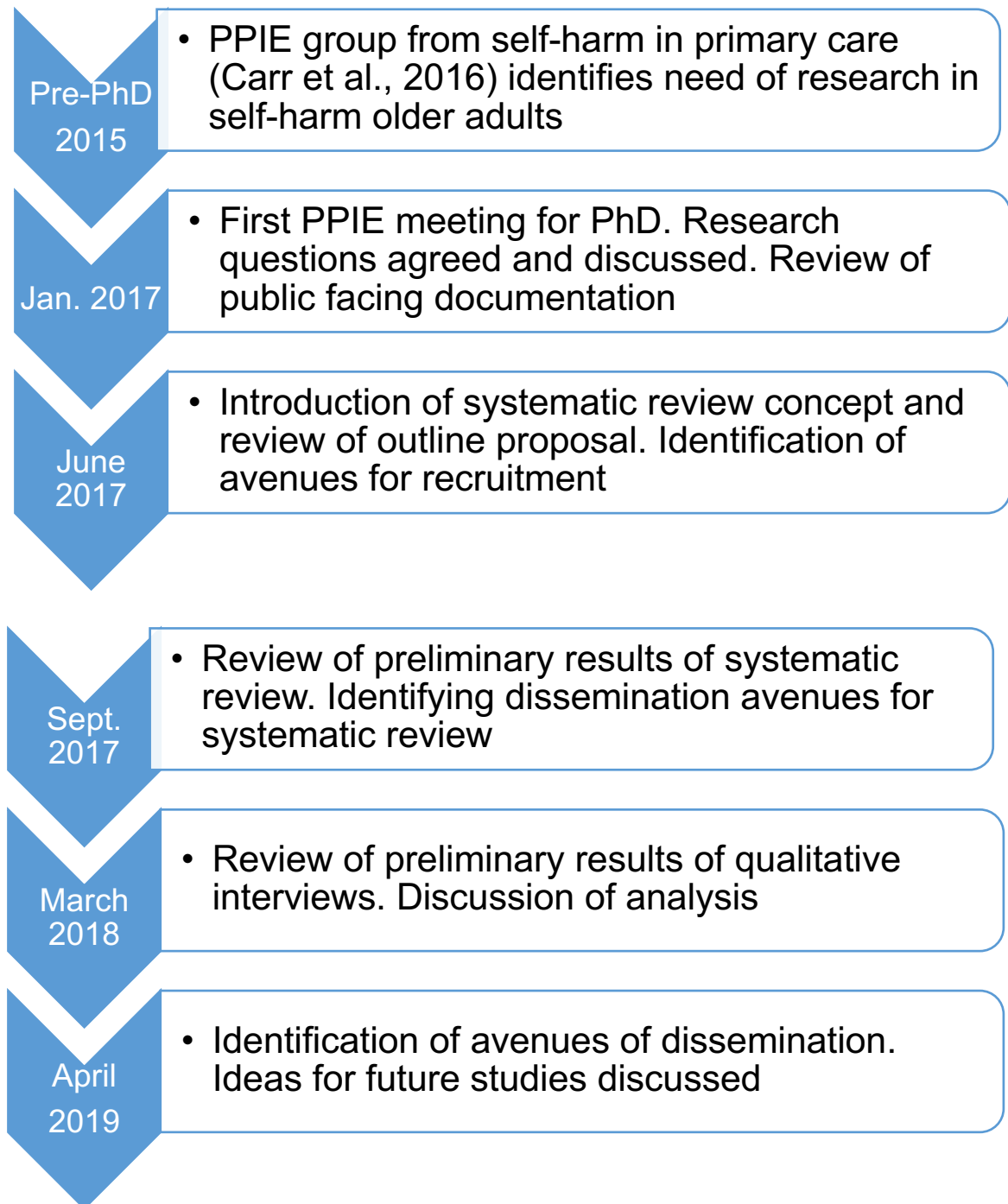


Figure 4. 4 Ongoing PPIE involvement in the PhD

4.6 Ethical considerations

Research conducted with any living being requires careful consideration with regard to ethical and moral principles and values. The field of ethics in medicine and healthcare has developed significantly since the second half of the twentieth century, when research conducted and treatment delivered had no set of guidance, resulting in severe attempts against human life evidenced in the Nuremberg trials and Tuskegee Syphilis Study (Brandt, 1978; Taylor, 2012). With ethics having the indispensable role it now has in health research, it is important to acknowledge and address ethical considerations that come as a result of conducting health research.

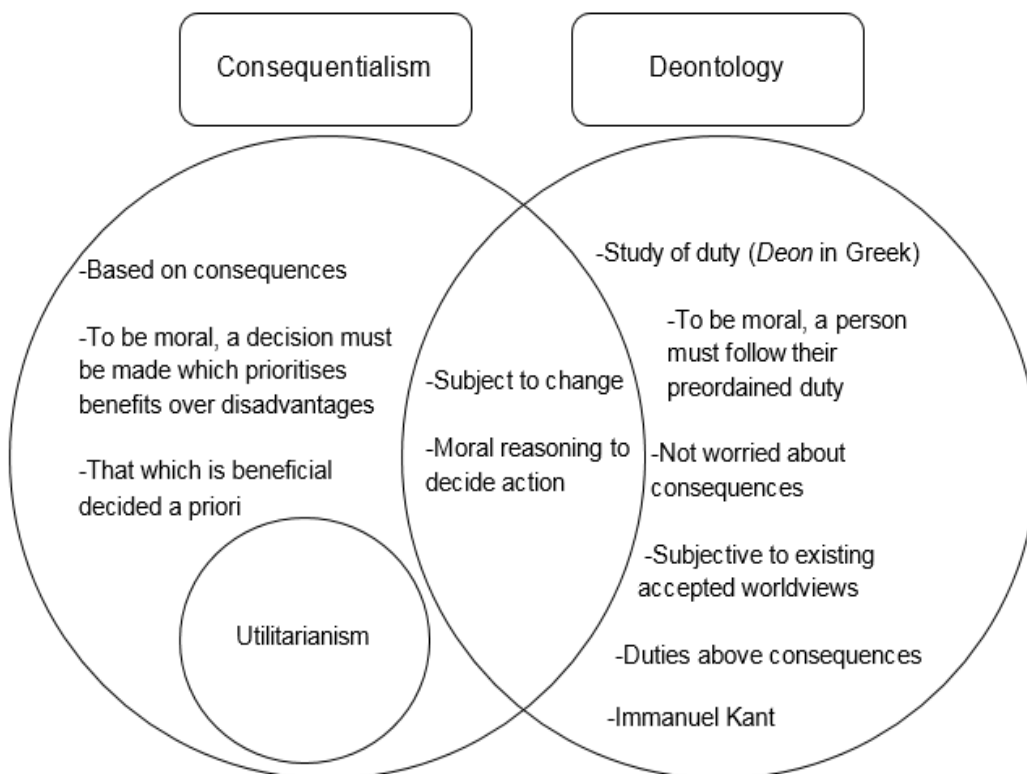


Figure 4. 5 Ethics and moral reasoning in health research (adapted from Seedhouse, 1991)

Ethical theory emerged from moral reasoning and philosophy. Therefore, to comprehend ethics and its considerations in research, an overview of moral philosophy and its classic theories is warranted. As summarised in Figure 4.5, the two classical theories of moral philosophy are deontology and consequentialism. In one end, deontology bases its values in

fulfilling a predetermined duty in order to be moral (Seedhouse, 1991). While consequentialism prioritises moral reasoning and decisions to be made based on the final consequences of an action. Within health research, there is no strict adherence to either of the two main theories of philosophy, but instead both are considered when assessing whether research is being carried out with ethical standards.

Ethics as a term has been present and developed for many centuries, having as a result multiple varying definitions. Seedhouse (1991) described ethics founding question as “how best to conduct one life’s in the presence of other lives”. In health research, ethics becomes an integral pillar due to the inherent and inevitable nature of the field of healthcare involving human participants. Ethics enriches research conducted as it allows researchers to gain further insight of participants views, by thinking thoroughly and a priori to possible ethical concerns that may be encountered when conducting research. It does so by allowing the formulation and creation of research designs which take into consideration the nature of intrinsic values and principles adhered to health research guided by ethics, morals and values.

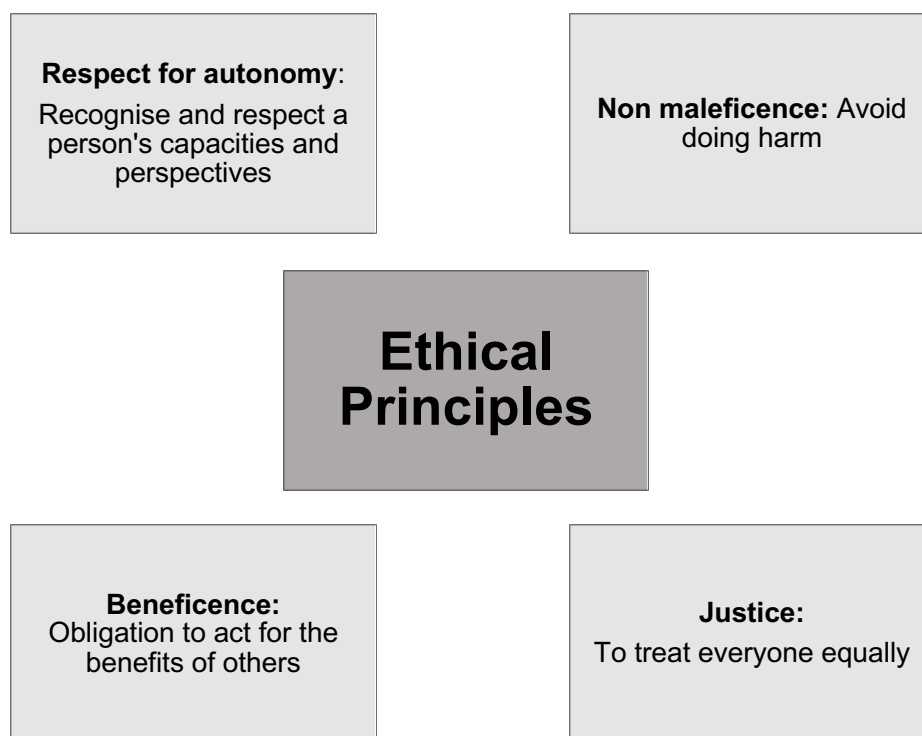


Figure 4. 6 Ethical principles (Beauchamp, 2007)

Worldwide, there are four ethical principles for healthcare that are universally followed which involve respect for autonomy, nonmaleficence, beneficence and justice (Beauchamp, 2007) (Refer to Figure 4.6). I adhered and followed these ethical principles when conducting interviews and throughout the entire PhD.

4.6.1 Researching potentially vulnerable populations

Following ethical standards and basic principles in healthcare research is not sufficient when conducting research with potentially vulnerable populations. Additional precaution, based on following guidance from ethical principles, is needed when the subject of research includes the involvement of potentially vulnerable populations. The declaration of Helsinki held in 1964 by the World Medical Association gave researchers in the biomedical area guidance towards medical research involving human subjects, including vulnerable populations. Vulnerable populations are known as a disadvantaged sub segment of the population that require particular care, considerations and protections when involved in research (WMA, 2008). They can be classified as vulnerable for multiple reasons such as lack of freedom, or capacity to protect themselves, or inherent risk which does not allow them to make informed decisions (Shivayogi, 2013; WMA, 2008). Vulnerable groups include prisoners, minors, pregnant women and institutionalised people.

The research topic of this PhD consisted on a sensitive research area. Mental health problems are commonly stigmatised and there is a general reluctance of sharing personal accounts due to this. This is also the case with self-harm, as not only is there stigma towards this type of behaviour but many times it is a coping mechanism used to deal with possible existing problems. Due to this, necessary precautions and ethical considerations were taken in place when interviewing participants. The potential impact interviews could have on the participants was considered, so necessary precautions were put in place as further described in Chapter 5.

4.6.2 Obtaining ethical approval

Due to the importance of conducting research with the appropriate ethical considerations described earlier, following ethical considerations was seen as an ongoing process rather than a static one time element.

Also, the research topic not only was one that was sensitive but this also meant that participants could be potentially vulnerable. This is why from the beginning of the conceptualisation of the study, ethical considerations and potential patient vulnerability was acknowledged and taken into consideration, being a critical component of the research project.

Concerns regarding ethical matters were considered in the early stages of the research project involving research design amongst others. Further details regarding the informed consent process are described in Chapter 5.

4.7 Conclusions

This chapter gave an overview of the research methodology I used when answering the study's research questions, as well as my theoretical perspective and stance. It gave further information regarding the setting and context this PhD was set in, as well role and influence of the researcher. The importance of establishing methodological rigour was described as well as the value of patient involvement. Finally, ethical considerations were described. Overall, Chapter 4 has set the scene for subsequent chapters, particularly Chapter 5, where the used methods are described in the context of my methodology.

CHAPTER 5: METHODS

5.1 Introduction

The aim of this chapter is to present the methods used when conducting the qualitative study. The methodology and overall research paradigm were presented in Chapter 4. Here, I present the methods used which are congruent with the previously described methodology. The research design and methods are presented, including study design and setting, participants, procedure, sites, ethical considerations and data analysis. Then, I describe the involvement of PPIE in the methods and study design of this research.

5.2 Research design and methods

5.2.1 Study design

When thinking about research design, it is essential to choose one that is congruent with answering the research questions and objectives (Prince, Stewart, Ford & Hotopf, 2003). To address the previously identified research questions (see section 4.2), a qualitative methods approach was adopted to explore the views and experiences of older adults who self-harm, as well as third sector workers. Semi-structured, in-depth individual interviews were the selected data collection methods (Green & Thorogood, 2010; Kvale & Brinkman, 2008; Mason, 2017). The advantage of semi-structured and in-depth interviews is that they elicit extensive accounts from participants' narratives, while allowing participants to be guided by the interviewer's predetermined topics. The combination of semi-structured and in-depth interviews allowed for inclusion of the benefits of both types of interviews: in-depth, extensive reports from participants, following a semi-structured predetermined list of topics to be covered. Particularly, semi-structured in-depth interviews have been frequently reported in suicidal behaviour research given the described benefits of these type of interviews when conducting research with potentially vulnerable populations (Knizek & Hjelmeland, 2018). Furthermore, observational field notes were also taken. These were essential to capture non-verbal

communication in the case of face-to-face interviews, as well as keeping a reflexive account of the conducted interviews (Green & Thorogood, 2010).

5.2.2 Participants

Two participant groups were involved: (1) older adults with current or recent self-harm history; (2) third sector support workers with previous and/or current experience supporting people who self-harm, including older adults. All of the participants were recruited from England in the different sites described in section 5.2.4. Inclusion and exclusion criteria are described below:

1. Older adults with self-harm behaviour

Inclusion criteria:

- 60 years or older
- Disclose history of self-harm behaviour, defined according to NICE (2011)
- Location: England

Exclusion criteria:

- Are unable to understand and give informed consent
- Insufficient English to consent to interview and participate in interview

2. Third sector support workers

Inclusion criteria:

- Third sector workers with previous experience working with people who self-harm in England
- Location: England

Exclusion criteria:

- Are unable to understand and give informed consent
- Insufficient English to consent to interview and participate in interview

Older adults were invited to consent to one initial interview. Once this first interview had been conducted, older adult participants were asked if they would consent to be contacted to participate in a follow-up interview. The optional follow-up interview method was chosen because of the highly sensitive nature of the topic, the need to establish rapport between interviewer and participant (Saldana, 2003), so a second interview might offer more in-depth discussion. Repeat interviews with populations with suicidal behaviour have been previously used to offer the opportunity to develop a deeper understanding of the individual's experience and allowed participants to reflect on the first interview, thinking on their self-harm behaviour or thoughts to discuss in the second interview (Chandler, 2010). Furthermore, follow-up interviews allowed me to see if there had been any negative impact brought to individuals after their participation in the study, something particularly important given the research area and population (further details of ethical considerations in section 5.2.6). These interviews were spaced approximately one-month apart to allow for data transcription and identification of emerging themes to be explored in the next interview, as well as allowing the participant to have some time in between the interviews to reflect further on their experiences.

Third sector support workers were invited to consent to one interview of approximately 45 to 60 minutes, exploring the participant's experience of working with older adults who self-harm. No follow-up interview was requested.

Alongside collecting field notes, an interview topic guide, developed from the literature and with the advice of the PPIE group, was used. A separate topic guide was used for older adults and support workers, but they both collected participants' socio-demographic data, information about self-harm history (of either older adult participants or older adults supported by support workers), motivations and access to care. Participants were encouraged to elaborate as extensively as possible on their accounts.

5.2.3 Study setting

Situated in a midway point between a rural and urban setting, Keele University is located in Newcastle under-Lyme, in the West Midlands of England. This is where the doctoral study was based and some of the interviews conducted. Other interviews took place in third sector organisations or homes of participants, which were recruited throughout England but mostly based in the West Midlands and Northern England. Telephone interviews were conducted within the facilities of Keele University.

5.2.4 Sampling and recruitment strategies

Recruitment and the use of the different recruitment strategies was guided by the sampling approach taken. Purposeful sampling aims to select information-rich cases who are able to provide information regarding the research questions (Emmel, 2013; Patton, 1990). The adhered sampling approach aimed to obtain a diverse range of both participant groups, which were able to help in the process of answering the study's research questions. In an effort to obtain a diverse sample, a range of different avenues were used for recruitment of participants varying from the third sector, local community and online advertisement. The characteristics of each are detailed below including why these sites were chosen. Furthermore, section 5.2.6 further expands on how ethics amendments were sought and obtained in an effort to expand the initial recruitment strategies, so a wider sample was captured. In Appendix 3, I show how careful and meticulous notes were taken for each of the recruitment sites contacted.

i. Third sector

Increasingly, governments worldwide are relying on third sector organisations. More specifically, the British government has called for help and cooperation from other institutions such as third sector organisations to help with the support of patients (Drinkwater, Wildman & Moffatt, 2019; NHS, 2013; Scottish Government, 2011). Within the UK, the NHS has also encountered decrease in budget, particularly in mental health, therefore assistance from other organisations is needed to support patients (NHS Providers, 2016).

The third sector offers a crucial role within health and social services (Bach-Mortensen, Lange & Montgomery, 2018; Brandsen & Pestoff, 2006). With collaboration from the third sector, mental health services offered to the public and health promotion have the potential to improve, as not everyone presenting to health services will disclose mental health issues, such as self-harm behaviour. The latter has already proved to be a potential avenue when offering additional resources in the UK within the context of delivering mental healthcare for those with substance misuse (Aldridge, 2005), improving mental health services for the Black African and Caribbean population (Office of the Deputy Prime Minister, 2004), social inclusion for those suffering from serious mental disorders (Department of Health, 1999), amongst others (Tait & Shah, 2007). In the older adult population, the third sector has had a crucial role in care-coordination and delivery of social and healthcare services (Abendstern, Hughes, Jasper, Sutcliffe, & Challis, 2018). Therefore, third sector organisations potentially act as a link with existing NHS services and support as well as complement health services already offered. These services might be more acceptable to some groups of people due to lack of perceived stigma.

Despite the existing support given by the third sector to health and social services, scarce literature exists on the role of the third sector in health research. Some mental health studies have mentioned the role and importance of the third sector in mental health services offered, specifically self-harm behaviour (Chantler, 2003; McManus et al., 2019b).

Since there has been an already identified presence of help-seeking from those who self-harm in the third sector, gaining the perspective of third sector workers does not only add to the literature of the role of third sector workers in health services, but also helps with a further understanding of self-harm, from those who are supporting and seeing them often.

In addition, the PPIE group suggested including the perspectives of third sector workers as it is where they have experienced receiving support for their self-harm, as is further described in section 5.3.

ii. Online advertisement

Recruitment of participants through online advertisement has been increasingly popular amongst populations such as teenagers and young adults, which are known to frequently make use of this platform of communication (Amon, Campbell, Hawke & Steinbeck, 2014; Christensen et al., 2017; Frandsen, Thow & Ferguson, 2016; Prescott et al., 2016; Ramo & Prochaska, 2012). It has been particularly used in hard to access groups with stigmatised research conditions, such as mental health and amongst ethnic minorities or the LGBT community (Martinez et al., 2014; Pedersen et al., 2015; Ramo, Hall & Prochaska, 2010). Social media platforms used included Facebook, Twitter and Online forums.

Older populations have started to engage with this platform of communication and have become active participants of online groups in social media (Friemel, 2016; Smith, 2014). This increased activity makes recruitment of older participants through social media a possible avenue of engagement in mental health research studies (White et al., 1999; Wright, 2000). As this doctoral study researched a stigmatised behaviour such as self-harm and increased access to social media and the Internet has been found in older populations (Friemel, 2016; Smith, 2014), recruitment from social media was found appropriate by both PPIE members and me.

Additionally, support workers are often involved in social media to see relevant updates from organisations and researchers and overall health education (Cartledge, Miller & Phillips, 2013). Targeting social media platforms to recruit third sector support workers was another appropriate platform for recruitment for this doctoral study.

However, alongside this relatively new recruitment method comes additional ethical considerations which must be acknowledged (Bender, Cyr, Arbuckle & Ferris, 2017; Gelinis et al., 2017; Lunnay, Borlagdan, McNaughton & Ward, 2015). These is further discussed in section 5.2.6.

iii. Advertisement in the local community

Recruitment of older adults can be difficult as multiple health research studies have found complications when recruiting from this population in terms of access and participation (McMurdo et al., 2011; Townsley, Selby & Siu, 2005). Provencher and collaborators (2014) explored strategies to include older populations in research studies and found that recruitment through advertisement in the local community can increase participation if conducted in sites commonly frequented.

5.2.5 Procedure

Prior to recruitment of participants, ethical approval was sought and obtained from the Ethics Review Panel at Keele University (Ref: ERP1333). Further detail regarding ethical considerations are described in section 5.2.6.

Recruitment from the different avenues varied in how participants were approached. All avenues were approached from September 2017 to September 2018. In all cases, I adhered to the Lone Working Policy from Keele University (www.keele.ac.uk/dohs/a2z/loneworking/). Figure 5.1 summarises the participants recruited through the different avenues.

i. Third sector

Self-harm support groups and older age groups were the two main types of third sector organisations involved in the recruitment of participants. All identified national self-harm support groups were contacted ($n=25$), while third sector organisations for older people from North Staffordshire were contacted ($n=8$).

The procedure to approach self-harm support groups and older age groups consisted of contacting the group's manager or administrator to inform them about the study and see if they were interested in sharing the study's information with members. This was done either by email, telephone, social media, or in person, where information about the study was shared. When the group's manager or administrator agreed, I was invited to attend meetings where members attended and briefly presented my research project and left recruitment posters

(Appendix 4) and information leaflets (Appendix 5), as well as interacted with members and possible future participants. The same approach for recruitment of both older adults and support workers in the third sector was followed. This was the most successful strategy as initially recruitment was being proven to be difficult as explained later in section 5.2.6. By being in regular contact with third sector members, they were less hesitant to come forward and volunteer to take part. Regular contact with third sector members did come with some ethical considerations which are further explored in section 5.2.6. In certain occasions, group administrators did not find it suitable for me to visit their organisations, so they shared information about the study to members, showing the relevant documentation. In one instance, a group manager did not find the recruitment posters and information leaflets to be appropriate to be distributed in their third sector group in the current format. Therefore, changes to the public-facing documentation were made after meeting with the group manager and agreeing on updated public-facing documentation. This was then re-submitted for an amendment to ethical approval, prior distribution to members from the third sector organisation (see further details of amendment in section 5.2.6). Subsequently, interested third sector members made contact by calling the study's mobile telephone number expressing interest, or emailing the given email address. Once it was determined that participants met eligibility criteria for the study, they were invited to an interview taken place at their preferred site being the University, self-harm support group, or participant's home.

ii. Advertisement in the local community

Recruitment of participants from the local community consisted of displaying recruitment posters (see Appendix 4) across different sites around the city of Stoke-on-Trent in North Staffordshire in addition to newspapers ads (see Appendix 6). To recruit participants from different settings, diverse rural and urban sites were contacted. Libraries, pharmacies, museums and fire stations were sites where advertisement was made. To advertise the study's recruitment poster, I visited 18 locations asking for permission to put the advertisement after briefly describing the research project to the store's manager. The same approach for

recruitment of both older adults and support workers when advertising in the local community was followed. Participants that had seen the study advertisement and were interested, made contact by either telephone or email. Again, after checking if individuals met criteria for the study after a telephone or email conversation, participants were invited to an interview at their preferred locality. As is further discussed in section 5.2.6, recruitment through this avenue provided some ethical issues to be considered regarding accessibility of researcher's information being publicly available.

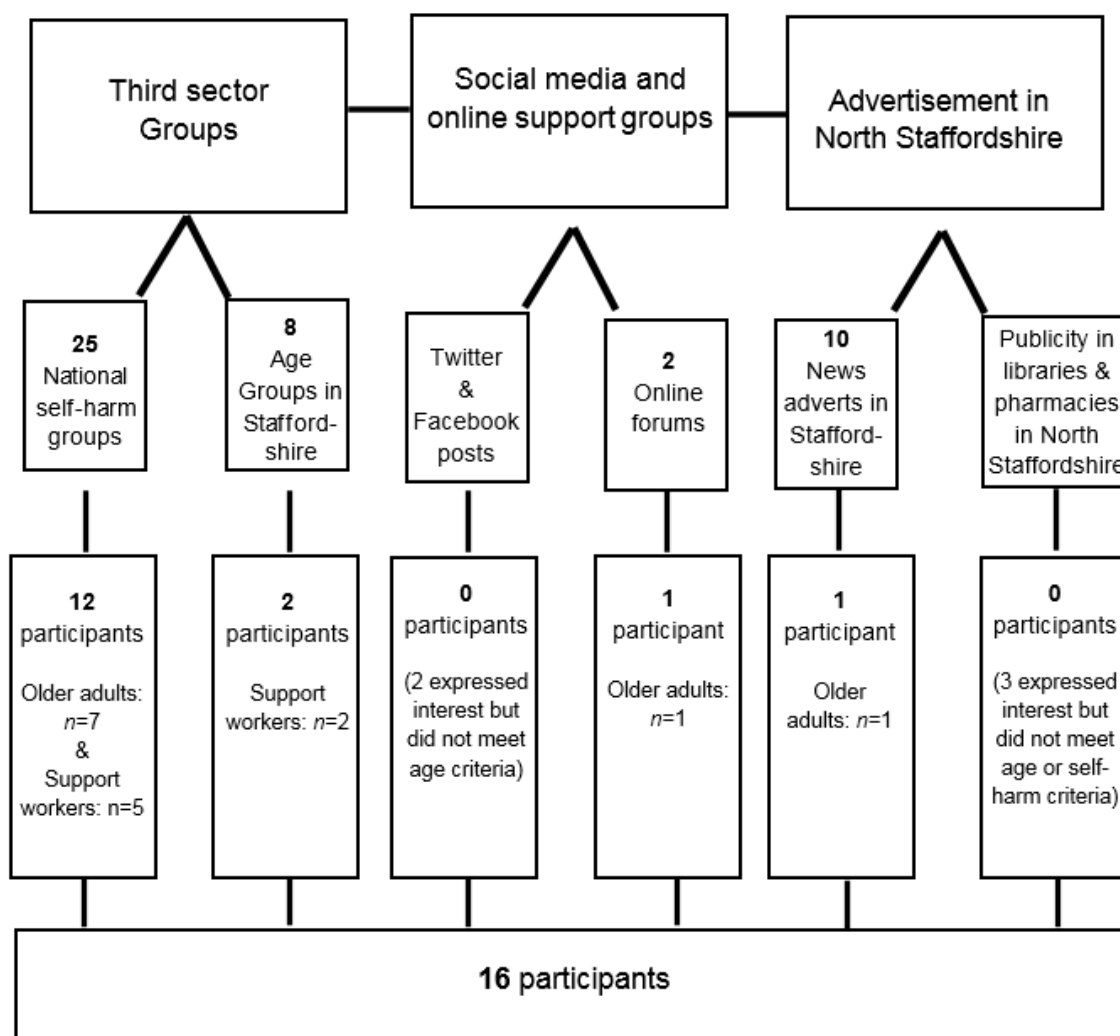


Figure 5. 1 Recruitment of participants

iii. Online advertisement

Recruitment from social media and online advertisement was made through contacting Facebook groups of self-harm support, sharing Twitter feeds advertising the study and posting in online self-harm forums. Targeted organisations for Twitter, Facebook and forums included self-harm support groups, age support groups and foundations, as well as using diverse types of hashtags to highlight study. Prior to posting the advertisement in the group, I contacted the group administrator online to be granted permission to either post the advertisement by myself, or it be posted through the administrator's account. Like the other two avenues of recruitment, once participants had expressed an interest and eligibility criteria was assessed, participants were invited to an interview at their preferred locality. The same approach for recruitment of both older adults and support workers through online advertisement was followed.

iv. Approach to recruitment

During the entire duration of recruitment, I was flexible and participant-orientated when conducting the interviews; no two interviews were the same or followed the same order or pattern. I mostly followed participants' pace when it came to disclosure of sensitive subjects such as those that were in the topic guide. This did not mean I was not consistent or thorough throughout the interviews when it came to ethical considerations or depth in context of interviews. Interviewing each participant was a unique process where I had empathetic skills and active listening to follow participants' accounts, but also kept in mind the topic guide to be covered. Despite not following the same order of the topic guide, participants narrated their accounts and I led them to answering other questions or areas following each participant's pace. Due to the inevitable individual characteristics of each participant's account, certain areas (e.g. access to care, motivations to self-harm) were covered when this was brought up by participants (at the beginning, end or throughout the interview). Furthermore, throughout the interviews, I made sure to follow ethical considerations, including ongoing informed consent, as is further described in Section 5.2.6.

5.2.6 Ethical considerations

This section presents ethical considerations present in this study. Firstly, I present how I obtained ethical approval to conduct this research, then I explain the informed consent process, followed by ethical considerations to be held when conducting follow-up interviews and repeat contact with participants. Lastly, I present the ethical considerations taken into account when recruiting from online advertisement and the local community. As further described in this section, in addition to adhering to institutional processes and regulations when it came to ethics, I also had to make informed decisions regarding different ethical considerations. Given the complexity of research conducted on individuals, situational ethics can be often experienced by researchers when faced with situations more complex than those described by institutional regulations (Goodwin, Pope, Mort & Smith, 2003). Therefore, alongside the described sub-sections that summarise the different ethical considerations, it is worth noting that ethical considerations were taken throughout the entire duration of the study: from when preparing for the interviews until after the interviews had been conducted and analysed. Throughout the entire conduct of the study, I was aware of my role as a researcher, being in contact with possible interested individuals and participants in a sensitive research area. Thus, it is important to highlight ethical considerations were embedded throughout every stage of the research.

i. Ethics approval

Prior to seeking ethical approval, the study documents underwent review with Independent Peer Review in April 2017 by Research Governance of Keele University (see Appendix 7). Following this approval, University Ethics was sought in May 2017 and obtained in June 2017 (see Appendix 8). Three amendments were submitted in November 2017, February 2018 and March 2018 to expand the location of recruitment (from North West and West Midlands to all of England) and add the option of telephone interviews for the first amendment given that I was experiencing difficulties recruiting participants. The second amendment included changes in information leaflets to be made most suitable for older age third sector organisations after

having met with the chief executive of a local third sector organisation of older adults. The last amendment consisted on expanding the participant group of support workers to those working with people who self-harm of all ages and not just older adults given that difficulties were encountered when recruiting from the first proposed group. Approval for these amendments were received November 24th 2017, February 9th 2018 and March 26th 2018 respectively.

ii. Informed consent process

Informed consent was obtained from all participants prior starting data collection. The process of informed consent started by contacting possible participants that had made contact after reading the information leaflet. In this document, participants were informed of the aim of the research project, what will happen if he/she participates, voluntary participation and he/she can withdraw from the study at any moment, benefits and risks of taking part of the study, how his/her information will be used, who will have access to his/her dataset, confidentiality concerns and what to do in case of a problem occurring. On the day of the interview, I ensured participants had understood and subsequently signed the informed consent. Interviews did not start until participants had fully understood and signed the informed consent, after I had answered any question(s). Two copies of the Informed Consent were signed by each participant, one to be stored in a safe location following ethics procedure and the other for the participant to keep. In the case of telephone interviews, verbal consent was recorded. Additionally, because of the sensitivity of the research subject, throughout the duration of the interview, consent was checked at multiple occasions in order to confirm whether or not participants were still happy to share their accounts. In the case the participant agreed to take part in a second follow-up interview, informed consent was again separately obtained as previously described, with participants reading and signing another informed consent sheet, or consenting verbally as was the case with telephone interviews.

iii. Ethical considerations of follow-up interviews and repeated contact

Alongside the potential benefits of follow-up interviews allowing a more in-depth reflective account of participants understanding and experiences of self-harm behaviour, several ethical

considerations had to be considered. Repeated contact with participants has both the benefit and disadvantage of increasing and improving rapport and relationship dynamics amongst participants and interviewers (Saldana, 2003). Whilst repeated contact can allow participants to feel more comfortable with the interviewer to share sensitive life-event accounts, it also creates the opportunity for participants to confuse the boundaries of the researcher-interviewer relationship if not conducted with precaution. Given the highly sensitive topic and research area of the study, there was the potential of confusion of research interviewer roles with therapeutic roles. To avoid any confusion or mislead participants, I made sure to clarify the purpose of the interview throughout the duration of it. I did so by framing the interview within a research context, so participants understood the implications of their participation. Additionally, in certain occasions participants and I read the study information leaflet together, to ensure this was clear or if there were any questions about the process arising.

As previously mentioned in Section 5.2.5, repeated contact with participants and third sector members arose as part of the recruitment process. In some third sector groups, I was in contact through hourly weekly visits, being invited to group meetings so that members could become familiar with me. Prior to attending the groups meetings, I had been invited by the group facilitator, who then asked members permission so I could sit in meetings. When attending groups, I was presented as a PhD student and researcher interested in self-harm in the older adult population. There was one self-harm support group I was particularly in regular contact with, where I attended two-hour weekly meetings for four months. After considering the benefits and consequences of regular visits, I made the informed decision to regularly attend the group's meetings for a time-period given that recruitment by lone advertisement was not as successful as expected and regular contact with potential participants has been proved as a successful strategy in studies researching vulnerable populations (van Wijk, 2014). Through being in regular contact with third sector members and potential participants, increased participation came as a result. At the same time, I also increased rapport with, staff and possible participants, resulting in a formed relationship with them. Throughout the entire

duration of my regular visits to third sector groups, I was aware of possible ethical concerns. In particular, given the frequent and regular contact, I reminded myself the role I had within the group, where I was an observer rather than active participant. On occasions this was difficult to maintain as group members often forgot I was a researcher and not another group member. Additionally, because I was introduced as a researcher in the area of self-harm, I was aware that some members thought I had the clinical and research knowledge to deal with self-harm. Nevertheless, as I had not entered the group with that role, I found I had to redirect members' questions and remind them my presence as an observer. Overall, it was difficult to maintain the balance of having the needed distance whilst keeping a good relationship with group members, but this was achieved by thinking constantly and reflecting on my role as a researcher and the ethical considerations that needed to be taken. Through the use of my research diary and discussion in monthly supervision meetings, this was achieved.

Another concern when conducting follow-up interviews, especially within research involving sensitive personal topics, is the potential of unsettling participants when being asked to reflect repeatedly on past life-events (Ryan, Rodriguez & Trevena, 2016). Bringing back difficult memories or events repeatedly may be painful for participants. However, I made sure to remind participants about sharing as much as they wanted to, with no need of going forward if they felt overwhelmed. In reality, I felt that participants were comfortable sharing these difficult moments and even relieved; no participant stopped sharing their life events or expressed feeling overwhelmed. However, in one occasion I did feel the need to restrict myself from asking further around a certain topic which seemed to upset a participant. I did so after using my clinical, researcher and personal judgment and avoiding causing the participant any distress or harm.

Furthermore, the follow-up interview allowed me to see the impact the first interview had on participants, seeing whether they had been negatively impacted or burdened when participating. Once again, I felt that all of the participants who took part in the follow-up

interview found their participation in positive terms, as giving back to society through research despite having had to revisit some difficult memories.

iv. Recruiting from online advertisement

Social media and online advertisement has become an increasingly popular tool amongst researchers as an avenue of recruitment of participants. Alongside the expanded opportunity of reaching a wider audience through the use of social media come ethical considerations which must be taken into account (refer to Figure 5.2). I was aware of the identified ethical considerations from Figure 5.2 when recruiting from social media and online advertisement.

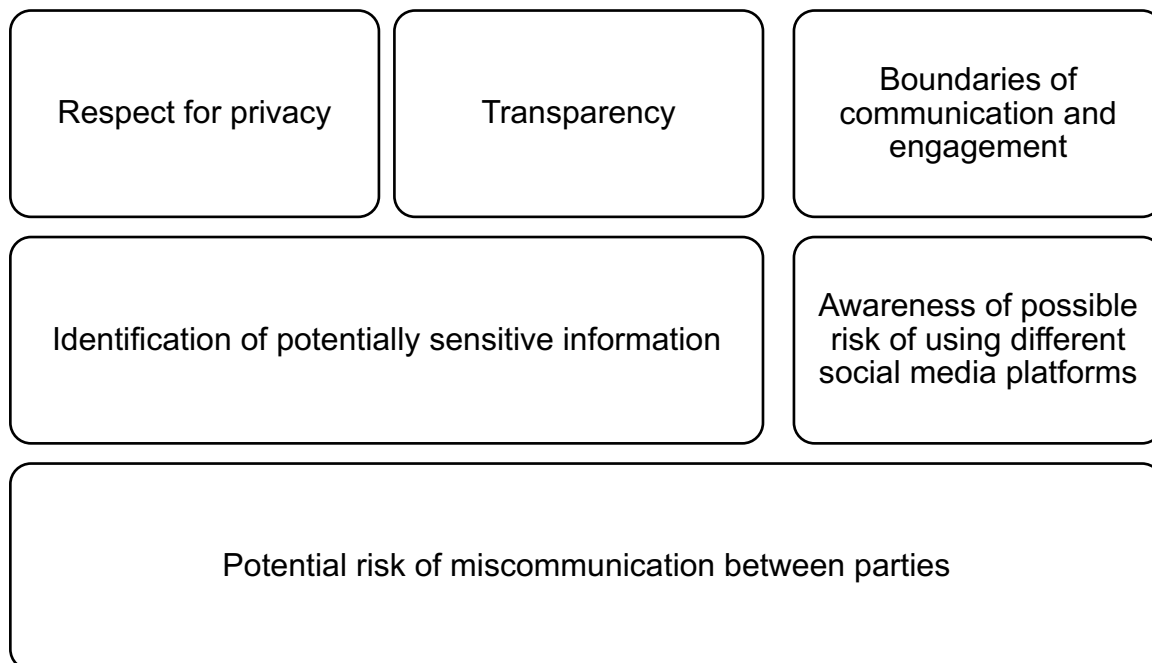


Figure 5. 2 Ethical considerations when recruiting from social media (adapted from Lunnay, Borlagdan, McNaughton & Ward, 2015)

Depending on the different use of social media in research, ethical considerations regarding participant privacy, transparency and overall honest communication and interaction must be prioritised. Following ethical principles highlighted in Chapter 4 section 4.6, I ensured these were also adhered throughout the entire research project, including social media recruitment. Recognising the complexity that can involve when conducting researchers with individuals, situational ethics was considered throughout the duration of the study, meaning

careful consideration and informed decisions were made when faced with complex ethical situations (Goodwin, Pope, Mort & Smith, 2003). When recruiting from social media and online advertising, I clarified the recruitment dates (September 2017-September 2018), to ensure that any contact made by individuals would have to be within the recruitment period. This was also done to avoid individuals contacting myself for participation in the study outside the recruitment period, as this would not have been possible. I found the boundaries of communication and engagement to be breached once during the duration of this study when an individual had made contact with myself after seeing my study advertised in a self-harm group's Facebook page. The individual was interested in learning about self-harm in another area and decided to contact me to get my opinion as a researcher. Once I confirmed the individual was no threat to herself or others and explained the limits of my research, I let the individual know I would not be able to assist her and re-directed her to other avenues that she may find of benefit. There was no further contact made by this individual or by any others enquiring outside the limits of the research when using online advertising.

v. Recruiting from the local community

Recruiting from the local community through advertisement of study posters in public places such as libraries and pharmacies held some ethical challenges. Researchers advertising studies within the local community also share details and information about the researcher when publicising details about a research study. Contact details about the research also become publicly available when choosing to recruit through the local community. Even when taking necessary precautions such as using institutional email addresses as well as exclusive study mobile numbers, researchers sharing their contact details give the public access to their personal information. With a rapidly evolving technological world, where personal information is easily publicly available to anyone, researchers can be placed in a vulnerable position when advertising through the local community. Because of it, ethical considerations must be taken into account when choosing this recruitment avenue, as researchers expose themselves to contact from people that are not necessarily interested in

the study but in the researcher. I faced this in two occasions in the duration of the study when two separate individuals made contact to my insitutional email address and designated study mobile through a text message to express interest in myself rather than the research. This placed me in a situation where I felt the vulnerability researchers can be exposed to when sharing their personal details to the public. After confirming that the individudals were in fact not interested nor eligible to take part in the study, I discussed the best way to deal with these situations with my supervisory team. These two occasions show once again how ethical considerations were present throughout the entire duration of the study (e.g. when in contact with possible participants).

5.2.7 Data analysis

Making sense and interpreting what is first unstructured collected material from the dataset is part of what entails qualitative data analysis. Researchers analysing datasets have the task of providing coherence and structure to the collected material, while maintaining the essence and original accounts of the interviews or selected method of data collection (Spencer & Ritchie, 2002). Green and Thorogood (2010) argue that high quality qualitative analysis locates key findings of the research to a wider context, drawing on wider social science knowledge, therefore the need of abstraction and rigour is needed.

Data analysis can be done through a range of different methods, but as was stated in Chapter 4, thematic analysis using a framework approach and constant comparison was the selected method of data analysis because of its fit with the research project's objectives. The steps and procedure involved in analysing are described below.

5.2.7.1 Process of data analysis

I was solely in charge of storage, transfer, access and archive of the dataset. I transcribed all of the interviews a verbatim at Keele University within a one-week period of the date of the interview. Transcripts were anonymised and designated pseudonyms after being uploaded and stored in a secure, password-protected computer.

Transcript conventions are commonly used when conducting qualitative research as it enables readers to have a broader context of the interview and enhances understanding of the interview. Table 5.1 summarises the used transcript conventions in this research project; this was adapted from transcript conventions used by Bailey (2008).

Table 5. 1 Transcript conventions

<i>Transcript conventions</i>	
(.)	Silence lasting up to 1 second
(..)	Silence lasting up to 3 seconds
(...)	Silence lasting up to 5 seconds
Underlined word	Emphasis
CAPITAL WORD	Loud
[brackets]	Notes and comments including body gesture

Pauses and silences occurred during interviews can be interpreted in different ways. There are specific streams within qualitative research which study and analyse these pauses and silences in more detail such as conversation analysis (Sacks, 1992) or discourse analysis (Wodak & Meyer, 2009). These analyses however go into further depth and detail such as analysing the power held between interviewer and participant, such is the case in discourse analysis, or how the structure and organisation of the conversation defines the content in conversation analysis (Wooffitt, 2005). Analysing interviews in such way was not the focus of this PhD. However, given the highly sensitive subject of the interview, it was important to note and reflect on the significance of these pauses. Silences and pauses in sensitive topics most likely suggest participants reflecting on some of the past difficult encounters experienced. Given the salience of this element, transcript conventions were used to provide readers a broader understanding of the overall context of the interview.

Data analysis software manager QSR NVivo 11 (www.qsrinternational.com/nvivo/home) was used to assist in the analysis of the dataset, which consisted on transcripts from the conducted interviews. Braun and Clarke (2012) highlight the six steps which are needed to carry out data analysis following a thematic analysis approach. Initial analysis was conducted within each participant group, with separate coding themes and categories created for each, as is further described. After coding, creating and revising the initial themes, themes were compared and contrasted across both datasets to integrate the overall findings. Summarised below are how I followed the six steps of data analysis suggested by Braun and Clarke (2012) as well as combining constant comparison methods and a framework approach.

i. Familiarisation

Prior to starting the development of themes or sorting data, familiarisation of the dataset is essential as this allows researchers to know what type of accounts are included in the dataset (Braun & Clarke, 2012). As I transcribed all of the interviews, the process of familiarisation with the data started from this point. However, familiarisation required further steps of immersion in the data such as listening to recordings, studying observational notes and revising transcripts (Braun & Clarke, 2012). In the case of this research project, familiarisation of the data began up to one week after the date of each of the conducted interviews when transcription started. It continued until after the last interview was conducted. Throughout the duration of the study, I was familiarising myself and immersing in the dataset. While there was an overview in terms of familiarisation of the two different participant groups (older adults and third sector support workers), these were also separated in order to be studied according to the diverse perspectives. Furthermore, given that my supervisory team was also involved in the analysis of the interviews, as soon as I had transcribed an interview, the transcript was sent to supervisors so they could also start with early stages of data analysis through familiarisation of the dataset.

ii. *Generating initial codes*

As a result of the first step, familiarisation of the dataset, key ideas were noted, and the generation of initial codes started. Different codes were created according to the different concepts that were being reported by participants. As well, initial codes were amended to encompass the different accounts narrated by participants. Table 5.2 shows an example of how preliminary coding from participants' experiences with illustrative quotes was conducted at this stage. These initial codes were generated at first by myself and then shared with my supervisory team to get input from them. They were discussed amongst all members of the supervisory team and me during monthly meetings.

Table 5. 2 Initial codes relating to the experience of self-harm: older adults

Initial codes (participant group)	Extract from transcripts
Relationship difficulties (Older Adults)	"There was a family argument last week with me granddaughter and she's brought all me past up a fortnight ago now. Although she's been in and apologised, I'm still struggling with it" – Hannah, older adult
Awareness of health conditions (Older Adults)	"Thyroid it affects your mental health and so does your fibromyalgia you know make each other worse if you know what I mean"- Hannah, older adult
The stigma of self-harm (Older Adults & Support Workers)	"Mmm they seem to they there's a massive lack of understanding like that example that chap and his mom uh around self-harm and I think some people are scared" - Lucy, support worker

When creating initial codes, Spencer and Ritchie (2002) state researchers involved make a series of judgements and interpretations regarding the value and meaning of the data, opening it to subjective judgement and differing interpretations of who is analysing the dataset. Inevitably, given the nature of this research, this indeed happened when I was interpreting the dataset. However as previously mentioned, this stage was discussed with members from the supervisory team to check and see whether they also agreed with how coding was being conducted. Monthly meetings and regular email correspondence allowed for the academic supervisory team to also input on data analysis. Regular meetings and discussion with the

supervisory team around the dataset was needed as this added to the interpretation of findings, influencing the analysis with the diverse perspectives from supervisors.

Furthermore, constant comparison methods started from this stage, when initial codes were subsequently compared across different cases to search and refine for future themes (Glaser & Strauss, 2017). Once again, this was done initially individually by myself, but then collectively when discussing codes at monthly meetings alongside my supervisory team. At this stage, separate coding was created for each of the two participant groups, which were then to be incorporated, compared and contrasted altogether

iii. Developing themes

The third step of analysing data involved transforming initial codes identified in the earlier stage into themes. According to Braun and Clarke (2012, p.82), themes “capture something important about the data in relation to the research question and represent some level of patterned response or meaning within the dataset”. To begin to develop themes, I reviewed the coded data and identified commonalities and overlaps between them to cluster them into main themes, in other words applying the constant comparison method as this was done across cases. This was done initially by myself, but as well received feedback from my supervisory team at monthly meetings. I created an initial thematic framework. Like the other stages, I created this framework initially individually, but then received feedback and discussed throughout monthly meetings with my supervisory team as well as email correspondence. Figure 5.3 describes the process of the identification of the thematic framework, when initial codes identified were grouped together to create framework categories and themes. I closely followed the process described by Spencer and Ritchie (2002) and reflect in Figure 5.3 how it was used within my research.

Although difficult to group together initial codes due to the varying accounts and perspectives, this was the best alternative to organise emerging data in a manageable way for subsequent stages. The construction of the thematic framework consisted on a priori areas

introduced to the interviews through topic guides and the arising themes from participants' responses (Pope, Ziebland & Mays, 2006; Spencer & Ritchie, 2002), as well as my clinical background and knowledge on the subject. The thematic framework was initially drafted as described above but was subsequently modified according to the emerging themes coming from transcripts (Pope, Ziebland & Mays, 2006; Spencer & Ritchie, 2002). The final version of the thematic framework was elaborated after having applied it to different transcripts and ensuring the broad range of themes were included; this was revised by the academic supervisory team and discussed at monthly meetings. This stage allows for data to be labelled and manageable for later exploration and analysis (Spencer & Ritchie, 2002). Given that there were two different participant groups with diverse views and perspectives, separate thematic frameworks were built for older adults and support workers. This allowed for the comparison and identification of common and divergent themes from each of the groups in later stages.

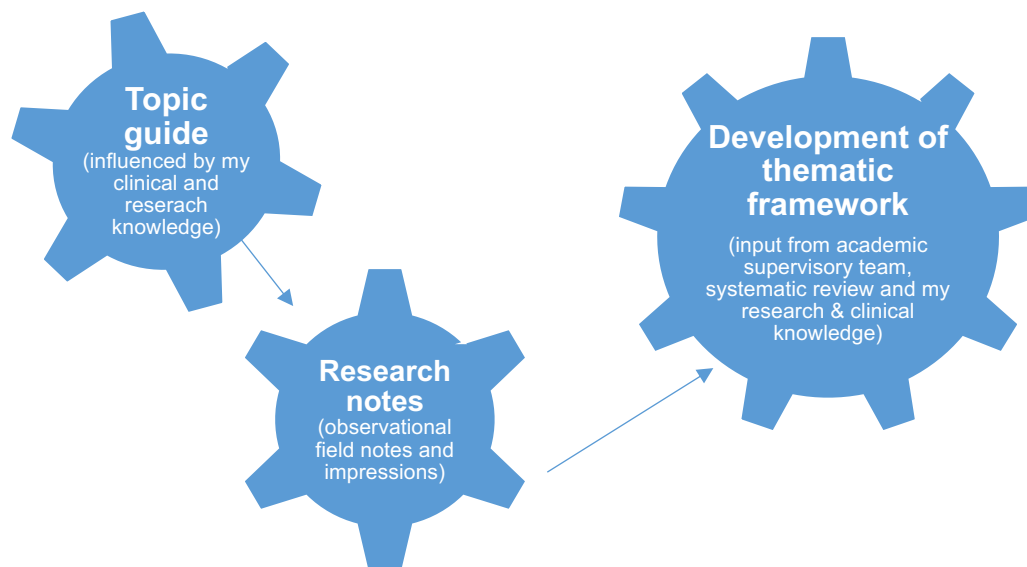


Figure 5. 3 Identification of thematic framework process (adapted Spencer & Ritchie, 2002)

iv. Reviewing potential themes

At this stage, the developing themes from the framework were reviewed in relation to the rest of the data (Braun & Clarke, 2012). This entailed a recursive process where themes were

checked with extracts from the dataset. In several occasions, codes and themes were slightly modified when comparing them to the data, given that they were not encompassing all of the material. Once again, this was done following constant comparison methods. Revision of potential themes was initially done by myself after the held discussions and feedback received from monthly meetings with my supervisory team as well as the PPIE group. As is further described in section 5.3, PPIE involvement in the data analysis commenced in this stage. Afterwards, a final overview of potential themes was discussed with my supervisory team.

v. *Defining and naming themes*

The previous stages enabled the dataset to be compared across the identified key themes (Pope, Ziebland & Mays, 2006). One of the final stages of the analysis involved the interpretation of the dataset as a whole by pulling together main elements from the data (Spencer & Ritchie, 2002). At this stage, a systematic approach was taken when going back to the research questions and objectives that guided the research and searching for key themes (Spencer & Ritchie, 2002). Throughout the entire duration of the analysis of the dataset, but even more at this stage, I had the research question and objectives in hand to go back to what was guiding and a priority for this research project. Finally, at this stage, findings which are described in the two following chapters, were grouped according to the different key themes. Once again, this was done separately in the two participant groups (see Appendix 9) and reviewed and discussed with the academic supervisory team as well as the PPIE group, as further described in section 5.3. Nevertheless, to compare and contrast the identified themes from the different participant groups, these were seen together after having done so separately. In Appendix 10 I provide an example of how I conceptualised and summarised the findings for one of the research questions.

Alongside the entire data analysis process, three questions as summarised in Figure 5.4, guided the analysis, as suggested by Srivastava and Hopwood (2009). These were important to consider throughout the data analysis process, as it ensured reflexivity.

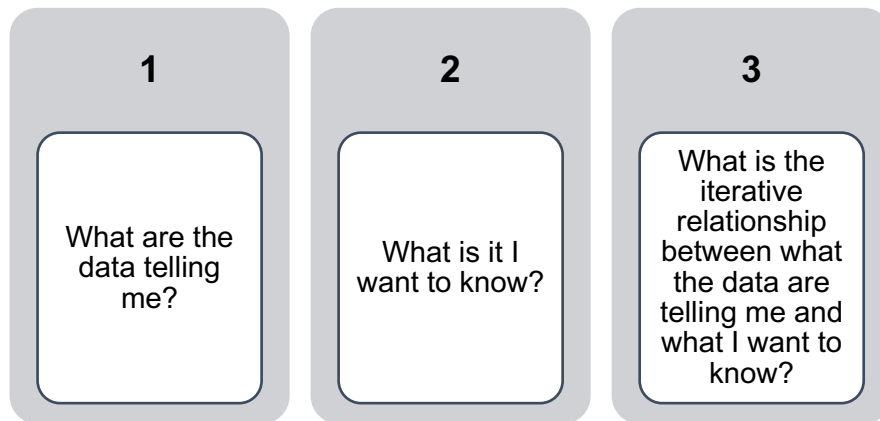


Figure 5. 4 Questions for analysis in framework (adapted from Srivastava & Hopwood, 2009)

vi. *Producing the report*

The final step of the analysis involved the elaboration of this thesis and subsequent reports that arose from the analysis (see Troya et al., 2019b). However, as Braun and Clarke (2012) state, despite it being the final stage of the analysis, producing the report was not something that was done exclusively at the end of the analysis, rather was an ongoing process which started from when developing the research question, reflecting on meanings from the data and conducting the analysis. Similarly, this was the case when I wrote the thesis and other publications that arose from the analysis.

5.3 Patient and Public Involvement and Engagement in methods

As has been previously described, PPIE has been present throughout my entire doctoral study. Chapter 1 introduced patient involvement within the policy context, while Chapter 3 gave a summary of the involvement of PPIE in the conducted systematic review. Chapter 4 highlighted the methodological basis and importance of PPIE in this doctoral study, particularly the value patient involvement can have in mental health research. This chapter describes PPIE's involvement in the study's methods. To document the involvement of PPIE in this research, the reporting checklist GRIPP2-SF (Guidance for Reporting Involvement of Patients and the Public-Short Format) was followed (Staniszewska et al., 2017). In the section that follows I describe the PPIE members involved in the study alongside the impact resulting

from the involvement of PPIE in my PhD. In Troya and collaborators (2019c), the impact and process from PPIE involvement is described in more depth.

5.3.1 PPIE members

During the five meetings, there was a range of different members involved from a local self-harm support group, varying from service users, third sector support workers and carers. Constantly involved in all of the PPIE meetings were three members which were: one carer (husband), one older adult with self-harm history and one support worker with previous personal experience of self-harm. In the first meeting, an additional support worker was present, but due to a change of job roles, she did not attend future meetings. In the last meeting, feedback provided from one of the members (support worker) was done via email given that she was unable to attend the meeting in person.

5.3.2 Impact on methods

PPIE members were involved throughout the different stages of the study, contributing to the selected methods. The impact and involvement of the different contributions from PPIE members are further described below. Table 5.3 summarises the described changes resulting from PPIE's impact to the study methods.

i. Research design

The first PPIE meeting was held in January 2017 (see Appendix 11). The study was introduced to attending members and consultation of the research focus, design and questions was made. Self-harm definition and age criteria was presented to members which commented and agreed on the used age criteria and self-harm definition. The three proposed research questions were introduced to members, who commented on the focus and wording of them, resulting in the modification of two of the research questions (see Table 5.3). Additionally, the proposed research methods were described to consult whether they would be appropriate: individual in-depth semi-structured interviews with two participant groups: older adults and third sector support workers. Members felt the proposed research methods were appropriate.

ii. Public-facing documentation

During the first PPIE meeting held, the group gave their input on the proposed public facing documentation for the research project. This was needed to ensure these documents were accessible and easy to read for future participants. Involvement from PPIE members with public-facing documentation further described in Table 5.3.

iii. Recruitment

During the second PPIE meeting held June 2017, members were consulted on recruitment methods and strategies to be used in this doctoral study. As well as commenting on the proposed methods of recruitment, members added additional avenues of recruitment of participants including older age support groups, mental health groups and community groups.

iv. Systematic review

Members from the PPIE group contributed to the conducted systematic review as described in Chapter 3 during the second and third PPIE meeting. For further details of involvement of PPIE members in systematic review, refer to Chapter 3, section 3.3.8.

v. Data analysis and interpretation

The fourth and fifth meetings with the PPIE group were held March 2018 and April 2019 respectively. Members were presented with the initial findings from the qualitative study in the fourth meeting, with initial themes and accompanying transcripts being presented to the group asking members to comment and add to the data analysis. Discussion around the initially identified themes was held amongst PPIE members. During the fifth meeting, members were presented with the final round of identified themes based on the three research questions to obtain their final interpretation. Further details on PPIE's impact on qualitative findings are described in Chapters 6 and 7.

Table 5. 3 PPIE Contribution to methods (adapted from Troya et al., 2019c)

<i>Research element consulted/discussed</i>	<i>Study</i>	<i>Meeting</i>	<i>Before Meeting</i>	<i>Impact after PPIE involvement</i>
Definitions to be used	SR and Qualitative	Meeting 1	-Possible definitions: Attempted suicide, Non-suicidal self-injurious behaviour (NSSI), self-harm behaviour -Older adult: 40 years and older	-Collectively the decision to use NICE's definition for self-harm was made, highlighting the possibility of self-harm with and without suicidal intent -World Health Organization's definition of older adult
Research questions	Qualitative	Meeting 1	-Exploring the role of the formal sector in supporting older adults with self-harm -Understanding motivations to self-harm	-Role of the informal sector in supporting older people who self-harm -The identification of barriers to self-harm
Methods	Qualitative	Meeting 1	-Interview older adults and GPs -One interview with participant groups	-Interview older adults and third sector workers -Addition of a follow-up interview with older adults
Public-facing documentation	Qualitative	Meeting 1	-Information sheet, interview guide draft provided to PPIE group	-The word dissemination was removed from information sheet; it was not lay-friendly -The group commented on the order of items in interview guide, suggesting starting by asking demographic and clinical questions prior addressing motivations. Members suggestion of including triggers to self-harm incorporated
Search strategy	SR	Meeting 2	-Search strategy including different terms for self-harm and older adult	-Self-destructive and pensioners added to search strategy
Data extraction	SR	Meeting 2	-Elements of data extraction sheet discussed	-Subgroup analysis in different age ranges and non-suicidal self-harm and attempted suicide
Recruitment avenues	Qualitative	Meeting 2	-Proposed avenues recruitment: self-harm support groups, advertising local community, GP practices, social media	-Agreed avenues of recruitment: self-harm and age support groups, female support groups, advertisement local community, social media
Identification of limitations of SR	SR	Meeting 3	-To be discussed in meeting	-Majority of evidence from hospital-based settings, 'younger' older adults -Identification of gaps in the literature: alternative methods of self-harm (e.g. over-eating)
Interpretation of findings from SR	SR	Meeting 3	-Presentation of quantitative and qualitative data to the PPIE group	-Socio-demographic characteristics: likelihood of more 'younger' older adults captured due to 'older' older adults dying result of self-harm frailer health -Suicidal intent: although majority studies reporting attempted suicide, in reality suicidal intent is unclear even to patient. Accidental deaths caused due to self-harm

Difficulties in recruitment	Qualitative	Meeting 3	-Discussion of difficulties in recruitment due to low-participation rate	-Suggestion of IT attending self-harm support groups regularly so potential participants can feel more comfortable in being part of study. This reiterated discussions amongst the research team and resulted in increased participation
Dissemination of findings	SR	Meeting 4	-Information leaflet draft presented to PPIE group	-Alongside NICE definition of self-harm, another lay-friendly self-harm definition -Sources of support identified: helplines for older adults and GPs -Identification of avenues to disseminate: GP practices, libraries, retirement homes, third sector
Interpretation of qualitative findings	Qualitative	Meeting 4	-Quotes presented to PPIE group in order to review potential themes	-Themes suggested by PPIE group: difficulty asking for help due to shame in older adults, self-harm used as a coping method, difficulty stopping self-harm, self-harm due to different life-course stressors. These themes were similar to the already identified themes by the research team, and only slight modifications of wording resulted after consulting with the rest of the research team
Ethical considerations in recruitment	Qualitative	Meeting 4	-Examples of challenging situations in recruitment were presented to the group to seek feedback	-The PPIE group provided tips for encountering challenging situations in recruitment: a) ensuring to state clearly from the start the age range and self-harm definition used as eligibility criteria; b) discuss with support workers any difficulties encountered with participants wanting to engage in the study that were not eligible
Dissemination of findings	Qualitative	Meeting 5	-Draft lay summary information sheet summarising results from the PhD was presented to PPIE group. Also presented was draft video script summarising results of the PhD	-The PPIE group commented on the wording of both drafts including positioning of heading, font and suggested some minor modifications to the text. Overall, the members agreed with the script, highlighted the importance of creating awareness
Interpretation of qualitative findings	Qualitative	Meeting 5	-Final themes presented to group for comments	-The PPIE group commented on Figure 6.1, diagrammatical presentation of motivations of self-harm in older adults, particularly with regards to the relationship between suicidal intent and non-suicidal intent. A modification of the diagram resulted, with regards to the location of no suicidal intent to attempted suicide. Members agreed with the rest of the themes presented

vi. Dissemination

Throughout the duration of the research project, members from the PPIE group contributed to different avenues of dissemination for the different parts of the study (e.g. systematic review, qualitative study, etc.). As mentioned in Chapter 3, an information leaflet (see Appendix 2) based on the systematic review results was created and nationally distributed by the National Alliance for Suicide Prevention. In the fifth and last PPIE meeting held April 2019, members discussed avenues for dissemination of the findings of the qualitative study.

5.4 Conclusions

An overview of the study design and setting, procedure for recruitment, data analysis method and ethical considerations has been presented in this Chapter. The selected methods enabled the previously identified research questions to be answered. Chapters 6 and 7 describe findings from the qualitative study from the perspectives of older adults and support workers, responding to the identified research questions.

CHAPTER 6: FINDINGS 1

UNDERSTANDING SELF-HARM IN OLDER ADULTS

6.1 Introduction

Chapter 6 is the first of two chapters which present findings from the qualitative study from the perspectives of older adults and third sector support workers. This chapter explores motivations for self-harm in older adults. Findings from this chapter are presented in view of how participants gave meaning and constructed their perceived motivations for self-harm behaviour in older adults. I start by presenting the characteristics of included participants, giving the reader an overview of informants' backgrounds. Then, I describe the self-harm experience as perceived and lived by participants, adhering to a life-course perspective. Lastly, I present the different motivations as well as barriers for self-harm behaviour in older adults, as interpreted by participants according to their experiences. The involvement of the PPIE group and contribution to the findings is also presented throughout this chapter.

6.2 Characteristics of participants

Sixteen participants were involved in this study: nine older adults and seven support workers. Eight older adults were interviewed twice, resulting in 24 interviews. Despite criteria for support workers having been supporting anyone with previous self-harm, all support workers reflected on their experiences working with the age group of older adults. Data were initially analysed separately by participant group, then the two data-sets were compared and contrasted in order to gain a more in-depth and comprehensive understanding of the research area as described in Chapter 5. Table 6.1 summarises the main characteristics of participants, including personal history and psychosocial background. All older adults self-reported experiencing both physical and mental illness and over half of the support workers ($n=5$) disclosed having had personal experience with self-harm behaviour

Table 6.1 1 Characteristics of older adults

Pseudonym	Gender	Age	Start of self-harm	Health conditions ¹	Psychosocial context	Support
Hannah	F	62	Early teens	-Personality disorder -Fibromyalgia, diabetes, heart disease, scoliosis, arthritis	-Early start of mental illness, child sexual abuse experience -Limited social support from family, living alone, loneliness -Family history of mental illness -Experienced loss of children in adulthood -Limited mobility due to health	-Long history of hospital admissions -Limited family support -No longer attending group for self-harm -GP prescribes & reviews medication -Infrequent contact with CPN
Alice	F	72	Early childhood	-Depression, alcohol misuse -Irritable bowel syndrome, arthritis, pancreatitis	-Childhood sexual abuse and overall stressful upbringing -Interpersonal difficulties with family. Family history alcohol misuse -Early retirement due to mental disorders	-Regularly attends group for self-harm -Previous contact with secondary care -Now overseen by GP
Edith	F	60	Early teens	-Personality disorder -High blood pressure, hypothyroidism	-Multiple childhood stressors including sexual abuse, bullying, neglect, encounters with judiciary system -Family history of mental illness -Partner bereavement leading to loneliness -Full time factory worker	-Regularly attends group for self-harm -GP prescribes & reviews medication -Support received by CPN -Long history of contact with primary and secondary care
Leonard	M	67	40s	-Depression -High blood pressure, heart disease	-Childhood experience of shame caused by secrecy of adoption -Experienced multiple losses of family & friends -Health conditions disrupted life since early 40s leading to job loss -Previous experience in research as a participant	-Multiple experiences with counsellors, contact with primary and secondary care -Regularly attends group for self-harm -GP prescribes & reviews medication

¹ As reported by participants

Audrey	F	65	40s	-Personality disorder, eating disorder, post-traumatic stress disorder (PTSD) -Osteoporosis, high blood pressure	-Early childhood experiences of sexual abuse, violence and neglect -Family history of mental illness -Previous experience in research as a participant	-Recently joined third sector self-harm group -Support from primary & secondary care services -Receives family support
Barbara	F	62	60	-Depression -Fibromyalgia, sciatica, ankylosing spondylosis, arthritis	-Early childhood experience of loss with death of mother -Conflict with husband and problems with neighbours -Multiple bereavements -Health conditions affecting mobility and everyday life -Stated preference of only conducting one interview (no follow-up)	-Recently joined third sector self-harm group -Previously support from psychiatrist -GP prescribes & reviews medication -Receives family support
Edward	M	61	40s	-Pica, anxiety, PTSD -Dystonia, heart failure, diabetes, liver disease, ulcerative colitis	-Limited mobility due to health, affecting everyday life activities -Several negative experiences with healthcare facilities -Loss of family members -First time talking about his self-harm experiences	-Previously support by counsellors -Currently sees psychiatrist -Attends third sector group for dystonia -No support for self-harm
Laura	F	62	Early childhood	-Depression, eating disorder -Arthritis, walking disability	-Ongoing experience of violence and abuse -Escaped violent marriage, forcing her to relocate cities -Lived with self-harm for over 50 years -Identified as ethnic minority, stating difficulty to access support	-Received limited support for self-harm -Attends third sector self-harm group -Soon to start seeing a private counsellor
Fred	M	60	Early childhood	-Eating disorder, obsessive compulsive disorder, Personality Disorder -Anaemia	-Divorce of parents experienced in childhood -Self-identified as gay -Recently moved to England from the United States -Highly educated and with previous experience in research	-Talking therapy received for over a decade -Attends service user group and waiting list for a self-harm hospital programme -No family support

Table 6.1 2 Characteristics of support workers

Pseudonym	Gender	Age	Role ²	Personal background
Georgina	F	46	Volunteer lead at self-harm charity	<ul style="list-style-type: none"> -Previous self-harm history -Started the only self-harm group in [city in North West England] -Has only recently started the group and supported people who self-harm -Looking for funding for a third sector organisation for people who self-harm
Lucy	F	36	Support worker at self-harm third sector group	<ul style="list-style-type: none"> -No mention of self-harm or mental health history -Has worked with vulnerable populations (supporting abused women) -Majority of experience supporting people who self-harm through observation
Sally	F	52	Support worker at self-harm third sector group	<ul style="list-style-type: none"> -Previous self-harm history -Support worker for many years but only recently with people who self-harm -Looking to receive further training for supporting people who self-harm
Mary	F	49	Main facilitator at self-harm third sector group	<ul style="list-style-type: none"> -Traumatic experience in teens (rape) which led to self-harm -Received support from family and local third sector group for self-harm -Started support worker/facilitator role 11 years ago, while still in recovery -Has completely stopped self-harming for 8 years -Multiple experience with research as well as being a lay board member for local suicide prevention boards
Penny	F	40	Support worker at older adults third sector group	<ul style="list-style-type: none"> -No mention of self-harm or mental health history -Support offered to older adults focused on social services benefits -Has not received training on how to manage with people who self-harm -Has trouble relating and understanding self-harm in members
Mark	M	42	Support worker at older adults third sector group	<ul style="list-style-type: none"> -Previous counselling/psychology background -Previous experience in research with older adult's population and mental health
David	M	50	Main facilitator at self-harm third sector group	<ul style="list-style-type: none"> -Previous history of self-harm and suicidal attempts from early adolescence due to childhood sexual abuse -Only received support for his mental health when diagnosed with cancer -Started facilitating group after volunteering at service user led group -Participated in other research projects and actively involved in public speaking in mental health and self-harm awareness

² As identified by participants

6.3 The self-harm experience in later life

6.3.1 Lifelong stressors: a life-course perspective to self-harm

Self-harm, as described by participants followed a life-course perspective, where self-harm was reported as one of the expressing symptoms of overall accumulated lived stressors and experiences. Participants constructed their views of self-harm experiences according to a life-course perspective. As was described in Chapter 1, a life-course perspective considers the different social structures and impact these have on life trajectories. An individual's life is composed by the accumulated overall lived experiences and social structures which formed part of their lives from early childhood to later years. These lived experiences and social structures are composed by different events and factors, including mostly permanent ones such as ethnicity and gender, but also more malleable factors such as socio-economic status, health and social interactions. Participants described the stressors present during the different points of older adults' lives which to an extent contributed to their self-harm.

i. Impact of early life experiences in life trajectory

Participants described early life experiences as having an impact throughout the life-course of older adults. In particular, adverse childhood events were interpreted by participants to have an impact on older adults' health and overall wellbeing, accumulating in later years. The consequences from these adverse childhood events, often led participants feeling distress and engaging in self-harm to deal with such distress, according to participants accounts. One commonly described factor experienced in early life years which impacted health and wellbeing was socio-economic status, a well-known social determinant of health. Participants described the difficulty encountered when growing up with poverty:

I grew up quite abusively, an abusive environment. A lot of it was because the poverty, me mom suffered with mental health problems, me dad was a long-distance lorry driver not there very often and he passed away when he was 51 anyway which left me mom with us all you know. Edith, 60

In this account, the participant not only described the difficulties due to poverty whilst growing up, but as well how she felt how other social determinants had an impact on her. For instance, participants described what was interpreted as rupture in the family due to parents' divorce, which also resulted in participants experiencing a negative impact. For some, the effect of parents' divorce experienced during childhood years was attributed to the start of self-harm behaviour which then carried on:

I was 8 or 9. My parents divorced when I was 7 and we had moved and I remember going into the shed and trying to break either my arm or leg with hammers (.) my mom moved us up to a remote island off the coast of [east coast of the United States] so it was (.) you know very different environment and yeah I was probably angry or hurt (.) I I felt as if I had a cast on my arm or a broken leg I would have attention and (.) [Exhales] pity comes to mind but that's not the right word. Kind of like you know people would feel sorry for me.

Fred, 60

Social environments during childhood and teenage years were described and experienced by participants as having an impact on older adult's health, influencing their self-harm behaviour. Fred described starting his self-harm behaviour from early on to deal with the impact of his parents' divorce. Another added childhood stressor described by some participants was abuse, including physical, emotional and sexual. Some older adult participants described these abuse encounters, but the majority were still reluctant when reminiscing these particular events:

So, it wasn't just problems with my dad, it was problems with my grandad, some sexual abuse. And uh with my dad it was a lot of physical and emotional abuse. I don't know, there might be other things that went on as well, but I don't know, I find those hard to look at.

Audrey, 65

Support workers also described seeing and working with older adults who reported previous traumatic childhood experiences, the effect of which persisted decades later, resulting in participants' views of it impacting older adults' wellbeing and influencing their self-harm:

There's a majority of people who have suffered quite significant trauma. And there's a high number that have experienced childhood sexual abuse.

Lucy, support worker

Whilst support workers talked about their experience supporting older adults who self-harm, some also disclosed adverse childhood experiences which they felt had impacted their wellbeing and contributed to their self-harm behaviour. Despite not being within the age range of older adults, support workers' adverse childhood experiences highlight the impact of adverse childhood experiences in the life trajectory. This is the case with David, a support worker in his fifties with history of self-harm, who described how he felt the impact of early life events contributing to his self-harm behaviour:

I was being sexually abused by one of me dad's best mates and I actually tried to end me life, I cut me wrists. It was the feeling I got of all this load this pressure had been lifted off me shoulders and I used self-harm as a way of coping for 20 years.

David, support worker

Older adults and support workers reported abuse experiences from different sources, ranging from inside the household to exterior ones. The abuse experiences threatening older adults' wellbeing were interpreted by participants as having a significant impact on older adults that felt overwhelmed and could no longer deal with these adverse childhood events and leading to feelings of helplessness:

When I went to school I was having abuse in school with bullying and all that. Nobody wanted me around them. When I was at home I was having more or less the same things [...] I got me brother kicking at me all the time and what not. (.) when I went bed I felt like I was out of the way and it was fine but

even in bed it wasn't nice because it was just like that wet and everything and it stunk you know it was that rotten it got a whole in the mattress and the springs underneath were all rusty. I was always like my legs were always chapped and burnt, and you know wearing the same clothes go school as I come to bed in, and it was like uh there was no escape. Edith, 60

The overwhelming feelings of helplessness described by Edith was common in participants. Participants attributed these adverse childhood events as the reason why older adults started their self-harm behaviour, in response to dealing with these detrimental experiences.

It's just something I've always done, it's always been part of me life. I know there are older people now that have started later in life but mine has come through from childhood. [...] I mean I was abused as a child, so I just knew I was no good. And to add this personality disorder just made me more no good. Hannah, 62

Some older adult participants recalled evidence of early mental health problems present from childhood. Reported early mental health problems from a young age were experienced as childhood adverse events by participants, which once again were interpreted by participants as having an influence in self-harm in later life.

Well it was quite obvious as a child that I wasn't balanced, I had a lot of tantrums and my dad saw a psychiatrist and he'd take me to see the psychiatrist as well. I just know I was an awful child, I just knew I was horrible, and I had issues. Silly things that I can look back now and think oh yeah, I was a bit crazy. Audrey, 65

Some older adults stated growing up in an environment where mental illness was experienced by other family members, as was the case with Audrey. The experience of growing up with parents or close family members with mental illness was interpreted by

participants as also having influenced older adults' overall wellbeing and their self-harm behaviour, as often neglect and abuse were reported.

Overall, participants described different childhood events that were experienced as stressful and led to adverse effects not only during childhood years but throughout the life-course. These events varied from neglect, poverty, abuse, early psychiatric manifestations and family history of mental illness. The interrelationship between early experiences as well as future ones, shaped older adults' lives and many cases contributed to their self-harm according to participants' constructed accounts.

ii. Loss, bereavement and loneliness

Loss, as expressed in its different forms (e.g. end of relationships, disability or loss of function, loss of custody of children, loss of income), was experienced throughout the life-course of older adults. Some manifestations and reactions to loss may include self-harm. As was reported in Chapter 3, bereavement and loss often contributed to older people's self-harm behaviour. This was also experienced by older adult participants, where feelings of loss and bereavement were described as contributing to older adults' self-harm.

I went to see that counsellor during that time my dad died and that's when it all started really uhm I was fortunate I was seeing somebody at the time [...] she helped me through the feelings of my dad but it was like uh and that's when I started self-harming.

Audrey, 65

The only the only time I've taken an overdose of morphine and that's that was when me dad died in the July.

Leonard, 67

Leonard described the majority of his self-harm behaviour as self-injury (e.g. cutting). However, when experiencing bereavement, Leonard described more severe intentions with his self-harm using overdosing which lead to hospitalisation.

Loss in other forms of bereavement were also experienced by older adult participants. In the following extracts, loss due to the end of a marriage, or loss of custody of children were encountered:

My first marriage breaking down and then [husband] dying, it was more than I could handle. Alice, 72

I was that drugged up that I was so upset that I tried to kill myself so they took my children away. Then I lost my children and ended up in [local] hospital for people with personality disorders. [...] I had me children taken away through the medication and I had to fight all the way and all the time thinking am I going mad. Hannah, 62

The experiences of loss and bereavement throughout the life-course, were described as leaving many of the older adult participants in isolated positions, where they no longer had the support they would normally receive from friends and family. Often too, this isolation caused by bereavement and loss, was perceived as contributing to participants feelings of loneliness. As described in Chapter 3, loneliness was one of the main influential factors which contributed to self-harm in older adults. This was the case with the following participant that described the loss of her friends and family.

They have all died. They're all passed away yeah they have. I mean some of them that I went to school with, some of them they uh don't live around here no more you know they moved away but work friends uh when I had work friends, they've all passed away, all of them. Barbara, 62

The impact caused by bereavement not only had effect on the emotional wellbeing of participants, but also influenced other external factors such as finances, which were an added stress to many that were already dealing with the loss of a loved one. In the following account,

Edith described how the added financial stress was also a contributing stressful factor after the death of her partner:

I was with me partner Sam 16 years. He's been passed away 4 years. Since then I've found it harder to cope because I've had a big change like number 1 I adored him and he adored me. I found it really hard because it was like number 1 I was on me own. Number 2 I've only got uh I've gone from having 2 wages coming in, to 1 but you know, I found that struggle. Edith, 60

Support workers also reported older adults' response towards loss. In the following account, Penny described how she believed the bereavement experience led to self-harm in one of the older adults she supported:

You know I was obviously sorta probing quite a lot on how it was affecting him and when this particular gentleman (.) He had come home from work to find his mother dead on the floor on the home that we were in. So, it was obviously like a grief reaction. Uhm he told me during the interview he couldn't even attend his mother's funeral. So yeah, the loss of his mom yeah so that's how it come about. Penny, support worker

According to some support workers, loneliness and isolation caused by different forms of loss can contribute to self-harm in older adults. In the following account, Mark described how he viewed older adults being particularly vulnerable to social exclusion and isolation due to different life circumstances:

I think a lot of times, isolation and too much being alone can harvest sort of bad thoughts and feelings. I suppose isolation and depression go hand and hand. (...) They've maybe not got as many friends as they used to have. (.) Maybe because their friends have died or they're not around anymore. They might be the only one in the street who was born in such and such year, so

Margaret has moved because she has had to go to a care home and there's only me left who was here 20 years ago. Mark, support worker

Older adult participants reported experiencing loss, bereavement and loneliness in various instances throughout their lives. The way in which they dealt with and the severity of the impact of these loss experiences were different across participants. Nevertheless, most accounts described a common element where self-harm was described as being used to help alleviate, and deal with, the distress caused by loss.

iii. Interpersonal problems

Closely related to the previous stressor, interpersonal problems also shaped and influenced older adults' lives throughout the life-course. The social interactions we have with one another vary and can cause conflict and interpersonal problems. Participants' accounts described how they interpreted interpersonal problems experiences throughout the life-course often leading to self-harm behaviour in later life.

Family members, neighbours and other external individuals caused interpersonal conflict amongst older adult participants. In the following account, Alice described the abuse received from her former husband, being a threat to herself as well as other family members.

Well I married my third husband and he was suffering from mental health problems unbeknown to me, he could also be quite violent, I didn't know that. And when he was constantly challenging my son to fight him and god knows what else and then when he put his hand around my throat, I said that's it you know, just go. Alice, 72

Alice's account described abuse experienced during her mid-adulthood. However, interpersonal problems were also reported by Alice earlier in her life. Similarly, Laura shared the interpersonal problems she experienced from the start of her marriage that continued throughout her later life.

I was fleeing violence from a very violent husband and the police sent me to the hostel (.) He attempted to try and kill me a couple of times, so it was for my own safety really. During this time, I just self-harmed in any possible way I could because that's what I knew how to do best. Laura, 62

Laura described a position of vulnerability that she faced when running away from her husband's violence earlier in her life. The combination of the experience of interpersonal problems with her self-harm history seem to have exacerbated her self-harm, as she described engaging in this behaviour as a way of coping with the violence.

Sources of stress caused by interpersonal problems also originated from outside the household as described in the following account.

Harassment, that's what it was [...] he (neighbour) did things when he knew there was nobody else. He knew when me wife was working because we lived in the same road, so his house is there my house here, but his garden was a long garden, so it backed on to mine and he used to have digs and play music really loud. One way I'm gonna get you one way or another, it was a record. Leonard, 67

Prolonged interpersonal conflict both in and outside the household was described by participants as leaving older adults feeling disempowered and uncomfortable with their current living situation. In the following account, Barbara described this sentiment which were a result from conflicts within her marriage as well as problems and disputes with her external sources, her neighbours.

*I'd move tomorrow. I would move tomorrow, because I **hate** where I am, I feel as I'm being watched all the time.* Barbara, 62

Support workers also described experiences of working with older people who self-harm that had gone through interpersonal problems. In the following account, Mark described

how an older adult he had supported experienced domestic violence from her partner which he interpreted as leading her to self-destructive behaviour.

For instance, that lady had taken an overdose uh she disclosed to me that it was after she had been in a marriage of years of abuse and maybe domestic violence, emotional violence and her husband was a drinker as well. So, uh that's why you know she was uh she was depressed, anxious and very emotional.

Mark, support worker

Several older adult described experiences of interpersonal problems such as violent relationships and harassment, which resulted in them feeling threatened and vulnerable according to participants' accounts. These feelings contributed to older adults' self-harm thoughts and behaviour as a form of escape and coping method to deal with the interpersonal problems.

iv. Comorbid health problems

As identified in Chapter 3, comorbidities, either physical or mental health related, are closely related with older adults who self-harm. All older adult participants had at least one chronic health condition as summarised in Table 6.1. In participants' reports, comorbid health problems were experienced as exacerbating self-harm behaviour by impacting older adults' day to day life.

It has affected my self-harm. [...]. There's a lot of things I'd like to do but I can't, not now. I used to do a lot of knitting, no not anymore, bloody thumbs. It has affected my everyday life. Turning jars, opening them [mimics opening a jar], you know simple things. You gotta shout somebody if they're coming so they know and all that. And it's frustrating.

Barbara, 62

Barbara described how her chronic illness (fibromyalgia) has impacted her daily routine, impairing her functioning. The effects of having a debilitating health condition caused

frustration in the case of Barbara, who reported her self-harm also being affected and worsened due to these feelings.

Comorbid health problems could have been newly experienced situations occurring during later years in the life-course. Such is the case with Leonard, who described how his life was impacted and disrupted from the onset of his multiple medical conditions in his forties, which led him to lose his job and contributing role held within his family and society.

So back in back in 1991 in me 40th birthday, that's when I noticed that I started to lose the use of me fingers, hands and I was dropping lots of things. I haven't worked since then because things have led from that to depression and it seems like everything after that just went down bank [...] And because I was a workaholic, that's one reason me body give up because I was on the same job and in the job all the time, doing the different movements, lifting things and what have you [sighs] and as I say I did like 7 days of week so me body never had a rest and then they had uh bowling, so I had to give that up you know because I couldn't use me hands well. Leonard, 67

It was only after this experience of poor health that Leonard started to feel suicidal ideation and to self-harm, given the impact and disruption of his illness to his everyday life. The loss of his job and previous role in society caused by his health condition, is also very much related to one of the previous stressors, loss, given that Leonard experienced loss of function within his job, family and society.

Leonard: You know going back a long time from when I come out of work, it was straight away that it was hitting me and uhm as I said I was just wanting to uh well I did it many times that I just got in me car and gone off and take the pipe with me and I was gone for hours. That was uh there was no self-harm in such as in cutting or anything then, it was just going out.

Interviewer: Mmhm so what was the purpose behind this?

Leonard: Suicide uh yeah I couldn't do the things I wanted to do. Everything was a bit you know I couldn't use me arms from one day to the other.

There were different experiences and disruptions to the self, happening in later life which were described by participants as being caused by health problems. However also present were such experiences and disruptions to the self, caused by health problems present since childhood. Such is the case with Hannah, who described her diagnosed mental illness as something which unwarrantedly defined her.

Me mental health issues I've had since I was 15. I took my first overdose when I was 14 and it's gone on from then. I was told that I got a Borderline Personality Disorder and that's who I was. To me I had to fight not to go over that edge, that's how I felt. As if I was at the edge of a cliff and if I let people push me I'd end up off the cliff you know going into the abyss. That's exactly how I felt about me mental illness.

Hannah, 62

Hannah described how she had to deal with her mental illness from early on in life and the effects it had on her life. In addition to her mental health problems, Hannah also developed a physical health condition which impaired her daily living and functioning. The effects of her physical health condition left Hannah in an isolated position:

I can do anything I take my hand into but I never last because of my mental ill health. I used to be able to. Since 1985 I've had physical health problems that have just escalated until now that I'm practically housebound without an electric wheelchair.

Hannah, 62

Because of her comorbid physical health problems, Hannah experienced mobility restrictions, which as was mentioned previously may lead to increased isolation and feelings of loneliness. Hannah is an example highlighting how both physical and mental health problems can be intertwined and present in participants' lives, affecting their overall wellbeing and self-harm.

According to some support workers, mental health and self-harm were closely related and connected. In the following account, David described the relationship he saw between self-harm and mental health problems, both from a perspective of a support worker and someone with previous self-harm history.

Yeah cause mental health problems are a big one. You very rarely get someone who self-harms that doesn't have a mental health issue on the side. And sometimes it's getting that person to realise there's something wrong with their mental health.

David, support worker

Some older adults lived with debilitating physical health conditions that affected their functioning from a younger age. The experience of having comorbidities and an overall debilitating health condition throughout the life-course differed to other accounts of health conditions developed later on during the life-course. Such is the case of Edward, who was born with a physical health condition which affected his life from early on and continued to develop other physical and mental disorders during his life. He described how this experienced affected his self-harm.

This [points at head scar] this came on (..) Whenever I had the head operation and when I came back almost immediately, I started getting very strange sensations. An incredible sense of smell. It was amazing I used to walk outside and just sniff the air and I could smell all the different things that made up the environment but also it made me you know start biting my nails first and then when I was doing some gardening, I actually cut both arms in quite big rose thorns. And then one day they actually started to heal up I thought uhm I have been playing with them now for a year.

Edward, 61

Regardless of the long duration of his comorbidities, Edward only started to engage in self-harm behaviour later in life, unknowingly, as at first, he reports that he didn't know that what he was doing (scratching skin with thorns) was self-harm. In Edward's case, his self-harm

was quite different compared to other older adult participants because of his multiple medical conditions which led to invasive procedures that may have affected his self-harm. Edward described changes in his functioning and sensory nervous system caused by invasive medical procedures (e.g. peripheral denervation surgery) used to treat his diagnosis of the neurological disease of cervical dystonia.

Some older adults gave examples of how they engaged in different methods of self-harm to worsen their health (e.g. binge-eating sugary things whilst having a diagnosis of diabetes, not taking medication). The relationship between suicidal intent and the overall different functions of self-harm in older adults is further described in section 6.4.

Now with the anaemia, not to sound dramatic but you know, with the extreme low-level anaemia and the doctor calling and saying you could die [laughs]. But it's then the pressure of getting the blood transfusion to get the hb level up. But then in my head, if this is now part of the self-harm and the cutting is not only to experience you know the release and coping mechanism but is it also a point of uhm to bring my hb level down.

Fred, 60

Some older adult participants identified a mental health diagnosis (such as eating disorders) as a method of self-harm. Despite most self-harm definitions from leading health authorities excluding self-harm as a method of self-harm, several older adult participants identified their eating disorders as another avenue of engaging in self-harm behaviour.

I started comfort food eating when I was at that age as well which then evolved to an eating disorder uhm but just to clarify what is self-harm?
[Laughs]

Fred, 60

Coming to terms with ageing and the effects it has on the bodily physical appearance was something participants had to deal with as well as having debilitating health caused by comorbidities. This is the case with Edward that reflected back to the past where his health was better and assumes responsibility for the poorer health condition he is in currently.

I just feel bad cause I look at what's happened at what I used to be like and I used to be fit and healthy and be able to do all sorts of things but due to fault of me own I look in front of the mirror and I can't. I know I shouldn't really but when you compare when I compare myself to other people and what they do to themselves and their bodies, the abuse that they take, and they just manage ok. But (.) not really with me.

Edward, 61

Both physical and mental health problems were described as impacting older adults' lives and wellbeing. Whether it being mental or physical health related, the impact caused due to the medical conditions also extended to older adults' self-harm behaviour. Despite the tendency of mind and body dualism in medicine, older participants' accounts confirm that physical and mental disorders should not be appraised separately given the combined impact they may have on individuals. The treatment for the different health conditions and the experiences with support for these is further discussed in Chapter 7.

v. Self-harm experiences throughout the life-course

Different stressors have been part of older adults' lives throughout the different stages of the life-course. The stressors accumulated over the life-course which were experienced by participants as leading to self-harm in older adults are summarised in Figure 6.1. Figure 6.1 was created during the recollection and analysis process alongside participants and presented so they could contribute and add to the understanding of self-harm in older adults. Some older adults were surprised and even relieved to find out they were not the only ones experiencing multiple adverse events leading them to engage in self-harm.

Oh yeah it definitely does make sense, I can see like one thing leads to another from childhood to later on and yeah they all influence each other. So yeah for instance for me if I would've carried on to 65 working with no major health problems and no problems with me neighbours than maybe the self-harm would have never been there. [...] yeah but as I said this looks good it

makes sense to me at least and uh yeah, it's funny to learn I'm not the only one, a relief even. Leonard, 67

Figure 6.1 highlights the continuity and impact different accumulated stressors may have over the life-course. Regardless of the start of self-harm behaviour, self-harm in older adults was a result of different accumulated stressors as experienced by participants. In some occasions, participants reported the start of their self-harm from early childhood or teenage years, with this behaviour carrying on to later life due to the lack of appropriate support and care received as is presented in the following chapter. Like Hannah, Laura described how her self-harm started early on during her teenage years and persisted until her later years.

Through my whole adult life self-harm. I didn't know it was self-harm. I was just taking overdoses and when I was very distressed, I couldn't stop scratching. But uh like I say it was, it's just something I've always done, it's always been part of me life. I know there are older people now that have started later in life but mine has come through from childhood. Hannah, 62

I'm 62, I used to self-harm a lot when I was little and that was because I was sexually abused and not understanding what was going on and had to deal with it. Uhm but as I've got older I no longer cut as much as I used to obviously but I still self-harm and do so more in other ways either with food or drink but I don't drink anymore so now it's food. Laura, 62

However, other participants described experiencing stressors throughout the life-course and self-harm only manifesting itself later on in life due to the accumulating stressors and lack of alternative coping mechanisms as highlighted in Figure 6.1. As is further explored in section 6.4, the different functions and motivations self-harm had to the individual might have brought a later or earlier manifestation (e.g. coping mechanism).

I think it's just been things over the years. It's about 2 years ago I started self-harming.

Barbara, 62

Additionally, participants reflected on the effect the different stressors had over the course of their lives.

And to be honest I'm still very mangled at the moment because I've had no counselling with my dad dying, he died at 11 and mother died when I was in my 30's and I've had no counselling, nothing. Self-harm, violent husband, sexual abuse, bereavement, you name it, I've been through it. I had a violent brother, brother that beat us every day when my dad died, and I've had no counselling. All of that pain is inside of me waiting to come out. And I know with the new counselling it's gonna be hard when she starts and it's gonna be difficult because she's gonna have to go back you know 40-50 years of damage. And none of it has been handled, I think it's gonna be quite hard and it'll be tearing away the layers of pain, so it'll take time.

Laura, 62

Laura described how the different accumulated stressors affected her during her life. In Laura's case, she used self-harm to deal with the impact of these different stressors given that she did not receive any support for her self-harm previously and is only recently going to start accessing care and support.

It is worth highlighting how older adults identified their self-harm behaviour as the sole coping mechanism helping them deal with the negative events experienced throughout the life-course. In absence of an alternative coping mechanism, self-harm took the essential role of aiding older people manage and deal with their distress, even when self-identifying the potential negative impact to be caused because of their self-destructive behaviour. Despite identifying other coping mechanisms that could have been used without being detrimental to their wellbeing, older adults engaged in self-harm behaviour as a coping method as this was

the way they had learned to do so during the course of their lives. Section 6.4 further explores self-harm as a coping mechanism.

I use it to cope and also because I don't have other resources of coping. I guess there are probably other positive ways to cope like oh yeah go for bike ride [laughs] or you know the good ways to cope [...] it's something I learned to do from early on. I think definitely it has something to do about me starting self-harming as a child.

Fred, 60

Finally, participants reflected on the potential of learning from self-harm in later life and applying this to prevent or treat younger populations, given the long-standing presence of self-harm throughout the life-course. This confirmed how participants viewed self-harm as being present throughout the life-course due to the different experienced accumulated stressors.

You know cause I think that would also help them understand how the road for other generations [...] you know clearly cutting has been going on for ages uhm you know if a woman who is 60 you self-harmed when she was younger but then stopped you know where it was a phase, versus another woman or a man who is 60 and has been self-harming consistently uhm what could that benefit the treatment for younger people?

Fred, 60

An earlier draft of Figure 6.1, was presented to participants during the recruitment and analysis process, resulting in Figure 6.1 being developed with input of participants, alongside the PPIE group. When discussing findings related to stressors encountered throughout the life-course leading to self-harm, PPIE members confirmed Figure 6.1, stating all the stressors were identified in participants' transcripts. Figure 6.1 summarises the different accumulated life-course factors involved in self-harm in later-life. The combination of the different factors at varying stages of the life-course and permanence of them in later life, was experienced as resulting in older participants' self-harm behaviour regardless of the start of this behaviour. Section 6.4 further explores the motivations for self-harm participants gave to their behaviour.



Factors present at different stages in the
life-course

Figure 6. 1 Stressors throughout the life-course: self-harm in older adults

6.3.2 Secrecy, shame and stigma of self-harm in later life

Self-harm is a stigmatised behaviour as was mentioned in previous chapters. In the group of participants, self-harm stigma was reported as being high when presented in later life given that self-harm deviates from socially accepted norms in older adults. Georgina, a support worker, described in the following account a situation where an older adult felt shame due to their self-harm behaviour, particularly because of the age and life stage.

The older somebody gets, the harder it's to talk about it. Cause they think I shouldn't be doing this silly behaviour, everyone will think I'm just silly [...] some people think oh I'm too old to be taking on to start this behaviour that's like teenage behaviour.

Georgina, support worker

Feelings of shame in participants are described as felt stigma. The fear felt by older adults emerges from thinking society will have negative views towards their self-harm behaviour, particularly in later life. This fear often made older adults feel shame and self-stigmatise their condition. Leonard reinforced this view in his account where he stated the fear, he had of his self-harm being negatively viewed by others.

I felt embarrassed because of me age. [...] Like I say I'm thinking its girls that only should, 16, 17 year olds you know and they're self-harming and here is me you know, I should know better.

Leonard, 67

As Leonard's narrative presented, due to the feelings of felt stigma, older adults often felt ashamed and embarrassed of their behaviour. This was closely related to the perceptions participants had about how later life should be lived and the role of older adults in society, with self-harm being incongruent to how older adults should live. In the following account, David a support worker, shared his views about the societal and family role older adults often have.

It's the stigma around it, Isabela. When they're in their 60s and 70s there might be a bit of shame in telling people what they're doing (.) And for the grandma or granddad to turn around and see scars in your arms you know it's a stigmatising thing as well and surprising to them. Because you know if you have a problem you always go to grandma, granddad, they'll put it right and if they let that barrier down and they're harming themselves (.) it could affect relationships and everything [...] They're the role models aren't they. Who you look up to you know they're the strong ones, they're the ones that can face anything, get through anything, but they don't realise that everyone has got thoughts and feelings.

David, support worker

The social and family expectations older adults are often expected to fulfil can be part of the reason why shame and stigma are described as high in this age group. It is often unexpected to think people in later life would engage in such behaviour because of social

expectations. This may explain why self-harm many times is preferred to be kept hidden from family due to the potential negative impact on family. In the following account, Barbara described how she would have preferred for her self-harm to be kept a secret from family members.

I didn't tell them [family]. I think I would've preferred it to stay a secret. Because I see granddaughter, he'll [son] fetch her on a Tuesday from school, have tea and then takes her back for 9. And then she'll come on a Friday and then he takes her back Sunday. First thing she does is lifts me trousers up, she checks to see whether I have any new cuts. Yeah, she does. And she says Nan please, please stop.

Barbara, 62

As well as the societal and family role and expectations, ageing had an impact on self-harm in older adults. Georgina continued to reflect on the impact ageing may have in older adults' self-harm, highlighting the misconception that it does not occur outside teenage years.

Yeah, because a lot of people think that society think that it's a teenage girl thing and nobody else does it. And for some reason you outgrow it. You know you reach the age of 18 or something and it's gone magically you know. So, the fact that there is so many more people doing it that anybody is aware of and you know it's pretty much it's pretty certain that everybody knows somebody who self-harm. And that does apply to all ages, I mean some of the older ones even more so because they're more aware of consequences and all the shoulds and shouldn't and all that.

Georgina, support worker

On the other hand, there was some reflection from participants regarding the increasing awareness of mental health and more specifically self-harm in the media and overall society in the last decades. This increasing awareness was very different to how older adults had experienced talking or dealing with self-harm when they were younger.

A lot of things going on with the press at the moment about opening about your mental health with the princes talking about it and things like that, positive things like that coming out will probably help a lot more people being more open about their issues.

Penny, support worker

However, older adults manifested that they did not feel represented with the portrayals of the media regarding presence of self-harm given the exclusive focus on younger populations, in particular teenage girls. This misrepresentation further added to the shame and stigma felt by older adults regarding their self-harm, given that their voice was still not being acknowledged.

This day and age and yeah, it's in the media and yeah you see it in television shows, you see it in the movies, it's not representing my story, but am I supposed to connect to it? Would people ever think I would? does it make me feel more alone [...] regardless of male gay or straight, but it's kinda like this is this is a kid's thing.

Fred, 60

The explanation given by some older adults of why there was still a lack of representation in the media regarding older adults' self-harm behaviour was not that there was a lack of self-harm in later life, but rather it would deviate too much outside of the norm and it would be too difficult for society to accept.

The public can wrap their head around 14-16-year-old girls doing it. I don't know if they can about grandma or grandpa doing it yet.

Fred, 60

Society tends to see self-harm as a younger person's concern as participants point out. Nevertheless, the experience occurs in later life, whether it being that it has carried on from teenage years and maintained throughout the years, or that it has developed and manifested later in life. Regardless of the presence of self-harm in later life, stigma and shame may be accentuated in this life period as described above. Penny, a support worker in an older adult's

third sector organisation, described how she found it difficult for older adults to be open about their mental health problems, attributing it to shame and a generational change.

It's something [mental health] that isn't really that you open a conversation with. It's something that sorta comes to light through a more in-depth conversation. So, if someone has come to ask about a benefit you know usually if it's sorta through talking with them you find out that they do have some ill health, physical ill health problems, we sorta then start to talk about disability benefits. As you start to go into the ins and outs of the disability benefit with them, some of them then sorta have the confidence to tell you that they do have a problem with their mental health or they do self-harm but uh I do find that with a lot of older people that (.) uhm because of their generation, it's not something that they're willing to talk about, it's a shame tag for them really. They don't want to divulge they've got any issues in that way. (...) The older age groups they don't like to divulge and if they do you can see that they are quite ashamed of it you know I shouldn't really say you know there's people worse than me. But yeah, they will uh they will uh I think it obviously comes with if they're feeling comfortable with whoever they are with, whether or not they divulge.

Penny, support worker

Penny also described how some older adults tended to trivialise their self-harm behaviour and not identify it as a problem, comparing themselves to what they think others who self-harm are experiencing.

Other participants had mixed views about keeping their self-harm a secret and opening up to others. Mixed feelings surged from participants starting to accept and come to terms with their self-harm scars, enacted stigma and negative views from others. Once again, the family and societal role of being an older adult influenced the way older adults self-harm was perceived as is described by Audrey in the following account.

Well you know usually self-harm is thought to be a younger person's thing. I think I probably am more open about it now. I wanted people to realise you know (.) but uhm selective with who you want to let know. I think it's gone easier with the years. I mean don't get me wrong, in my mind I still think what are you doing you're a grown woman, a mother, a grandmother, you can't show this but yeah. It's gone easier as I've got the support and help because I've learned mental health shouldn't be pushed under the carpet. And I think most of the people are surprised because you see me, and you wouldn't take me as someone with mental health problems whereas with others you think they do. And a lot of time people don't realise you need help and support (.) and so I think I've been more open about it.

Audrey, 65

Although the participant group was a relatively small cohort of older people and support workers, there was some diversity). In the participant from an ethnic minority background ($n=1$), stigma was even more accentuated amongst family members and overall community. As Laura's account described, engaging in self-harm or any other behaviour deviant from the norm not only brought shame to the individual but also to the family.

They're just closed, the communities are closed. [...] uh the black communities are very stagnant they're very closed nit and they don't talk about things like that, they're closed, you don't discuss things like that. Like this whole conversation would not be happening in a black family or an Asian family. It's the decency, you've gotta keep decency. So, it's hard for them to get out because the family and the community don't want them out. [...] I had anorexia when I was about 11 or 12 and my mother handled it because she was a nurse, so my mother handled it and it wasn't discussed again because of the embarrassment of it. I mean I wasn't ashamed, but they were. I've never been ashamed of it.

Laura, 62

Laura described enacted stigma, with negative views coming from family and community members. This results in feelings of shame being brought to the individual who engages in self-harm behaviour. Secrecy and overall pernicious effects with regards to help-seeking behaviours are limited amongst ethnic minorities as is presented in the next chapter.

One participant self-identified as belonging to LGBT groups. In this participant, further stigma was described. Besides the commonly reported stigma from society of belonging to a LGBT group, older adults engaging in self-harm behaviour reported further stigma and discrimination due to their self-harm behaviour, as it was not accepted within LGBT groups. Fred reflects on this issue and how it isolated him from having any intimate relationship.

Just not feeling connected to the gay community because my body didn't look like theirs. And even when I lost weight, then people thought oh is he sick, does he have HIV. So, if you're gay and lost weight, people thought you were dying. And with the scars, within the gay community, an open cut is badly seen you know because of HIV you know it's negative. You know [laughs] gay people are afraid of blood because of it. Even if I stopped cutting, there is no way someone wouldn't notice, so I couldn't be intimate with someone without them going like ok there's some crazy there and do I wanna bring crazy into my life.

Fred, 60

Some participants suggested stigma and shame being caused by lack of understanding from others. The lack of education and misconceptions surrounding mental health and self-harm behaviour was often an explanation to why people may have negative attitudes towards individuals who self-harm. This is reported in the following account where Audrey and her husband Keith reflect on the matter.

Keith: yeah it has, and it's happened with really nice Christians. They just get fed up

Audrey: they don't understand mental health

Keith: they don't. It's a shame really. And that is one of the worse things that happens because they're expecting you to get better so it's your fault

Audrey: and blame is something I take up on myself all the time anyway, so it doesn't help when somebody else puts it on me. Oh, you haven't got enough faith or yeah [...] that's that feels a bit shameful as well. You feel that as a Christian you shouldn't have these issues. But you don't say the same about a diabetic, so you know.

In the previous account, Audrey reflected on the stigma mental disorders hold compared to physical health and how there is a general lack of understanding when it comes to mental health, particularly within religious communities. Overall, participants described self-harm as being a concealed and secretive behaviour due to both the felt and enacted stigma. Additionally, self-harm manifested in later life may have high levels of stigma and shame as described by participants. Often, this shame and stigma left older adults feeling isolated and vulnerable.

6.3.3 The self-harm cycle

Self-harm as experienced and narrated by participants was frequently described as being part of a cycle. This was reported in both participant groups that had either personally experienced it or had seen it occur with members. The overall process and experience of self-harm involving precursors and triggers which led to the self-harm act was described by several of the participants and summarised in Figure 6.2.

Yeah it makes you feel it's like going around in a train 'till you get to the point where you got self-harm. [...] so, you get to the point where you self-harm and then you're off the train for a bit, until somebody pushes you back on or something but there's always a trigger from your past that'll push you back on.

Hannah, 62

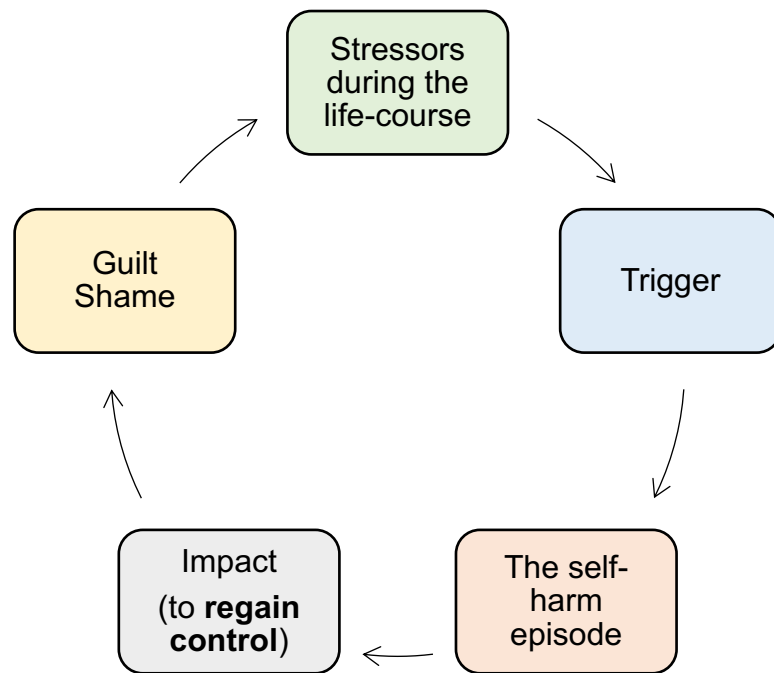


Figure 6. 2 Self-harm cycle

Triggers leading to self-harm varied according to the individual, but included the identified stressors mentioned in section 6.3.1. In some occasions, participants described the self-harm episode producing relief from the stressor or trigger which produced the desire to self-harm. However, shortly after engaging in the self-harm episode, the cycle continued and feelings described by participants were of guilt and shame, congruent with the previous theme of self-harm being a stigmatised behaviour.

Supporting someone to get over it, if they've just done it make sure they're alright and leave some of the guilt because guilt is one of the strongest emotions that kicks in afterwards that just feeds the cycle and then they start again. [...] we spotted it very quickly, and we're thinking how do they feel with all that guilt and shame. And then, they pretty much say actually it puts me back into the first position.

Georgina, support worker

As described by Georgina, guilt and shame may lead older people to feel bad about engaging in such behaviour and may trigger a new self-harm episode. However, Georgina also

described that the experience of these feelings of guilt which lead to repeated self-harm may be dealt with by accepting what has been done and moving forward.

But as soon as you put the guilt and the shame in this, it cancels them out. The person starts feeling really bad, and they will revert back to their uh whatever method they use to cope so they'll go back to position one and they'll start winding up ready for next time that they self-harm. So, if you start reducing this guilt by learning to accept what you did because you needed to do it and you did it.

Georgina, support worker

Georgina described how dealing with the feelings that came after the self-harm episode, older people can start accepting and even begin to break the cycle of self-harm. Other participants explained how they have started to break out of the self-harm cycle, relying on alternative coping mechanisms.

But instead of admitting I couldn't do it or deal with something, I would get admitted to hospital! Now I tend to avoid pressure by accepting my limitations, but becoming more isolated in the process. I also tend to turn to food and drink to cope, but at least that isn't causing anyone else a problem [...] I feel ashamed of some of my behaviour but pleased that I have found ways of dealing with it.

Audrey, 65

The impact felt by the self-harm episode was perceived as a form of regaining control by several participants. Given the different circumstances and accumulated stressors during the life-course, self-harm was described as helping regain control over older peoples' lives who engaged in such behaviour. The following accounts report how self-harm allowed participants to regain control:

It's doing something, taking an action. It's almost like taking control, I used to take out all my dressings and everything else before I self-harmed. It was sorta like it was something I could do, I could think about this. Audrey, 65

However, the line separating regaining control and self-harm behaviour becoming addictive was described to be very thin. Participants described how they would first engage in self-harm behaviour to deal with their sense of loss of control, but shortly this behaviour turned addictive and control was once again lost.

But you know she (mental health nurse) missed the point because it's like you don't have a choice. I can't fight it. Edward, 61

The biggest problem with self-harm is that it is very addictive, so the more it is used the more it takes over. And that's the irony of it all, that we do do it to regain control but then after a point self-harm takes our control away from us because it just kind of traps us in that cycle. Georgina, support worker

Both participant groups described self-harm as 'addictive', highlighting the addictive nature of the acquired behaviour used to regain control. Once the behaviour becomes 'addictive', participants described total loss of control over their behaviour. As a consequence, shame and guilt would accompany this feeling of loss of control and once again individuals find themselves in the self-harm cycle.

It has become addictive because like once you do it you just feel the shame like and that makes it all worse like it just reminds me of why I did it and all these intense feeling of Sam not being here come back. Edith, 60

The self-harm cycle initiated from the different stressors accumulated over the life-course as described in earlier sections. Triggers then induced participants to engage in self-harm, with feelings of guilt and shame coming after the self-harm episode produced some sort

of comfort and impact to the individual. To fully understand why participants self-harmed, further exploration in the matter is given in the next section of this chapter.

Discussions held with the PPIE group during the first two meetings helped conceptualise Figure 6.2 (Self-harm cycle). During these initial meetings, the group discussed how self-harm is often experienced in the context of repetition and cycle. Later on, during the recruitment and analysis process, participants' accounts also reflected the addictive and cyclic nature of self-harm in older adults. When Figure 6.2 was presented to the PPIE group, they confirmed that the Figure represented participants' accounts.

6.4 'Why I self-harm': motivations for self-harm

Participants identified different motivations behind self-harm behaviour in older adults. The identified stressors accumulated throughout the life-course placed older adults in a vulnerable position where they would engage in self-harm behaviour to deal with distress. However, more explicit reasons of why participants made use of self-harm are addressed in this section. Some of the identified motivations for self-harm were found by both participant groups while others were attributed by one group or the other. Motivations for self-harm are presented according to the perceived and lived experiences of participants.

Self-harm was presented within a spectrum of suicidal behaviour, with the far end of the spectrum representing a suicidal attempt and the opposite side showing no suicidal intent (Refer to Figure 6.3). Older adults' experiences with self-harm varied within the spectrum, with certain episodes holding no suicidal intent and others being classified as attempted suicides; these experiences varied across the years with self-harm holding different functions to older adults.

I don't think it's suicidal, it's a cry for help isn't it. It's a cry for help, I've never really uh well I only went out to try to kill myself twice and that was because I was in the abusive marriage but otherwise my self-harm hasn't been associated with suicide. It's just like a comfort, like a soothing blanket, even

when you're cutting, it's soothing, it soothes you, it gives you that comfort that you're not getting from other people. Laura, 62

As seen in the above account, older adults reflected and self-identified the difference of their self-harm, marking a distinction between behaviour with and without suicidal intent. This self-identification of the different functions of their self-harm reflects self-awareness of the purpose behind the behaviour.

The process of self-harm was explained by participants as following a certain order, congruent with the self-harm cycle presented in section 6.3.3. Self-harm was described as starting as a 'cry for help'. The reasons why older adults felt the need to reach out to others was that it was their way of managing distress and coping with the different motives which led them to feel distressed. The outcome of this self-harm behaviour often resulted in older adults feeling a sense of regaining control (as seen in Figure 6.2) and in some occasions produced gratification. This self-harm process experienced by older adults is further explained below, detailing the three different factors as shown in Figure 6.3.

i. Cry for help

The first overdose was because I was looking for some help [...] I knew when I was cutting, I knew how bad I felt, so I just wanted somebody to do something about it. And you just get fogged off, so you do something desperate. And so that's how I ended up in hospital. Audrey, 65

As described in section 6.3.1, older adults experienced a series of stressors over the life-course which in several occasions led them needing support and help for what they had encountered. For older adults, self-harm was used instrumentally, either consciously or unconsciously, in order to seek help and support. In an earlier account, Fred described how the experience of his parents' divorce led him to start self-harming in his childhood years through breaking his arm. Fred explained engaging in self-harm behaviour to 'gain attention' from others. Laura also described self-harm as a cry for help which produced her with comfort.

Like Laura and Fred, support worker Mary described how someone she once supported was also aware of the purpose of her self-harm and used this behaviour to avoid further damage including suicide.

She literally put herself in A&E every Friday night so they would keep her in during the weekend so she couldn't kill herself. So, she never took enough that would kill her, but she took enough that they'd keep her in. So, she'd worked out that was her way of surviving, when everyone else was thinking she was trying to kill herself, she was just like no I'm not, I wanted someone to help me. And eventually she did, she got the help. Mary, support worker

Other older adults were not as aware as the above described participants regarding the purpose and differentiation of their self-harming behaviour. Some older adults were just starting to accept their recently acquired self-harm behaviour and therefore were not clear of the function or purpose of their behaviour. As well, there was a difference in the way self-harm was perceived by support workers and older adults, with the latter classifying the behaviour as a 'cry for help'. On the other hand, despite many of them having personally experienced self-harm themselves, support workers used the more pejorative term of 'attention seeking'.

I do think that you have got a small proportion of people that self-harm to get attention. Sounds awful, but I've seen some of them. David, support worker

In contrast the term 'cry for help' was used by older adults to explain how desperate they felt and how self-harm was a behaviour used to seek help. However, some older adults were aware of how others viewed their self-harm pejoratively as described by Audrey:

I don't know what people think we're doing. Yeah ok we might be attention seeking, I don't know, maybe. Maybe as well there's something else. But if that's what people are doing and there's nothing for attention, no support, they're still gonna hurt themselves more and end up in hospital. And it's only

gonna cost the NHS more in the end. So why can't they just listen at the time and say what is it, what is it? And get an early intervention. Audrey, 65

Audrey accentuated the need for help and reflected on how there usually is a deeper-rooted issue which manifests in self-harm behaviour. Audrey also described how self-harm can be used instrumentally to get support or help from professionals (e.g. attention seeking). Like Audrey, Leonard identified his self-harm as a way of reaching out to others about a situation causing distress.

It's a cry for help, I did say that to you didn't I? (.) Cause I didn't think anyone was listening to me you know. Leonard, 67

As described in Figure 6.3, self-harm was also used as a coping mechanism or a way of managing distress by older adults who felt that way because of different stressors throughout the life-course identified in section 6.3.1.

ii. Coping mechanism

There were several reasons older adult participants described they felt the need to engage in self-harm in order to manage distress or find a way of coping. One of the most commonly reported reasons came from stressors accumulated throughout the life-course, particularly traumatic events they had experienced earlier during the life-course which had led them in a vulnerable position feeling the need to self-harm to manage with their distress.

That's why I started self-harming. The abuse and everything else. It was too much to handle. Hannah, 62

Self-harm is the result of something else so if someone has been abused as a child maybe long-term abuse throughout their life. There's a majority of people who have suffered quite significant trauma. And a high number that have experienced childhood sexual abuse. Lucy, support worker

As was described in section 6.3.1, adverse childhood events was experienced as leading older adults to self-harm from an early age to deal with the pain caused by previous experiences. But not all older adults started self-harming from a young age. Other participants used self-harm to deal with more recent events finding comfort using this behaviour.

I just went outside in me shed and just started (.) It's not much compared to what I used to do. But you can see I've done something [lifts sleeve up and shows arm with scars]. And this was because of the fight with me daughter, the stress and the nasty things she was saying after what I've done for her.

Leonard, 67

There were differences described amongst female and male older adults and the reasons why they self-harmed. Amongst older adult participants, only one female participant had not experienced or attributed her self-harm due to childhood sexual abuse, while the rest of female older adults regarded the experienced sexual abuse as the start of their self-harm behaviour. This was also reported by support workers, who in their experience of working with older adults, older women tended to have started their self-harm because of experienced sexual abuse.

I would say the highest percentage is females, sexual abuse. Males is normally either physical abuse. Most often by step-fathers or emotional abuse by mothers.

Mary, support worker

With this particular gentleman he had come home from work to find his mother dead on the floor on the home that we were in. So, it was obviously a grief reaction, the loss of his mom yeah, so that's how it come about, how his self-harm started. And with the chap that was cutting himself, his seemed to be sorta re-triggering through stress [...] And then there was another chap, he was schizophrenic, so you know that must've developed from that issue

but yeah there has usually been something within the younger years that has happened that has triggered their self-harm. Penny, support worker

Regardless of the source causing distress, older adults felt the need to escape undesired emotions caused by past events. Engaging in self-harm behaviour allowed older adults in this study to escape the undesired emotions.

There's a lot of people who want to figure out a way to deal with their feelings and uhm it's hard for them sometimes to even express what they're feeling, so I think maybe that's a lot of frustration that comes from that. You're not able to voice how you're feeling and uh they're very deep-rooted feelings.

Lucy, support worker

In some instances, self-harm was reportedly used by older adults to escape from a reality that was causing them to feel distress. This reality could have been something recently experienced or events accumulated throughout the life-course. Edith described how the different experienced stressors led her to a situation where she felt it was unbearable to carry on.

So, all them little things collected up and I just wanted die. I just thought there is no getting away from anything, so I just wanted to die. Edith, 60

And after 18 years of marriage I couldn't take anymore, I'd fallen out of love with him but all this time the drink was building up and building up and building up as well as my scratching. [...] I just couldn't cope. It was numbing, it had a numbing effect all-round, all the whole time I was drinking it was a numbing effect. I just didn't want to face up to things. Alice, 72

As Alice's description highlights, escaping from the undesired feelings and reality produced what was called a 'numbing' effect. 'Numbing pain' was another common term used

amongst older adults who engaged in self-harm behaviour. The action of self-harm allowed older adults to momentarily numb the pain felt by the different accumulated events experienced throughout the life-course.

I started self-harming because of the pain, not having anyone to talk to about it, I didn't know what was going on, this turmoil isn't it. Someone touching you and telling you to keep it quiet and you don't understand what's going on. You know it's wrong (.) so I was a very intelligent 6-year-old and knew it was wrong I didn't know how to deal with it.

Laura, 62

Overwhelming feelings of pain were described by participants who felt they had no alternative way of managing with the felt pain and emotions. Self-harm was the only way older adults felt they could deal with the pain. In the following account, Edith described how she could see the pain go away when she was engaging with self-harm behaviour, attributing pain to the blood that was exiting her body.

It was just like I said. It hurt inside that much you know. it was like (.) it was just too powerful [...] While I was laying on the bath, I just cut me stomach open and I'd just see the blood come out and it was like (.) [Exhales and brings arms down from head to stomach] like that you know. Like the hurt went away through there and yeah, I'd just go sleep.

Edith, 60

Self-harm gave older adults that escape from the undesired emotions as explained by participants. Participants described a release of the pain and undesired emotions through the self-harming behaviour. The felt pain and undesired emotions were alien and detrimental to their wellbeing and self-harm was the mechanism older adults managed their distress.

The reason you do it you know it's uh I feel from how I've felt is that when you self-harm when you cut yourself it's because you don't uh it's the pain you've got and it lets it, it brings it out of you instead of holding it in. I know

you're hurting yourself but it's letting the stress out in one way, you with me?

Leonard, 67

Like Leonard, other older adults described how they were conscious of the physical damage caused by their self-harm. However, the gain obtained was perceived as stronger as further explored in the next sub-section, given that it enabled older adults to cope and release the associated pain from earlier years. As well, older adults used different methods of self-harming to attribute different emotions as is reported by Audrey below.

At first it was like a punishment, cause I would whip myself as well like they used to do in the bible [laughs] so at first it was a punishment and then it became a way with dealing with feelings, just a way of getting them out, getting the badness out.

Audrey, 65

Furthermore, some participants explained their self-harm was used as a way of expressing the pain that was inside, letting it manifest physically. Gaining the physical aspect of viewing the results of their self-harm behaviour was described as allowing older adults to feel validated with regard to expressing painful feelings which were only felt internally. This seemed a way of older adults communicating with others and the outside world how they were feeling mentally.

It allows me to feel physically more equal to how I'm feeling mentally [...] It's about being able to physically see the pain, to physically see hurt and I think that's what without a doubt a very aligned theme with my reasoning of the self-harm, of to be able to go like ok that's broken.

Fred, 60

In some cases, self-harm was described as a coping mechanism to avoid suicidal behaviour. Whilst self-harm was mostly described by participants as a coping mechanism or cry for help, there were also descriptive accounts of self-harm with the purpose of ending one's life (e.g. attempted suicide). However, the relationship amongst suicidal and non-suicidal self-harm is complex and varying throughout the life-course as is highlighted in Figure 6.3, given

that self-harm's function is not always clear to participants when engaging in such behaviour. Some participants associated their self-harm as holding a positive function given that allowed them to deal with the felt distress and negative emotions, but at the same time left no space for further severer suicidal attempts. This differentiation between self-harm with and without suicidal intent was made by both participant groups that had either experienced or supported someone with self-harm behaviour. In the next section, participants described the outcome or gain that came as a result of engaging in self-harm.

iii. **Outcome: regain control versus gratification**

As described in section 6.3.3, in several occasions, self-harm was described as serving the purpose so that older adults could regain control. The sense of losing control of one's life and emotions came across after older adults had experienced adverse events during the life-course which led them to feel vulnerable and in many occasions powerless.

Really behind self-harm there's pretty much one reason uh behind most of it and that's all about getting control or regaining some sort of level of control basically, even if it is short lived. Usually for whatever reason, we feel that the situation or life in general is out of our control and that could just be an emotional state that is out of control a mental state that is out of control. And by making a decision to hurt ourselves we're just gonna put ourselves in the driving seat for a little bit.

Georgina, support worker

Participants described the positive outcome produced by their self-harm behaviour, regaining control, even if it was short-lived as described by Georgina. Congruent to Figure 6.2 (Self-harm cycle), participants gained a feeling of control over their lives. Some participants described they were aware their self-harming behaviour did not rationally make sense with regards to why it produced comfort, as they knew they were hurting themselves.

Nevertheless, older adults acknowledged how their self-harming behaviour, despite not being logical, helped them feel better even if it was just momentarily.

Yeah (.) Well I wasn't in control but yeah [...] logically it doesn't make sense but that's the fact that's what happens, I feel like it allows me to get back in control.

Edward, 61

Some support workers that had previously experienced self-harm personally, also described how this behaviour led them to feel control. Like Georgina, David explained how self-harm allowed him to have some control over his life through self-harm. Georgina then explained how from her point of view, self-harm experiences across the life-course are similar with regards to the purpose of regaining control.

I wasn't in control of any part of that life. I'd get drunk, I'd be sexually abused, I'd wake up, I'd feel dirty, I'd drink again, and I'd be coming home again and getting abuse. And at least when I was cutting meself I would choose where it happened, where it was on me body and when it happened. So that was a little bit of me life that I kind of controlled, the rest of it was just totally out of control.

David, support worker

It's very similar for that reason. For regaining control, it seems to go across them all from the youngest to the oldest.

Georgina, support worker

Despite the outcome produced of the self-harming behaviour of regaining control, as was presented in section 6.3.3, the sense of regaining control did not have long-lasting effects, resulting in the self-harm cycle continuation.

In a sub-set of participants, the gain produced from self-harming was not only to regain control but was also a result of sense of gratification. Older adults described how engaging in self-harm behaviour allowed feelings of pleasure from the act, either it being the physical act of self-harm or the psychological state it produced when self-harming.

It's also like an achievement you know successfully cutting or creating a scar or creating an incision, for myself it's powerful. And yes, you feel the pain but as kind of cliché as it is, it's kind of like opening a balloon. There's an element of accomplishment and success, gratification and reward. Fred, 60

It actually doesn't hurt. I remember somebody saying to me I don't care what you say it hurts. It doesn't, it doesn't hurt, I just get pleasure out of seeing me cut up and so yeah if it hurt I wouldn't have done it. Audrey, 65

For Fred and Audrey, the act of cutting was described as being pleasurable and not producing any discomfort as others would think. However other participants that described feeling gratification after their self-harm behaviour, stated the feeling being a mixture of pleasure and hurting. Below, Edward further explained how his skin picking made him feel the described sensations of pain and pleasure.

It was a funny feeling too (.) It hurt but it was satisfying at the same time (..) I also think it gives me nano seconds of pleasure when I do it (..) it's sorta like an exquisite pain. Edward, 61

Whether producing a sense of comfort because of regaining control, or leading to feelings of gratification, self-harm was experienced by participants as allowing older adults to gain these positive functions as a result of their behaviour.

Motivations for self-harm varied as described above in being expressed as a cry for help due to the accumulated life-stressors. Self-harm was also described as serving as a coping mechanism to deal with the effects produced by the life-stressors: numbing pain, avoiding suicidal behaviour, expressing intense emotions, dealing with trauma and/or escaping reality or undesired emotions. The result produced from self-harm as a way of managing distress was then regaining control and in some cases producing gratification to older adults. Once again, it is important to note how self-harm was used by older adults in certain occasions

to avoid suicidal behaviour and even deter them from more severe suicide attempts. Figure 6.3 accentuates how individuals can, throughout their life-span, vary within the suicidal spectrum with regards to having or not suicidal intent behind the self-harm behaviour.

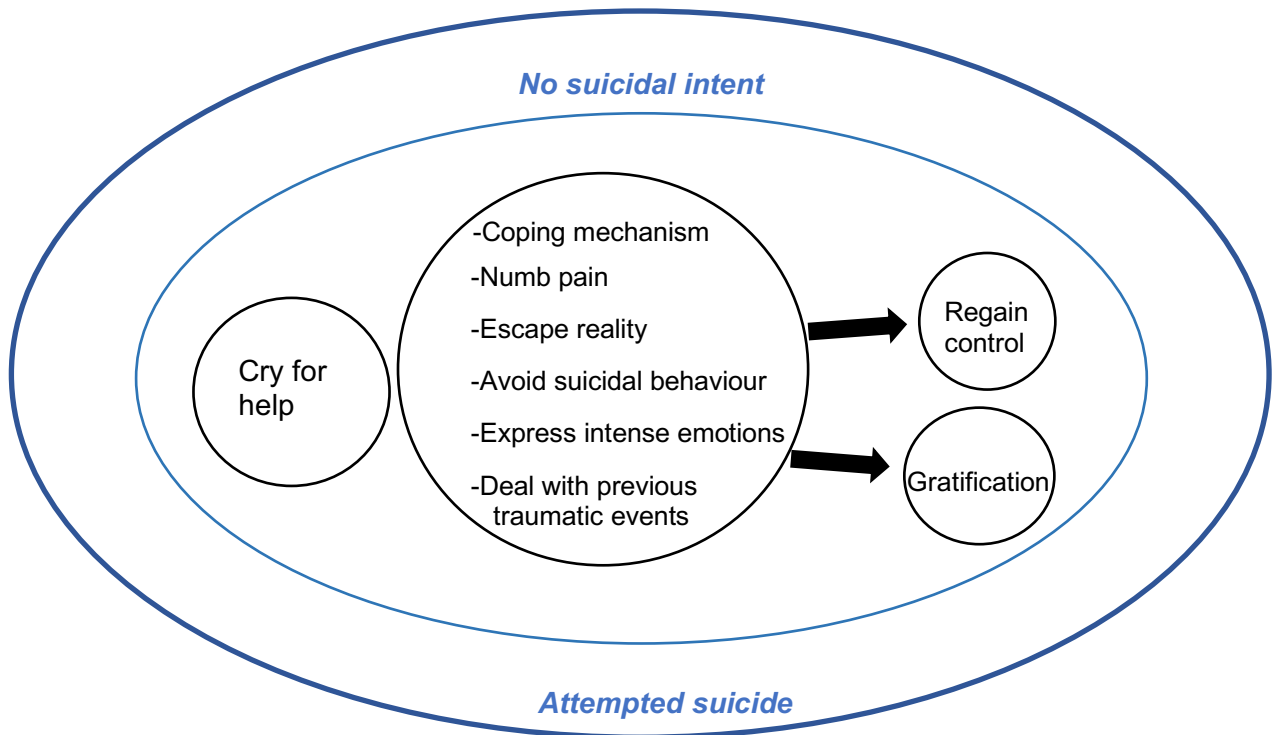


Figure 6.3 Motivations for self-harm in older adults within a suicidal spectrum

The different identified motivations of self-harm as presented by participants were discussed with PPIE members. Figure 6.3 (Motivations for self-harm) was presented to the group, which confirmed the importance of adding the suicidal spectrum to the representation of self-harm motivations in older adults and contributed to its development and elaboration.

6.5 Barriers to self-harm

Alongside the identification of motivations for self-harm in older adults, barriers to self-harm were also described by participants. Although the majority of older adult participants were still engaging in self-harm behaviour, they did reflect on some barriers to self-harm, which in certain occasions allowed them to stop self-harming, even if this was short-lived. For some

older adults, being in the company of others such as family and friends, allowed them to temporarily cease their self-harm behaviour. As well, because of the recurrence of self-harm behaviour throughout the life-course, some older adults reported being period-free of self-harm for several months and even years. The lack of adverse experiences during the period-free of self-harm was usually what older adult participants associated with the momentary stop of their self-harm behaviour.

Once I got here [laughs] and you know friends that were coming to town and I met up with them they'd say oh you look so good you look healthy you know and my joke was well it's hard to have an eating disorder or self-harm when you're happy. And I think a lot of that is very true. I then also think that just because you're happy today doesn't mean you'll [laughs] be happy forever.

Fred, 60

As previously explored, self-harm was many times attributed to different stressors experienced throughout the life-course. Given that the experience of self-harm and stressors varied throughout the life-course, there were periods where older adults could be self-harm free. But when faced with a trigger or stressor, often older adults engaged again in this self-destructive behaviour to cope.

And it does keep you from self-harming I mean I don't know everyone does it for different reasons, but part of my reason is that I get so frustrated that there's nobody listening to me. And other times I just wanna escape from myself. But when I have regular contact with the mental health nurse that helps me stop.

Audrey, 65

Positive support and treatment experiences often helped older adults stop their self-harm behaviour as experienced by participants. This is further explored in Chapter 7.

6.6 Patient and Public Involvement and Engagement (PPIE)

Chapter 5 described the involvement of PPIE within this PhD. Two of the meetings held with PPIE members were used to discuss the qualitative findings, review of transcripts, initial themes and initial development of the presented self-harm models. As has been presented throughout this chapter, the input of PPIE members and the discussions held, Figures 6.1, 6.2 and 6.3 were developed. Contribution of PPIE members to the analysis of the data ensured triangulation of the data analysis (Patton, 1999), as well as ensuring the inclusion of a patient and public perspective, ensuring more relevant interpretation of results to the population of older adults who self-harm. The PPIE group provided alternative interpretations and understanding of initially proposed themes and further explanation of the dataset throughout their contribution.

6.7 Conclusions

This chapter presented findings from the qualitative study, focusing on the experiences of older adults with self-harm regarding motivations and barriers to this behaviour. The experience of self-harm in later life was described by participants to be caused by different situations and stressors accumulated over the life-course. Particularly adverse childhood events, loss, interpersonal problems and comorbid health problems, were described as placing older adults in a vulnerable situation where they felt the need to self-harm. Shame and stigma were described by older adults who engaged in self-harm behaviour, which led them to keep their behaviour secret to others. The different motivations to self-harm are explored and explained according to participants' perspectives and experiences. Self-harm in older adults was presented as following a cycle which emerged from an adverse experienced event(s) during the life-course, followed by a trigger which led older adults to feel vulnerable and engage in self-harm behaviour to deal with the discomfort caused by these previous experiences. Self-harm then allowed older adults to feel they had regained control and in some cases gratification after engaging in such behaviour. However, guilt and shame often came after the event given the stigma associated with self-harm. The input and involvement of the PPIE group in the

analysis of the qualitative findings ensured the patient perspective was added to the interpretation of results, contributing to the understanding of self-harm in later life. Chapter 7 presents the findings regarding access to health and other informal services from older adults who self-harm.

CHAPTER 7: FINDINGS 2

ACCESSING CARE AND SUPPORT FOR SELF-HARM BEHAVIOUR IN OLDER ADULTS

7.1 Introduction

This chapter presents findings exploring experiences of self-harm in older adults, reporting the experiences of accessing care and support for older adults who self-harm. First, the factors leading to the decision to seek help for self-harm behaviour in later life are explored. Then I present the different avenues of support including, but not limited to, the health and third sector, followed by the barriers and facilitators to accessing care. Throughout this chapter, I describe how PPIE was involved in the analysis and interpretation of findings.

7.2 Help-seeking

i. The decision to seek help

Self-harm was often reported by participants as occurring throughout different stages of the life-course of older adults. Older adults mentioned decisions to seek help during different periods of their lives. However, what was commonly stated amongst both participant groups, was that a decision to seek help was not one that was reached easily or quickly. To the contrary, the decision to seek support occurred several months and sometimes years after engaging in self-harm.

Regardless of the start and experience with self-harm, all older participants reported seeking support for their self-harm. Part of the reason older adults came to a delayed decision of seeking help and maintained their behaviour disguised was the stigma and shame associated with self-harm.

Obviously it [self-harm older adults] happens but it's hidden. Fred, 60

Experiencing shame due to self-harm often deterred older adults from accessing care and support. This was recognised by both participant groups, mostly explained by the stigma associated with mental health problems and self-harm amongst older age groups.

It's just that you are ashamed of some of the things, so it's harder to talk about it and ask for help. Edith, 60

It's harder for older people to talk about their mental health (.) You can imagine more so with self-harm. Penny, support worker

However, all older adult participants reported reaching a point where they could no longer keep their self-harm hidden and had to disclose their behaviour to others to receive care and support. Participants described self-harm reaching a point where it was out of control and no longer serving as a coping mechanism. Once this point was reached, older adults made the decision to seek for help for their behaviour.

I think a lot of people only turn to help when it gets out of control so that I suppose eventually they just reach out for some help. Mary, support worker

It wasn't that I wanted help, I needed help, I couldn't deal with it any longer. Alice, 72

For those older participants who described self-harm starting in teenage years ($n=5$), limited support was described, due to either lack of appropriate support, or no support received because of absence of help-seeking. For the few that had received support in their early adolescence ($n=2$), it was often in the context of psychiatric support including medication. No further support through psychological therapies were described, however this may be due to changes to mental health support delivered by healthcare providers during the second half of the twentieth century. Section 7.3.1 further explores support received from health services.

I was in [psychiatric hospital] a couple of times because of the overdoses. Then I went to see a doctor, he was a psychiatrist when I was about 15, 16. So more or less since then on and off through me life I've been seen by someone and on medication. But never really discussed the self-harm.

Edith, 60

Older adults described these treatment experiences as superficial support given that self-harm or the issues leading to self-harm were never discussed. The limited support experiences during teenage years, suggests older adults might have been deterred from receiving further support for their self-harm. The remaining older participants ($n=3$) received no support during their teenage years given that their self-harm was kept hidden and no support was sought. It was only later on in life (mid-adulthood to later life years) that they sought and received support for their self-harm.

But rather than let people know what was happening to me, he [husband] wouldn't ask for help (.) And sometimes I wish he did.

Audrey, 65

On occasions, family members were described as keeping this behaviour hidden and no formal support was sought or received, as described by Audrey. Section 7.3.2 further discusses the role of family when supporting older adults with self-harm.

The PPIE group contributed to the interpretation of the analysis of this chapter, for example regarding the decisions older adults made when deciding to seek help for their self-harm behaviour. Members from the group reiterated how decisions to seek self-harm support could be often delayed and difficult as giving up on self-harm as a coping mechanism could be hard. They also confirmed the interpretation of findings regarding older adults' reaching a point where they needed to ask support, once self-harm stopped acting as a coping mechanism.

ii. Persistence

Accessing care and support for self-harm as described by participants was not experienced as straightforward. For many older adults, several attempts were made prior

receiving support for their self-harm. Furthermore, even further attempts for seeking help were made by older adults before receiving what was perceived to be *appropriate* support for their self-harm behaviour. It is worth noting that amongst the included older participants, several felt that still further support was needed to deal with their self-harm in a comprehensive way.

I was really frustrated by being given that support. It's not enough for me.

There is a programme at [mental health university hospital in south London] which is a self-harm specific service which I'm trying to get into. The GP wrote the letter but uhm because it's a different borough, I have to be approved before they can bring me in to assess me. So that's kinda what I'm hoping for now.

Fred, 60

Both external and internal factors influenced older adults' experience of repeated attempts to seek help before any support was found. Thus, some older adults found it difficult to ask for help given that they had lived with self-harm for several years and it was hard to share this 'shameful' secret with others.

For other older participants, it was difficult to receive support due to external factors. External factors such as lack of local services for dealing with self-harm in older adults was experienced by some such as Fred who described earlier how he is currently waiting for approval to attend a self-harm support service in a different borough.

Other external factors were strict referral criteria set in referral pathways for older people to access specialised treatment and support for self-harm. After living with self-harm for several years, Audrey's support experiences were limited to peer-support. However, because Audrey reported that she did not meet the criteria for receiving specialised treatment, she felt she had to engage in more severe forms of self-harm (e.g. overdose) which she had not previously done, in order to access support.

If I hadn't started with the overdoses, I would have never got access to support that I now have. Cause after we finished the personality disorder

group, I wanted to go onto DBT and when I mentioned it to the lady, she said 'no you won't fit the criteria, you're not ill enough'. So, then I got a lot worse after that. I don't know whether it was the first overdose that might have been the first overdose. But when I was in hospital, I got referred to CMHT and she referred me to DBT so I got in there which is a shame really. Why don't they listen to people when they're asking?

Audrey, 65

Regardless of internal or external factors, persistent attempts were experienced by older adults to obtain help for their self-harm. Section 7.4 further explores the barriers encountered by older adults when seeking support for self-harm.

I went to the doctors and said, I need help. And I sat in the waiting room crying my eyes out, I just couldn't do it anymore. And one of the doctors at the surgery called across to [mental health facility] and they said they'd call back. I sat there for an hour or more and they hadn't called back. In the end I walked myself over there and said I need help. I just cannot take anymore. And within a week I had an appointment to see the CPN and that helped tremendously.

Alice, 72

As described by Alice, once the decision to ask for help was made, older adults made persistent attempts prior to obtaining support. Having to make such efforts was time consuming and often led to delays in receiving adequate support.

iii. Self-management

Older adults stated learning to live alongside their self-harm throughout different periods of the life-course. Self-management of their self-harm with co-existing health conditions was described by older adults. Especially when waiting to receive care and support, older adults relied on self-management. Self-management of older adults' overall health and wellbeing existed when dealing with the physical and mental health effects of the existing health conditions as well as self-harm behaviour. However, alongside self-management, older

adults received care and support for their self-harm from the formal and informal sector as is below described.

7.3 Accessing care

Once the decision to access support for self-harm was made, there were different avenues older adults used to receive care. The different reported avenues are presented in two sections: formal sector (including health, social and third sector), informal sector (friends, family, faith and internet). Access to care through these avenues did not follow a straight or linear process as further explored. Instead, older adults accessed care from the different avenues depending on availability and accessibility of such avenues, varying within a spectrum of receiving support from both avenues, one of them, or none.

7.3.1 Formal sector

Findings from this study summarise access to care from three agencies of the formal sector: health sector, third sector and social sector.

i. Health sector

Participants reported older adults receiving support for their self-harm from the health sector, through the different levels of healthcare delivery: primary and secondary care. Use of tertiary care, highly specialised treatment services, was not described amongst participants. Linked to an existing health condition (e.g. mental or physical health diagnosis) or solely self-harm related, older adults accessed care for their self-harm from the health sector. Participants' accounts made reference to accessing healthcare through the NHS. Only one participant, Laura, reported needing to access the private healthcare sector to receive counselling, given that the support she had received over the years with the NHS had been in her experience inappropriate and superficial. Further encounters of this experience are described in section 7.4.

Next, I present the different support older adults described receiving in each of the departments that make up the health sector: primary and secondary care. However, prior to

that, it is worth noting that participants' experience across the health sector varied within the different departments.

a) *Primary care*

Acting as gatekeepers to more specialised treatment, primary care clinicians were the first point of contact and offered healthcare provision to older adults. Older participants frequently reported making contact with GPs, seeking support for their different health comorbidities.

They'll [older adults] mention the physical health to the GP but won't always mention their self-harm or mental health. Penny, support worker

However, not all older adults visiting primary care disclosed their self-harm. This was corroborated with Penny's quote. Such reluctance was linked to the shame and stigma associated with self-harm.

Older adult participants' frequent contact with GPs often meant they would receive medication not only for mental and/or physical health conditions, but also support for their self-harm. GPs were not only gatekeepers to secondary care, but also offered support and management to older adults with self-harm. However, the treatment offered, as described by older adults, was mostly pharmacological and further provision of psychological or talking therapies was not common practice given the lack of availability of specialist care services.

Well I got the medication from my GP and it was a case of seeing him once a week to see how it was affecting me. [...] Now I get a review every 6 months. Alice, 72

Nevertheless, in some cases, participants reported GPs offering regular support and care, as mentioned by Alice. Being a frequent point of contact, GPs were able to offer regular care for physical and/or mental disorders, alongside overviewing and monitoring self-harm. Other participants' accounts corroborate the positive support experiences received by GPs when seeking support for self-harm.

I have to say my GP has been fantastic, she's been very good. Very caring, she listens. Which is you know some of them. But she's been fantastic. She's given me all the literature for [local self-harm support group] and everything. The last time when I went right off again, that's when she says we need to change your medication, you've been on them too long. She's very thorough, very thorough. I couldn't have asked for anything better. Barbara, 62

Furthermore, participants reported how GPs made initial assessments and referred older adults to more specialised treatment from secondary care.

While I was there, the only support that I had was from my GP, I didn't have a mental health worker. The mental health worker came after when I started the overdosing. I was referred to a psychiatrist after having an assessment uh my GP sent me to the assessment, and I was referred to the psychiatrist.

Audrey, 65

However, not all participants experienced positive support from GPs when seeking self-harm support. Some participants felt that many GPs and doctors more generally dealt with older adults' self-harm through pharmacological treatment, which was, in their view, superficial.

There are lots of doctors out there that just want to pill pop [snaps fingers]; 'here, have a pill, have a pill'. That just masks it. You're just skimming over it; you're not talking to them. There're things in people's heads that a pill doesn't take. You know some doctors don't understand mental health, don't understand self-harm. And there is people out there that take overdoses and they're not given the correct support. Mary, support worker

Both participant groups reported support from GPs to be limited. This made older adults seek support for self-harm elsewhere.

He [older adult] was looking for some support because the GP basically didn't know what to do as is the case with many health professionals.

David, support worker

I: So you've not discussed it [self-harm] much with your GP?

Edward: Yeah 'cause they [GPs] lack the expertise.

Additionally, not all older adults felt they could talk about their self-harm with GPs despite the opportunity provided by frequent contact. Time constraints were experienced as precluding GP support in older adults with self-harm.

Edward: I do see me GP frequently but it's mainly for other things like blood tests and these sorts of things.

I: is there any reason why you don't talk about it with your GP?

Edward: well I've got so many other things that need to be checked and there just wouldn't be the time for it.

In Edward's case, it is not clear whether his preconceptions towards GP consultations have precluded him from speaking about his self-harm. Alongside time constraints, some older participants reported that GPs lack interest in mental health, including self-harm. As Laura described, her experience with GPs was predominantly focused on treating her physical wounds and overall physical health, making a distinction between physical and mental health. As described by participants, the perspective taken by GPs treating older adults reflected a mind-body dualism approach.

He [GP] just kept on looking at his watch and as soon as I stepped out, I thought I don't want that doctor again because all he was interested was his watch. He was interested in my physical ability. He was interested in

mending me physically but not mentally. And I've found that with a lot of the doctors you try and tell them you need help mentally but all they see, and care is your physical abilities.

Laura, 62

Participants described an over-reliance on pharmacological treatment when receiving support for self-harm by GPs.

Regardless of the perceived limited support, GPs held a fundamental role to older adults' wellbeing. By being the first point of contact, GPs were able to refer older adults to more specialised treatment or support. Furthermore, GPs offered frequent contact, monitoring, management and regular support. Partial findings from this chapter, specifically addressing the role of primary care supporting older adults who self-harm, can be found in Troya et al., 2019b.

b) Secondary care

Secondary care was offered to older adults referred by GPs following the need of more specialised treatment and identification of available services and referral pathways. Although self-harm is not a diagnosed mental illness, all older adult participants had at least one mental health diagnosis as seen in Table 6.1 Not all older adult had been assessed by a secondary care mental health specialist because some were still waiting to be referred or assigned to a secondary care professional at the time of the interviews.

Unlike primary care where all older adult participants accessed support for their self-harm from predominantly one healthcare professional group (GPs), within secondary care, older adults received support from different healthcare professionals including ED nurses and doctors, psychiatrists, community psychiatric nurses (CPN), psychologists, social workers, occupational therapists and other mental health nurses. Accounts of experiences with the different healthcare professionals varied, with some participants reporting positive treatment experiences, while others the contrary.

The counselling that I was having really helped. I had an appointment to see the CPN and that helped tremendously because I just shoved everything out into her.

Alice, 72

For Alice, being in contact with a CPN gave her the opportunity to further discuss and explore her mental health problems and stressors leading to self-harm. Positive support experiences within secondary care showed that healthcare professionals were giving space for further discussion of the complexities of self-harm. However, not all participants experienced positive treatment and support received from secondary care. For those encountering negative experiences with secondary care professionals, this was mostly due to stated limited support given that participants viewed services as being in high-demand with not enough time or support provided.

Other participants described secondary healthcare professionals not taking self-harm seriously given that it was not a mental health diagnosis but rather a behaviour. Therefore, participants' accounts described that their perception of secondary healthcare professionals was one of being interested in the illness or diagnoses rather than the underlying behaviour, emphasising the biomedical model which is reinforced amongst medical professionals. This was deemed as superficial care by participants and was not sufficient to help older adults manage their self-harm.

Older adult participants described secondary care also offering pharmacological treatment alongside monitoring of medication and re-assessment, as some participants experienced with primary care professionals.

I went to [mental health hospital] and I got some help that I needed. And then at the end of the 6 months I was re-assessed having been put on antidepressants.

Alice, 72

Older adults accessed support from secondary care in two settings: hospital-based settings (e.g. ED) or within Community Mental Health Teams (CMHT) offering support within

the community (e.g. GP surgeries or health centres). The services accessed within these settings varied as participants' accounts report.

Depending on the setting, participants reported different treatment experiences with secondary care. When accessing care from mental health hospitals as Alice described, older adults described being seen by psychiatrists and/or other mental health professionals to oversee their medication and were given support for mental health problems and self-harm. However, in other secondary care settings such as ED, treatment and support received for self-harm was more urgent and focused on treating the wounds or effects of self-harm (e.g. stitching cuts), rather than overseeing older adults' overall wellbeing and health. This left older adults feeling that the support received from ED was superficial and not enough to help them deal in long-term with their self-harm.

They will completely ignore it but, at the same time, not really want to deal with the root of the problem. But what needs dealing is the root of the problem because if you don't deal with the root of the problem then you just put your sticky plasters on the behaviour. You try to stop the behaviour and quite often when they try to do that, the person still hasn't got a better way to cope and the problem is still there so they will obviously still keep behaving in that way.

Georgina, support worker

I'd cut and if I'd cut too deep I'd go to hospital (..) but then you couldn't go to the hospital and ask to have a one to one with somebody, or them to help you because it's just not possible (.) We did suggest that they have a room in the hospital, like mental health room where someone can sit and drink coffee and talk to people, you know instead of you wondering around and losing it.

Hannah, 62

Both accounts report how support received from ED was perceived to offer superficial treatment. Participants noted the opportunity of ED being a setting where after attending injuries and effects of self-harm, referrals and assessments could be set in place as recommended by existing self-harm guidelines, however in reality this seldom happens.

However, some participants also recognised that service delivery of healthcare, particularly within ED settings, was strained as well as stressful for healthcare staff, therefore it is difficult to deliver adequate support. Mary, a support worker with previous self-harm history, reflected on the arduous task and role held by healthcare professionals working in ED given that she has previously worked within such settings. Section 7.4.1 further discusses barriers when accessing care such as structural barriers (e.g. lack of resources/staff) and attitudes of healthcare professionals, as reflected in Mary's account.

I've worked for A&E meself and I know that it's crazy. I suppose you might get one nurse who's just done a double shift or whatever and she's not got a lot of sympathy for that person. And she should have, but [exhales] I suppose when they're turning up every Friday night (.) same thing, I don't know. I see it from both sides really.

Mary, support worker

Furthermore, some participants described support experiences which consisted of more than pharmacological and/or emergency support. Secondary care settings such as CMHT allowed for the provision of talking therapies as described by participants. Although not specifically focused on reducing self-harm, these talking therapies for varying mental illnesses provided support and contributed to older adults' general wellbeing. Also experienced by older adults, were more holistic support experiences, supporting not only individuals' mental health diagnosis, but also taking into consideration the environment and other influencing factors important to older adults' wellbeing. This type of support is described by Audrey who accessed such support.

I went to [occupational therapy group] it's an occupational therapist who leads it and it's about occupation, it's about what you do with your time. It's group work but also get 1 to 1 and they take you out. I went out with an occupational therapist and went cycling because that's what I chose to do and that was really good.

Audrey, 65

However not all older adults had access to such healthcare professionals given that the provision of these services varied from locality, as further explored in section 7.4. Community nurses and mental health nurses were another group of secondary care professionals supporting older adult participants, again with variation in provision. However, those older adults that did state receiving support from community or mental health nurses, reported overall positive support experiences given that it allowed them to receive continuity of care as well as monitoring of their self-harm.

Having the mental health nurse, is just one of the best things, it's brilliant. Because she sees an awful lot of people and, from what I understand, the whole point of them is to see people that need to spend more time than the GP can. And then send them off to sign post them to people that can help. But if that doesn't help, she's still there so you can still ring her and go and see her again. While before, if it didn't help, there was nobody and you'd just go back to your GP and he'd throw some more leaflets at you and say try these. While I think having someone there with you that you can contact, I know for a lot of people it is just a short-term thing, but it is helpful and needed. I think I've been seeing her for about 3 years, and it gives me that continuity.

Audrey, 65

Audrey reflected on how these secondary care healthcare professionals provided support. Secondary care professionals also referred older adults to other self-harm services such as third sector services.

Furthermore, some participants described long-standing contact and engagement with secondary care given that, as described in earlier chapters, start of self-harm occurred in younger ages for several older adults. However, the contact and support for self-harm was not always periodical and there were several years and periods where older adults did not receive any support for their self-harm.

I think when I was about 16 I uhm took a couple of overdoses. I ended up in [mental health hospital] at a young age. It was quite whatsit, because I was so young and all to be in there, so it's quite frightening in a way. Because it's like most of the people in where I was in the wards, were a lot older, they were older people like my age now or just younger than me and middle aged.

Edith, 60

Given the different settings and healthcare professionals offering care to older adults, optimal communication amongst these sectors was needed to provide integrated care. However, participants' accounts reported good communication was not common which resulted in older adults receiving non-integrated care for their self-harm and other health conditions. This lack of communication amongst healthcare professionals then resulted in fragmented support for older adults' self-harm.

As has been presented throughout, support offered by secondary care and the health sector in general was not perceived as being sufficient to support older adults with self-harm behaviour. Either because of lack of staff, time, or adequate training, accounts of healthcare professionals referring older adults to third sector organisations were increasingly reported amongst participants to help support older adults with self-harm.

Some people have been referred by [local mental health hospital], you know the access team, or the emergency duty team. Sally, support worker

ii. Third sector

Alongside accessing care from the health sector, older adults often sought support for their self-harm from the third sector. Service provision from the third sector included: i) mental health charities supporting individuals with mental health problems (including self-harm) and ii) older adults' charities. For the latter, older adults' charities were not specifically focused on supporting mental health difficulties or self-harm but were rather spaces for overall support and socialising amongst older people.

All older adult participants stated accessing the third sector after being referred by healthcare professionals or having found these support groups as an alternative to help cope with their self-harm behaviour. Similarly, support workers reported how most people accessing support from the third sector had been referred by healthcare professionals.

GPs have rung me in the past so they could refer their patients to our group.

David, support worker

Often healthcare professionals, from both primary and secondary care, recognised their services were restricted due to limited resources, therefore would refer patients to the third sector to help them support older adults with self-harm behaviour.

Support from the third sector was provided by support workers as well as peers. Within third sector services focusing on supporting people with mental health problems and/or self-harm, support workers reported having training and experience in dealing with mental health problems. However, many support worker participants recognised formal training was limited and felt they could benefit from further training to support older adults.

I asked to go on training last year, but my manager said there was nothing that I needed to learn, I already knew it. It's only just to give you the guidance. You learn it as you go along. I mean I would love to get more into counselling training, but I've only been doing it a few years and it is expensive, but I mean

there is training out there. But the best training I've had is to be sitting in with them and learning. Sally, support worker

Due to the limited financial resources amongst third sector groups, further training for support workers was not provided as described by Sally. However, as Sally and other support workers from self-harm support groups described, despite the limited formal training, lived experiences, empathy and overall experience compensated such training as this allowed them to have a deeper understanding of self-harm which they saw as an advantage when supporting older people with self-harm.

Because it is survivor led so they're getting an inside view of things. We talk about stuff that most trainers wouldn't touch. Georgina, support worker

Positive treatment experiences with support workers with lived experiences was reiterated by older participants. Older adults reported feeling more open and understood when speaking with such support workers.

[Support worker] is brilliant cause you can contact him anytime and he's always there. You can talk to him, he understands. All members say that but it's real support if you need it. I only met the group via [service users' organisation] otherwise you're on your own. I've had to cope with it [self-harm] for nearly 40 years. You're on your own, there's nothing out there. Absolutely nothing out there. Laura, 62

Furthermore, Laura reiterated the essential role the third sector has with service provision for older people who self-harm, given that in her experience, the third sector was the only avenue where she received appropriate support. However, not having the enough support and training to run these support groups often left support workers vulnerable. As Audrey explained, she encountered discontinuation of self-harm support groups given that people running the groups did not have enough training and support to deal with the responsibility of a support group. In particular, those with lived experiences of self-harm.

Well there aren't many specific support groups for self-harm. I went to one and the guy who led it became ill, so it couldn't continue. And the other one the same thing happened. Because they're run by your peers, they are peer run and the nature of self-harm is that, as much as you think you're ok and then you take something like running a group and the pressure gets too much.

Audrey, 65

For the two support worker participants from older age support groups, previous training or experience supporting older people with mental health problems or self-harm was not reported as being a prerequisite for the role. However, both described their frequent contact with older adults experiencing mental health difficulties, including self-harm.

We do get quite a lot of them disclosing mental health difficulties and self-harm, we do. And it's usually it's something that isn't really that you open a conversation with it. It's something that sorta comes to light through a more in-depth conversation.

Penny, support worker

One of these support workers had an educational background in counselling which he felt had gave him an advantage and allowed him to further support older adults disclosing self-harm and mental health difficulties.

Fortunately for me I did a counselling course before, so I was a little bit more savvy I suppose to the difficulties and the opening up and disclosing and offloading [...] You do come across people who might not realise that they are struggling with mental health and possible abuse of themselves.

Mark, support worker

Mark reflected on the benefits of his previous training which allowed him to further engage with older adults disclosing mental health difficulties and/or self-harm. Shame and stigma associated with self-harm was further accentuated amongst older age groups. Particularly amongst older adults that had not yet accessed care or support for their self-harm

or mental health problems and were only attending older age support groups, it was even harder to disclose self-harm. Mark's previous mental health training was seen as essential, as it allowed him to further support older adults with self-harm behaviour.

However, not all support workers had an educational background or had received training which allowed them to adequately support older adults with self-harm behaviour. In such cases, difficulties were often reported when supporting older adults.

I remember quite vividly doing a home visit with a gentleman who told me about his PTSD and because of it he found he needed to cut himself. He sat on his sofa with a large knife and frequently picked it up and said I just have to have to do it, it just helps me. I found that quite difficult to deal with. I was with him on my own I felt (.) quite vulnerable myself and because of the nature of his mental health, you know, his surroundings weren't very tidy, it was very cluttered. I was sorta looking for easy access out of the property, I was quite scared. It was quite intimidating and scary, but I continued to do the form with the gentleman, but I did find it very very difficult [starts tearing up] I then came back to work, and I obviously told that to my manager at the time. To be frank, there wasn't much support. Penny, support worker

Penny describes here how difficult it was to encounter such situations given that she did not have the skills needed to offer support. Penny's story also highlights the vulnerability support workers can encounter when not having the needed knowledge and skills to adequately support and manage these older adults. Section 7.4.1 further addresses barriers to accessing care, including absence of training and support as experienced by Penny.

Support workers reported that amongst older adult support groups, there were no expertise or resources to fully support older adults with self-harm. In the instances where support workers were presented with older adults with self-harm behaviour, a referral was

made either to the health sector or other third sector groups specialising in supporting people with self-harm and/or mental health problems.

We do ask if they've got any support in place. If they haven't, we do have places to refer them to, we do have contacts with [national third sector groups for mental health] or NHS mental health services (.) so we do refer them to these agencies. Penny, support worker

Despite the existing stigma and initial reluctance to speak about self-harm, older adults accessing support from third sector groups aimed for people with mental health difficulties and/or self-harm, experienced these services as more acceptable. This was due to knowing that others in the group had similar experiences. For some participants, having this commonality allowed them to feel supported not only from support workers but also peers. As is further explored in section 7.3.2, support received from peers was deemed essential.

The only reason I went to [self-harm support group] was because I saw an announcement on the wall, but then I found they had other things going on like the art group. Initially I would go every day. It gave me what is called a social life. I was around other people like me. Like yesterday I went to the art group, I missed Wednesday, and I found I really missed that. Alice, 72

The third sector offered support to broader populations of people engaging in self-harm as compared to the health sector. Participants' accounts reported varying types of people with different self-harm experiences accessing self-harm support groups. As Mary described, within support groups she often encountered older people engaging in self-harm which was mostly concealed to others and only shared within that space.

Don't know what your statistics are on why people self-harm, but uh at the group we tend to get more people who haven't presented at A&E so they're like more like your self-harm in secret people. Mary, support worker

However, obtaining funding to run these support groups was reported to be a challenge to maintain service provision for older people with self-harm behaviour.

I do have [local self-harm support group], but I'm lucky, I'm one of the lucky ones. I could go, phone them up, say I need to talk to somebody. But if we didn't have [local self-harm support group] then I don't know what we'd do.

Hannah, 62

Despite all older participants attending third sector groups and most reporting positive support experiences, specifically those support groups focused for people who self-harm, in a sub-set of participants ($n=2$), these support groups were not found to be suitable.

I went to the [self-harm support] group but it was a bit too heavy for me. [...] some of the questions in that particular time it was too much for me. [...] I like it on a Thursday because it's just nice to have a chit chat and you know do a bit of art.

Barbara, 62

Depending on where in the stage of help-seeking older adults were, support from the third sector was deemed more or less appropriate. As mentioned in section 7.2, all older participants had made the decision to seek help, however not all of them were as comfortable talking and exploring their self-harm further in-depth. For instance, Barbara reflected how she preferred having a social space as opposed to addressing in-depth self-harm behaviour as was done in some of the support groups. Leonard reiterated the same point where he experienced attending support groups for the social aspect rather than addressing his self-harm. However, for Leonard, shame and stigma associated with self-harm played a big role in his reluctance to talk about his self-harm with others.

I've never really spoken to anybody about it [self-harm]. I come here [social space for people who self-harm provided by local self-harm support group] but I don't know uh I think with some of the people you can see they do it

and they've got marks but uhm I don't. I've never ever asked anybody because as I said I'm embarrassed.

Leonard, 67

Third sector groups were used by all older participants and seemed to provide a vital role in supporting older adults, closing the service provision gap identified in the healthcare sector. However, due to limited financial resources which resulted in lack of training and adequate support for support workers, vulnerability was present. Despite having an essential role in service provision for older adults, the third sector encountered limitations.

iii. Social sector

Traditionally, supporting self-harm has taken a medicalised perspective as reported by participants. However, self-harm was influenced by several health, social and overall broader multidimensional factors. Therefore, the need of taking a multidimensional and holistic approach to supporting older people with self-harm behaviour was recognised by participants. In particular, given the different social determinants influencing self-harm, participants reported the importance of receiving support from the social sector. Some participants stated older adults receiving support from social services which contributed to their overall wellbeing. In particular, support worker participants working in third sector organisations for older adults identified the need of older adults receiving a multi-sector approach to self-harm, including support from the social sector.

I did pass her also on to social services to, uhm, give her more support because I felt like she needed it. It was uhm (.) not enough with the support she was getting from doctors. It was said to me that she was happy for me to refer her to the social services to try and help with her situation that she was in.

Mark, support worker

Mark reflected on his experience supporting an older adult who he perceived to be in need of multi-sector support, including support from the social sector. In his role as a support worker in a third sector older adults' organisation, Mark reported that he would assist older

adults to receive comprehensive and holistic support for not only health conditions but also any other social conditions which may affect their wellbeing.

Well so when we are completing the forms, they disclose if they've got any mental health issues. But also, I am able to get their notes from the GP surgery so I do say to them, tell me as much as you can, tell me about the conditions that you have, how they affect you with your day to day tasks. And anything that you've forgotten, we'll go through the notes and you know edit after to make sure we're getting you the best chance to get it or give the people that will go around and see you a good clear insight of where you are in this current time.

Mark, support worker

As a result of this support, Mark suggested that older adults were provided with support from the social sector (e.g. housing assistance and other benefits) which was deemed as essential to contribute to older adults' wellbeing. For instance, for Leonard, support from the social sector was reported to be essential to his wellbeing given that he had experienced a range of health conditions in his mid-adulthood years which forced him into early retirement. Support from the social sector allowed Leonard to continue living his life without having to worry about financial concerns. Other older adult participants also reported receiving support from the social sector, mostly due to their health conditions, but which offloaded some of older adults' worries.

It [social services] allowed me and my family to live because I was on the sick money then, that was incapacity what it's called now.

Leonard, 67

However, not all older adults accessed this type of broader support offered by the social sector according to participants' accounts. Depending on the situation and need of older adults, the social sector was able to offer older adults financial, housing and/or any other social aid. For those older adults which situation reflected the need of support from the social sector, this type of support proved essential to the contribution of their wellbeing.

7.3.2 Informal sector

All older participants accessed support from the informal sector alongside receiving support from the formal sector. Participants mentioned several sources of support that belonged to the informal sector, including friends, family, peers and the Internet.

i. Family and friends

Older adult participants often lived and held close relationships with family members and friends. Despite this, not all older adults felt comfortable disclosing their self-harm to family and/or friends, with some older adults reporting feeling judged by family members and/or friends when disclosing their self-harm.

Everybody knew, but it's made it worse cause even in your family you get stigma. 'Oh she's nuts'. When you have a family argument, 'she's nuts, take notice of her' and that's it. My family never understood. They didn't understand what caused it, cause I never said it until after my mom and dad died. They didn't understand how borderline personality worked, because I couldn't tell 'em. And with that stigma there is a bit of fear as well, cause like I told you, I wanted to go to me daughter-in-law's hen party and she said to me daughter, 'I don't wanna take her in case she has one of her dos', so that's a fear from them. Their fear of what might or may happen, so they keep their distance.

Hannah, 62

As Hannah explained, some family members were reluctant to having close relationships with older adults engaging in self-harm. In majority, older adults that did not feel support from family members and friends reported feeling judged and misunderstood given the previously presented associated stigma associated with self-harm.

Mentally I don't think they [family] understood what was going with me.

Alice, 72

Other older participants reported not wanting to worry their close family members and friends, resulting in not disclosing their self-harm to them. As Edith explains, alongside the shame associated with the self-harm, she felt there was no point in worrying her family members given that she would still engage in self-harm.

Number 1, I'm ashamed of it when it's happened, but number 2, it's like (..) I don't think people understand it. I don't think it does anybody else good to know. I don't think it does to my children because they've got their own lives you know. And it's like if I did it and they knew, I know I'd upset them, but I don't think it would stop me from doing it. Like I know they don't like me doing it and I try not to do it, but when I have, it doesn't do them any good to know and it's like it would just worry 'em. Cause like when [son] found out he didn't wanna leave me at home on me own. And I was thinking he just can't say that, he's got his wife and kids.

Edith, 60

Furthermore, some older participants also expressed how difficult it was for them to share their self-harm with closed ones because of going against social expectations. In some cases, the result of sharing self-harm with family and friends led to this group feeling distressed and not knowing how to adequately support older adults. Such was the case with Leonard, who reported his wife feeling distressed.

Well I'm letting everybody down, I'm letting me family down aren't I? It's frightening. It's nothing nice. Because I don't think me wife's well. She tries her best but it's hard for her too. She's got uhm she's got dry skin, like eczema a bit but uh she's peeling and scraping her skin off and that's self-harming but she never really talks about it. I think it's due to all the pressure of helping me. At first, she never let any of the family know.

Leonard, 67

Leonard's account highlights how close family members and friends can be vulnerable when presented with older adults' self-harm. However, not all older adults had the support of

family or friends. Some older adults had no close friends or family members and therefore experienced being isolated and without social connections.

Well I really haven't got many [friends]. I've lost them all moving out of the area you know, I don't go out much you know. Laura, 62

These feelings of isolation and lack of social connections were often detrimental to older adults given that it increased the feelings of loneliness and not having anyone to share their concerns with. Other older adults described despite having close family members, these were not supportive and therefore had to hide their self-harm. Self-harm associated stigma amongst older ethnic minorities was further accentuated. Laura had no support from her family when engaging in self-harm throughout her life-course and reported family members keeping her mental health problems and self-harm hidden due to the shame brought.

Because of the embarrassment of it I wasn't allowed to seek help. [...] oh my family are horrible, they're evil. My brothers don't speak to me cause I won't go to bible study or won't go back to my husband. I've had no support from my family at all. I've just carried on, it's just been me and my boyfriend and that's it. I've only had him, I've had no family support. Only had my twin and she died. She was my carer my light, she did everything for me, she was everything and she died. So, I've got nothing, no one. Laura, 62

Furthermore, as presented earlier, some family members deterred older adults from receiving care for their self-harm. Such was the case with Hannah, who had an early history of self-harm, with several hospital presentations in her teenage years because of self-harm.

My parents kept on saying there was nothing wrong with me and they signed me out into their care. Hannah, 62

Similar accounts were reported by other older participants that held their self-harm secret to others outside the close family circle. However, this concealment often resulted in older adults feeling regret as they would have benefited from receiving support earlier on.

He never let anyone else know. Rather than let people know what was happening to me, he wouldn't ask for help (.) and sometimes I wish he did.

Audrey, 65

However, the close encounter with family and friends also led to some older adults receiving support from this group when regarding self-harm behaviour. Several participants reported family and friends as providing important support for older adults with self-harm behaviour given the proximity of these relationships.

My wife knows and well nobody, uh, I don't have any relationship with my family actually. So, I don't have anyone to talk to other than her which is not fair on her really, (..) cause this is the first time that I've actually expressed anything purely about this subject. I wouldn't tell anybody other than [wife's name] about this.

Edward, 61

Due to the intimacy and proximity of close relationships, older adult participants often reported disclosing their self-harm to family members or friends prior to seeking formal support (e.g. health sector). Support worker participants recognised the important role held by family members and friends when it came to older adults' recovery process. As David mentioned, when supporting older adults, he recognises the value of involving family members and friends as this can help towards older adults' recovery and overall support.

I do offer if anybody has got a partner that doesn't understand why the partner is acting like that, I invite the partner to come along as well and involve them all as one unit. And then they'll know, if the person has the need to self-harm, they know how to react, you know what I mean? Whoever you live with can get an understanding as well.

David support worker

For some older adults, close relationships held with family and friends could even deter further engagement in self-harm. As Barbara describes, the close relationship held with some of her family members stopped Barbara in engaging in suicidal behaviour.

I just didn't wanna be here (.) I just didn't wanna be here and I would, I would've finished it definitely. But (..) it's the kids int it [tearing up], grandkids, I'm very close to my granddaughter. She checks me legs all the time she comes. I just couldn't do it to them.

Barbara, 62

Support worker participants recognised the importance of social connections and the potential role these had when supporting older adults with self-harm behaviour. Given the initial reluctance to ask for help from healthcare professionals, support workers recognised the potential role of close family members or friends and often recommended older adults disclosing their problems to them as an initial step to asking for help.

Well the first time I say if anybody has got any problems or anxiety or you know you say go and see your GP. If some of them say yeah, I don't want to then I would say if uh they talk about self-harm or taking their life the most obvious one would be the Samaritans you know get in touch with them, speak with them. Friends and family, they're a big part of anybody who's going through mental health problems and self-harm. Sometimes friends and family might not be the best people to go over and talk to. They might want somebody that is not familiar with them.

Mark, support worker

Moreover, older adult participants reflected on the importance of intimate relationships with family members and friends, in particular spouses. For Leonard, being in company of his wife encouraged him to attend third sector groups for people who self-harm, alongside giving him the familiar company.

Coming here [social space run by third sector group for people who self-harm], this is help here. Because you know [wife's name] wasn't a member

of this which they knew but she's been coming with me. That's one of the things as well, I don't like uh well my wife too, we don't like going places on our own, we like each other's company.

Leonard, 67

ii. Peers

Participants identified peer support as being an important source of informal support. The term 'peer' was described by participants as a person that shared similar lived experiences, in this case self-harm. Often, peer support was described in the context of third sector groups, therefore being peers that attended the same group. The shared lived experience with peers was reported by participants as being a facilitator when engaging with someone in a conversation.

Yeah because they have gone through the same thing. And I've talked to them about the things I've gone through and [friend] has opened up which is nice because she usually doesn't. I don't judge her, she doesn't judge me, you know. And she's just a little bit older than my own daughter, so they're my adoptive daughters [laughs]. We're going on holiday in May, Monday to Friday and then again in September.

Alice, 72

Those support workers with previous self-harm history self-identified as peers with other people attending self-harm support groups. Both participant groups identified support workers' lived experiences as an advantage in offering support given the empathy and common understanding and experience with self-harm.

I just think, what would have made me well in them times I was self-harming? And I'm just telling you, it's somebody that hasn't read a book thinking they know it all, but someone that has actually got the scars to show it and someone that's open as well. [...] Because if you speak to a healthcare professional, there is always that barrier that they're judging you, you know, that they're the professional, you're below them, you do what they say.

Whereas, if you've got average Joe such as meself, somebody with self-harm, you want to speak to somebody that has experienced what you have and come to terms with it and then that person can see the light in the end of the tunnel.

David, support worker

As David explained, being able to provide that empathetic support gained from having lived experience, further allowed him to support other people engaging in self-harm. Furthermore, for some older participants, relationships with peers evolved into deepened friendship relationships. Stepping outside the remit of supporting solely self-harm, some older participants described these newly formed friendships with peers not only supported them to positively manage their self-harm, but also contributed to their overall wellbeing.

It's a socialising group as well which is necessary. I've got some new friends I'm going on holiday with [friends' names] in May. It really is nice because I've not had that growing up, I didn't have anybody.

Alice, 72

Informal peer support complemented formal avenues of support, giving older adults the opportunity to discuss their concerns with others besides support workers and healthcare professionals.

iii. Internet use

Internet use for supporting older adults with self-harm behaviour was explored amongst participants.

We've got the Facebook page and we've got something like 2,800 members there that get support for their self-harm from there.

Mary, support worker

There were mixed views regarding Internet use appropriateness when supporting older adults engaging in self-harm. Firstly, not all participants saw the internet as being accessible for older adults despite the worldwide increasing use.

A lot of older people haven't got the access to the Internet or they haven't got any computer skills or haven't got a computer. There are libraries, the council has got facilities and things like that, but older people haven't got the confidence. There's quite high proportion of illiteracy in older adults in the area so we've got that issue as well. Penny, support worker

Some older adults also expressed how the Internet was not an appropriate avenue for support for their self-harm given that it was perceived to offer 'superficial support'. 'Superficial support' was described in the context of lack of human contact to support older adults and overall lack of professional support. Participants also identified the Internet as a possible avenue for supporting self-harm.

I don't use it for that. Because some of them are encouraging people to do it so no I wouldn't. And then anyway I'd rather see someone and talk to someone in a group. I'm a very visual person, I'm an artist. No, that wouldn't do me, that wouldn't satisfy me, it wouldn't nourish me. And I talk, I'm proactive, I like to talk to people so no that wouldn't to me at all. Laura, 62

Furthermore, participants reported that when making use of the Internet, it was not seen as a trustworthy source to provide support or information on self-harm. However, when being used by older adult participants, the Internet was mostly being used as a platform of maintaining communication with others through social media.

To be honest I haven't used anything like that [online self-harm support groups] no. But I haven't looked either to be fair. But I do use Facebook on me phone, just not for groups like that. I mean I do share things that people have put about mental health or self-harm awareness and all that. But I haven't further than that. I'm not very good with computers. Edith, 60

Support worker participants commented on how the Internet is an increasingly used platform to support people with self-harm through social media platforms of self-harm support.

Some support workers highlighted this online platform was mostly being used by younger people given the generational change in older adults where Internet use was not common practice. However, some participants reported how for some older adults, this online platform was utilised.

We put on the group page once when they'd done a big thing on the news about self-harm being a teenage thing. I put just as a matter of interest, would people be willing to leave their ages, just so we can get an idea like who we've got on the page and stuff and one woman put well I'm certainly not in the teenage trend, I'm 76.

Mary, support worker

Participants identified older adults as having preference towards face-to-face support, especially with regards to sensitive subjects such as self-harm. Not being a generation that had been brought up with access to the Internet was a particular barrier and reason why participants reported older adults feeling uncomfortable when using the internet.

With it being an open environment, it's not like they're in their home and can discuss it sorta privately. And older people like their face to face, a lot of older people do like the face to face contact you know.

Penny, support worker

However, other participants expressed the advantage of anonymity when accessing the Internet for self-harm support. This was found particularly beneficial to those older adults who were experiencing feelings of shame due to their self-harm.

It's (online groups) completely anonymous and that's helpful. Fred, 60

Participants described the Internet as a form of enabling older adults to further engage in self-harm rather than deter such behaviour. Increasing information regarding different self-harm methods was reported amongst participants as being available on the Internet.

With some of the social media groups is specially the ones run by younger people, tend to be quite a lot pro self-harm. And they will compare a lot and unfortunately, they learn from each other. Georgina, support worker

Sometimes I just put on things like, uhm, help for mental health and all kinds of things come up. It's not safe actually, I shouldn't use it. Uhm, a friend of mine told me she was feeling really bad one day and she went on the Internet one day to look how she could slit her wrists and it takes you to all type of suicide forums uhm so and I think to look at that, when you're desperate, isn't great. And I have put, sometimes when I'm feeling down, I put on search and then nothing comes about and that feels worse. Audrey, 65

Participants recognised the importance of being careful with Internet use given the risk of not only learning new self-harm methods, but also triggering self-harm. Furthermore, the need for monitoring this online platform was recognised by participants given that many times the Internet can be used as an avenue for asking help and support, which is not always received.

It [Internet] is a very tricky one cause it could trigger people and you could get someone that you know what would happen if somebody online says I'm gonna commit suicide so that puts the pressure on the person's page. So, it has to be monitored very well, but there are pages where you can see they self-harm together. That's very frightening. So social media can be good but then not because it can pressure people into harming themselves more than intended to even if they didn't. David, support worker

Overall, the Internet was reported by participants as being a potential platform for older adults accessing informal support with regard to their self-harm. Despite several limitations

being identified for adhering to Internet use amongst older populations, there were reports of older adults making use of this platform to obtain another form of support.

iv. Faith and spirituality

Faith and spirituality were experienced by some participants to support older adults with self-harm. Expressed by participants in broader terms as opposed to following or being part of one single religion, faith and spirituality encompassed diverse belief systems.

Regular attendance and socialising with other members from the same spiritual belief proved to be a support system for some older adult participants. As a result of this, some participants reported having strong support systems from people of the same spiritual belief, where a guidance was provided.

I see a friend regularly to talk about it, she's a vicar, sort of like a Christian mentor I suppose, I see her once a month.

Audrey, 65

Furthermore, believing in a higher power seemed to give some older adults comfort when it came to dealing with their self-harm behaviour and broader concerns.

Religion helps me a lot. I believe in angels I do. God as well. [...] Yeah, I'm a big believer in angels and that helps me a lot.

Barbara 62

However, older participants also reported negative aspects related to faith and spirituality. For those that were part of wider religious community groups, there was reluctance to disclose self-harm and broader mental health problems, given the fear of stigma and lack of understanding from those groups.

Faith is important to me and that feels a bit shameful. You feel that as a Christian you shouldn't have these issues, but you don't say the same about a diabetic. But yeah, I don't think everyone at church understands it. So, there is still that lack of understanding.

Audrey, 65

Audrey drew on the stigma associated with mental disorders and how this exists within religious settings. Similarly, other older adult participants reported negative experiences with faith and spirituality.

With my family I got along really well until I stopped being a Jehovah's Witness and they all just stopped talking to me. They are horrible. [...] I hate religion, absolutely hate it because of my family but no I'm not religious at all.

Laura, 62

Overall, faith and spirituality served as a support system for some older adult participants when it came to dealing with their self-harm. Self-management also played an important role when older adults utilised faith and spirituality for supporting their self-harm. However, not all older adults reported positive supporting experiences with faith and spirituality, with some stating negative effects, including stigma.

7.3.3 Multi-sector approach to self-harm management

Older adults made use of more than one of the reported avenues when dealing with their self-harm given that the need of support from different agencies. A multi-sector approach was emphasised by participants.

Contact their support external support and maybe have a meeting. A meeting involving the customer to see exactly what's going on because sometimes you can have a better understanding because you know multi-agency meetings is different. And when that person sees that you are all working together to help them, they might not be able to say it to their CPN and they might not always get on with them (.) but there has been times when I've been involved in multi-agency meetings and we're all fighting for the good of that person to keep them well. Because the last thing we want is somebody to be, uh, have a hospital admission.

Sally, support worker

Moreover, older adults accessed the different sources of support depending on the need and availability of the services, resulting in none linear pathways to accessing care. Third sector workers shared their views on the importance of having several agencies, or a multi-sector approach when supporting older adults with self-harm behaviour. Through a multi-sector approach, collaboration and support from different agencies, including the health, social and third sector, can offer support to individuals who self-harm. Working across sectors may help individuals avoid crisis and improve their overall wellbeing as highlighted by Sally. Furthermore, Sally was one of the support workers who disclosed a personal history with self-harm. These personal experiences with self-harm were claimed to give support workers further understanding of the multi-agency approach needed to fully support self-harm. Figure 7.1 summarises the different avenues that older adults accessed to receive self-harm support.

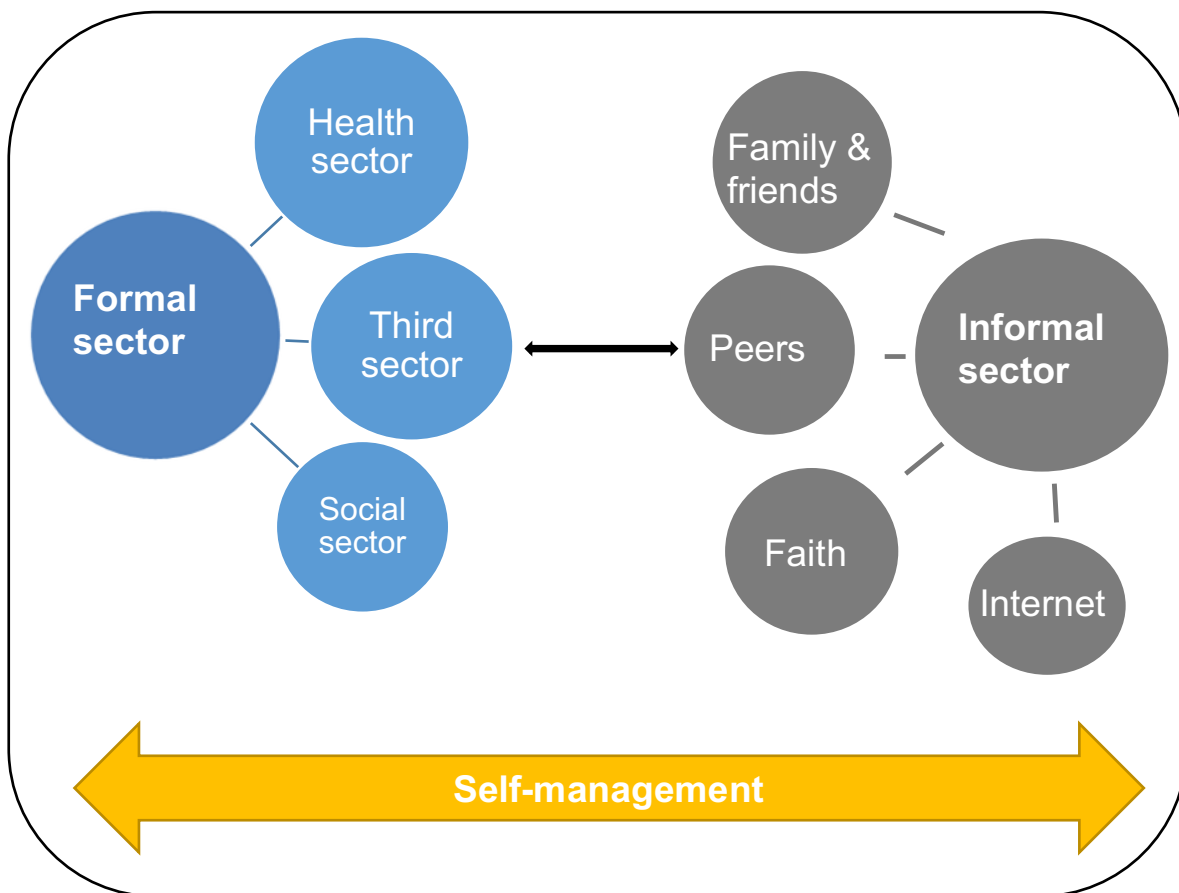


Figure 7. 1 Sources of support for older adults with self-harm behaviour

The PPIE group was asked for their opinion on Figure 7.1. Members of the group commented on the importance of both the formal and informal sector being accessed simultaneously, and overall confirmed the summarised sectors as potential sources of support and being accessed by older adults who self-harm.

7.4 Barriers and facilitators to accessing support

Throughout this chapter, several barriers and facilitators for older adults with self-harm behaviour accessing care have been briefly elucidated when describing avenues for accessing care. This section specifically addresses and describes in-depth the different barriers and facilitators identified by participants for older adults accessing care for their self-harm.

7.4.1 Barriers

Earlier in this chapter, I described the process of older adults' decision to seek help. Briefly, I described how after having taken the decision to seek support, older adults often had to make several persistent requests before adequate help and support was found for their self-harm.

One of the most significant barriers for accessing care and support for older adults with self-harm behaviour was, as identified by participants in the previous chapter, stigma and shame experiences. Experiences of shame and stigma often led older adults to live with self-harm in secret, prolonging the process of help-seeking. Even after older adults made the decision to seek help months or years after living with self-harm, stigma associated with self-harm was still present and acted as a barrier for accessing care.

The doctors are crap. You tell them about it and they're not interested about self-harm. I've seen it myself, anyone that comes in with mental health problems they're just dismissed. It's still something not taken seriously like it'll just go away. Or you'll grow out of your self-harm. When the truth is you don't, you don't grow out of it if you don't receive the help the support it's

gonna stay there. And if you're not willing or able to seek other support than you might as well not even be here.

Laura, 62

However, as Laura's account suggests, older adults' preconceptions about doctors also seemed to influence their help-seeking behaviour, acting as a barrier to care. Some older adult participants' accounts reflected their lack of trust towards healthcare professionals when dealing with older adults' self-harm.

Most GPs don't know how to deal with it, much less from an older adult and much less from a functioning adult.

Fred, 60

Other participants' accounts reflected similar experiences. Participants reported encounters with healthcare professionals that were not dealing with older adults' self-harm appropriately, dismissing such behaviour without support. This was often due to the combination of limited resources and high-demand of healthcare services.

You're just a number. Once you're out of the bed, someone else is gonna come so to the nurses and doctors you are just a number.

Leonard, 67

Despite not being older adults, several support workers with lived-experience of self-harm also reported encountering negative experiences when accessing care for self-harm. In particular, negative attitudes by healthcare professionals were described when dealing with people presenting with self-harm behaviour, reflecting on the need of improvement of healthcare professionals' attitudes towards people who self-harm.

One of the nurses said to me, 'you know you're wasting our time, there's people who are really ill we need to treat'. Which then got me to trying to treat me own wounds. So I'm trying me best to get somebody, who is self-harming that has come to terms with it, to be available to talk to people who are presenting with these issues.

David, support worker

Accentuated experiences of shame and stigma were described by participants when being in later life stages. These experiences often acted as a barrier to receiving support for self-harm in older adults, given the reluctance of older adults disclosing their self-harm.

I went to the self-harm group only once. But as I said, I went only once because as well, uh, there must've been about 12 of us. And I sat there, and I looked around and there were quite a lot of younger, young teenage girls with bandages around their wrists and there's another lad sitting aside from me and he was in his 30's, 35 and, you know he'd cut and you could see his arms, you know. And what I've done it's nothing really compared to them you know. I never went to the group again.

Leonard, 67

However, it was not only the reported healthcare professionals' attitudes towards older people engaging in self-harm that acted as a barrier, but also older adults' attitudes towards health workers which did not allow them to seek support for their self-harm. As Fred and other older adults described, particularly male participants, did not feel comfortable asking for help. Chapter 8 further discusses the implications and draw on broader literature reporting limited help-seeking, but what the accounts of participants suggest are reluctance from older adults as well when asking for help. Whether this reluctance was caused by previous shame experiences and stigma, or emerged prior to them, is not clear from data provided by participants, but the consequences of this is clear: older adults are more reluctant to help-seeking from healthcare professionals.

As a male, I tend to not go to the GP [laughs] it's kind of being very appreciative of the NHS, I'm not someone to call the GP all the time and kinda go like oh I wanna tell you this.

Fred, 60

In addition to stigma and shame (including healthcare professionals' and older adults' attitudes) acting as barriers for older adults accessing care, limited funding amongst services providing support for self-harm was a barrier, including within the third sector.

We operate, uh, or we did operate a drop-in service. Clients would come down when the drop-in service was open. Unfortunately, due to funding cuts we've had to cut back on that, so it's sorta like booked appointments only. But we, you know because not everybody realises that we're not open all the time, we do still get what we call walk-ins. So, provided that I'm here, because unfortunately I'm the only adviser at the moments, if somebody has made the effort to attend, I'm not gonna turn them away, I will help them as much as I can (.) if I'm here.

Penny, support worker

Penny described the reality of third sector older adult support groups which have had to reduce their services due to limited funding. Similarly, third sector groups aimed for people who self-harm were also experiencing funding cuts and shortages. Furthermore, several stated being commissioned to provide services for younger people. For the existing third sector groups that were providing support whilst this research project was conducted, funding concerns were stated by both support workers and older adults.

You can't say that enough, but nobody listens, they just keep cutting the funding. Now they're cutting the funding for [third sector group]. So, they might shut it now and I don't know what we'd do then.

Hannah, 62

Funding concerns was reported to result in instability, change of venues and reduced frequency of support provided to attending members, resulting in disruption of services as well as causing uncertainty amongst members.

Last year, the funding was to go to [local city] only, which uh made it hard for people from different places. People didn't want to walk through that door and come to [current venue] to come into [local self-harm support group] because they didn't want people to know. It is that thing about uh still that secrecy, that shame. [...] With the funding being cut it's been hard for us, it's been a hard transition for them [members], because before they had the

privacy of [ex-venue #1] and [ex-venue #2] so people didn't see them going there to attend the group and now here when they come here there isn't that privacy. Sally, support worker

The uncertainty caused by financial concerns resulted in members' experiences of receiving ongoing support from third sector groups being disrupted.

I think that's always a problem because I've been to a few support groups and I've thought 'oh this is great', I've got the support. And then the funding runs out and then you suddenly realise that nothing is permanent. And this (.) yeah somehow you need some permanence, continuity. Audrey, 65

The third sector was not the only sector which had their services impacted because of limited funding. Some participants described the health sector having limited funding, which resulted in older adults receiving disrupted services to support their self-harm behaviour.

I remember being told well 'we've done the course, there's nothing else we can do uhm if you're not feeling better that's your problem' and it's not like that. It takes you time, maybe years and years to open up and accept everything. That was because of limited funding so I couldn't stay over a year. But she [psychologist] tried to get me somewhere else but she couldn't because of funding. She really did care, she wanted to keep seeing me but it just wasn't possible with funding. Audrey, 65

As Audrey highlighted, healthcare provision was provided within a time-limited frame. Participants noted the importance of ongoing continuous support to help them deal with their self-harm, which was often linked to accumulated problems of the past, with time-limited support not being enough to meet the needs of older adults. Furthermore, other participants reflected on how difficult it was to access support from the health sector when it came to receiving care for mental health and self-harm. According to participants' experiences, given

the limited funding, mental healthcare was only provided for those who were very ill, as opposed to those who were not but were still in need of care.

I can't see the point in it, duck. They turn up and then they don't do it, I can't see the point in it. I mean I've done the CCMH which is all about mental health support. They don't do anything that says on the letter unless you're absolutely completely and utterly mentally ill. Which is fair enough for those who are like that. It's hard to explain uh I think there are degrees in mental illness you know. Because they're so stretched, they don't do much for you unless you're absolutely crawling up the walls.

Hannah, 62

Another reported barrier experienced in the health sector was the disparity of service provision amongst different localities. Although current self-harm guidelines recommend multi-disciplinary teams (including different healthcare professionals such as doctors, nurses, occupational therapists, amongst others), not all older adult participants were offered support from the different healthcare professionals. Given the different funding and service demand across the nation, older adults received inconsistent care across the health sector, with not all services being offered to older adults (e.g. only one older adult participant was offered occupational therapy support).

I just find the health service in the [area in England] not good, not good. [...] The counsellors that I find in the [area in England] are absolutely dire. They're absolutely crap because the council are not prepared to pay. [City in West Midlands] or an enormous city like London, you get the best counsellors, here? No. They should pay for it, but they don't. Everyone I know is waiting for NHS, I'm going private because I can't wait anymore and can afford to do so, but not everyone can.

Laura, 62

Often as well, participants encountered that the support and treatment received for their self-harm consisted in short-term interventions, which left them feeling frustrated and discouraged them from seeking further help.

I mean, they'll do something like 6-week counselling and that's great. If at the end of the 6 weeks you feel like it's helped, that's fantastic, off you go. But if at the end of the 6 weeks you still feel you're struggling, then surely, they should do something have another source of support. I remember being told well we've done the course, there's nothing else we can do uhm if you're not feeling better that's your problem.

Audrey, 65

Participants also described poor communication between healthcare professionals supporting older adults. Given that service provision was provided by both primary and secondary care, it was important for them to be aware of the treatment being given to older adults in each sector. The problem of poor communication was further complicated when older adults reported receiving treatment for different health conditions. Edward described lack of support for his self-harm given the focus on his principal diagnosis of dystonia.

Well I saw her [psychiatrist] but I think it was only a couple of times. The big issue there that never really got addressed was the self-harm, because basically they were saying they didn't have the expertise 'cause I'd be going through the NHS so you have to go through different referrals. But people with dystonia it's more complicated. So, people would normally go to a smaller hospital, but I go to the bigger one. [...] I don't really know what happened then. It was really bizarre but that department there is quite chaotic really. I was promised a structure plan to help support me you know, very detailed and they said yeah 'we'll do this and that', but they didn't do anything.

Edward, 61

As Edward highlighted, other complications acted as barriers to care such as perceived lack of expertise and once again lack of communication between healthcare professionals. Furthermore, all older adult participants had comorbid health conditions, which often resulted in needing care and support for these health conditions. For some older adult participants, these experiences inevitably shaped their views about accessing care, particularly from the health sector. Negative healthcare experiences for physical health problems deterred him from accessing further support from the health sector.

I have another condition called ulcerative colitis which actually I'm surprised I haven't mentioned that, because that was uhm (..) that was such a bad time. I was in hospital with this, like an inflammatory bowel disease and uhm (..). And I was in an isolation ward and there were windows, little old-fashioned isolation hospital and uhm I (..) I think the nurses got a bit tired of, uh taking it [waste] to have it checked so they'd just let it pile up and uhm I was there with, you know, 40-50 of these things. It was, it was uh a horrible time for me. They didn't have curtains, so I was, you know, pretty embarrassed about the whole thing.

Edward, 61

Participants reported that the treatment received in the health sector was fragmented, focusing either on the physical health aspect or the mental health aspect, with the latter being more neglected. However, older adults recognised the importance of receiving comprehensive (both physical and mental health) support to help them deal with their self-harm behaviour and overall wellbeing.

I mean like the other day, I was supposed to get uhm you know, they scheduled me for a blood transfusion, and I cancelled the appointment which isn't helping things. But uhm yes, I'm self-harming by not getting the transfusion but then at the same time, I'm like 'but that's not the help I need'. I need my mental health fixed because otherwise I'm just gonna keep on

wasting the blood you're giving me [laughs,] you know, that could be for someone else that needs it.

Fred, 60

Furthermore, support for self-harm was difficult to access as it was not seen as an urgent priority. Older adults reported experiencing difficulty when seeking help to treat the physical wounds of their self-harm.

I cut my stomach and it was really quite bad and I phoned my GP, and nobody would see me, even though I had got a priority plan. They said, 'oh come here tomorrow, you can see a nurse tomorrow'. And I said, 'I need to see somebody now' and they said, 'well we've got no appointments'. So, I phoned my CPN and she said, 'well obviously this priority care planning isn't working' and she phoned them and they called straight away.

Audrey, 65

Lastly, participants described structural barriers such as difficulties in reaching venues, as stopping them from receiving care. Given that several of the older participants had mobility issues, it was not easy for them to get around independently, meaning they had to rely on someone else taking them to receive support. However, as Hannah's account highlights, not all older adults had the capacity to pay for such transportation services.

Well when the [local self-harm support] group started I thought uhm I'm going to encourage that you know and start going to that one, but like I said the weather has stopped me. It costs me 20 pound to get there which is a lot of money. So yeah, I just have to have to sit tight and wait for the snow to go but it doesn't seem like it wants to go. And then of course you've got hospital appointments and everything that stop you going the meeting. I've got all that as well.

Hannah, 62

Figure 7.2 summarises the different encountered barriers older adults experienced when seeking support for their self-harm. As conceptualised in Figure 7.2, older adults had to go through several barriers and layers to receive support for their self-harm. Acting as a barrier

throughout all factors was stigma. Nevertheless, as the next section addresses, there were also facilitators experienced by older adults when seeking support for their self-harm, making it easier for them to ask for help and continue receiving support for self-harm.

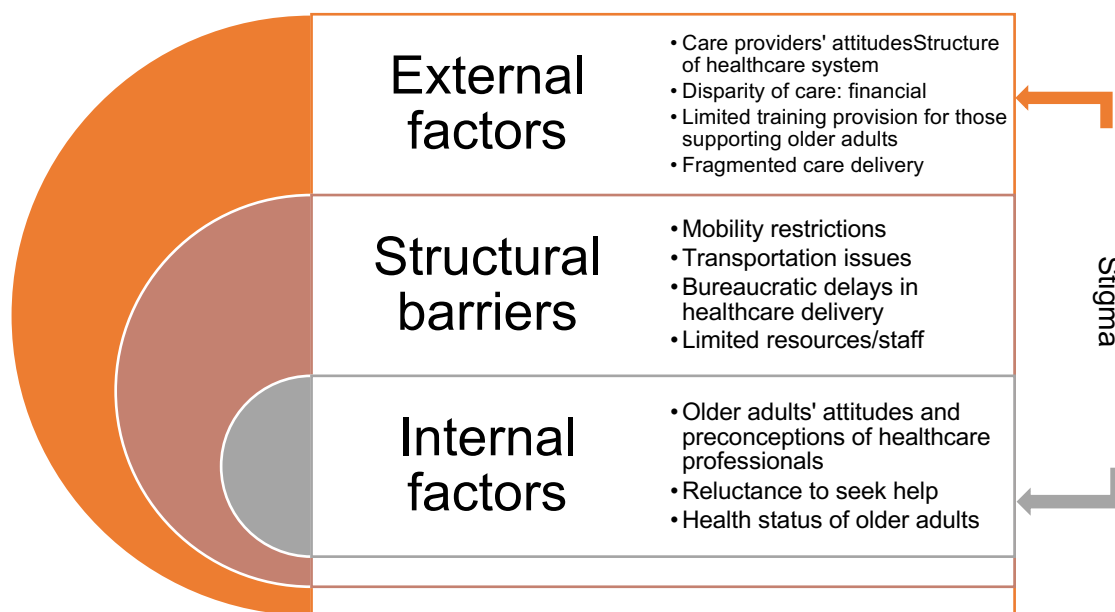


Figure 7. 2 Barriers to accessing care for self-harm in older adults

The PPIE group commented on the different identified barriers to older adults accessing care and support for self-harm behaviour. Figure 7.2 was presented to participants, who commented on several of the identified barriers: stigma, structural barriers and attitudes from healthcare professionals and older adults. The PPIE group’s interpretation further deepened the analysis of the findings from this chapter with regards to barriers to accessing care.

7.4.2 Facilitators

Participants also identified facilitators which enabled older adults to receive support for their self-harm. One of the most frequently mentioned facilitators was empathy and overall positive support given by healthcare professionals and support workers. Given that it was difficult for older adults to take the first step of seeking help, when they encountered positive

treatment experiences with empathetic staff, this often acted as a facilitator and encouraged them to further seek support for their self-harm.

I got a new CPN who was absolutely amazing and that's when I can say the healing started. She was real for start, uhm, I felt as I was gonna to see somebody I could talk to, as opposed as to somebody that was going to sit behind a desk and talk to me. uhm as well I didn't feel like a burden like with the other one. I did say to her what had happened, and she said don't worry about that, this is your time, I'm with you, it doesn't matter how many others I've got on, this is your time. Whenever I would ring up, she would always get back to me. I could rely on her completely and just that uh continuity yeah, she was really really good.

Audrey, 65

As Audrey mentioned, the positive treatment experience, supportive attitude and empathy from the healthcare professional enabled her to start her 'healing'. Furthermore, over half of the support worker participants reported previous self-harm history. The previous self-harm history often benefited support workers when supporting older people who self-harm as they felt they could empathise with older adults with self-harm behaviour.

[Support worker] as a counsellor, she gave insight on to why and how things happened and how to deal with it because she had gone through it herself. So, there's an empathy there and that really, really helped.

Alice, 72

It was this empathy and understanding received by support workers that made older adults access the third sector more often, as they felt it was a more positive environment where they could share their stories.

That's the big step forward, you know if you don't open up about it and then actually find out that you're not alone and that happens quite a bit in the group.

David, support worker

Participants identified being offered continuity, by having regular and ongoing support, as a facilitator for accessing care. As Audrey highlights, this ongoing support allowed her to stop contacting support, because she felt she did not need them anymore.

It was the ongoing support. I mean ok I don't go to the groups now, part of me wishes I still did, I mean I still could, but I think I'd find it quite hard to go back now. But uhm just knowing when you are there that no one is ever gonna tell you that you can't come anymore. Just knowing you can go, as long as you need to. You've always got somebody you can contact. This ongoing support is really really helpful. Because it's like, if you leave, there's that more chance you're gonna relapse. While if you stay, there's more chance you'll keep clean.

Audrey, 65

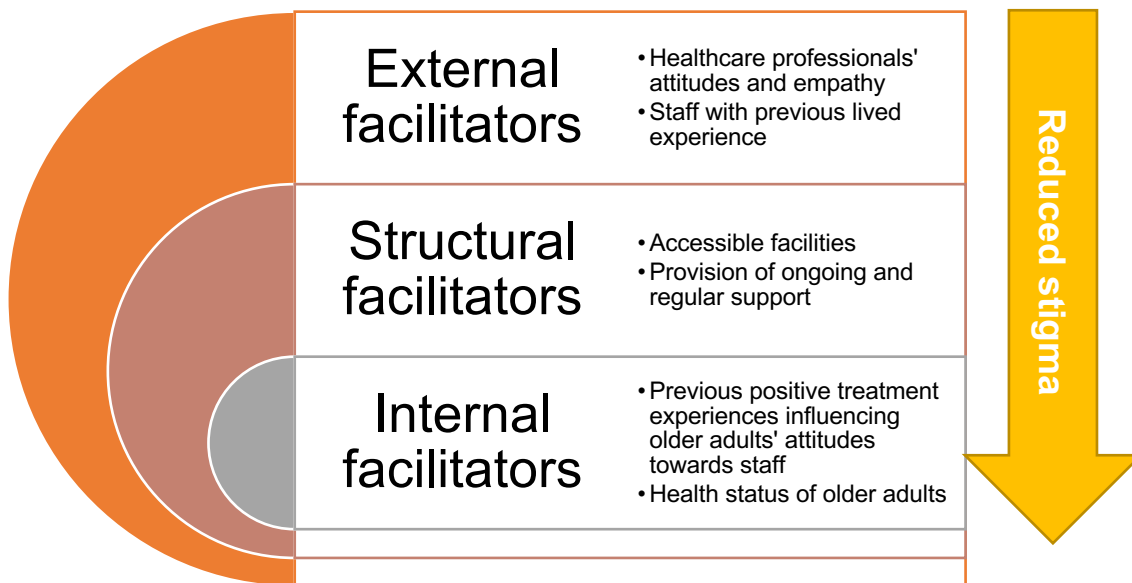


Figure 7. 3 Facilitators to accessing care for self-harm in older adults

Lastly, closely linked with the previously identified structural barriers (limited mobility, transportation issues, amongst others), having accessible facilities- both healthcare as well as third sector groups- often made it easier for older adults to access support for their self-harm

behaviour. Figure 7.3 summarises the different facilitators for older adults accessing support for self-harm.

The different identified facilitators for accessing care were discussed with PPIE members. Figure 7.3 was presented to the group, which agreed on the identified facilitators, accentuating the importance of stigma reduction to improve access to care for older adults who self-harm. Overall, members confirmed the interpretation of the different identified facilitators for older adults accessing care and support for their self-harm behaviour.

7.5 Patient and Public Involvement and Engagement

As mentioned in previous chapters, the PPIE group was involved in the design, interpretation and analysis of findings, contributing to the understanding of the research questions. As has been presented throughout this chapter, the PPIE group was involved in the interpretation of the findings regarding access to care and support for older adults who self-harm. Specifically, the PPIE group commented on the delayed help-seeking process, followed by the identification of the different avenues used to access self-harm support from both the formal and informal sector (Figure 7.1). Lastly, the PPIE group commented on the barriers and facilitators to access to care, contributing to the interpretation of these findings as summarised in Figures 7.2 and 7.3. Thanks to the contribution made from the PPIE group, a more in-depth interpretation and identification of understanding the process of accessing care for self-harm behaviour in older adults was reached.

7.6 Conclusions

This second findings chapter aimed to describe older adults' experiences when accessing support for their self-harm. By using both older adults' and support workers' views, the findings offer an insight to the services available for self-harm, from both the formal and informal sector. Furthermore, in this chapter I have presented how participants described older adults' decision-making when asking for support. Contributions made from the PPIE group to the analysis of this chapter ensured the patient perspective was added to the interpretation of

results. Lastly, the identified barriers and facilitators shed light into what can enable or deter older adults from seeking help for their self-harm. In the next chapter, I consider the findings presented throughout the previous chapters in the light of current literature and discuss the clinical and research implications of this research.

CHAPTER 8: DISCUSSION

8.1 Introduction

In this final chapter, I provide a summary and discussion of key findings of this thesis in the context of my research questions and the existing literature. The essential role patient involvement contributed to this research is also discussed. The strengths and contributions of this study to advance our knowledge of self-harm in older adults is outlined. I then present the limitations of this research, followed by my reflections from conducting this research. Implications for clinical practice, social care and third sector are then provided. Lastly, I discuss suggestions for future research.

8.2 Summary of results discussed with existing literature

The overall aim of this research was to increase the understanding of self-harm behaviour in older adults. In order to present these key findings, I structured this section according to the previously identified research questions.

1. What are the perceived motivations of self-harm behaviour in older adults?
2. What are the barriers and facilitators of access to care and support for older adults who self-harm?
3. What are the potential roles, if any, of family, friends, third sector support groups and primary care professionals, in supporting older adults who self-harm?

8.2.1 Motivations of self-harm behaviour in older adults

The first research question addressed the motivations of self-harm behaviour in older adults. Motivations for self-harm varied among the research participants depending on the perspective taken to explore such motivations. Chapter 2 introduced the different motivations for self-harm as identified in the literature (and summarised in Figure 8.1). However, these motivations were not exclusive to an older adult population. In fact, many of the identified

frameworks were based on younger populations and their applicability to older adults remains unknown (Edmondson, Brennan & House, 2016; WHO, 2016b).

Chapter 3 presented the systematic review which addressed this gap in the literature (Troya et al., 2019a). Table 3.2 summarised the identified motivations for self-harm in older adults as summarised in the existing literature, however, the systematic review had several limitations that may limit its generalisability to the wider older adult population (Troya et al., 2019a). The majority of included studies had a self-harm definition that suggested suicidal intent (e.g. attempted suicide) and most self-harm presentations in the studies were from ED settings, representing only a proportion of self-harm presentations, with self-harm occurring in the community and being managed in primary care are hidden in the literature. Therefore, the identification of motivations to self-harm in older adults was limited to this sub-section of older adults.

By making use of a broad definition of self-harm as the one adopted in this study and through the use of diverse recruitment strategies, the qualitative study, with interviews conducted with participants of my research (older adults and third sector workers) aimed to gain a wider understanding of the motivations of self-harm behaviour in older adults. Furthermore, participants had experience of self-harm behaviour from both community and hospital settings. However, it is important to highlight that the presented motivations to self-harm behaviour in later life are as experienced and reported by older adults and third sector worker participants. The discussion of findings that now follows is based on how the two participant groups gave meaning and constructed their accounts to the experience of self-harm behaviour in later life. As summarised in Chapter 6, participants from this study described similar motivations to self-harm in older adults as previously identified in the literature for general populations (refer to Figure 8.1). However, when compared to what had been previously summarised in the literature of older adults, new motivations for self-harm in older adults were identified by participants from this study: gratification, coping mechanism, avoiding suicide.

In Figure 8.1 I summarised the different identified motivations to self-harm, developed from Chapters 2 (Background), 3 (Systematic Review) and 6 (Findings from my qualitative study). Overall self-harm was seen to be a complex behaviour influenced by different personal, health and social factors. Results suggested that there is no single factor contributing to self-harm, but rather the accumulated experiences throughout the life-course as described by participants contribute to self-harm amongst older adults. As reflected in Figure 8.1, there are similarities between the previously identified motivations for self-harm in the general population and older adults. There are also differences between what has been previously summarised in the literature, with the qualitative study adding to current evidence. My most significant finding is how participants described self-harm behaviour holding different functions throughout the life-course, varying within a spectrum of suicidal to non-suicidal behaviour. Older adult participants lived with self-harm behaviour for several years, if not decades, with self-harm holding different functions to older adults. However, self-harm was described as a response and coping mechanism to the experience of accumulated stressors over the life-course.

This study also contributed to building initial evidence on older minority groups. Older minority groups may experience self-harm behaviour differently as those not belonging to minority groups as suggested by my research. Further research is needed to explore the perspectives of older adults from ethnic minority groups and their relationship with self-harm as is explored in section 8.8.

As seen in Figure 8.1, loss (including bereavement), health conditions, amongst others, were reported stressors contributing to self-harm according to older adults from the systematic review and qualitative study. As Chapter 6 further explored, these and other accumulating stressors throughout the life-course, could lead older adults to use self-harm behaviour as a coping mechanism to deal with such stressors.

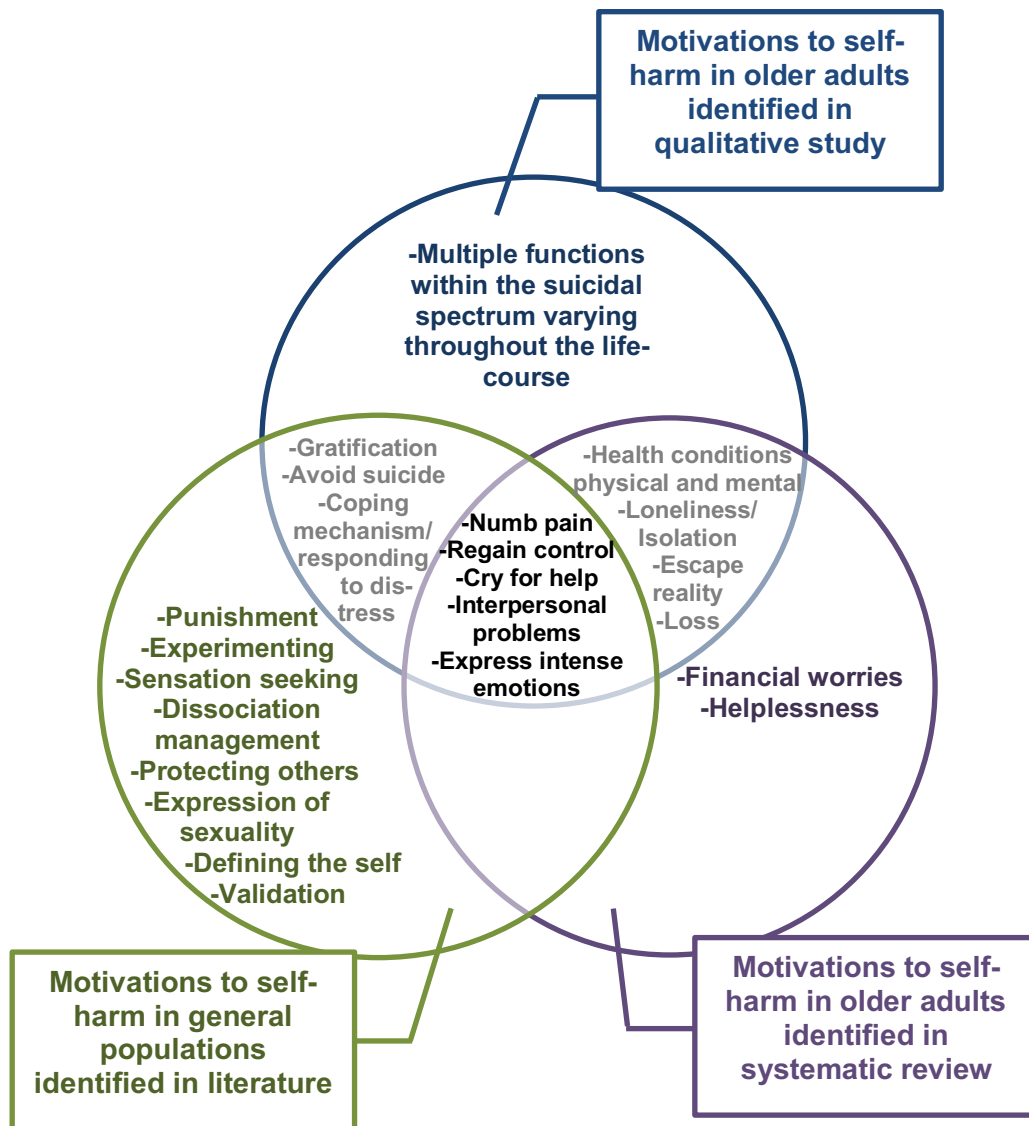


Figure 8. 1 Motivations to self-harm in older adults in comparison to existing literature

i. Impact of early life experiences to life trajectory and self-harm behaviour

Early life experiences can have consequences on health and overall wellbeing in later life as summarised in the literature (Dannefer & Philipson, 2010). This was also reflected in the accounts of participants, when they described adverse childhood events leading to distress and the use of self-harm behaviour. One of the most influential early life experiences impacting health conditions and wellbeing is low socioeconomic status (Lawlor et al., 2006). This was reflected in similar findings among my research participants who identified low socioeconomic status influencing their health and wellbeing, leading to early manifestations of distress and self-harm.

Some older adult participants described difficulties with their mental health since childhood. The interrelationship between these early psychiatric manifestations and the experienced adverse events in childhood is common as described by Lund and collaborators (2018). These authors highlight the critical period of childhood, given that adverse experiences in this period can be detrimental for cognitive, emotional and behavioural development in subsequent years (Lund et al., 2018). Therefore, evidence from my study and existing literature suggest there is a complex relationship between different factors experienced in childhood and negative outcomes such as self-harm and mental health problems, which are manifested in later life.

Furthermore, some older participants described growing up in an environment where mental illness was present in other family members. The impact of caregivers' or close family members' mental illness on children has been extensively researched, including neglect and abuse (Aldridge, 2006; Houlihan, Sharek & Higgins, 2013; Trondsen, 2012). However, my study is the first to describe reports of its impact maintained throughout the life-course and expressed as self-harm behaviour in later life, as experienced by participants.

The experience of adverse events during childhood, including neglect, abuse (physical, sexual and emotional), may lead to increased self-harm behaviour as summarised in the literature (Kwak & Ahn, 2019; Liu, Scopelliti, Pittman & Zamora, 2018). Moreover, lower social support in combination with adverse childhood events has also been associated with increased self-harm behaviour and suicidal risk as reported by Wan and colleagues (2019). Findings from my research add to the literature on experienced adverse childhood events influencing self-harm behaviour in later life, in combination with low social support. The findings from my research in combination with previous research support the life-course perspective to self-harm behaviour given that accumulated earlier stressors and adversities continued to influence individuals' wellbeing and self-harm behaviour.

As seen in Figure 8.1, loss was an identified motivation for self-harm behaviour both in the systematic review and qualitative study. Loss is an inevitable element to be experienced throughout the life-course. Commonly thought to be caused by bereavement, loss experiences

can also include end of relationships, disability (loss of function), loss of custody of children, loss of income, amongst others (Machin, 2013). In older adults particularly, loss of function related to loss of economic role and sense of productivity has been reported to be one of the major contributing factors to self-harm and suicidal behaviour, being further accentuated in older men (Apeso-Varona, Barker & Hinton, 2018). The experience of any of the different forms of loss has an impact on individuals. In later life, experiences of loss have been already shaped by the different endured encounters throughout the life-course (Bartlam & Machin, 2016), therefore older people's experiences with loss are composed by the accumulated reactions towards loss throughout the years.

Responses to loss include grief, which in some cases may turn into complicated grief. Complicated grief can impair functioning at a social and work level, involves feelings of meaninglessness and 'a prolonged yearning for the deceased' (Bartlam & Machin, 2016). Some manifestations and reactions to loss may include self-harm. As was described in Chapter 3, bereavement and loss often contributed to older people's self-harm. This was also experienced by older adult participants, when feelings of loss and bereavement often were described to contributing to older adults' self-harm behaviour.

The experience of loneliness also can affect self-harm behaviour in older adults. It is estimated that in England, one out of three older adults are living alone (Randall, 2017). Increased vulnerability is associated amongst these older individuals lacking in social connectedness and experiencing loneliness (Victor & Sullivan, 2015). Heuser and Howe (2019) recent systematic review found that often isolation and loneliness are related to suicidal ideation in older adults. Moreover, increased healthcare utilisation has been reported amongst English older adults living alone, being 50% more likely to access emergency care services (Dreyer, Steventon, Fisher & Deeny, 2018). Although this longitudinal study does not specify the reasons for healthcare utilisation for older adults living alone, authors highlighted the vulnerability of this population group (Dreyer, Steventon, Fisher & Deeny, 2018). Findings from

both the systematic review and qualitative study suggest loneliness being a contributor to self-harm behaviour in later life.

Interpersonal problems were also reported as motivations for self-harm in older adults as seen in Figure 8.1. Understanding social interactions that lead to maladaptive behaviours like self-harm behaviour and suicide has been explored by many researchers who theorised that social isolation can lead to suicide (Durkheim, 1951; Trout, 1980). Interpersonal problems were described by participants as also shaping and influencing older adults' lives throughout the life-course. Social relationships are part of everyday encounters, having an influence on wellbeing. The social interactions we have with one another vary and can cause conflict and interpersonal problems. Participants' accounts described how interpersonal problems experienced throughout the life-course were interpreted as contributing to self-harm behaviour in later life.

Lastly, comorbidities, either physical or mental health related, are closely linked with self-harm behaviour in older adults (Morgan et al., 2018; Troya et al., 2019a). Both the systematic review and qualitative study found health comorbidities influencing older adults' self-harm behaviour. Comorbidities can lead to health complications and lower quality of life and are often common in later life (Hutchison et al., 2015). In participants' narratives, comorbid health problems, which impact on everyday life, often exacerbated self-harm behaviour.

ii. Expanding our understanding of self-harm: from a medical to an overall biopsychosocial model of health and wellbeing

Traditionally, self-harm behaviour has been conceptualised within a more clinical and medical perspective. Even whilst conducting my research I was unconsciously pushed to follow a more clinical perspective given my academic background, supervisory team and the research institute where my PhD is situated. Nevertheless, when familiarising myself with the literature, and soon after the start of data collection, I quickly started to notice the importance of taking an overall comprehensive perspective in understanding self-harm behaviour,

composed by several social determinants which undoubtedly influence health and wellbeing. Dahlgren and Whitehead (1991) were one of the first to elaborate on social determinants influencing health and wellbeing. These determinants, which include unchangeable aspects such as age and sex, and changeable ones like education and living conditions, are summarised in Dahlgren and Whitehead's (1991) well-known Social Model of Health (see Figure 8.2). Within mental health research, the Dahlgren and Whitehead (1991) model has commonly been used to demonstrate the significant influence social determinants have on mental health and overall wellbeing. Mental disorders are not merely composed by their symptomatology and presenting evident complaints. Due to the strong influence from broader psychosocial factors, mental disorders and behaviours (such as self-harm) cannot be supported without taking into consideration the different influencing psychosocial determinants.

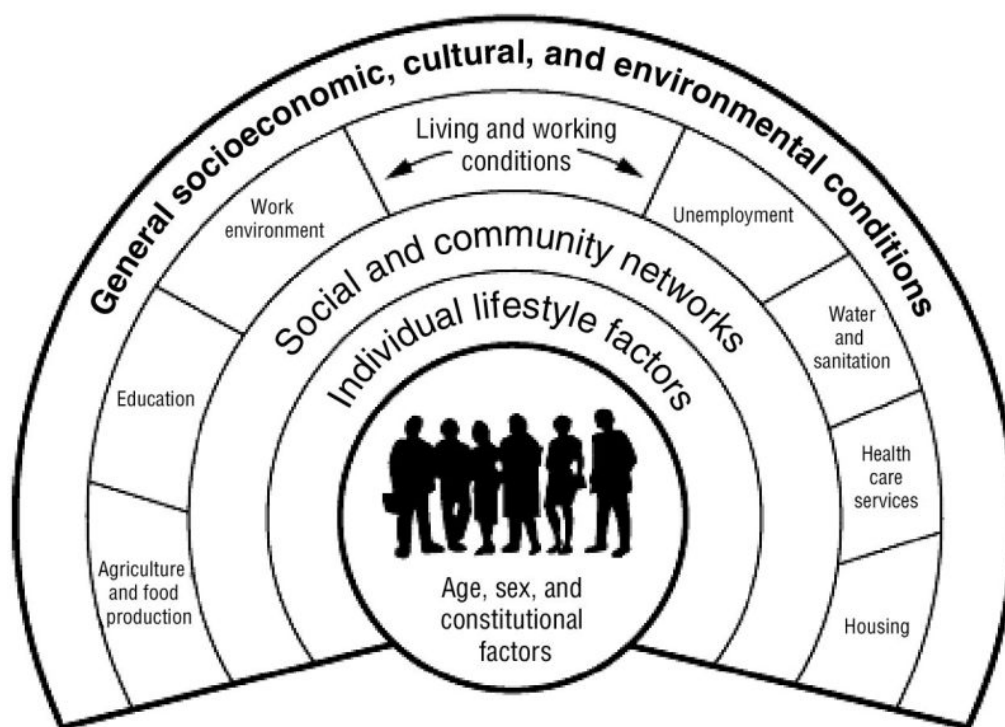


Figure 8. 2 Social model of health (with permission from Dahlgren and Whitehead, 1991)

When analysing transcripts and conceptualising participants' narratives, psychosocial determinants of health were commonly referred to and described to influence self-harm

behaviour. Likewise, as discussed in Chapter 3, findings from the systematic review resulted in the model of influencing factor for self-harm behaviour in older adults (see Figure 3.4), which included several of Dahlgren and Whitehead's (1991) social determinants of health. Lastly, as summarised in Figure 6.1, psychological traits also influenced the way older participants assimilated the stressors accumulated throughout the life-course and contributed to engaging in self-harm behaviour. Therefore, a broader biopsychosocial model of understanding self-harm behaviour was expanded as a result of this study.

iii. Comparisons with existing self-harm literature

Findings from my research add to the previously identified motivations of self-harm in older adults, in addition to expanding the range of self-harm behaviour in older adults (both non-suicidal self-harm and attempted suicide). As other authors have previously conceptualised (O'Connor & Nock, 2014; Podlogar et al., 2018) my findings support the theory of self-harm and suicidal behaviour being more than unidimensional constructs. Self-harm behaviour is more complex than singular behaviour processes given that according to participants' narratives, self-harm was presented within a spectrum of suicidal behaviour.

Moreover, previous research suggests that the relationship between self-harm behaviour and suicide in older adults is unambiguous (Morgan et al., 2018), also confirmed from my PhD research (Troya et al., 2019a and Chapter 3). However, findings from my qualitative study suggest that the relationship between self-harm, self-harm repetition and possible suicide is more complex given that in some older adults, engaging in self-harm was experienced as allowing them to avoid suicide. My research, the first conducted with older adults, contributes to existing arguments from other qualitative studies conducted with younger populations which have already begun the job of unsettling the relationships that are claimed between self-harm and suicide (Adler & Adler, 2011; Brossard, 2018; Chandler & Nugent, 2016; Chandler, 2018; Inckle, 2017). My findings confirm that the relationship between self-harm and suicide is more complex than previously conceptualised. Similarities between my research and previous

research conducted with younger populations exploring self-harm motivations suggests some aspects of self-harm may be resilient across the life-course.

The way self-harm behaviour is constructed and conceptualised by individuals has an impact on the meaning and motivations attributed for self-harm. Research conducted with younger populations engaging in self-harm behaviour has shown that people will give different individual attributes, constructions and meanings to their self-harm behaviour (Scourfield, Roen & McDermott, 2011). By having both lived-experience perspectives from older adult participants, as well as the views from third sector workers supporting older adults, my research identified the meaning and construction of self-harm from both participant groups. This was of particular importance when addressing the first research question regarding motivations of self-harm in older adults, given the increased relevance of the different viewpoints offered by both participant groups.

Within medical sociology, stigma is a well-known concept (Goffman, 1963). Within the self-harm and suicide literature, stigma is also well-known, attributed to the high levels of shame reported by those who self-harm (Carpiniello & Pinna, 2017; Goffman, 1963; Oexle et al., 2018; Scambler, 2004). The relationship between self-harm and stigma can be complex, given that there is evidence of them influencing each other (Carpiniello & Pinna, 2017). Older adults' description of self-harm being concealed, and secretive behaviour is congruent with the literature of stigma and self-harm. Traditionally, self-harm has been conceptualised as being a younger person's concern, also highlighted by participants. However, self-harm in older adults may hold higher levels of shame and felt stigma because of social expectations around older people (Scambler, 2004). These higher levels of shame and stigma may result in older people being even less willing than younger populations to disclose their behaviour, which in turn may be leading to the under-estimation of self-harm in older adults - the documented 'iceberg model of self-harm' (Geulayov et al., 2018). As stated by Geulayov and collaborators (2018) in this model, self-harm presentations which are overt to others consist merely on the tip of the iceberg, given that these are the presentations which often result in help-seeking and service

provision. However, Geulayov and collaborators (2018) suggest that the majority of self-harm episodes are not always visible, especially when no help is sought. Felt stigma and shame can also have repercussions on access to care as is explored next.

8.2.2 Barriers and facilitators to accessing care in older adults with self-harm behaviour

My research identified barriers and facilitators to accessing care for self-harm behaviour in older adults as was aimed to explore with the second research question. Reported experiences of accessing care varied across participants, however all older adults disclosed difficulties in asking help for self-harm behaviour. Older adults suggested that they had lived from several months to years with their self-harm hidden before seeking help and reported feelings of shame associated with such behaviour.

The decision to seek help for self-harm behaviour was not easy for older adults. Older adults did not tend to identify their self-harm behaviour as needing a medical consultation. As Dixon-Woods and collaborators (2006) have outlined, identification of candidacy is the term used to describe individuals' decision to seek help after identifying their symptoms or behaviour as worthy of a medical consultation. The delayed identification of candidacy by older participants resulted in them not seeking help for their self-harm immediately. However, according to Dixon-Woods and collaborators (2006) candidacy is a dynamic concept which can change over time, through encounters influenced by social norms and cultural circumstances (Mackenzie, Conway, Hastings, Munro & O'Donnell, 2013). As is furthered discussed in section 8.7, this has several implications for older adults and overall policy.

Also influencing older adults' decision to seek help was recursivity, described by Rogers, Hassell and Nicolaas (1999) as how help-seeking behaviour is shaped and determined by patients' previous experiences with healthcare. According to Rogers and collaborators (1999), future demand for healthcare services are shaped by the previous experiences patients had with the health sector. Both terms, recursivity and identification of candidacy, are further explored in the next sub-sections describing barriers to and facilitators of accessing care.

i. Barriers to accessing care

Older adults described a delayed identification of candidacy due to several barriers summarised in Figure 7.2, including both external and internal factors, as well as structural barriers. Some of the barriers have been previously identified in other research conducted with younger populations, in particular stigma (Chan, Batterham, Christensen & Galletly, 2014; Chandler, 2018; Fulginiti, Pahwa, Frey, Rice & Brekke, 2016; Gulliver, Griffiths & Christensen, 2010; Hom, Stanley, Podlogar & Joiner, 2017; Sheehan et al., 2019). Stigma and shame acted as significant barriers to accessing self-harm support. Research conducted amongst individuals with mental illness has documented how difficult it can be to disclose mental illness and in consequence access support due to stigma associated with the condition (Corrigan et al., 2010; Corrigan, Druss & Perlick, 2014; Gulliver, Griffiths & Christensen, 2010). Although self-harm behaviour is not a mental illness, older adults also had difficulty disclosing their self-harm behaviour due to feelings of shame and stigma, limiting their access to care.

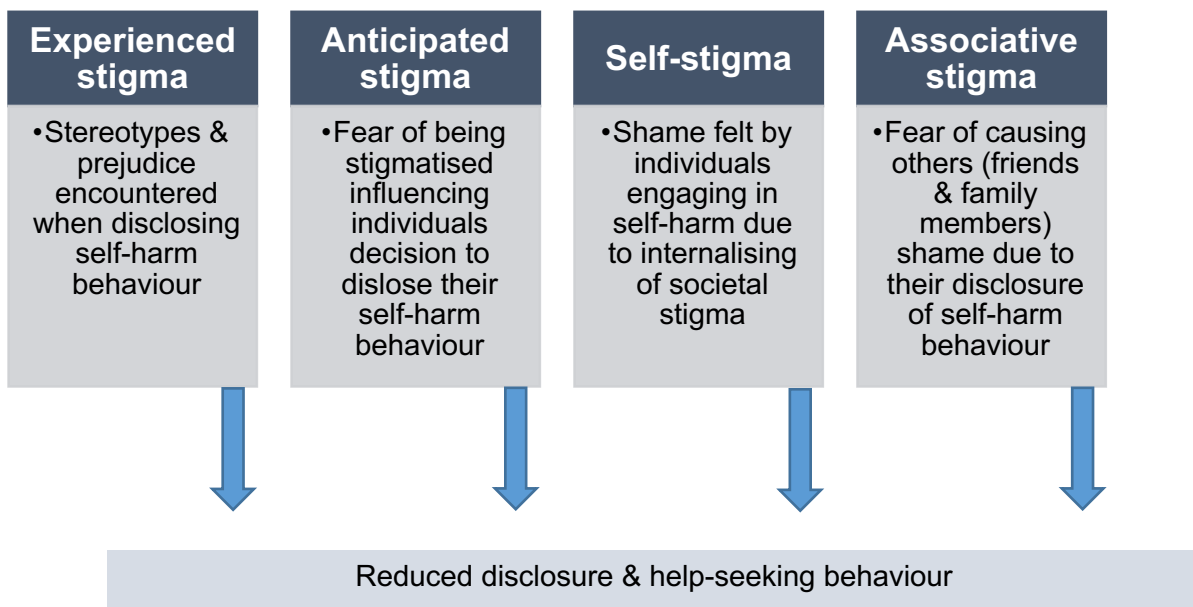


Figure 8. 3 Stigma sub-categories as identified by Sheehan et al., 2019

Findings from my research are congruent with Sheehan and collaborators (2019) previously conceptualised sub-categories of stigma related to suicidal behaviour: experienced

stigma, anticipated stigma, self-stigma and associative stigma. Analysis of the data from my research suggests that the four types of stigma identified by Sheehan and collaborators (2019) are represented in participants' accounts which delayed their experiences of help-seeking (see Figure 8.3).

Experienced stigma was present amongst the narratives of many of the older adult participants, which often led to anticipated stigma. Self-stigma was also strongly present amongst older adult participants, with feelings of shame caused by experiencing self-harm. Lastly, associative stigma was present, in particular with regard to older adults' family, given the impact it may have on them. These four sub-categories of stigma caused older adults to delay their help-seeking for self-harm support. In particular, self-stigma and experienced stigma influenced older adults' help-seeking behaviour due to the internalised shame impeding older individuals from asking support for the first, and previous prejudice experiences for the latter. As described by some older participants, experienced stigma occurred when disclosing their self-harm behaviour to healthcare professionals. The experienced negative reactions arising from the disclosure of self-harm seem to have resulted in recursivity, where older adults did not feel comfortable further discussing or disclosing their self-harm with others given the previously experienced stigma.

Closely related to stigma, the attitudes healthcare professionals had towards older adults who self-harm also acted as a barrier to accessing care. The systematic review presented in Chapter 3 identified older adults' frequent contact with the health sector given older adults' comorbid health conditions. Findings from my qualitative study also confirmed older adults' frequent contact with health services, particularly primary care. However, participants did not describe being in contact with the health sector specifically to address their self-harm, rather it was due to other health issues. Alongside stigma, older adults were not accessing care from the health sector given previous past negative experiences with healthcare professionals where their self-harm was dismissed, or negative attitudes had been held from healthcare professionals. These findings are congruent with what is described in the

literature given that different healthcare professionals (Cleaver, 2014; Heyward-Chaplin, Shepherd, Arya & O'Boyle, 2018; O'Connor & Glover, 2017; Saunders, Hawton, Fortune & Farrell, 2012), including nurses (Karman, Kool, Poslawsky & van Meijel, 2015; McAllister, Creedy, Moyle & Farrugia, 2002; McCann, Clark, McConnachie & Harvey, 2006; Rayner, Blackburn, Stephenson, Ousey & Edward, 2019) and GPs (Grimholt, Haavet, Jacobsen, Sandvik & Ekeberg, 2014; Uncapher & Areal, 2000), have disclosed negative attitudes and limited empathy towards people who self-harm, influencing individuals' support experiences. However, findings from the narratives of older adults show how their help-seeking behaviour was also influenced by previous experiences with healthcare professionals that were not related to their self-harm behaviour but were regarding other underlying medical conditions. As has been described earlier, previous experiences with healthcare professionals can shape and determine future demand for healthcare- recursivity (Rogers, Hassell and Nicolaas, 1999).

Poor mental health literacy has been outlined as a barrier for younger people accessing support for mental health problems, including self-harm behaviour (Gulliver, Griffiths & Christensen, 2010; Zhang et al., 2016). Not being able to recognise symptoms seems to impair younger people's ability to seek for mental health support (Gulliver, Griffiths & Christensen, 2010) as well as older adults. Research suggests health literacy in older adults is low (Protheroe et al., 2016), particularly in mental health, resulting in low levels of help-seeking (Farrer, Leach, Griffiths, Christensen & Jorm, 2008; Piper Bailey, Lam & Kneebone, 2018). Closely related to identification of candidacy, older adults from my research had delayed encounters with access to care, given the lack of identification of their symptoms as worthy of a medical consultation. Poor mental health literacy and lack of recognition of symptoms (in this case self-harm) seems to have resulted in older adults delayed access to care as found in my research.

Moreover, older adults identified stigma related to self-harm as well as ageism. Ageism amongst healthcare practitioners is an encountered problem that has shown to have a significant negative impact on mental health outcomes in older patients (Lyons et al., 2017;

Minichiello, Browne & Kendig, 2000; Wyman, Shiovitz-Ezra & Bengel, 2018). The Royal College of Psychiatrists (2018) reports how often ageism is still a problem in the UK amongst the NHS, particularly around mental healthcare of older adults. Findings from this thesis confirm this with regards to older adults who self-harm, facing the double jeopardy (Bodner, Palgi & Wyman, 2018; Herrick, Pearcey & Ross, 1997) of the stigma of ageism and self-harm.

This is the first study addressing older populations describing how previous negative treatment experiences may deter older adults from seeking help for self-harm behaviour. According to the literature, healthcare professionals feel frustrated when working with people who self-harm, influencing the support given (Saunders, Hawton, Fortune & Farrell, 2012). Furthermore, lack of education and training in healthcare professionals supporting people who self-harm has been reported to be one of the reasons for negative attitudes towards people engaging in self-harm behaviour (McHale & Felton, 2010; Taylor, Hawton, Fortune & Kapur, 2009). Research conducted with Australian GPs showed that GPs did not see a role for themselves supporting older adults presenting with self-harm behaviour given the complex contributing factors to self-harm (Wand et al., 2018b). Complexities leading to self-harm in older adults include a range of social, health and interpersonal problems, which GPs reported not having the time or scope to deal within a medical consultation (Wand et al., 2018b).

Medical sociologists have explored how patients' expectations and attitudes towards medical consultations can have an impact and influence such consultations (Oskay-Özcelik et al., 2018; Wensing, Jung, Mainz, Olesen & Grol, 1998). Findings from my research suggest this is also the case in older adults engaging in self-harm behaviour given that some participants were not seeking self-harm support from healthcare professionals, specifically GPs, because they did not see them as having the expertise or time to deal with their self-harm. As previously described, recursivity, how previous experiences with healthcare influence patients' future help-seeking behaviour (Rogers, Hassell & Nicolaas, 1999) may have had an influence on patients' expectations towards their future health provision. Other research has already identified individuals' strong preference of receiving support from mental health

specialists, given that other non-specialised healthcare staff were not perceived as skilled to deal with self-harm (Cooper et al., 2011). Moreover, findings from my study suggest participants held certain expectations when being offered support for self-harm, with time-limited or pharmacological support being described as superficial. This is congruent with literature reported in other populations with self-harm behaviour that also perceived medical professionals support as mostly pharmacological and superficial (Hunter et al., 2013; Lindgren, Svedin & Werkö, 2018; Taylor, Hawton, Fortune & Kapur, 2009).

Furthermore, reports of older adults suggest that they prioritise their physical health conditions over their mental health, given that often older adults were choosing not to disclose their self-harm behaviour. Older adults' own expectations around physical and mental health and help-seeking in later life may also act as a further barrier to older people getting support as has been previously described (Palmore, 2015; Taylor, Hawton, Fortune & Kapur, 2009).

According to participants' accounts, the treatment and support received for self-harm was not integrated, with older adults describing a mind-body dualism approach to self-harm support received and a reported over-reliance on the offer of pharmacological treatment. These support experiences acted as barriers to accessing care. Findings from my study mirror the experiences of older adults from recent research that found that older adults with one of the major risk factors for self-harm, depression, are not being referred to psychological therapies and are mostly treated solely with medication (Frost, Beattie, Bhanu, Walters & Ben-Shlomo, 2019). Moreover, Morgan et al (2018) research conducted with English older adults presenting with self-harm behaviour to primary care also found that referral rates to mental health services were low. Additionally, Morgan et al (2018) found that prescription rates were high for those older adults presenting with self-harm, specifically psychotropic medication, including tricyclic antidepressants. Despite current guidelines for long-term management of self-harm (NICE, 2011) warning about prescription of potentially toxic psychiatric medication to those who self-harm, older adults from this study were given access to potential methods of self-harm (Morgan et al., 2018). Amongst individuals with self-harm behaviour, an over-

reliance on medication has also been reported, although some recognised the importance of medication when being offered support (Lindgren, Svedin & Werkö, 2018; Vannoy et al., 2018). Furthermore, participants' accounts of healthcare professionals' sole interest in treating self-harm related physical injuries has been previously summarised in the literature, with individuals feeling the need of further support (Harris, 2000; McHale & Felton, 2010; Pembroke, 2006; Taylor, Hawton, Fortune & Kapur, 2009; Warm, Murray & Fox, 2002).

Lastly, difficulties in accessing care were described not only due to mobility and transport issues as has been previously summarised in other older adult populations (Syed, Gerber & Sharp, 2013; Popplewell, Rechel & Abel, 2014), but also due to digital exclusion (Greer et al., 2019; Olphert & Damodaran, 2013). Being an increasingly used platform and possible avenue for support, participants commented on the appropriateness of using the Internet as a way of offering support to older adults who self-harm. Increasingly, the health sector amongst other supporting avenues are offering their services online, however participants did not see this as an accessible or trustworthy avenue, mirroring results from previous research conducted with older populations experiencing mental health difficulties (Moult, Burroughs, Kingstone & Chew-Graham, 2018). Internet use as a potential avenue for support is further discussed in section 8.2.3.

Previous research has explored how men are less likely to ask for help given conceptions of masculinity (Chandler & Nugent, 2016), also reflected in research conducted with older men (Apesoa-Varano, Barker & Hinton, 2018). The narratives from participants of my research did not specifically explore masculinity as a barrier in help-seeking amongst older men. Nevertheless, previous research with older men has highlighted masculinity impacting help-seeking in older men (Apesoa-Varano, Barker & Hinton, 2018), warranting future research with the older adult population. However, as argued by Jordan and Chandler (2019), understanding masculinity and its relationship with suicide and help-seeking warrants careful consideration and in-depth analysis of the situational context. As such, future research should explore and critically reflect on the role of masculinity in older men seeking help, taking into

consideration the wider social environment and cultural norms which older men are embedded in.

Findings from my research suggest that decreased help-seeking may be accentuated in minority groups such as ethnic minorities and LGBT groups, which has been already reported in the literature (Gary, 2005; Kidd, Veltman, Gately, Chan & Cohen, 2011). However further research with older minority groups is needed to confirm such findings given the small representation of such groups in my research.

ii. Facilitators for accessing care

Alongside barriers to accessing care, my research also identified facilitators as summarised in Figure 7.3. Several facilitators for accessing care in older adults were identified as reported in younger populations, such as empathetic staff (Cooper et al., 2011; Lindgren, Svedin & Werkö, 2018; Rowe et al., 2014; Svedin & Werkö, 2018; Shand, Vogl & Robinson, 2018; Taylor, Hawton, Fortune & Kapur, 2009), ongoing continuous support (Cooper et al., 2011; Lindgren, Svedin & Werkö, 2018; Shand, Vogl & Robinson, 2018), reduced stigma towards self-harm behaviour (Taylor, Hawton, Fortune & Kapur, 2009) and previous positive treatment experiences (Lindgren, Svedin & Werkö, 2018). However, one of the facilitators identified in older adults was exclusive to this population: repeated contact with healthcare professionals. Given the increased health comorbidities reported amongst older adults, complex health conditions gave older adults more contact with healthcare professionals where they could potentially explore self-harm behaviour further. A recent study conducted in England by McManus and collaborators (2019a) also identified older adults being more likely to receive care as compared to younger populations. However, further exploration is needed to see whether healthcare professionals would be able to provide adequate support to older adults, given that previous research conducted with Australian GPs showed that GPs did not see a role for themselves supporting self-harm in the older adult population (Wand et al., 2018b).

Increasingly, peer support has been cited as a facilitator for accessing care amongst people with mental disorders (Bradstreet, 2006; Faulkner & Kalathil, 2012); Kingstone et al., 2019). This research is the first to identify peer support, referring to support received by those with lived-experience, as a facilitator for accessing care amongst older populations engaging in self-harm behaviour. Interestingly, although support workers recognised lack of training as impeding their service provision to older adults, this was not experienced as a barrier by older adults. Rather, it was third sector workers' previous lived-experience and empathy which acted as facilitators to accessing care, given the reported positive treatment experiences.

Moreover, although not specifically described amongst participants, previous research (Rowe et al., 2014; Shand, Vogl & Robinson, 2018) suggests the importance of receiving holistic support, which not only targets self-harm behaviour, but as well health conditions, as well as a broader psychosocial approach including familial, social, occupational and financial aspects. Given that participants from my research identified an over-medicalised perspective and exclusive mind-body dualism approach as a barrier to accessing future treatment, findings from my study support research from Shand et al (2018) who identified broad and in-depth psychosocial assessment as facilitating access to care in individuals who self-harm.

Lastly, as reported in other older adult populations (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007), having accessible facilities where older adults can easily access support was an identified facilitator for obtaining support for self-harm.

8.2.3 Role of the formal and informal sectors supporting older adults who self-harm

The third research question addressed the role the different avenues had when supporting older adults with self-harm behaviour. Chapter 2 (section 2.2.12) identified the different avenues for accessing self-harm related care in the UK, which included sources from the formal and informal sector. This included support from friends and family, the health and social sector, as well as the third sector. However, Chapter 2 did not explore the applicability of these avenues within the population of older adults.

Chapter 3 identified different health sector avenues older adults used to obtain support for their self-harm (see section 3.5.3). Primary care and secondary care, in particular mental health services, were two avenues older adults often accessed. However, the identification of sources of support were limited to the health sector and further exploration of other sources of support, including the informal sector or third sector, were not explored or reported.

Through analysis of interviews with older adults and support workers, Chapter 7 described the different avenues older adults used to seek support for their self-harm behaviour. Given the previously described difficulty older adults encountered when accessing care, a range of other avenues for obtaining support were used, from both the formal and informal sector. Access to care from the different sources was not sequential or linear, rather help-seeking varied amongst sectors depending on older adults' perceived needs as well as availability of services.

Furthermore, as previously explored, self-management of the different health conditions of older adults occurred throughout the period of help-seeking. Self-management of health conditions has been increasingly reported in the literature, in particular long-term conditions, including mental health (Davidson, 2005; van Grieken, van Tricht, Koeter, van den Brink & Schene, 2018). Although the specific aspects of self-management were not explored, findings from my research are congruent with the literature that suggests patients increasingly relying on self-management when waiting to receive treatment for their health condition (van Grieken, van Tricht, Koeter, van den Brink & Schene, 2018). Moreover, the relationship between health literacy and self-management in older adults with chronic health conditions has been explored, with low health literacy being associated with poor self-management skills (Geboers, de Winter, Spoorenberg, Wynia & Reijneveld, 2016; Mackey, Doody & Werner, 2016). Older adults from my research seemed to reach a point where they relied on self-management skills, however this was only in the context of waiting to receive care. Further research is needed to explore whether self-management could be used alongside health literacy to promote the management and wellbeing of older adults with complex health conditions. Section 8.8 further

discusses how self-management of self-harm, alongside health comorbidities, could be explored in future research.

i. Formal sector

There are different networks within the formal sector that support older people who self-harm, including the health sector, social sector and third sector. Within the self-harm and broader mental health literature, the health sector is reported to be the main support provider for individuals who self-harm (Hawton et al., 2015b; 2016; Rowe et al., 2014). Given that individuals with self-harm behaviour often present with comorbid mental illness and physical illness, the health sector is often the most visited setting when it comes to self-harm support.

Within the health sector, there are different settings that can support older adults who self-harm. Findings from my qualitative study suggested primary and secondary care, in particular mental health services, to be the two main avenues that support older adults who self-harm. There is a range of potential support offered by the health sector to people who self-harm, including pharmacological, such as antidepressants and mood stabilisers, for diagnosed mental illnesses (Hawton et al., 2015b) and psychosocial interventions (Hawton et al., 2016a), including CBT, problem-solving therapy, dialectical behavioural therapy, amongst others. Specifically, in older adults, the majority of interventions created to support and reduce self-harm behaviour are delivered within the health sector, with strongest evidence to those delivered in primary care (Almeida et al., 2012; Okolie, Dennis, Thomas & John, 2017). Furthermore, because of older adults increased contact with healthcare settings due to their complex health conditions and comorbidities, the health sector has been identified as an appropriate avenue to manage and support older adults with self-harm behaviour (Almeida et al., 2012; Okolie, Dennis, Thomas & John, 2017).

Interventions delivered in primary care which aim to reduce self-harm behaviour are being increasingly reported. A recent systematic review assessed interventions to reduce suicidal behaviour in older adults, finding strongest evidence for interventions that had

multifaceted components delivered primarily in primary care (Okolie, Dennis, Thomas & John, 2017). These interventions consisted on screening and managing depression, community-based programs, telephone counselling and pharmacotherapy as well as psychotherapy (Okolie, Dennis, Thomas & John, 2017). However, the majority of studies from the systematic review were ranked of low methodological quality, with the exception of primary care interventions (Okolie, Dennis, Thomas & John, 2017). However, other authors have reported the shortcomings of interventions delivered in primary care, including time-limited consultations (Chandler, King, Burton & Platt, 2016; Leavey et al., 2017), lack of GPs' confidence, capacity and willingness to support (Leavey et al., 2017; Wand et al., 2018b) and an over-reliance on pharmacological interventions (Leavey et al., 2017). The previously identified limitations of managing self-harm in primary care are also reflected in older adults according to findings from my research. Primary care presents itself with an opportunity to assess and manage self-harm in older adults, due to the increased contact with this population due to comorbid health conditions. However, several factors need to be revisited for primary care to successfully deliver self-harm support and management. Section 8.7 further discusses implications for clinical practice, taking all evidence into consideration.

Secondary care was another identified source of support within the health sector, where older adults accessed care for their self-harm behaviour. Chapter 3 identified specialist mental health services and ED departments as the two main avenues within secondary care where older adults access support for their self-harm. Similarly, as summarised in Chapter 7, older adults accessed ED departments when it was in response to self-harm episodes needing medical attention for related injuries. Psychiatric care was accessed once older participants' GPs identified this as being the appropriate care pathway to follow. Usually this support was delivered by psychiatrists or CPNs, as described by participants. Evidence supports the effectiveness of the provision of pharmacological treatments as well as psychotherapy for self-harm behaviour (Hawton et al., 2015b, 2016; Okolie, Dennis, Thomas & John, 2017). Provision of psychological therapies to adults in the UK is offered in the programme Improving Access

to Psychological Therapies (IAPT). Talking therapies are often preferred by patients when compared to pharmacological treatment as this allows greater rapport with the healthcare professional delivering the intervention (Leavey et al., 2017; Lindegren et al., 2018). However, evidence suggests that British older adults are under-referred to IAPT, with recent evidence suggesting less than 5% of IAPT referrals are for older adults (Prina et al., 2014). Findings from my research show that older adults' experiences accessing care are congruent with what has been reported in the literature regarding psychological therapies for self-harm support, as older adults state a preference for talking-therapies where they could deal with the multiple factors influencing their self-harm behaviour. Similarly, pharmacological therapy was often seen as superficial treatment for individuals who self-harm (Leavey et al., 2017), which was also highlighted by older adults in my research. Lastly, older adults from my research found that ED was mostly a setting they would attend when needing to deal with severe self-harm episodes when medical attention for sequelae of self-harm was needed. Findings from older adults' experiences with ED settings are similar to those reported in the literature, where there is an emphasis on treating the body and injury caused by the self-harm episode, as opposed to the individual as a whole entity (Hadfield, Brown, Pembroke & Hayward, 2009). As summarised by other researchers (Barr, Leitner & Thomas, 2004; Taylor, Hawton, Fortune & Kapur, 2009), individuals encountering such experiences in ED often felt discouraged to further seek support, due to the perceived negative attitudes of ED healthcare professionals, as summarised in section 8.2.2.

However, not all individuals who self-harm present to healthcare settings. As has been previously presented and discussed most individuals who self-harm do not seek help from healthcare settings (Geulayov et al., 2018). There is the need to fill in the crucial gap of care provision for those individuals who self-harm in community settings. Services offered in the community such as the third sector or social care sector might be able to fill in the gap of care provision for individuals who self-harm.

Within the third sector, there is increasing evidence of how individuals who self-harm prefer this avenue when seeking support (McManus et al., 2019b; Okolie, Dennis, Thomas & John, 2017; Rowe et al., 2014). As previously summarised, empathy and positive support were facilitators to accessing care, both which were often found amongst support worker participants. Previous lived-experience seemed to have given support workers the needed skills and empathy to offer support to older adults. GPs offering referrals to the third sector is not often cited in the literature, however, more recently McManus and colleagues (2019b) have found that individuals who self-harm are making contact with the third sector after being referred by clinicians. Furthermore, Hafford-Letchfield and colleagues (2018) explored the views of paid carers supporting older people who self-harm in care home settings, highlighting the important role played by such carers when supporting older individuals with self-harm behaviour.

Lastly, social care is closely linked when offering support to individuals who self-harm given that many risk factors for self-harm lay within the remit of the social sector: financial difficulties, housing insecurity and homelessness, provision of benefits due to disability, amongst others. As previously explored, these social determinants influence individuals' wellbeing and support provision of the social sector can help offer integral support to those who self-harm. Sinclair et al (2011) estimated visits to the different sectors offering support following a self-harm episode and found that approximately 15% receive support from social services. Findings from my research contribute to this evidence, given that older adults who self-harm often required support from the social care sector. However, according to participants' accounts, such support was not often described as being accessed. Despite social determinants having significant effects on older adults' self-harm, the majority of support provision was dealt within the health sector, third sector and the informal sector, as is next presented.

ii. Informal sector

Beyond exploring the role of the formal sector (including health services, social care and third sector) in supporting older adults who self-harm this research is the first to address access

to care in the informal sector. Amongst adolescents, the self-harm literature suggests the informal sector, in particular friends and family, to be the main source where individuals obtain support for their self-harm behaviour (Rowe et al., 2014). In other older adult populations, evidence suggests there is an important role played by family when supporting older adults with dementia (Brodaty & Donkin, 2009; Schulz & Martire, 2004), mental illness (Cummings & Kropf, 2009; Lyberg, Holm, Lassenius, Berggren & Severinsson, 2013; Magliano et al., 2005; Zhang & Li, 2011), amongst other health conditions (Miller & DiMatteo, 2013; Wen, Shepherd & Parchman, 2004). Findings from my research provided evidence on the important role family has in supporting older people who self-harm given the close relationship and social connections. Furthermore, lack of support from family was found to be detrimental to older adults' wellbeing, given that this often accentuated the stigma and shame associated with self-harm behaviour and resulted in delayed help-seeking.

Alongside family, the Internet is another commonly reported support avenue from the informal sector for individuals who self-harm. There is increasing evidence on the role the Internet has in supporting teenagers who self-harm (Daine et al., 2013; Jones et al., 2011; Marchant et al., 2017; Rowe et al., 2014). In particular, advantages of preserving anonymity when disclosing self-harm to others (Jones et al., 2011; Rowe et al., 2014). However, the Internet has also been associated with negative effects amongst younger groups, given the vulnerability and lack of monitoring amongst online platforms (Daine et al., 2013). In particular, the potential of learning strategies to hide self-harm behaviour from others, avoid seeking help and receiving encouragement to self-harm has been summarised as potential negative implications surrounding Internet use (Daine et al., 2013; Marchant et al., 2017). Although Internet use is indeed increasing amongst British older adults (Office for National Statistics, 2018), such use is not associated with help-seeking behaviour. As briefly mentioned in section 8.2.2, digital exclusion (Greer et al., 2019; Olphert & Damodaran, 2013) still prevails amongst older people. The Internet was not a commonly used avenue by older adults to receive support given the lack of trustworthiness towards this online platform, in particular when it came to

accessing health-related support (Moult, Burroughs, Kingstone & Chew-Graham, 2018; Zulman, Kirch, Zheng & An, 2011). Findings from my study confirm that older people interviewed did not feel comfortable disclosing self-harm through the Internet, given the lack of trust.

Support delivered by peers, or those with similar lived experiences, is often presented as having an important role in the literature amongst older populations with certain health conditions such as depression (Lester Mead, Graham, Gask & Reilly, 2012; Mead, Lester, Chew-Graham, Gask & Bower, 2010; Ong, Martineau, Lloyd & Robbins, 1987), diabetes (Ghasemi, Hosseini & Sabouhi, 2019), cancer (Huber et al., 2018) and those experiencing loneliness (Hemberg, Nyqvist & Marina Nassman, 2018). In younger groups, advantages of peer support have been specifically reported amongst those with suicidal thoughts or self-harm behaviour, being one of the most frequently accessed support sources for young adults (Michelmore & Hindley, 2012; Rowe et al., 2014). The importance of peer support in older adults who self-harm has started to be recognised, given the potential of improving social connections and reducing loneliness, one of the major risk factors for self-harm in older populations (Van Orden & Conwell, 2011). Findings from my research provided evidence on the importance of peer support in older adults who self-harm. Specifically, older adults identified several facilitators to accessing care from peers, including the already identified social connections and reduced loneliness, but also people who could relate and understand their experiences. Furthermore, support workers that had previous lived-experiences were also seen as more approachable to older adult participants from my research.

The literature suggests increased faith and spirituality amongst older populations (Hayward & Krause, 2015). The impact faith has in overall wellbeing of older adults has been widely reported, with findings showing increased wellbeing, social connections and mental health, amongst those older adults having active faith or spirituality (Arcury, Quandt, McDonald & Bell, 2000; Chen et al., 2019; Leach & Schoenger, 2008; Malone & Dadswell, 2018; Pentz, 2005; Peteet, Zaben & Koenig, 2019; Whitehead, 2018). Also summarised in the literature is

that older adults with a religious or faith background have decreased suicidal thoughts and behaviour compared to those older adults not reporting any faith (Heisel & Flett, 2008; Jacob, Haro & Koyanagi, 2018; Nisbet, Duberstein, Conwell & Seidlitz, 2000; Rushing, Corsentino, Hames, Sachs-Ericsson & Steffens, 2013). In particular, religion seemed to result in increased social connections (Nisbet, Duberstein, Conwell & Seidlitz, 2000), psychological resilience (Heisel & Flett, 2008) and overall social support (Rushing, Corsentino, Hames, Sachs-Ericsson & Steffens, 2013). Previous research conducted with older depressed men found that religion was one of the deterring factors to avoiding suicide as described by participants (Vannoy et al., 2018). Findings from my research are congruent with what has been summarised in the literature. However, findings from participants' accounts were specific to faith encounters as opposed to adhering to specific religious communities. Less is discussed in the literature regarding the role of faith in self-harm and suicide prevention in older adults. When mentioned (Segal, Mincic, Coolidge & O'Riley, 2004) faith is often presented in the context of religion, being used interchangeably, with no distinction made between the two. Although for some older adult participants, faith was associated with a particular religion, faith was discussed in a religion-independent context. Therefore, findings from my research add to the wider literature on faith as serving as a support network in older adults, specifically those engaging in self-harm behaviour. However, it is worth noting that faith was not always positively associated as a support system in older adult participants. Some participants' accounts reflected how religion hindered self-harm support, given the stigma and shame associated with self-harm amongst certain religious groups. Further exploration of the role of faith and religion is needed in the older adult population that engage in self-harm behaviour.

8.3 PPIE role in this PhD

Throughout the thesis, I have demonstrated the essential role PPIE has had in developing and conducting my research. In Chapter 1, I described how the idea for my research originated from a previously convened PPIE group. In chapters that followed, I described how the PPIE group was formed and how it influenced and impacted the different

elements of my research, including the systematic review, study design and methods and interpretation of findings. In this section, I make reference to the added value resulting from the involvement of PPIE throughout my research (see Troya et al., 2019c).

Through a series of five meetings in the 3-year duration of the research, the PPIE group made substantial contributions working collaboratively with me. To maintain regular communication with PPIE members throughout the duration of the research, quarterly updates were provided to PPIE members (see Appendix 12). To sustain PPIE involvement throughout the three years, several factors were considered, including receiving support from the established PPIE team within the Research Institute. The wellbeing of PPIE members in workshops was prioritised, therefore steps to not overburden members were taken, as well as providing further support if needed. Considerations of the capacity, level of involvement and unwanted added burden to PPIE members must be taken into account when involving them in research, but even further careful consideration should be taken with vulnerable populations such as those with self-harm history (Troya et al., 2019c). Thoughtful consideration, support, training and experience was provided to ensure PPIE members' wellbeing, including supporting PPIE staff.

The impact of PPIE involvement in my research project resulted in refining the scope of the systematic review, revising definitions, search terms and outcomes to be used, the analysis and interpretation of the review findings through the development of a conceptual framework of influencing factors of self-harm in older adults and elaboration of an information leaflet based on review findings as a user-friendly dissemination avenue. In the qualitative study, PPIE group's input resulted in modification of the study methods and recruitment strategies, ensuring a comprehensive capture of populations of interest. Involvement also strengthened the methodological rigour of results, by adding validity through triangulation of the analysis and interpretation of findings. The involvement of PPIE in the research process contributed to improving the validity and relevance of the findings. Continuous PPIE

involvement was achieved through careful consideration of the PPIE group's capacity, level of involvement, respect of wellbeing and adequate training and support (Troya et al., 2019c).

However, as is further discussed in section 8.5, despite the contribution from the PPIE group to my research, there are limitations to consider regarding the characteristics of the members included in the PPIE group. Furthermore, although meaningful contribution was sought to avoid tokenistic involvement, the inevitable shift in power dynamics between researchers and members of the public most likely had an impact in the level of involvement from the PPIE group. Nevertheless, continued involvement and critical reflections of PPIE involvement throughout the duration of the research ensured thorough consideration was taken regarding PPIE involvement.

8.4 Contributions to knowledge

This is the first study to explore self-harm behaviour in older adults in England. My research has made several contributions to existing knowledge, specifically to the literature of self-harm and suicidal behaviour, as well as the wider mental health gerontology literature. Firstly, the systematic review conducted assessed current evidence regarding self-harm behaviour in older adults, providing an up-to-date and robust synthesis. The systematic review informed the conduct of the qualitative study that followed with regards to most recent evidence on the characteristics, risk factors and motivations of self-harm in older adults. By taking an exploratory approach with the qualitative study, my research provides contributions and lived-experience insights to understanding self-harm behaviour in older adults.

This is the first research conducted to explore motivations to self-harm, and access to care in older adults who self-harm. As summarised in the upcoming sections, there are both clinical and research implications that follow the findings from access to care and support that can help inform clinical practice and research in order to better tailor and deliver support to older adults. The contributions to knowledge made are informed by the narratives of participants from a community sample. As previously mentioned, the majority of existing

research in self-harm populations is based on hospital-based samples, therefore my research adds to the knowledge about people who seek help from the third sector, and who are often excluded from research.

The qualitative approach taken provides evidence to research and clinical practice, challenging the commonly assumed understanding of self-harm behaviour and its relationship with suicide. The majority of existing research suggests that the relationship between self-harm behaviour and suicide in older adults is unambiguous. However, my thesis argues that the relationship between self-harm, self-harm repetition and possible suicide is more complex given that some older adults engage in self-harm behaviour to avoid suicide. Moreover, several participants lived with self-harm behaviour for several years, with this behaviour acting as a coping mechanism rather than a predictor for suicide. Although previous research (Brossard, 2018; Chandler & Nugent, 2016; 2018) has already started to challenge the assumed association between self-harm and suicide, this is the first study contributing evidence to the older adult population. This has wider implications for researchers in the field, specifically when conceptualising self-harm behaviour throughout different age-groups.

The presence of self-harm behaviour throughout different stages of the life-course contributes to the wider literature of self-harm given that it may have implications for younger populations. Understanding how self-harm behaviour maintains or changes throughout the life-course is key for management and prevention. As well, the varying presence of self-harm behaviour throughout the life-course suggests that individuals may be able to manage their self-harm behaviour with help of different support avenues. Once again, this may have implications for younger groups who self-harm.

The contributions to knowledge made by this thesis are enhanced by the inclusion and sustainment of a PPIE group that was involved in the research project throughout its 3-year duration.

8.4.1 Outputs and dissemination

A series of outputs and dissemination, aimed for both the public and academics, resulted from the conduct of this PhD. Appendix 13 summarises the list of academic publications, followed by the different conference presentations. Throughout the different publications and conferences, I presented the findings of my research, from the systematic review, to the role and impact resulting from PPIE to the PhD and the results from my qualitative study. Outputs resulting from the PhD to the wider public ranged from information leaflets to blog posts. As mentioned in Chapter 3, Appendix 2 (Self-harm in older adults information leaflet) was one of the outputs resulting from the systematic review, which was produced in collaboration with the PPIE group. This information leaflet, endorsed by the National Suicide Prevention Alliance, was distributed both locally and nationally to different self-harm and mental health support organisations, as well as older age support groups, pharmacies, general practices. Lastly, as mentioned in Chapter 5, the last PPIE meeting was used to discuss possible outputs resulting from the qualitative study, with a short video script being reviewed by the PPIE group. I plan on securing funding to develop a 1-2-minute video which will provide a lay summary of the overall findings from the PhD, aiming to be an informative video to create awareness of self-harm behaviour in older adults (see Appendix 14).

8.5 Strengths and limitations

Alongside the contributions to knowledge there were several strengths from my research. The qualitative methods and research design chosen not only allowed for an in-depth exploration of the subject of enquiry through inclusion of participants' narratives but also allowed a close encounter from first hand lived experiences. By including older adults with experience of self-harm behaviour in my research, a close encounter with self-harm in later life was reached through the narratives and construction of meaning of participants. Furthermore, the views of this participant group were complemented with the perspective of third sector support workers. The contribution of third sector workers is of great value given the repeated

contact of older populations and people who self-harm with these groups, as well as giving a complementary understanding of self-harm behaviour in older adults from the views of those offering support. This is the first study to include the narratives of both those with lived experiences (older adults) and support workers to develop its findings.

The interview process allowed me to explore in-depth the subject of enquiry. Specifically, the follow-up interview offered to older adult participants not only allowed me to check the impact interviews had to older adults, but it also provided me with time to establish rapport between participants and me. Given the sensitive nature of the subject of enquiry, it was important to establish rapport with participants so extensive accounts could be provided regarding the experiences of self-harm. The follow-up interview gave me a deeper understanding of individuals' experiences with self-harm behaviour. Although other research has been conducted using follow-up interviews with individuals who self-harm, this is the first study which does so in older populations, bringing insight to the utility of follow-up interviews in older adults who self-harm.

A further strength of this research is the ongoing collaboration with the established PPIE group. Including the patient and public perspective gave space for the opportunity of improving relevance, legitimacy and validity of results through the added perspective. Collaboration and ongoing collaboration with the PPIE group in the research process provided a wider interpretation of the findings as presented in section 8.3 (Troya et al., 2019c).

Despite the contributions made from my research to understanding self-harm behaviour in older adults, there were several limitations which must be acknowledged.

As previously presented in Chapter 3, the systematic review had three main limitations: majority of studies reporting self-harm with exclusive suicidal intent (e.g. attempted suicide), self-harm presentations limited to hospital-settings with very few community-based studies and the poor reporting of studies included which did not allow for a comprehensive capture and statistical synthesis of the predefined outcomes.

The self-harm behaviour definition adopted in my research could be seen as a limitation. As previously summarised, there are ongoing debates on what is the most appropriate term to be used to refer to self-harm behaviour, varying from excluding suicidal intent (e.g. non-suicidal self-injury), to episodes which only include suicidal intent (e.g. attempted suicide). Given that these definitions are exclusive to each other, the more inclusive definition of self-harm used by NICE guidelines (2011) was adopted. This was done to capture all types of self-harm behaviours, both exclusive and inclusive of suicidal intent. NICE guidelines (2011) definition of self-harm excludes eating disorders and substance misuse as being self-harming behaviours. It also excludes indirect self-harm (e.g. refusal to eat). These exclusions may be problematic to some given the potential views of such behaviours being regarded as self-harm, particularly in previous research conducted with older adults (Hafford-Letchfield et al., 2018; Wand et al., 2018a). However, as adhered to in my research, the definition used within NICE guidelines (2011) was the most appropriate due to its wide capture of self-harm behaviour (varying from non-suicidal to exclusively suicidal), as well as distinction from other clinical behaviours (such as eating disorder or substance misuse).

As a response to the limited community-based studies and aiming to explore the project's research questions, the qualitative study was conducted by recruiting participants from a variety of community avenues. However, there were certain limitations which are now addressed. Although data saturation was reached with both participant groups and diverse recruitment strategies informed by PPIE discussions were taken in place to have a heterogeneous sample, the study may have been strengthened by having a more diverse and larger sample. Firstly, the majority of included participants ($n=12$) came from one recruitment avenue: self-harm support groups. This could be explained by older adults attending self-harm support groups feeling more comfortable disclosing their self-harm to others, as opposed to the alternative recruitment avenues where perhaps self-harm had not yet been disclosed or discussed. Furthermore, as summarised in Chapter 5, two ethics amendments were sought and obtained to be able to expand the recruitment avenues given the initial paucity in

recruitment. The first amendment consisted on expanding the study location to England rather than being limited to the West Midlands, while the second amendment consisted on adding advertisement through local media such as newspaper ads. These amendments did indeed result in further participant engagement in the study. However, despite efforts to include a diverse sample, older adult participants were confined to a 'younger age group' (mean age: 63.4; SD=3.72), which may limit the transferability of findings to other later life cohorts. Moreover, participants were predominantly White British and heterosexual, meaning these results may not be applicable to ethnic minorities or LGBT groups. Research conducted with older ethnic minorities or LGBT groups may have resulted in further themes in analysis. Lastly, a balanced gender ratio was not achieved in both participant groups. The sample would have been more diverse and benefitted if it would have included older age cohorts, minority groups (LGBT and ethnic) and more male participants.

The findings and analysis of the qualitative interviews are limited to the perspectives of older adults and third sector workers. Interviewing other participant groups such as healthcare practitioners or carers would add other important perspectives to understanding self-harm behaviour in older adults.

Reported as a strength of my research, the PPIE group involved also had some limitations which must be acknowledged. Firstly, the number of PPIE members ($n=3$) included in this study was small. Despite, these members belonging to different groups of the population of interest, including support workers, carers and older adults with experience of self-harm, other voices were not included. Furthermore, it was also not possible to recruit any PPIE members belonging to minority groups: ethnic minorities or LGBT groups. PPIE members in my research were each of a white-British heterosexual background, limiting the voice of these minority groups in the research. Therefore, this study may have benefited from having PPIE group members from more diverse communities.

Lastly, despite the lived-experience perspectives which contributed to the understanding of self-harm in older adults obtained through the qualitative methodology, this

research did not establish causal relationships between motivations of self-harm in older adults and previous experienced stressors. Longitudinal studies would be needed in order to establish such causal relationship between previous events influencing future motivations of self-harm in older adults. Instead, this research reported accounts of participants on how they perceived and attributed different events experienced through the life-course as influencing their self-harm behaviour.

8.6 Reflections

This study was constructed, conceptualised and interpreted following a critical realist perspective. By following a critical realist perspective, my conceptualisation of self-harm as a behaviour acknowledged the different biological and social factors that influence mental health and illness and which may precipitate behaviour as experienced by individuals: biopsychosocial model of health (Engel, 1977; Wade & Halligan, 2017). As addressed in Chapter 4, this study was shaped by my view of the world, my previous experiences in education and research, the research institute I belonged to, as well as the breadth of my supervisory team's expertise.

The culture of the Research Institute and its focus on primary care had an influence in the study's focus. Furthermore, conversations held with my academic supervisory team, alongside their areas of expertise and interest, also helped shape and focus the research. Moreover, my academic training in Clinical Psychology and Global Mental Health also had an influence on how I understood, conceptualised and prioritised the area of research. As a result, the methods chosen to conduct the research were influenced not only by the research questions and aims, but also my previous experience and training. My lack of previous experience conducting qualitative research meant I had to ensure receiving adequate training and guidance to conduct a qualitative study, throughout the duration of the research. Conversations with my academic supervision team alongside colleagues with qualitative expertise allowed me to deepen my understanding of qualitative research in the study I was undertaking. Lastly, working collaboratively with a PPIE group, as described in the previous section, and published in Troya et al., 2019c did indeed result in an added perspective of those

with lived-experience when conceptualising and conducting the study. Working closely with the PPIE group meant I prioritised the group's perspectives when conceptualising self-harm behaviour. However, although the PPIE group was sustained throughout the duration of the PhD, it was a small group which was unlikely to be representative of all those with experience or supporting older adults with self-harm behaviour.

8.7 Implications for older adults, clinical practice, other sectors and policy

In this section, I summarise implications of my research for older adults, clinical practice, as well as other sectors that may work with older adults who self-harm or are at risk of doing so. In line with the fourth object of my thesis, I also highlight policy recommendations for the different areas involved in supporting older adults with self-harm behaviour.

8.7.1 Implications for older adults

My research highlights several implications for older adults, both those who are currently engaging in self-harm behaviour, and those who are at risk of self-harm behaviour. Mental health literacy of older adults needs to be improved. As summarised previously, health literacy of older adults is poorer compared to younger populations, and this reduction is further accentuated in mental health. The resulting effect of poor mental health literacy leaves older adults at risk of not recognising their behaviour or condition as something which requires help and/or medical attention. In consequence, delayed treatment and access to care often results from this. As previously mentioned, the notion of identification of candidacy (Dixon-Woods et al., 2006) is a dynamic concept which is modifiable and can be augmented depending on individuals' knowledge and recognition of symptoms. There are many aspects which may influence poor mental health literacy in older adults, but perhaps one of the most prevailing is stigma. In order to deal with this issue of mental health literacy, reduction of stigma around mental health and self-harm behaviour in later life is needed. Health literacy of older adults may also be improved through awareness public health campaigns as will be further described.

The link between the education sector and self-harm is commonly associated with younger population groups. However, my research with older adults highlights implications for the education sector. Firstly, although the focus of my research was to explore self-harm in older adults, self-harm was experienced during different stages of the life-course. For several participants, self-harm began in early childhood and teenage years and was sustained until later life years. Having a wider impact than just to the older adult population, findings from my research can provide lessons for all populations who self-harm given the life-course perspective taken to self-harm. From primary school education to university degrees, the education sector could be instrumental to continuing to increase self-harm and mental health awareness. This would help with symptom recognition and improvement of mental health literacy. In particular, there is a need to end the stigma associated with self-harm behaviour as this has shown to result in difficulty accessing support. Increasing awareness for self-harm and challenging the commonly associated negative connotations will allow for there to be a societal and cultural change to viewing self-harm.

Public health campaigns encouraging people to seek help for their mental health could facilitate the process of help-seeking in older adults. More specifically, if these campaigns are focused on older populations, older adults may be more open to accessing support for their self-harm behaviour. Lastly, in conjunction with reducing stigma and improving awareness of self-harm, those older adults that may be at risk of self-harm behaviour could identify their distress and seek support from the different avenues that may provide mental health and broader support.

8.7.2 Implications for clinical practice

There are several implications for clinical practice resulting from findings of my research. Self-harm behaviour is complex and multi-factorial, involving different health conditions. All clinicians (including GPs, psychiatrists, nurses) working with older adults, need to thoroughly assess and manage self-harm behaviour in older adults, according to their areas of expertise. Clinicians supporting older adults who self-harm should ensure patients

understand their self-harm is taken seriously, and that the language is used is one of affirmation and thoughtfulness, being empathetic with older adults. As a result, improved help-seeking may follow as well as a possible reduction of repeat self-harm in older adults. Lastly, when supporting older adults who self-harm, clinicians should be aware of the complexity behind motivations of self-harm, not taking for granted the different functions self-harm may hold to older adults.

Across clinicians supporting older adults, more awareness of self-harm behaviour in later life is needed. Given that many older adults may not seek help, it is important that clinicians are aware of the existence of self-harm behaviour in later life so identification of individuals at risk can assist in care provision, planning and management. It is therefore suggested that clinicians supporting older adults assess and ask about self-harm.

All clinicians supporting older adults who self-harm should follow current guidance on self-harm longer term management (NICE, 2011), with particular importance on not providing patients with medication that could result in toxic overdoses such as tricyclic antidepressants. Morgan et al (2018) research found that this was not being followed, given that there were still high prescription rates of these drugs which are toxic in overdose.

Clinicians in all sectors of health services may wish to take into account the similarities between motivations for self-harm in younger and older adults. Being aware of this may allow clinicians to further understand patients who are presenting with self-harm behaviour. When assessing older adults who self-harm, it is important for clinicians to individually assess each patient, considering their previous medical history, as well as the risk for self-harm repetition and suicide. Nevertheless, clinicians should consider that not all older adults who self-harm have suicidal intent and should assess whether self-harm is acting as a coping method for older adults.

Lastly, everyone involved supporting older adults who self-harm, should avoid stigmatising language when it comes to self-harm, mental health, or ageing. Doing so will allow older adults to feel more comfortable when requesting support.

- Be aware that self-harm can occur in older adults and although suicidal intent is not always present, it is important to consider patients' suicidality
- Consider the stigma attached to self-harm, and ensure an empathic approach, so that the patient feels listened to
- Be responsive to the distress associated with self-harm; do not focus exclusively on the physical sequelae of self-harm
- Consider offering longer appointments to provide comprehensive assessment and support to the patient for physical and mental health needs
- Consider arranging follow-up as part of on-going assessment and management
- Review current medication to assess whether these may act potentially as a method of self-harm (e.g. overdose)
- Assess patient safety throughout the consultation and advise on access to means of potential self-harm
- Liaise with the third or social care sector, or refer to specialist care where indicated
- View the consultation as an opportunity to provide self-harm management and avoid repeat self-harm and suicide

Figure 8. 4 Suggestions to GPs supporting older adults who self-harm (Troya et al., 2019b)

In primary care, clinicians should be aware of the potential they have when supporting older adults who self-harm. The Centre for Mental Health (2019) has already stated the crucial role primary care has with regards to suicide prevention. Primary care also has a crucial role for self-harm prevention and management. Primary care is the first point of contact for older adults, therefore the opportunity to identify, manage and support older adults who self-harm is present. Primary care is a potential avenue for effective support and management of older adults with self-harm behaviour. Despite criticisms made about self-harm management and suicide prevention in primary care regarding GPs over-reliance on medication and structural inadequacies in service provision (Leavey et al., 2017), GPs are well placed to manage and support all people who self-harm (Centre for Mental Health, 2019; Mughal et al., 2019) including older adults who may be consulting with physical health problems. GPs can help legitimate distress and self-harm as a reason for consultation and support in a variety of ways,

from ensuring patients understand their condition is taken seriously and that the language used is one of affirmation and thoughtfulness. For this, further research may be needed to see whether GPs within the UK setting would have the training, time and predisposition to successfully attend self-harm in older adults. Effective self-harm management in primary care may improve future help-seeking and healthcare access in older adults and thus reduce repeated self-harm and suicidal risk. Moreover, GPs can refer older adults to further support including IAPT or signposting to third sector services if needed, and acceptable. NICE guidance (2018) suggests multi-agency partnerships for self-harm management, therefore primary care should work with other sectors (health, social and third sector), to provide support for older adults who self-harm. In Troya et al (2019b) I provide a list of suggestions for GPs working with older adults who self-harm based on the findings from the qualitative study in combination with current NICE guidance (see Figure 8.4).

8.7.3 Implications for other sectors

Specialist healthcare professionals also have the opportunity to support older adults who self-harm. Depending on the setting (ED, community mental health teams or mental health hospitals) secondary care professionals attending older individuals who self-harm, can offer appropriate management, support and referrals. For staff working in ED settings, despite the urgent priority of focusing on attending individuals' injuries resulting from self-harm, it is fundamental mental health is also considered when attending to patients' wellbeing. For this, risk assessments (including comprehensive psychosocial assessments and medical history) can be conducted as recommended by current NICE guidance and ensure adequate referral and support is put in place after individuals are discharged. Increased awareness about self-harm behaviour and empathy is needed amongst ED staff. Training may help provide this increased awareness and empathy. For mental health professionals working within hospitals or the community, it is essential that overall health is considered, including the different comorbidities and stressors which may be leading to self-harm, offering continuous support until self-harm is managed.

Finally, it is important to highlight the need for primary care and secondary care to work collaboratively to comprehensively support older adults who self-harm. As suggested by NICE guidance (2018) working across the different sectors (health sector, social care sector and third sector), may allow for holistic support and management of older adults who self-harm.

Findings from my research have implications which are wider than clinical practice. Wider implications result from my research, including implications for the social sector, third sector and broader society. As presented by participants, older adults had several factors which influenced their self-harm behaviour. These factors were not exclusive to health, but also involved wider societal, cultural, amongst other factors. In this section I summarise the wider implications of my research.

i. Social care sector

Several of the influencing factors for self-harm in later life are linked to social determinants of health. This is why it is essential to involve the social care sector in supporting older adults who self-harm. Firstly, awareness of the risk factors for self-harm in older adults is needed, so that social workers know who is most at risk and feel confident to enquire about self-harm. Second, communication and coordination with the healthcare sector and other supporting organisations is essential when offering support to older adults who self-harm. Through improved communication, all sectors supporting older adults who self-harm will be aware of the current status of older adults and possible stressors and influencing factors. This will also allow the provision of thorough and comprehensive support by supporting individuals holistically, as opposed to offering fragmented care. With better coordination across the different agencies supporting older adults who self-harm, all factors influencing older adults' health and wellbeing will be able to be considered when offering support. Lastly, through increased awareness of self-harm existence in later life, stigma reduction amongst social workers may result.

ii. Third sector

The third sector is increasingly involved in the provision of support to people, as an adjunct to health and social care, and thus in supporting older adults and individuals who self-harm. Therefore, there are several implications for the third sector resulting from findings of my research. Although more generally the majority of support workers were supporting and empathetic to older adults who self-harm, there was still lack of awareness of the existence of this behaviour in later life, as well as the differences it may have with younger groups. Increased resources and training are needed in the third sector if it will continue to deliver support to older adults who self-harm. Further training will allow support workers to be able to better respond to self-harm, especially to those workers who are not familiar with offering mental health or self-harm support. Lastly, to offer continuous support, regular funding needs to be allocated to third sector groups. Commissioning decisions need to ensure that services are maintained. Third sector groups aimed for people who self-harm experience funding cuts and shortages, forcing groups to close down. For this research project, initially, 25 self-harm support groups had been identified nation-wide to be contacted. However, when making contact with these groups, a quarter ($n=6$) had closed their services due to funding cuts. Furthermore, several reported being commissioned to provide services for younger people exclusively. Third sector groups have an important role when supporting older people who self-harm, therefore it is important for there to be funding allocated for these groups.

8.7.4 Implications for policy

Reducing self-harm and suicide, and improving access to healthcare in older people are national priorities: Five Year Forward View for Mental Health (NHS, 2016a), Improving Care for Older People (NHS, 2016b), Suffering in silence: age inequality in older people's mental healthcare (Royal College of Psychiatrists, 2018), Preventing suicide in community and custodial settings (NICE, 2018), NHS Long Term Plan (NHS, 2019). Findings from my research result in several implications for policy which are in line with current national priorities.

The Five Year Forward View for Mental Health has already highlighted the need of reducing stigma for people who experience mental health difficulties. Improving care for older people (NHS, 2016b) is also a national priority. In line with both policies and national priorities, a variety of local and national campaigns are needed in order to reduce stigma and improve access to care amongst older adults with self-harm behaviour.

The NHS Long Term Plan (NHS, 2019) states the importance of managing and supporting individuals with mental illness and prioritises the reduction of self-harm and suicide. The need of integrated primary care and community models for supporting individuals with self-harm behaviour is also highlighted (NHS, 2019). Alongside having an integrated approach in the health sector to supporting and managing individuals with self-harm behaviour, inter-sector collaboration (health sector, social sector, third sector) is also needed to comprehensively support older adults with self-harm behaviour.

Self-harm was experienced throughout different stages of the life-course of older adults and not exclusively in later life. Despite this, the majority of existing national policy (NICE 2011) focuses on younger age groups with little mention to implications for older adults' self-harm behaviour. Funding for the treatment of older people's mental healthcare is also disproportional as reported by the Royal College of Psychiatrists (2018). Policy specifically targeted for older adults with self-harm behaviour should be developed in order for this age group to be considered a national priority and receive the needed attention, funding and support.

8.8 Future research

After taking into consideration current literature as well as the summarised contribution, with its limitations, directions for future research are presented.

Firstly, given that this was a study conducted with a predominantly White-British population, future research should to explore self-harm with different older adult populations. Furthermore, future research exploring the perspectives of healthcare professionals (e.g.

nurses, GPs) and family members or carers, on older adults' self-harm behaviour will assess whether findings from my research are reflected in other participants' accounts.

Future research is needed to explore longitudinally the functions and motivations of self-harm across the different stages of the life-course (teenage years to mid-adulthood to later life). Participants from my research described experiences with self-harm across the life-course. However, the focus of my research was to explore self-harm in older adults, therefore an assessment or exploration of the functions of self-harm throughout the life-course was not possible. Findings from my research provide accounts of how participants gave meaning and understood self-harm behaviour in later life. Given the reported accounts of participants with their experiences of self-harm in varying points, longitudinal research could help further understand the changing role self-harm has in individuals' lives. In particular, further research exploring how self-harm can be used as a coping mechanism to deal with adverse events and in some cases avoid suicidal behaviour is needed. Future research could explore the varying functions self-harm has in older adults, to continue building evidence challenging the commonly assumed notion that self-harm and suicide are inexorably connected in older adults.

With regards to access to care and support, older adults reported self-managing their self-harm behaviour instead of seeking, or when waiting to receive support. It is not clear how self-harm can serve as a coping mechanism and help self-manage overall wellbeing, including physical and mental health. Self-harm behaviour usually holds negative connotations given the obvious reasons of damage to oneself. However, an exploration of how self-harm helps older individuals manage and cope with different adverse influencing factors is needed, as well as a harm reduction approach to self-harm. Further research is needed to explore the use of self-management skills when dealing with self-harm behaviour in combination with physical and mental disorders as well as the potential use of health literacy to improve self-management of older adults. Exploratory research using qualitative methods could further explore this.

Future research with older minority groups is needed. More recently, Capistrant and Nakash (2018) assessed suicidal risk among older LGBT groups, reporting that older LGBT

groups are at a higher suicide risk than non-LGBT groups. Further exploratory research is needed with older LGBT groups to explore the role self-harm has amongst this group and whether the initial findings of accentuated stigma amongst LGBT groups are confirmed. Qualitative methods could further explore the experiences of older LGBT groups with self-harm behaviour. Moreover, further research amongst older minority ethnic groups is needed to explore whether self-harm motivations and experiences to access to care are similar or different when compared to other older adults. Although accentuated shame and therefore difficulties and delayed help-seeking was reported amongst the one participant that belonged to an ethnic minority group, further research is needed to confirm these findings amongst broader groups of older ethnic minorities. Previous research (Clark, Burbank, Greene & Riebe, 2018; Ward, Mengesha & Issa, 2014) has suggested minority groups have strong support systems and resiliency, therefore future research could explore how older ethnic minorities experience self-harm and self-harm support.

This research included PPIE throughout the duration of the study and reported on the impact of such involvement. Further research describing the involvement of patients and public in healthcare research is needed, particularly documenting transparently the process and impact of such involvement. Furthermore, research addressing PPIE involvement with at risk or vulnerable populations is needed to describe further challenges and opportunities when working with such groups. Lastly, future research involving PPIE should summarise and address possible ethical concerns and document the steps taken to address these. Mixed-methods research could further explore this.

The present research addressed the motivations to self-harm as narrated by older adults and third sector workers. I have highlighted how, according to participants' accounts, diverse reasons were attributed to the start of self-harm behaviour in older adults. Findings suggest that those older adults facing adversity in childhood and throughout the life-course are often prone to engage in self-harm behaviour as described by participants. However, future research could explore other individuals' experiences with adversity and the lack of

engagement with self-harm behaviour. This research could further add to the understanding of what factors lead older individuals to self-harm.

Lastly, as has been argued throughout this thesis, a multi-factorial approach to self-harm is needed in order to fully support older adults with self-harm behaviour given the multiple aspects influencing self-harm. This has also implications for self-harm research, warranting a change in the way researchers conceptualise and study self-harm. As highlighted by Chandler (2019), self-harm and suicide research has been predominantly led by (health) psychologists, with very little attention being focused to broader social aspects of self-harm and suicide. Stanley and collaborators (2016) reviewed psychological and sociological theories of suicide in older adults, finding very limited theories, which lack extensive empirical investigation and scrutiny. Furthermore, the scarce existing sociological research in self-harm and suicide, tends to be seen separately to psychological research in the field. In line with Chandler's (2019) work highlighting the importance of considering broader influencing factors to self-harm and suicide, reconciling the two disciplinary perspectives, alongside findings from this research supporting multi-factorial approaches to self-harm support, future research must take a broad multi-factorial approach when studying self-harm and suicide.

This research was conducted within an applied health research institute, with a predominant focus on primary care. Although the supervisory team had wide methodological expertise and included a multi-disciplinary focus, results from this research were focused on applied health research and the implications for clinical practice and research. Further exploration and enquiry on self-harm behaviour in older adults from a sociological perspective for example could result in a complementary, in-depth understanding in the subject of enquiry, with the potential of building theoretical frameworks.

8.9 Conclusions

This research was conducted to further understand self-harm behaviour in older adults, in particular motivations to self-harm, as well as access to care and support. Through the

narratives provided by 16 participants, older adults and support workers, in 24 interviews, I have presented how self-harm behaviour was conceptualised and experienced in later life. No one single factor leads to self-harm behaviour in older adults. Influenced by different personal, health, social and cultural factors, self-harm behaviour as experienced by participants, was a result of the different accumulated experiences throughout the life-course of older adults. I have argued how self-harm behaviour in older adults is more complex than commonly thought of and conceptualised. Self-harm behaviour holds no clear singular function for older adults, with motivations varying throughout the years and self-harm being used from a coping mechanism, to avoiding or seeking suicidal behaviour. It is essential to explore the different functions self-harm has for an individual throughout their different periods of the life-course. These varying functions amongst individuals have implications for clinical practice and all those supporting older adults. I have highlighted the importance of addressing self-harm in older adults as a whole, including the different factors which may influence self-harm behaviour, from internal factors such as health status, to wider factors such as social factors including stigma and resistance to accessing care. Clinicians and those supporting older adults who self-harm must work collaboratively to enable the provision of comprehensive support of the varying influencing factors of self-harm in older adults. This thesis has provided evidence on self-harm behaviour as experienced in later life, having several implications for research and clinical practice. By examining self-harm behaviour in older adults through an exploratory approach with narratives of those with lived-experiences, this research adds to existing evidence which is commencing to detangle the assumed notions of self-harm behaviour.

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Appendices

Appendix 1 Search strategy systematic review

MEDLINE (OVID)

1. Self mutilation/
2. Self-injurious behavior/
3. (self or selv* or themself* or themselv*) adj3 harm* (search title or abstract)
4. (self or selv* or themself* or themselv*) adj3 mutilat* (search title or abstract)
5. (self or selv* or themself* or themselv*) adj3 injur* (search title or abstract)
6. (self or selv* or themself* or themselv*) adj3 poison* (search title or abstract)
7. (self or selv* or themself* or themselv*) adj3 cut* (search title or abstract)
8. Parasuicid* (search title or abstract)
9. Para suicid* (search title or abstract)
10. Self destruct* (search title or abstract)
11. Overdos* (search title or abstract)
12. Attempt* suicid* (search title or abstract)
13. 1-12 or
14. Aged/
15. Geriatrics/
16. Frail Elderly/
17. Aging/
18. Ag?ing (search title or abstract)
19. Elder* (search title or abstract)
20. Geriatric* (search title or abstract)
21. Senior* (search title or abstract)

22. Late* life (search title or abstract)
23. Late* adulthood (search title or abstract)
24. Old* age (search title or abstract)
25. Old* people (search title or abstract)
26. Old* person* (search title or abstract)
27. Old* citizen* (search title or abstract)
28. Old* adult* (search title or abstract)
29. Old* m#n (search title or abstract)
30. Old* wom#n (search title or abstract)
31. Old* male* (search title or abstract)
32. Old* female* (search title or abstract)
33. Old* patient* (search title or abstract)
34. Old* population* (search title or abstract)
35. Pensioner* (search title or abstract)
36. Retired (search title or abstract)
37. Retirement age (search title or abstract)
38. 14-37 or
38. 13 and 38

PSYCINFO (EBSCO)

1. Self-destructive behavior/
2. Self-inflicted wounds/
3. Self-injurious behavior/
4. Self-mutilation/
5. (self or selv* or themself* or themselv*) N3 harm* (search title or abstract)
6. (self or selv* or themself* or themselv*) N3 mutilat* (search title or abstract)

7. (self or selv* or themself* or themself*) N3 injur* (search title or abstract)
8. (self or selv* or themself* or themself*) N3 poison* (search title or abstract)
9. (self or selv* or themself* or themself*) N3 cut* (search title or abstract)
10. Parasuicid* (search title or abstract)
11. Para suicid* (search title or abstract)
12. Self destruct* (search title or abstract)
13. Overdos* (search title or abstract)
14. Attempt* suicid* (search title or abstract)
15. 1-14 or
16. Aging/
17. Geriatrics/
18. Ag#ing (search title or abstract)
19. Elder* (search title or abstract)
20. Geriatric* (search title or abstract)
22. Senior* (search title or abstract)
22. Late* life (search title or abstract)
23. Late* adulthood (search title or abstract)
24. Old* age (search title or abstract)
25. Old* people (search title or abstract)
26. Old* person* (search title or abstract)
27. Old* citizen* (search title or abstract)
28. Old* Adult* (search title or abstract)
29. Old* m?n (search title or abstract)
30. Old* wom?n (search title or abstract)
31. Old* male* (search title or abstract)

32. Old* female* (search title or abstract)
33. Old* patient* (search title or abstract)
34. Old* population* (search title or abstract)
35. Pensioner* (search title or abstract)
36. Retired (search title or abstract)
37. Retirement age (search title or abstract)
38. 16-37 or
39. 15 and 38

Ageline (EBSCO)

1. (self or selv* or themself* or themselv*) N3 harm* (search title or abstract)
2. (self or selv* or themself* or themselv*) N3 mutilat* (search title or abstract)
3. (self or selv* or themself* or themselv*) N3 injur* (search title or abstract)
4. (self or selv* or themself* or themselv*) N3 poison* (search title or abstract)
5. (self or selv* or themself* or themselv*) N3 cut* (search title or abstract)
6. Parasuicid* (search title or abstract)
7. Para suicid* (search title or abstract)
8. Self destruct* (search title or abstract)
9. Overdos* (search title or abstract)
10. attempt* suicid* (search title or abstract)
11. 1-10 or

CINAHL (EBSCO)

1. Self-injurious behavior MM
2. Self-inflicted injuries MM
3. (self or selv* or themself* or themself*) N3 harm* (search title or abstract)
4. (self or selv* or themself* or themself*) N3 mutilat* (search title or abstract)
5. (self or selv* or themself* or themself*) N3 injur* (search title or abstract)
6. (self or selv* or themself* or themself*) N3 poison* (search title or abstract)
7. (self or selv* or themself* or themself*) N3 cut* (search title or abstract)
8. Parasuicid* (search title or abstract)
9. Para suicid* (search title or abstract)
10. Self destruct* (search title or abstract)
11. Overdos* (search title or abstract)
12. Attempt* suicid* (search title or abstract)
13. 1-12 or
14. Aging MM
15. Geriatrics MM
16. Frail Elderly MM
17. Aged MM
18. Ag#ing (search title or abstract)
19. Elder* (search title or abstract)
20. Geriatric* (search title or abstract)
21. Senior* (search title or abstract)
22. Late* life (search title or abstract)
23. Late* adulthood (search title or abstract)

24. Old* age (search title or abstract)
25. Old* people (search title or abstract)
26. Old* person* (search title or abstract)
27. Old* citizen* (search title or abstract)
28. Old* Adult* (search title or abstract)
29. Old* m?n (search title or abstract)
30. Old* wom?n (search title or abstract)
31. Old* male* (search title or abstract)
32. Old* female* (search title or abstract)
33. Old* patient* (search title or abstract)
34. Old* population* (search title or abstract)
35. Pensioner* (search title or abstract)
36. Retired (search title or abstract)
37. Retirement age (search title or abstract)
38. 14-37 or
38. 13 and 38

Web of Science

1. TS=(self NEAR/3 harm*)
2. TS=(selv* NEAR/3 harm*)
3. TS=(themselves NEAR/3 harm*)
4. TS=(themselv* NEAR/3 harm*)
5. TS=(self NEAR/3 mutilat*)
6. TS=(selv* NEAR/3 mutilat*)
7. TS=(themselves NEAR/3 mutilat*)
8. TS=(themselv* NEAR/3 mutilat*)

9. TS=(self NEAR/3 injur*)
10. TS=(selv* NEAR/3 injur*)
11. TS=(themself NEAR/3 injur*)
12. TS=(themselv* NEAR/3 injur*)
13. TS=(self NEAR/3 poison*)
14. TS=(selv* NEAR/3 poison*)
15. TS=(themself NEAR/3 poison*)
16. TS=(themselv* NEAR/3 poison*)
17. TS=(self NEAR/3 cut*)
18. TS=(selv* NEAR/3 cut*)
19. TS=(themself NEAR/3 cut*)
20. TS=(themselv* NEAR/3 cut*)
21. TS="parasuicid**"
22. TS="para suicid**"
23. TS= "self-destruct**"
24. TS="overdos**"
25. TS="attempt* suicid**"
26. 1-25 OR
27. TS= "aging"
28. TS= "ageing"
29. TS="elder**"
30. TS="geriatric**"
31. TS="senior**"
32. TS= "late* life"

33. TS= "late* adulthood"

34. TS="Old* age"

35. TS="Old* people"

36. TS= "Old* person*"

37. TS= "Old* citizen*"

38. TS= "Old* adult*"

39. TS= "Old* male*"

40. TS= "Old* female*"

41. TS= "Old* patient*"

42. TS= "Old* population*"

43. TS= "Old* woman"

44. TS= "Old* women"

45. TS= "Old* men"

46. TS= "Old* man"

47. TS= "pensioner*"

48. TS= "retired"

49. TS= "retirement age"


50. 27-49 OR

51. 26 AND 50

Appendix 2 Information leaflet developed from systematic review

SUMMARISING WHAT WE KNOW

- Self-harm in older adults is a concern.
- There is increased risk of self-harm repetition and suicide in older people.
- Other health related problems are frequent in older adults, and therefore increased access to means (e.g. medication).
- Social isolation, previous mental health problems, financial problems, alcohol and drug use increases risk of self-harm in older adults.
- Older adults visit their GP more frequently, giving an opportunity of detection, access to support and possible prevention.



GETTING HELP

HELPLINES

Samaritans
(Open 24/7)
116 123

Silver Line
(Helpline for older people)
0800 470 8090

Age UK
(Helpline for older people)
0800 055 6112

ONLINE


Mind
(National Organisation)
mind.org.uk

National Self-harm network
(Online forum)
nshn.co.uk

Harmless
(National Organisation)
harmless.org.uk

YOUR GP

Your local GP will be able to provide advice and support.



SELF-HARM IN OLDER ADULTS

This leaflet aims to give information to people affected by self-harm.

The difference

Developed by I. Troya
(PhD student at Keele University)
In collaboration with the study's Patient and Public Involvement and Engagement Group

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INTRODUCTION

Self-harm can affect anyone regardless of age but most of the research on self-harm is about younger people.

WHAT IS SELF-HARM?

There are different definitions as well as words used to describe self-harm.

In the UK, the definition which is mostly used is the one provided by NICE (National Institute of Health and Care Excellence):

"any act of self-poisoning or self-injury carried out by a person irrespective of motivation".

Other words used to describe self-harm:

- Self-injury
- Overdose
- Cutting

Others define self-harm as a coping mechanism that is harmful to a person's well-being.

*NICE (2012). Self-Harm: longer term management. London: NICE

COMMON SELF-HARM METHODS

People self-harm in different ways, but common methods are cutting, burning, overdosing, and hitting one self. In older people, overdose of tablets, often in the context of alcohol use, is common.

WHY IS SELF-HARM IMPORTANT IN OLDER ADULTS?

Despite not being as common as in younger people, self-harm is a concern amongst older adults as self-harm is a risk factor for suicide, and suicide rates are amongst the highest in older men. Self-harm can be hidden – and is not always recognised as a problem by the person or others.

HOUSING OR FINANCIAL WORRIES
BEREAVEMENT OR SOCIAL ISOLATION
HEALTH CONDITIONS
ALCOHOL AND DRUG USE
PAST MENTAL HEALTH PROBLEMS AND/OR SELF-HARM

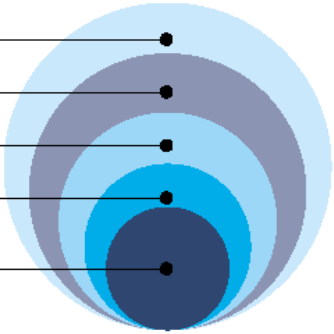
WHAT MAKES OLDER ADULTS SELF-HARM?

Not every older adult who harms him or herself does so with the wish to end their life. Other reasons may be to seek help, gain relief from emotional pain, escape a situation they feel is intolerable, amongst others.

WHO IS MOST AT RISK?

Research suggests that older people with mental health, physical, social, and personal problems are at increased risk of self-harm.

RISK FACTORS FOR SELF-HARM IN OLDER ADULTS



Appendix 3 Recruitment sites contacted example

Available	Organisation	Type	Contact name	Email	Telephone	Website	Address	Contact made	Email	Phone	Response	Action	Number of recruited participants
	Approach	Mental Health older adults	Hilary Stefanelli and Will Voice	enquiries@proachstaffordshire.co.uk	1782214999	http://www.proachstaffordshire.co.uk/	10 Stoke Road. ST42DP	Yes	Email sent Sept 22	Oct 23. Followed up Oct 30 as no response, got new email address	Nov 1 Will Voice CEO from Approach called to set meeting for Nov 16	IT to go to staff meeting Nov 22 and introduce study . Study introduced to staff members which stated not many participants would fit criteria	0
NO	Beyond the scars	Self-harm	Viki	vguy@beyondthescars.co.uk	7876234509	http://www.beyondthescars.co.uk/home.html https://www.facebook.com/beyondthescars1/?ref=timeline_chaining	The Marjorie Griffiths Learning Centre, Beaufort Street. WA51AB	Yes email sent Oct 17	Sent FB message Oct 23 and another one on Oct 30.	Called Oct 23, left voice message	FB response on Oct 30 stating my email will be replied soon. Response Oct 30: Oldest member is 30. No older adults	Sent through post posters and info. Sheet for members to have and refer potential participants- Nov 2. Sent email 03/04/18 inviting support workers of all ages. Response 9/04/18 stating they have no SW just peers	0
	Butterfly Project	Self-harm	Abi Groucutt	butterflyprojectcontact@gmail.com		https://www.butterfly-project.org/ https://www.facebook.com/Thebtrflyproject/	Tontine Road. Chesterfield, Derbyshire	Yes email sent Oct 17. FB message Oct 23	Sent FB message Oct 23	No answer	Yes, no older adults attending	Sent email 03/04/18 inviting support workers of all ages. Response 18/04/18 stating happy to respond via email. No volunteers interested in taking part in telephone interview 01/05/18	0
			Lorraine	lorraine@chan		http://www.changes.org.uk/html/60_mental_health.htm	Victoria Court.		Email sent Sept 22. Follow up email sent Oct 16		Yes, cannot help after LR checked with line manager and suggested to	Sent another email Nov 22 to invite to interviews to support	



Are you willing to help with a study about self-harm and older adults?

Are you...

- 60 years old or older and have, or are currently self-harming?
- OR someone who works with people who self-harm?
- Living in the West Midlands or North West England?
- Willing to speak to a researcher about your views and experiences of care and support for older people who self-harm?

What will I be asked to do?

- Participate in an interview with a researcher

Who is the researcher?



Isabela Troya
PhD Researcher
Research Institute of
Primary Care and Health
Sciences
Keele University

To find out more, please contact Isabela Troya
Email: m.i.troya.bermeo@keele.ac.uk
Telephone: TBC

Appendix 5 Study information leaflets for participants

Understanding self-harm in older adults from support workers' perspectives



THE PROJECT

Not much is known about the experiences of older adults living with self-harm or how best to offer support. This research aims to find about:

- Experiences of older adults who live or have lived with self-harm.
- The sorts of support that might help.

WHY HAVE I BEEN INVITED?

You have been invited to participate in this study because of your work with older adults with self-harm behaviour.

WHO WANTS TO KNOW?



I'm Isabela Troya. I'm doing this research for my PhD at Keele University. My supervisors are Prof. Carolyn Chew-Graham and Dr. Bernadette Bartlam.

WHAT WILL HAPPEN IF I TAKE PART?

If you choose to participate, you will be asked to participate in one 45 to 60 minute interview about your experiences working with older adults who self-harm. Location and time of these will be chosen by you, in order to best suit your convenience. I will ask about your experiences working with older adults who self-harm. Please note that you will not be asked to refer to any identifying information or specific cases when talking about your experiences. With your permission, I will use a digital voice recorder to tape the interview. All the information will be anonymised, so your privacy as a participant can be maintained according to Keele University requirements and the Data Protection Act 2003. Information from our conversation will be transcribed and anonymised, and some parts of it will be included in my doctoral thesis and other academic publications.

HOW WILL MY INFORMATION BE USED?

Information from our conversation(s) will be stored in a password protected computer and locked filing cabinet. The level of identifiability will be reduced to minimum by using pseudonyms and removing identifiable information when writing transcripts. Anonymised information from our conversation(s) will be used when presenting findings in my doctoral thesis, academic papers, and conference presentations. Audio-recordings from your conversation(s) will be destroyed at the end

THE PROJECT

Not much is known about the experiences of older adults living with self-harm. This research aims to find about:

- Experiences of older adults who live or have lived with self-harm.
- The sorts of support that might help.

WHY HAVE I BEEN INVITED?

You have been invited to participate in this study because of your contact with a local self-harm support group and/or being an older adult with previous or current self-harm behaviour.

WHO WANTS TO KNOW?



I'm Isabela Troya. I'm doing this research for my PhD at Keele University. My supervisors are Prof. Carolyn Chew-Graham, Dr. Bernadette Bartlam, and Dr. Opeyemi Babatunde.

WHAT WILL HAPPEN IF I TAKE PART?

If you choose to take part, you will be asked to participate in an interview about your experiences of self-harm. The interview will last between 45 minutes and an hour at a place and time that suits you, or over the phone. With your permission, I will audio record the interviews. At the end of the interview I will check with you that you are still happy to take

part. If you are, I will invite you to have a follow-up interview. Again, you do not have to agree to this - you can decide to take part in one or in both interviews.

HOW WILL MY INFORMATION BE USED?

Information from your interview(s) will be stored on a password protected server at the University. Only I and my supervisors will have access to it. The anonymised information you give will be included in my PhD thesis and in other publications and presentations to other researchers, service providers in the NHS, social care and the voluntary sector and older people themselves. When the research is finished, identifying information and the audio recordings will be destroyed. But, if you agree, the anonymised information will be kept for 5 years. This is so that it can be used in future research. The consent form asks you to tick a box if you agree to this use of your interview in future research.

WHAT ARE THE BENEFITS TO TAKING PART?

If you participate, you will help to increase understanding about reasons older people may self-harm and the impact this can have. This understanding may help improve support and care for people in this situation. There are no direct benefits to you.

WHAT ARE THE RISKS OF TAKING PART?

Talking about previous and current experiences around self-harm might be upsetting. You can ask for the interview to be stopped at any point, and you can change your mind about taking part. As part of the information about the study, you will be given a list of support services for people who self-harm.

DO I HAVE TO TAKE PART?

You do not have to take part. If you do take part, you can stop the interview at any time without giving a reason. For up to three months after the interview you

can change your mind and ask for your interview to be removed from the study. This time period of three months is so that you have time to think about whether or not you still want your information to be used as part of the study.

WHO IS FUNDING THE RESEARCH?

Keele University is funding this research.

WHAT IF I HAVE A CONCERN?

Please contact Prof. Carolyn Chew-Graham on c.a.chew-graham@keele.ac.uk
Telephone: 01782 734717.

If you remain unhappy about the research and/or wish to raise a complaint please write to:

Nicola Leighton – Research Governance Officer
iC1 Building,
Keele University,
Staffordshire ST5 5BG
E-mail: n.leighton@keele.ac.uk

Tel: 01782 733306

NEED MORE INFORMATION?

I'm happy to discuss the research in person or over the phone. Contact at:

Research Institute for Primary Care and Health Sciences, Keele University,
Staffordshire ST5 5BG
Study mobile 07901110472
Email:
m.i.troya.bermeo@keele.ac.uk



Understanding self-harm in older adults

Research Information Sheet

Appendix 6 Newspaper advertisement used for recruitment

30 M.E.N. SATURDAY, FEBRUARY 24, 2018

Classified

Blinds/Curtains

Bond Street Factory Blinds
WE MANUFACTURE ALL OUR BLINDS IN-HOUSE
BIG SALE Lowest Prices

FREE Same Day
Measuring & Next Day Fit
Discounts for Senior Citizens

7 Verticals from only **£99.00**
6 Rollers from only **£99.00**

0161 951 7868
Open 7 Days a Week 8am-10pm

SPEAKY BLINDS
QUALITY BLIND YOU CAN TRUST

3 Verticals from £89 • 3 Rollers from £89
3 Rigid PCV Verticals from £129
Day and Night Rollers, Sangir 3D Blinds from £90.
Restock Latest Capelli, Venetian System 24hrs.
4 Wood Venetians from £199
Turnaround Quickest Turnaround in the UK.

FREE ESTIMATES
0161 9308015



VERTICAL BLINDS SALE!

comfort blinds

3 for £89
UP TO 6FT WIDE
6FT DROP

ALL COLOURS & DESIGNS AVAILABLE!

Domestic Appliances

WASHING MACHINES
From £99
Ex Display/New/Refurbished all available from
www.chopforbargains.club
Tel: 01613558254
Mobile 07905 829 760
Up to £100 Off RRP
COOKERS, FRIDGE FREEZERS, DRYERS, DISHWASHERS.

Kitchens

FITTED KITCHEN

Mill Shops

ADAMLEY TEXTILES



A sale is being held at Adamley Textiles on Saturday 24th February from 10.00 till 1.00 we will have a selection of both woven and printed silks River mills, Langley Macclesfield, Cheshire SK11 0FR 01260 252 483
Tea, coffee and cake for charity
01260 252 483

Wanted

PARTICIPANTS WANTED FOR STUDY ON SELF-HARM***

Are you...
60 years old or older and have, or are currently self-harming?
OR
Someone who works with people who self-harm?
Willing to speak to a researcher about your views and experiences of care and support for older people who self-harm?
What will I be asked to do?
Participate in an interview with a researcher (in person or over the phone)
To find out more, please contact:
Isabela Troya, PhD researcher at Keele University
Email: m.i.troya.bermeo@keele.ac.uk
07901110472

Articles For Sale

Appendix 7 Independent peer review approval



RESEARCH SUPPORT SERVICES

18 April 2017

Isabela Troya
Research Institute for Primary Care and Health Sciences
Keele University

Dear Isabela

Understanding Self-harm in older adults: a qualitative study

The above project has received approval from the Keele Independent Peer Review Committee and is permitted to progress for ethical review. Please find attached the peer review comments and accompanying letter for the above project. NHS RECs request that all peer review proforma/s are submitted along with your NHS REC application.

Although this project has been deemed appropriate based on scientific merit, you may wish to incorporate the reviewer's constructive comments to strengthen your protocol.

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Clinical trial of a medicinal product

Please remember that, if your project is a clinical trial of a medicinal product, MHRA approval is required. You must submit a request for a clinical trial authorisation under the Medicines for Human Use (Clinical Trials) Regulations 2004. Further details can be found at <http://www.mhra.gov.uk/home/groups/l-unit1/documents/websitesresources/con2022633.pdf>

If you have any queries, please do not hesitate to contact Nicola Leighton on 01782 733306

Yours sincerely

A handwritten signature in black ink that reads 'N. Leighton' with 'pp' written below it.

Professor N Edelstyn
Chair – Independent Peer Review Committee

Enc

CC R&D Office

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK
Telephone: + 44 (0)1782 734466 Fax: + 44 (0)1782 733740

Appendix 8 Ethics approval granted from Keele University



Ref: ERP1333

9th June 2017

Isabela Troya
Research Institute of Primary Care and Health Sciences
David Weatherall Building
Keele University

Dear Isabela,

Re: Understanding self-harm in older adults: a qualitative study

Thank you for submitting your revised application for review. The panel would like to commend you for your clear and comprehensive response and amendments.

I am pleased to inform you that your application has been approved by the Ethics Review Panel. The following documents have been reviewed and approved by the panel as follows:

Document(s)	Version Number	Date
Flow Chart – Recruitment of Participants	1.0	24-04-2017
Risk Protocol	1.0	24-04-2017
Recruitment Poster	1.0	24-04-2017
Invitation Letter	1.0	24-04-2017
Older Adults Information Sheet	2.0	19-05-2017
Support Workers Information Sheet	2.0	19-05-2017
Text for Social Media	1.0	24-04-2017
Recruitment Strategies	1.0	24-04-2017
Consent Form – Older Adults Interview 1	2.0	19-05-2017
Consent Form – Older Adults Interview 2	2.0	19-05-2017
Consent Form – Support Workers	2.0	19-05-2017
Cover Letter final report findings	2.0	19-05-2017
Participant Withdrawal Letter	1.0	27-04-2017
Topic Guide Adults – First Interview	1.0	24-04-2017
Topic Guide Adults – Second Interview	1.0	24-04-2017
Topic Guide – Support Workers	2.0	19-05-2017

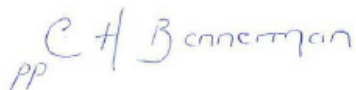
Directorate of Engagement & Partnerships
T: +44(0)1782 734467

Keele University, Staffordshire ST5 5BG, UK
www.keele.ac.uk +44 (0)1782 732000

If the fieldwork goes beyond the date stated in your application, 30th September 2020, 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 ERP1 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on research.governance@keele.ac.uk stating ERP1 in the subject line of the e-mail.

Yours sincerely

Handwritten signature of C H Benneman in blue ink. The signature is written in a cursive style. To the left of the main signature, the letters 'PP' are written in a smaller, simpler font.

Dr Jackie Waterfield
Chair – Ethical Review Panel

CC RI Manager
Supervisor

24/11/2017

Dear Isabela

PI: Isabela Troya

Title: Understanding self-harm in older adults: a qualitative study


ERP No: ERP1333

Thank you for submitting your revised application for review. I am pleased to inform you that your application has been approved by Chair's actions.

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 <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries please do not hesitate to contact me stating **ERP1333** in the subject line of the e-mail.

Yours sincerely
PP.



Andrew Rutherford
Acting Chair – Ethical Review Panel (ERP1)

16/02/2018

Dear Isabela

PI: Isabela Troya Bermeo
Title: Understanding self-harm in older adults: a qualitative study
Ref: ERP1333

Thank you for your request to amend your study.

I am pleased to inform you that your request, received on 9th February 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 ERP1333 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 Andrew Rutherford
Chair – Ethical Review Panel

26/03/2018

Dear Isabela

PI: Isabela Troya Bermeo
Title: Understanding self-harm in older adults: a qualitative study
Ref: ERP1333

Thank you for your request to amend your study.

I am pleased to inform you that your request, received on 1st March 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 **ERP1333** 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.



Andrew Rutherford
Chair – Ethical Review Panel

Appendix 9 Coding of separate groups from Data Analysis from NVivo 11

Self-harm in older adults (Recovered) (7).nvp - NVivo Pro

FILE HOME CREATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW

Go Refresh Open Properties Edit Paste Copy Merge Cut Copy Merge B I U A Format Paragraph Styles Reset Settings Select PDF Selection Text Region Find Replace Delete Insert ABC Spelling

Workspace Item Clipboard Editing Proofing

Nodes Look for Search In Nodes Find Now Clear Advanced Find

Nodes

- Nodes
- Cases
- Relationships
- Node Matrices

Name	Sources	References	Created On	Created By	Modified On	Modified By
(OA) Sources of support		10	23 12/01/2018 13:50	IT	19/09/2018 16:18	IT
Family		16	89 12/01/2018 13:50	IT	19/09/2018 16:04	IT
Friends		8	17 22/01/2018 14:50	IT	19/09/2018 16:02	IT
Insufficient staff funding healthcare		5	9 14/02/2018 09:26	IT	30/07/2018 15:33	IT
Internet		11	25 12/01/2018 13:50	IT	19/09/2018 15:18	IT
Other		5	7 14/02/2018 14:39	IT	18/06/2018 11:44	IT
Pharmacological treatment		5	6 14/02/2018 10:10	IT	04/06/2018 13:33	IT
Primary care		15	58 22/01/2018 14:22	IT	19/09/2018 16:12	IT
Secondary care		16	101 22/01/2018 10:46	IT	19/09/2018 16:12	IT
Self-management		8	22 08/03/2018 15:22	IT	30/07/2018 14:56	IT
Social services		4	6 27/02/2018 09:13	IT	19/03/2018 14:43	IT
Spirituality		6	19 13/02/2018 18:51	IT	18/06/2018 12:01	IT
Third sector		15	80 12/01/2018 13:50	IT	19/09/2018 16:16	IT
Work and volunteer		7	13 29/01/2018 15:19	IT	30/07/2018 15:39	IT
(OA) Start of SH		10	16 12/01/2018 13:46	IT	19/09/2018 15:18	IT
(OA) Stressors and social factors leading to SH and MH problems		8	49 12/01/2018 14:43	IT	30/07/2018 15:41	IT
(OA) Views of the future		1	1 16/04/2018 09:48	IT	18/06/2018 12:08	IT
(SW) Age		7	27 14/12/2017 09:30	IT	04/06/2018 15:49	IT
(SW) Cycle of self-harm		2	9 14/12/2017 10:04	IT	16/04/2018 11:11	IT
(SW) Limited understanding and stigma of self-harm		4	10 20/12/2017 10:27	IT	02/05/2018 12:22	IT
(SW) Other		2	5 14/12/2017 16:49	IT	04/06/2018 14:06	IT
(SW) Reasons and function of self-harm		5	19 13/12/2017 11:58	IT	04/06/2018 15:54	IT
(SW) Role as support worker and organisation		6	51 13/12/2017 10:08	IT	24/05/2018 16:33	IT
(SW) Seeking help and support for self-harm		4	6 13/12/2017 11:45	IT	04/06/2018 15:40	IT
(SW) Self-harm definition		4	6 14/12/2017 13:26	IT	24/05/2018 16:33	IT
(SW) Self-harm experience in later life		4	8 14/12/2017 10:14	IT	02/05/2018 11:30	IT
(SW) SH recovery		2	10 16/04/2018 10:26	IT	04/06/2018 15:53	IT
(SW) Support		2	4 14/12/2017 10:16	IT	04/06/2018 15:17	IT
Family		6	18 14/12/2017 10:16	IT	04/06/2018 15:47	IT
Hollistic		2	10 24/05/2018 15:36	IT	04/06/2018 15:51	IT
Internet		5	9 16/04/2018 11:32	IT	04/06/2018 15:48	IT
Multifactorial support and treatment		4	7 19/12/2017 11:03	IT	04/06/2018 15:17	IT
Primary care		6	13 19/12/2017 11:12	IT	04/06/2018 15:40	IT
Social care sector		3	8 02/05/2018 11:12	IT	04/06/2018 15:38	IT

Sources

Nodes

Classifications

Collections

Queries

Reports

Maps

Folders

IT 235 Items

Appendix 10 Illustration of data analysis



Appendix 11 Notes from first PPIE meeting

Understanding self-harm in older adults

PhD project Isabela Troya

Notes of Patient and Public Involvement and Engagement (PPIE) meeting 19/01/2017

Present

Isabela Troya PhD student (IT)

Carolyn Chew-Graham PhD supervisor (CCG)

Adele Higginbottom

Carrol (attended at ECHO)

Chris (husband of Carrol)

Fiona (support worker, ECHO)

Introductions

Isabela introduced herself and her project, as well as the Academic supervisory team, Professor Carolyn Chew-Graham and Dr. Bernadette Bartlam, with the aid of a Power Point Presentation (attached) and the group introduced themselves. Isabela explained that the idea for the PhD project had come from a PPIE group working with CCG. The PhD sits within the Mental Health Research Programme in the Research Institute (Primary Care & Health Sciences) and is funded by Keele University. This demonstrates how important mental health and self-harm are perceived to be by Keele University.

The project

IT introduced her research questions and the group discussed them. Experiences were shared and the research team are very grateful for the openness. We discussed the stigma associated with self-harm and why people find it difficult to seek help. It was agreed that the second research question would be modified to include an exploration of what helps and what stops people seeking help. It was suggested that the third question might assume that people always have family support, or that family is always helpful. The question needs to be re-phrased to be more neutral. Fiona highlighted that there are very few statutory services for people who self-harm.

The term 'self-harm' was discussed, Fiona advised that ECHO use the term "a coping mechanism that is detrimental to a person's well-being"; and the reason for the definition of an older adult being over 60 years was agreed (World Health Organisation definition).

IT outlined her plans for interviews with older adults. For the second part of her project, IT asked the group whether she should interview GPs or support workers in support groups/non-statutory services. CCG advised that if GPs were interviewed, we would most likely interview GPs who are already interested in the topic, and we might uncover a lack of knowledge about how to manage people who self-harm. CCG suggested that interviewing support workers would enable us to describe current good practice. It was suggested that another group to interview might be psychologists or psychotherapists. CCG advised that as most people who

self-harm do not access specialist care and as the PhD is situated in primary care, this is perhaps of less value. IT and CCG will take views on whether to interview GPs or support workers back to the research team for further discussion.

Documents for ethics application

IT advised that she had to obtain approval from an ethics committee before she is able to conduct the study.

Poster

This was thought to be clear and easy to read.

It was suggested that the phrase 'contact your local support group administrator' should be removed.

CCG advised that, as there is no ansaphone facility on the student office telephone, we need to organize a 'pay as you go' phone for IT.

Topic guide for interview

Carrol said that the suggested questions are acceptable.

Consent form

It was suggested that in point 3, the statement includes '...I have up to three months from the date of the first interview to inform the researcher that I do not want any information collected about myself to be used'.

Information sheet

Adele suggested that 'dissemination' is not a word that should be used in a document intended for a lay audience. Adele also highlighted a number of typographical and grammatical errors. Carrol felt the information sheet was clear.

Wording for social media (Facebook and blogs)

No comments

IT asked that if anyone had further comments, then she would be happy to receive them by e-mail.

PPIE input

IT outlined her hope that further meetings would be held so that she could have PPIE input into her study, early analysis and advice about how to publicize the results of the study. She suggested a further meeting on March 8th 2017; Adele advised that IT needs to ensure a room is available.

IT agreed to check room availability and then to contact the group to confirm or change this date.

IT thanked everyone for attending.

CCG 22/01/2017

Appendix 12 Example of quarterly updated with PPIE group: postcard

Study feedback for the Research User Group

Understanding self-harm in older adults

March 20th, 2018

Dear

Thank you for your continued involvement in the UNDERSTANDING SELF-HARM IN OLDER ADULTS study. Your contributions are extremely important, and our researchers value them highly.

To keep you informed of the progress of the study, here is a brief update:

What has happened in the study since the last PPIE meeting?

The information leaflet (based on the systematic review) on self-harm in older adults has now been completed and approved by the University for distribution. The information leaflet will be distributed to GP practices, third sector organisations, pharmacies, libraries, amongst others.

Recruitment for the qualitative study has now stopped, resulting in a total of 24 interviews with older adults and support workers after 12 months of recruitment. Analysis of the interviews is currently ongoing.

How will we change /have changed the study as a result of your contribution?

After getting your input and interpretation of the systematic review results over the last couple of workshops, the information leaflet produced will be accessible and of use to older adults, carers, support workers and health care providers.

Furthermore, the initial discussion held during our last meeting has helped me further understand self-harm in older adults. When reviewing the interview transcripts during our last meeting,

What will happen in the next few months?

I will continue analysing the interviews conducted with older adults and support workers, and further develop themes. I hope to have a final meeting with you next Spring in order to finalise the development of the themes emerging from the analysis of the interviews. I also hope we can think of avenue of dissemination for the findings of the qualitative study.

Kind Regards

M. Isabela Troya

Appendix 13 List of outputs resulting from PhD

Peer-reviewed publications

Troya, M. I., Bartlam, B., & Chew-Graham, C. A. (2018). Involving the public in health research in Latin America: making the case for mental health. *PanAmerican Journal of Public Health*, 42, e45. <https://doi.org/10.26633/RPSP.2018.45>

Troya, M.I., Babatunde, O., Polidano, K., Bartlam, B., McCloskey, E., Dikomitis, L., Chew-Graham, C.A. (2019a) Self-harm in older adults: a systematic review. *British Journal of Psychiatry*, 214(4), 186-200. doi:10.1192/bjp.2019.11

Troya, M.I., Chew-Graham, C.A., Babatunde, O., Bartlam, B., Mughal, F., Dikomitis, L. (2019b). The role of primary care in supporting older adults who self-harm: a qualitative study. *British Journal of General Practice* [In press]

Troya, M.I., Chew-Graham, C.A., Babatunde, O., Bartlam, B., Higginbottom, A., Dikomitis, L. (2019c). Patient and Public Involvement and Engagement in a doctoral research project exploring self-harm in older adults. *Health Expectations*, 00, 1-15. doi: 10.1111/hex.12917

Troya, M.I., Dikomitis, L., Babatunde, O., Bartlam, B., Chew-Graham, C.A. (2019d). Understanding self-harm in older adults: a qualitative study. *EClinicalMedicine*, <https://doi.org/10.1016/j.eclinm.2019.06.002>

Conference Presentations

Troya, M.I. (2019). Self-harm in older adults: a qualitative study. Oral Presentation International Association for Suicide Prevention Congress, Derry, Northern Ireland, September 17-21, 2019.

Troya, M.I. (2019). Self-harm in older adults: a qualitative study. Oral Presentation International Association of Gerontology and Geriatrics European Region Conference, Gothenburg, Sweden, May 23-25, 2019.

Troya, M.I. (2019). From neonatal to elderly care: What can we learn from healthcare systems abroad? Invited panel member Global Health Challenges Conference, Keele University, February 23, 2019.

Troya, M.I. (2018). A qualitative study on self-harm in older adults. Oral Presentation European Symposium for Suicide and Suicidal Behavior, Ghent, Belgium, September 2018.

Troya, M.I. (2018). Self-harm in older adults: a systematic review. Oral Presentation British Society of Gerontology, University of Manchester, England, July 2018.

Troya, M.I. (2018). A qualitative study on self-harm in older adults. Oral Presentation Early Career Researcher's Forum in Suicide and Suicidal Behavior, Glasgow, Scotland, June 2017.

Troya, M.I. (2017) Self-harm in older adults: a systematic review. Oral Presentation Society of Academic Primary Care North, Kendal, England, November 2017.

Lay dissemination

Troya, M.I. (2018). Self-harm in older adults information leaflet developed from systematic review <https://www.nspa.org.uk/resources/4020/>

Troya, M.I. (2018). The value of qualitative research methods in suicide prevention & suicidal behavior research. Blog post written for The International Network of Early Career Researchers in Suicide and Self-harm. <https://bit.ly/2yt3aDE>

Appendix 14 Video script for dissemination of PhD

Video script: Self-harm in older adults

This is Larry. Larry is 66 years old and recently widowed. Larry has been struggling to cope since he lost his wife Edith to cancer. Larry hasn't been feeling very well since and has started to fall back to some patterns he used to rely on when he was younger and found himself in distress. It's been many years since Larry stopped hurting himself, as he had found other ways to cope with distress [show images of children, marriage, work, etc.]

Larry knows he needs to ask for help because his suicidal thoughts are back and doesn't know whether he'll be able to cope without hurting himself again. However, there are many reasons that are preventing Larry to get the support he needs. Larry doesn't want to worry his children, they've had a tough time getting over their mother's death and are all very busy with their own families. Larry had to give up his car a few years ago, after complications due to diabetes which affected his eyesight.

Even if he were to manage to go see his doctor, Larry feels embarrassed. It had been a long time since he had suicidal thoughts and had hurt himself, he was not a child anymore he said [speech bubble I shouldn't be feeling like this]. What would he say? How would he bring it up in the consultation? How would the doctor react? Would he be unsupportive or even dismiss Larry's thoughts?

Despite all this, Larry reaches out and asks for help (show images of Larry visiting his doctor, peer support groups)

Not everyone will have the same problems as Larry does. However, struggling with suicidal thoughts and self-harm can be hard, lonely, and isolating. You don't have to do it alone. Ask for help, get support. Call [support line], tell your doctor. Challenge the stigma behind mental health, the change begins with you.

Targeted duration: 1 minute