

EXPLORING THE NEEDS AND EXPERIENCES OF FAMILY CARERS AFFECTED BY
HARMFUL BEHAVIOUR BY THE OLDER PERSON FOR WHOM THEY CARE

by

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Abstract

This thesis reports a qualitative, empirical study that explored the experiences of family carers affected by violent, abusive or harmful behaviour by the older person for whom they cared. Co-designed with a network of carer-advisors, the empirical phases of the study involved: a systematic literature review of qualitative, quantitative and mixed-methods research; in-depth interviews with twelve female carers affected by harmful behaviour; and five focus groups with thirty-eight health and social care practitioners. Orientated within a social constructionist framework, the carer and practitioner accounts were initially analysed using a thematic approach (Braun & Clarke, 2006). The theory of epistemic injustice and the concept of ‘hermeneutic injustice’ (Fricker, 2007) informed a ‘deeper’, theory-informed synthesis of the accounts. This study suggests that surfacing the powerful and distinctive epistemic and ethical practices that can shape intimate relationships opens important, under-explored lines of inquiry and discussion about what constitutes harm, abuse and risk. Such an approach also highlights how the framing of ‘carer harm’ as a private, moral issue reinforces the view that if adults have the cognitive capacity to make decisions, then they are free to do so and, in effect, to tolerate and live with harm. This study critiques this view and explores the unintended implications that such a perspective can engender. It concludes by considering future directions for research, practice and policy with the aim of improving identification and responses to carer harm.

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Chapter 1: Introduction

Carer harm in the context of a globally ageing population

In the last fifty years the average age of mortality has risen steadily and the proportion of older people relative to younger adults and children continues to increase year-on-year (World Health Organization, 2015). Within these ageing populations, many people are experiencing chronic and complex health conditions in later life and living at home at end-of-life (Pin & Spini, 2016). Families are the single largest group of caregivers for older people, with elder spouses and adult children being the family members most likely to take on the role of caregiver (Pinquart & Sörensen, 2011). For some families, the challenges of illness and caregiving are particularly intense and complex and ‘caregiver burden’ can increase the risk of poor care developing into elder abuse (Momtaz, Hamid & Ibrahim, 2013). This involves caregivers acting in an abusive, neglectful manner towards older family members: exploiting their position of vulnerability and/ or failing (by omission or commission) to meet the health and welfare needs of someone who is dependent on them in a significant if not total way (Cooper, Seelwood & Livingston 2008). Research has played a critical role in mapping the prevalence and impact of elder abuse. In turn, this has shaped an increasing concern in health and social care practice to identify, prevent and intervene in cases of elder abuse in families (Pillemer, Burnes, Riffin & Lachs, 2016).

However, there has been much less consideration of what happens when it is the family caregiver who is adversely affected by the violent or abusive behaviour of the older person for whom they care. This can arise from the following types of behaviour: when caregivers experience frequent and extreme verbal, physical and sexual violence; when caregivers feel manipulated and controlled by their family member; and when families live in unpredictable, often chaotic circumstances in which the dynamics of power, love and duty are complex and

closely intertwined (Daniel & Bowes, 2010; Probst, Di Gregorio & Marks, 2013). This in turn gives rise to a number of key questions: How do caregivers respond to violent and abusive behaviour and how do they make sense of it? What is the impact of such behaviour on both the caregiver and older person? To what extent is it an extension of ‘caregiver burden’ and is it a form of domestic abuse or harm? These questions highlight the importance of giving careful consideration to how we talk about and identify harmful behaviour when issues of vulnerability, need and risk are blurred. In the following sections of this chapter, I outline some of the contexts in which carer harm by older people may occur.

Older age violence and abuse in illness and disease

One of the most prevalent and disabling diseases affecting older people is dementia. Prince, Bryce, Albanese, Wilmo, Ribeiro and Ferri (2013) estimated that the number of people affected by dementia would double every twenty years, reaching a total of 115.4 million by 2050 (Prince et al., 2013). There is an association between increased rates of violent behaviour - often referred to as ‘behavioural disturbance’ or ‘challenging behaviour’ – and dementia type illnesses. This is because the intensity and frequency of somatic symptoms (such as pain, tiredness and hunger) can result in the person affected finding personal care invasive and unwanted. This, in turn, can make some caregiving situations sites of tension and conflict (Enmarker, Olsen & Hellen, 2011). Additionally, day-to-day social activities and conversations can lead to feelings of stress, anxiety and frustration if communication and memory are impaired. This can lead to physical and verbal violence as forms of alternative communication (Duxbury, Pulsford, Hadi & Sykes, 2013). People with dementia can also experience emotional dysregulation, which is manifested in limited impulse control and an impaired ability to anticipate and address emotional cues (Gormley, Lyons, & Howard,

2001). This too may result in aggressive behaviour, physical and verbal violence and sexual disinhibition (Rosen, Lachs & Pillemer, 2010).

To date, most research about violence towards caregivers by dementia patients investigates the experiences of formal caregivers working in nursing home and hospital settings, rather than those of family caregivers (Wharton & Ford, 2014). There may be some common elements found in formal and informal caregiving situations, however, there are also significant differences. For example, a review of studies that had investigated violence by adults with a serious mental illness (SMI) towards their family members, found limited research on the topic (Solomon, Cavanagh & Gelles, 2005). The authors found prevalence rates of violence towards family members by people with SMI to be between 10-40% and concluded that there are multiple and complex reasons why people may become violent, including how their caregivers recognise and respond to signs of illness and distress (Solomon et al., 2005). Furthermore, family caregivers are likely to have less training and education than professional caregivers when it comes to violence prevention and de-escalation (Philips, deAron & Briones, 2001). Research finds that the emotional impact of being subject to violence or abuse is particularly acute for family caregivers (Hsu & Tu, 2014).

Another aspect of informal caring relationships is that coming to terms with the loss of physical and cognitive function is often a difficult and emotionally demanding experience for older adults with dementia and for their families (Desai, Schawrtz and Grossberg, 2012). Illness can bring about loss of role, status and profound changes to a person's identity and relationships with others. In dementia, as with other illnesses, such existential challenges may cause some people to find new ways of exerting power or influence in their intimate

relationships: for example, by taking on new roles and responsibilities or by demanding high levels of attention and emotional support (McDonald & Thomas, 2013). Thus the dynamics of care and dependency are often complex in intimate relationships in later life and the causes and nature of violence or 'dysfunctional' behaviour can take on new meanings, particularly in illness (Roberto, 2016). In extreme cases, lethal violence is a way of alleviating suffering, as in the case of mercy killing or homicide-suicide 'pacts' between couples when one or both people are affected by a terminal disease (Cohen, 2004). More commonly, patterns or incidents of difficult and abusive behaviour are shaped by expectations and obligations that arise from caring in the context of a long-term relationship, infused with personal meaning and social implications.

Older age intimate partner violence

Harmful and violent behaviour by and towards older adults may take place within the context of older age intimate partner violence (IPV). IPV in older age is associated with complex and enduring negative health outcomes for those affected (Beaulaurier, Seff, Newman & Dunlop, 2006) and is frequently characterised as a sensitive and mainly 'hidden' issue (Crockett, Cooper & Brandl, 2018; Safe Lives, 2016). In a qualitative literature review of studies investigating IPV towards older women, Fingfeld-Connet (2014) found that generational and gendered norms about the privacy and sanctity of family life inhibited disclosure and help-seeking by older women and normalised patterns of abuse and violence (Fingfeld-Connett, 2014). In addition, feelings of moral obligation, social shame and concerns about the emotional and practical upheaval of re-building a life after decades of married and family life affect decisions about remaining in abusive relationships (Policastro & Finn, 2015). The limited visibility and lack of awareness of the needs of older victims of IPV and the paucity of tailored domestic abuse services for this population have also been identified as an area of

concern (Lundy & Grossman, 2004; McGarry & Simpson, 2011). Domestic violence ‘grown old’ - understood as a continuation and development of abusive behaviours that stem from adulthood but are also manifest in later life – also remains a poorly recognised issue in terms of research literature and service organisation (Brossoie & Robert, 2015; McGarry & Simpson, 2011; McGarry, Robins, Bellamy, Banks & Simpson, 2017). Moreover, until recently there has been limited research or practice guidance that focuses specifically on the intersection between dimensions of elder and domestic abuse in later life (Strumpel, 2011).

Care and caring in the context of family relationships

There is a well-established evidence base highlighting that caring for someone with complex needs is associated with increased risks of poor physical and mental health, higher levels of social isolation and unstable or poor employment (Age UK & Carers UK, 2016; Carmichael & Ercolani, 2016). Yet, in a recent large-scale scoping review, Larkin, Henwood and Milne (2018) found that there is a relative paucity of research that explores caring from a relational or systemic perspective. The authors suggest that much contemporary research does not capture the “complexity of caring” (p.7) and “runs counter to the lived experience of carers and to the life-course of the dyad” (p.8) because it fails to recognise that many carers experience the role as primarily relational, imbued with biographical and social meaning (Larkin, Henwood & Milne, 2018).

There is a small but growing body of research and theoretical literature that conceptualises giving and receiving care as primarily relational and emotional experiences people engage in throughout their lives (for example Barnes, 2011; Kittay, 2011). This work, sometimes referred to as the ‘ethics of care’ movement, stems from feminist critiques about the hidden and gendered nature of informal and formal care work. One of the movement’s principal

aims is to challenge the conceptualisation of care as a prescribed set of tasks, predicated by an individual's medical needs. Advocates of the ethics of care approach also highlight that this perspective tends to overlook the complex technical skills and specialist knowledge often required to care for another person (Barnes, 2011). It also tends to minimise 'non-visible' dimensions of caring dynamics, such as the cultivation and expenditure of emotional labour, particularly when carried out on a regular or long-term basis in formal care contexts (Hewison & Sawbridge, 2016).

Scholars and practitioners also argue that 'private' and 'personal' spaces are significantly shaped by the (unequal) distribution of social and political resources that characterise other areas of social life and that informal care needs to be understood within this wider context (Kittay, 2009; Barnes, 2008). Thus, the low social and economic value placed on formal and informal care practices reflects latent assumptions that caring is a 'natural' exercise: an expression of common humanity or empathy, and one that women are socially conditioned to value and to accept, in their personal and professional lives. Instead, ethics of care scholars argue that caring is a multi-dimensional, dynamic process, particularly in informal relationships. It is foregrounded in inter-dependent and reciprocal relationships that are often based on identities, commitments and feelings forged across the life-course (Fine & Glendenning, 2005; Lloyd, 2000; Forbat, 2005).

Overview of this thesis

It is against the backdrop of these intersecting debates and issues that this study was conceived and, as an initial step, a systematic literature review of mixed-methods research investigating the 'hidden' issue of harmful, violent and abusive behaviour towards family carers was conducted. The following chapter reports on the findings of this review. The next

chapter outlines the principal methods and methodological features of this study. Following this, the empirical findings are shared and discussed in three chapters: the first chapter presents a thematic analysis of the carers' accounts, the second presents a thematic analysis of the health and social care practitioners' accounts and the third chapter synthesises these findings and explores them with reference to Fricker's theory of epistemic injustice. Following this, the next chapter focuses on my reflections on the principal practical, ethical and methodological issues that arose when recruiting and engaging with advisors and participants. This thesis concludes by discussing to what extent it is valuable and appropriate to consider carer harm a 'type' of abuse, as defined and operationalised under the Care Act (2014). With the aim of improving identification and responses to carer harm, this discussion foregrounds the study's recommendations about future directions for affected families, research, practice and policy.

Chapter 2 Literature review

Chapter overview

This chapter reports the findings of a systematic literature review of eighteen studies that investigated violent and abusive behaviour by older people towards their family carers. The review identified three central themes in the literature: 1) There are inconsistent definitions and measurements used in research on harmful, violent and abusive behaviour towards family carers. 2) Violent and abusive behaviour towards carers is frequently framed as a sensitive and hidden topic. 3) There is some evidence to suggest that people who were violent and abusive in their earlier life - or who had a poor relationship with their family member in the past - are more likely to continue to experience violence and abusive behaviour in later life. There were two main ways in which violence and abuse were conceptualised and investigated: as a 'symptom of illness' and as an 'act of abuse'. To conclude, I present a visual map of the relationship between these two conceptualisations, drawn from my analysis of the literature. My supervisors and I published the findings of the review (Isham, Hewison & Bradbury-Jones, 2017) and, as the main author and primary researcher of this work, I have included material from the manuscript in this chapter (see appendix 6).

Methods

A review of mixed-methods research

The aim of the review was to identify, synthesise and examine critically the available empirical and theoretical literature relating to family carers' experiences of violent and abusive behaviour from the older person for whom they care. Because carrying out a literature review is a useful exercise in the initial stages of developing knowledge about a topic, I started work on this review in the early months of this doctoral project. Although the process of analysing and synthesising the empirical findings was refined and developed over

a longer period, the initial findings from the review informed the empirical and conceptual design of the project thereafter.

By systematically identifying literature from a wide range of sources, the review process can identify areas of agreement and consensus between studies as well as areas of difference. It can also pinpoint where there is limited work on a topic and this identify so-called ‘gaps’ in the research landscape. I used a mixed-methods research synthesis approach for this review (Joanna Briggs Institute, 2014). The term ‘mixed-methods’ has different definitions in the context of reviewing literature (Harden, 2010) and I use the term to reflect that the review encompassed studies which used a range of methodological designs. This approach is increasingly used in the study of complex topic areas that are multi-dimensional and difficult to capture using only one theoretical or technical approach (Grant & Booth, 2009). It has also been used to explore new or developing areas of study, particularly those where there is limited empirical evidence or a lack of clarity concerning the central concepts and definitions of the phenomena in question (Pluye & Hong, 2014). For example, Stewart, Jackson, Mannix, Wilkes and Lines (2005) carried out a mixed-methods review of the complex and previously under-researched issue of child-to-parent violence. They drew on studies reporting analyses of crime statistics as well as studies that presented qualitative data about parents’ experiences. As a result, their mixed-methods synthesis helped to map what was known about the issue across a range of empirical fora. This in turn foregrounded their recommendations about how child-to-parent violence could be helpfully conceptualised in future practice and research-orientated work (Stewart, Jackson, Mannix, Wilkes, & Lines, 2005). Thus, there is value in comparing, contrasting and integrating different types of evidence. In this review, examining studies which employed different methods to investigate

carer harm enabled me to critically engage with an issue that was conceptually complex *and* under-researched and under-theorised.

Identification of studies

The first phase of the review took place between October and November 2015 and consisted of an exploratory search for relevant papers. This exercise informed the development of the review's inclusion/ exclusion criteria. Following this, in December 2015, I carried out a systematic search using four electronic databases: Web of Science, ProQuest Nursing and Allied Health, Medline and Cinahl Plus. These databases cover a range of clinical, practice and research interests and specialisms, which gave the review breadth. However, for the most part, these databases include medical, health and social science studies. As a result, studies from the psychological and philosophical disciplines may have been under-represented in the review. During this stage of identifying papers, I did not set a period for publication as a criterion for inclusion and I only included papers published in the English language. This may have limited the number of studies and the range of cultural and social perspectives encompassed in the review process. The studies included in the final sample were published between the years 1992 and 2014.

Table 1 shows the inclusion criteria used to identify papers for review. In order to identify the maximum number of potential papers, I used a range of paired search terms in conjunction with Boolean operators. To identify literature relating to family carers, the terms 'carers', 'informal carers', 'family members' and 'carer burden' were used. These synonyms were combined with a group of terms to identify older people. The phrases 'older people', 'elderly' and 'geriatric' were used to identify studies relating to this population. For some databases, it was appropriate to select the relevant 'population' group (people aged over 65

years old) if this option was available. In order to capture papers relating to violence and abuse, the terms ‘violence’, ‘patient aggression’, ‘patient-initiated assault’, ‘family violence’, ‘IPV’, ‘patient-initiated violence’ and ‘carer assault’ were used as synonyms. Figure 1 outlines the results of the search and screening process.

Inclusion criteria	<ul style="list-style-type: none"> • The care recipient is as an older person. Age is identified by any appropriate synonym (i.e. elderly, aged, geriatric) rather than an age range. • The care recipient has health needs that require care giving (e.g. they have a physical and/ or mental health illness that is either diagnosed or recognised as such). Care-giving is not defined by number of hours caring per week or by the nature of the family member’s health condition. The paper may not use the term ‘carer’ but the experience of caring and violence within illness is a major theme/ finding. • The care-givers are family members of the care-recipient (spouse, adult child, sibling, etc) and the care relationship takes place in a domestic setting. • The research explores care-giver experiences of violence and abuse from the care recipient towards the care-giver. Violence and abuse can be identified by an appropriate synonym (i.e. aggression, power and control, attack). Violence and abusive behaviour encompasses physical, psychological, sexual and financial acts/ patterns of behaviour.
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Table 1: Inclusion criteria for reviewed studies

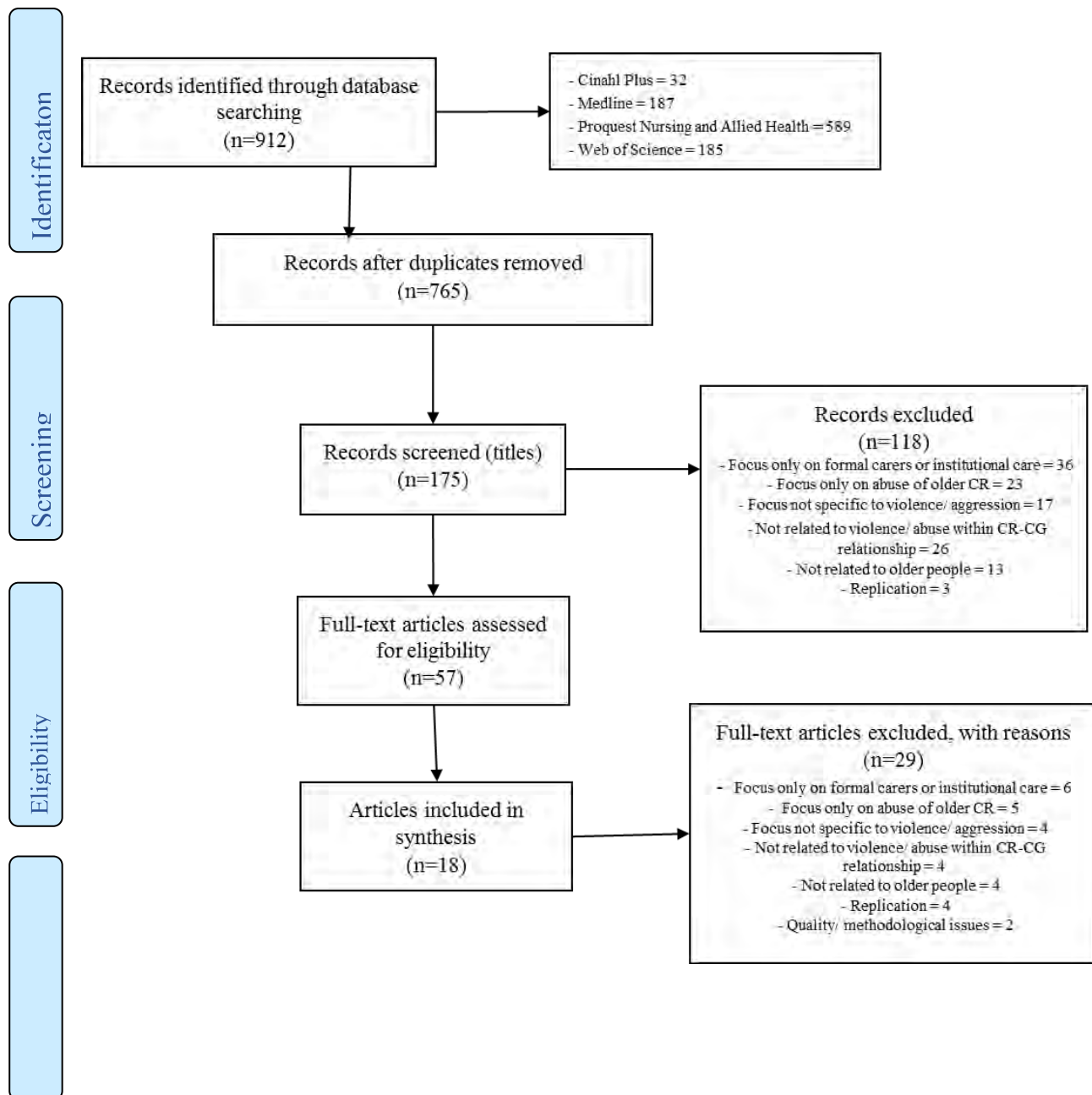


Figure 1: PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) flow diagram of search and screening process (Liberati, et al, 2009)

Quality appraisal and methods of analysis

I used three tools to assess the quality of the different papers and made detailed assessments of each paper as appropriate to the standards and expectations of the methodological approach taken. For the observational quantitative research, I used the National Institute for Health and Care Excellence assessment tool (NICE, 2012); for the qualitative studies, I applied the Critical Appraisal Skills Programme tool (CASP, 2013) and for the mixed-methods papers, I used guidance set out by Pluye, Gagon, Griffiths & Johnson-Lafleur (2009). Following this, the findings from each study were synthesised using a thematic approach (Pluye et al., 2009). This is a common feature of literature reviews of papers incorporating mixed-methods literature because the quantitative data being reviewed cannot be aggregated and analysed using statistical methods. This is often because the studies employ different measurement tools and/ or the study populations are too dissimilar and therefore results cannot be compared on a 'like-for-like' basis (Thomas & Harden, 2008). Because this review included studies of varying design and quality, a thematic approach was considered the most appropriate way of making sense of this heterogeneity.

Thematic analysis, as characterised by Thomas and Harden (2008) involves three steps. Initially, the texts (in this case, the papers) were read and coded in small text segments. At this stage, codes reflecting the descriptive meaning of the text were assigned. The second step involved grouping the codes and interpreting how they related to one another. Finally, the overarching themes were drawn out and a 'narrative' or framework for understanding was developed (Hannes & Macaitis, 2012). As the primary researcher, I led this process of coding and thematic development. My work was subsequently checked and discussed critically with my supervisors and this facilitated an iterative, reflective process of interpretation. It was particularly valuable, for example, to consider together why and how there was such

heterogeneity of terms and concepts. As a novice researcher, initially I found it difficult to recognise the interpretive meaning and value of these differences in terminology as anything other than impediments to synthesising the studies. However, my supervisors helped me to reflect on this issue from a more critical perspective and to consider what this finding ‘said’ about the way carer harm was hitherto conceptualised and described.

Analysis of the papers identified three central themes: 1) There are inconsistent definitions and measurements used to research harmful, violent and abusive behaviour towards family carers. 2) Violent and abusive behaviour towards carers is a sensitive and hidden topic across the different studies. 3) There is some evidence to suggest that people who were violent and abusive in their earlier life are more likely to continue to be so in older age and that family members with poor relationship quality are more likely to experience violence and abusive behaviour in later life. These three themes are discussed in detail in the following section.

Findings

Eighteen studies were reviewed and their findings and methods are summarised in Table 2. The review was international in scope with the reported work conducted in North America, Europe, Australia and one study from Taiwan. Nine studies employed cross-sectional study designs, six qualitative and three adopted a mixed-methods approach. Most of the studies reflected a largely health or medical science perspective although several (mainly qualitative) papers adopted a sociological and feminist theoretical perspective. The studies employing a cross-sectional design (and two of the mixed-methods papers) reported investigations of the experiences of carers of older people with dementia. Most of the qualitative studies did not specify the illness or health condition that gave rise to the need for care and caregiving.

Instead, they focused on women affected by violence throughout their lives, either from their partners or parents. The analysis of the papers revealed three central themes:

1. Inconsistent definitions and measurements

The studies used different terms to describe violent and abusive behaviour. Furthermore, amongst the nine cross-sectional and three mixed-methods studies, investigators adopted different models to measure the nature, severity and extent of ‘challenging’ or ‘violent’ behaviour. At times, this made it difficult to be clear whether different studies meant the same thing when employing these terms. Estimates of the extent and nature of violence towards carers reported in the cross-sectional and mixed-methods studies also varied. For example, in a study of 220 family carers of people diagnosed with dementia in the previous three months, Cooper, Selwood, Blanchard and Livingston (2010) found that 82 carers (37.3%) reported abuse from their family member ‘at least sometimes’ (Cooper et al., 2010). Similarly, in a study of 198 carers of people with Alzheimer’s disease, O’Leary, Jyringi and Sedler (2005) found that 25% of this carer population had also experienced violence from their family member (O’Leary et al., 2005). Coyne, Reichman and Berbig (1993) found that 33.1% of carers reported abusive behaviour from the person with dementia they cared for and 33 carers (11.9% of the total population) reported that they had ‘retaliated’ towards the older person and acted in a violent or abusive manner (Coyne et al., 1993). These studies indicate the broad spectrum of harmful behaviour that affects family carers. However, estimating the extent, nature and impact of this behaviour in precise terms accurately is not yet possible, mainly because of the limited and diverse nature of current empirical research.

The cross-sectional studies (and survey data from the mixed-methods studies) examined the patient and carer factors that may be associated with violence towards carers. In these

studies, data were collected using a series of structured questionnaires and psychometric measures which tended to require yes/ no (dichotomous) responses and the completion of rating scales (Likert). Many of these measures were drawn from the medical and psychiatric fields and operationalised definitions of violence, health and relationships that reflected these disciplinary perspectives. However, despite this common approach there are some significant differences in the findings. For example, some studies found that the greater the level of cognitive impairment, the greater the severity and duration of violence towards the carer (Pillemer & Suitor, 1992) whereas others found no evidence for such an association (Hamel et al, 1990; Phillips, de Ardon & Briones, 2001; O'Leary, 2005). The studies also report different findings concerning the extent to which people's physical impairments and intensity of care needs affected the type and nature of violence that they instigated. Cooper et al. (2010) found an association between higher levels of violence and higher physical impairment (and care needs), although this association was not found in other cross-sectional studies. In addition, several studies reported that higher levels of depression in carers and care recipients correlated with more frequent reports of violence towards carers (Hughes, 1997; Paveza, et al., 1992; VandeWeerd & Paveza, 2006).

In the majority of the qualitative studies and qualitative data from the mixed methods studies, violence and abuse were conceptualised primarily as patterns of behaviour that could include physical, psychological, emotional and sexual dimensions of harm. This incorporated patterns of interaction and behaviour that played out over time, often across the 'life-course' of the family relationship. The qualitative studies tended to focus on psychological and emotional harm and the importance of recognising the ways that violence and abuse affect different people. There was little discussion in these papers about how and in what ways different types of physical, psychological and cognitive illness might affect the nature of

abuse, violence and care in families. As with the cross-sectional studies, terminology was unclear when it came to identifying what was different about the context of violence towards carers from other types of violence and abuse. In addition, the term ‘carer’ was not always used, or used in a consistent manner, throughout the studies in question. Instead, people were referred to according to their status as family members or intimate partners. Nevertheless, all of the studies described relationships between family members in which care, caring and ill health played a significant role.

No	Author, publication year, country	Aim	Design and study type	Analysis methods	Participants
Quantitative studies					
1	Cooper, C et al (2010), UK	To investigate levels of dysfunctional care giver coping and likelihood that care giver experiences abuse from those receiving care.	Quantitative-observational, cross-sectional	Spearman r, Mann-Whitney U and Pearson correlation for analysis	220 family carers of patients with dementia
2	Coyne et al, A. (1993), USA	To explore if care givers who experience abuse are more likely to abuse.	Quantitative, cross-sectional	Multi-variate analysis of variance statistical tests.	342 carers
3	Hamel, M. et al. (199), USA	To estimate the prevalence of aggression and responses of care givers.	Quantitative, cross-sectional	Multiple regression and discriminant function analysis	213 care receiver-giver dyads
4	Huang, H. et al (2009), Taiwan	To explore association between care receiver aggression and carer resilience	Quantitative, cross-sectional	Descriptive statistics	80 care receiver-giver dyads,
5	O'Leary, D. et al (2005), USA	To explore whether behaviour patterns in early life are associated with greater prevalence of aggressive behaviour.	Quantitative, cross-sectional	Chi-square tests	198 care receiver-giver dyads
6	Paveza, G. et al (1992), USA	To identify risk factors for 'severe' violence in family care receiver and care giver dyads	Quantitative, cross-sectional	Logistic and stepwise regression	184 care receiver-giver dyads,
7	Phillips, L et al. (2001), USA	To analyse correlates of abuse amongst older women who provide care for a family member.	Quantitative, cross-sectional	Analysis of variance and hierarchical regression	93 older female care givers
8	Weerd C. et al (2006), USA	To identify risk of verbal aggression towards carers for people affected by Alzheimer's Disease.	Quantitative, cross-sectional	Logistic regression analysis	254 care givers and 76 care receivers
9	Wilks, S. et al (2011), USA	To investigate the association between aggression in Alzheimer's Disease and carer coping skills and styles.	Quantitative, cross-sectional	Logistic regression analysis	419 care givers,

Mixed-method studies					
10	Cahill, S. et al (1993), Australia	To identify experiences of female carer affected by aggression from older family members	Mixed-methods (interviews and questionnaire/ survey)	Descriptive statistics and narrative interview data	39 carers recruited from services
11	Hughes, M. (1997), Australia	To investigate factors associated with higher rates of abuse and violence during the caring relationship.	Interviews and survey instrument for statistical analysis	Descriptive statistics and narrative presentation of qualitative data	47 care receiver-giver dyads
12	Pillemer, K. et al J. (1992) USA	To explore care givers' feelings and fear of violence with the experience of acting out violently.	Semi-structured interviews and validated questionnaire	Logistic regression and narrative presentation of qualitative interview data	236 care givers, referred by medical practitioners
Qualitative studies					
13	Ayres, M. (2001), USA	Concept analysis of abuse of ageing carers by elderly people who received care.	Qualitative, theoretical/ conceptual study	Concept analysis	NA
14	Band-Winterstein, T. et al. (2009), Israel	To explore intimate partner violence in older age/ life-span perspective.	Qualitative, semi-structured interviews	Phenomenological analysis of interview transcripts	40 (20 couples) from social services
15	Band-Winterstein, T. (2012), Israel	To explore how long term intimate partner violence shapes people's relationships and experience of abuse.	Qualitative, semi-structured interviews	Categorical-content analysis of interview transcripts	30 individuals (15 couples) from social services
16	Koenig, T. et al (2006), USA	To explore experiences of caregiving women who continue to experience intimate partner violence in older age	Qualitative, case studies	Empowerment model to discuss cases	Two female carers
17	Pickering, C. et al. (2014), USA	To explore the dynamics and nature of conflict between adult daughters who care for their mothers.	Qualitative, semi-structured interviews	Grounded theory and constant comparison analysis	13 daughters
18	Zink, T. et al. (2003), USA	To understand women's reasons for continuing in long-term abusive relationships in older age.	Qualitative, semi-structured interviews	Thematic analysis	36 older women,

Table 2: Literature review included studies

A 'hidden' and sensitive topic to research

All the papers reported the considerable methodological challenges involved in recruiting and engaging with affected family carers and this may account for the small and unrepresentative nature of the sample populations reported in the cross-sectional studies. In the six qualitative studies, and qualitative components of the mixed-methods studies, the sensitive and complex nature of the topic was identified as a central rationale for using in-depth, exploratory techniques and analysis methods. Several studies suggested that carers would be reluctant to speak out against their family member for fear this would place the individual at risk of being taken into state care or that the carer would be seen in a negative light (Cahill & Shaprio, 1993; Pillemer & Suito, 1993). Hughes (1997) and Coyne et al. (1993) suggested that some carers worried that violent or abusive behaviour could be interpreted as a 'failure' to protect and care for their family member and this inhibited discussion of the issue.

Several of the qualitative studies also identified that carers may not recognise their situation as one of violence or abuse. Instead, it was found that carers may regard challenging behaviour or unequal power relationships as part of the normal practice of care (and love) in their relationship (Band-Winterstein, 2012). This may be more common for women habituated to living in long-term relationships involving IPV (Zink, Regan, Jacobson & Pabst, 2003). Whereas in other studies it was suggested that carers may over-estimate and misattribute violence and harm because they do not properly understand its aetiological causes and/or lack the skills to de-escalate and prevent conflict. For example, in two of the cross-sectional studies, it was found that carers often 'over-estimated' the severity and level of violence they experienced (O'Leary et al., 2005; Cooper et al., 2010). This was considered an issue of (subjective) bias that complicated attempts to estimate the prevalence and type of violence and abuse experienced by carers. Unsurprisingly, bias was not identified as a

concern in the qualitative studies, which did not question the veracity of participants' accounts but rather sought to explore individuals' experiences, views and beliefs.

The sensitivity of language and its role in maintaining secrecy and inducing feelings of shame about unusual or distressing experiences was evident in the qualitative studies. For example, Band-Winterstien (2012) and Band-Winterstein and Eisikovits (2009) found that some couples who had experienced many years of domestic abuse found new meanings when they had the opportunity to reflect and talk about their experiences. For some people, caring and illness provided an opportunity to become closer and to re-frame their relationship, thus 'minimising' or overlooking past violence in the context of newly found respect or appreciation of one another's care needs and 'vulnerabilities'. In other cases, the concept of 'victim' and 'perpetrator' were more useful as terms to make sense of difficult experiences and conflicting, often painful feelings. Thus, a 'narrative of suffering' provided a coherent way of codifying and explaining feelings of powerlessness brought about by long-term IPV (Band-Winterstein & Eisikovits, 2009; Band-Winterstein, 2012). Koeing, Rinfrette and Lutz (2006) found that having the space to reflect on and talk about difficult experiences and decisions was important for some female survivors of IPV (Koeing, Rinfrette & Lutz, 2006). This study reported on two case studies involving women affected by long term IPV, who were better able to engage with the ethical dilemmas and complex life choices they faced as carers and victims of domestic abuse as a result of counselling support (Koieng et al., 2006).

Although some of the papers highlighted the potential overlap of IPV and carer harm (Cooper et al., 2010; Pillemer et al., 1992), only one paper engaged critically with the vocabulary and concepts of 'abuse' by means of a systematic concept analysis (Ayres & Woodtli, 2001). One of its central findings was that carers were unlikely to identify with the terms 'abuse' and

‘victim’ as they were too emotive, simple and associated with perceptions of IPV. As a result, Ayres and Woodtli (2001) suggested that researchers and practitioners need to be sensitive to this and develop nuanced ways of discussing the issue with families. In turn, this could help families disclose and discuss the issue in a more timely and meaningful way (Ayres & Woodtli, 2001).

3. Relationships and interactions

The nature, quality and life-course trajectory of family relationships were identified as important issues in understanding the nature of violence and abuse towards carers. This was a finding in all of the studies irrespective of design or disciplinary perspective. Within the cross-sectional studies, low quality or ‘dysfunctional’ relationships were consistently associated with more severe and more frequent aggression towards carers (Cooper et al., 2010; Paveza et al., 1992; Hamel et al., 1992). Those carers reporting experiences of violence prior to diagnosis of dementia in the person being cared for, were also exposed to more severe forms of violence following its onset (Cahill & Shapiro, 1993; O’Leary et al., 2005). In addition, how carers ‘coped with’ and responded to their family member’s violence correlated with the quality and stability of their relationship prior to illness and care (Phillips et al., 2001; Hamel et al., 1990; Coyne et al., 1993). Those carers found to be less emotion-focused in their care and who identified the causes of aggression as a personality trait or deliberate act of challenging or disruptive behaviour on the part of the family member, were also found to have poorer quality relationship histories (Wilks, Little, Gough & Spurlock, 2011; Vande Weerd et al., 2006; Huang, Shyu, Chen & Hsu, 2009). However, there was limited evidence that this group of carers reported experiencing higher levels of violence from their family member (Hughes, 1997; Cooper et al., 2010).

Collectively, these findings highlight that people's understanding of and responses to their family member in illness and in violence were shaped in part by their experiences with them over their life-course. This was particularly the case in long-term spousal relationships and between adult children and elderly parents. Indeed, several studies identified that, in this context, there was a risk that carers would become less caring and potentially violent in retaliation towards their family member, leading to a situation of 'bi-directional' or mutual harm. O'Leary et al. (2005) suggested this could lead to the premature ending or 'relinquishing' of the care relationship as people with dementia were placed in institutional care. However, although this seems a plausible consequence of violence towards carers, in this small study sample there was limited evidence of this (e.g. Hamel et al., 1990).

In the qualitative studies, family and intimate relationships were a central factor influencing people's experiences of care and violence. Individuals with a history of conflict, violence or abuse with their parent or spouse found different ways to find meaning or exert agency when faced with decisions about becoming their carer later in life. This ranged from turning away and 'relinquishing' the carer role, to committing to it as an opportunity to reshape and re-order memories of powerlessness and abuse. Relationships were the primary context in which power (and its abuse) played out and decisions and responses to violence were understood. For example, it was identified that relationships of violence and abuse in child and adulthood may influence how people responded to experiences of being cared for and providing care later in life (Pickering, Moon, Pieters, Menten & Phillips, 2014; Phillips et al., 2001). Illness appeared to complicate and compound dysfunctional and harmful dynamics already present in violent relationships. This was the case, for example, in Pickering's (2014) study of daughters who engaged in 'spiteful aggression' and retaliatory violence towards older mothers who were neglectful or abusive towards them in childhood. Caring needs and caring

roles could also heighten feelings of obligation and duty to family members. This was more often an issue for older women caring for husbands and partners who had strong views about the unconditional nature of family duty and marriage in particular (Zink et al., 2003; Band-Winterstien, 2012). In some cases, caregiving for a physically ill or disabled partner altered the status and increased the power of the carer in a long-term intimate, and often difficult, relationship (Koeing et al., 2006; Band-Winterstein & Eisikovits, 2009).

Discussion

This review found that there is limited research examining violence and abuse towards family carers of older people and the research that does exist is diverse. There is a body of research that focuses on family carers for people with dementia type illnesses which, in the main, adopted cross-sectional or mixed-method designs and sought to establish the nature and prevalence of violence and abuse towards carers. There was a smaller body of qualitative studies (and mixed-methods studies using qualitative methods) that focused on the experiences of families involved in violent and abusive relationships prior to the onset of older age and illness. These studies explored how violence and abuse continues or changes in older age. Figure 1 presents a conceptual map characterising these two categories and identifies some of the conceptual differences between the studies. The aim in developing this map is to highlight the conceptual and linguistic resources that are necessary to define and engage with the issue of violence and abuse towards carers. This is important, not only for definitional clarity and research measurements, but also for practice in this area.

Reflecting on the review findings, I suggest that there is a need to move beyond understanding harm to carers either as a ‘symptom of illness’ or as an ‘act of abuse’ and to investigate and consider how it can be both. This involves exploring aspects of current legal,

medical and social practice that are creating the circumstances in which the issue is hidden from view. In addition, developing theory and analysing evidence about the nature of violence and harm towards carers may help practitioners from a range of disciplines identify and support affected families. Another line of inquiry is to explore some of the reasons that illness has been the primary and central lens through which violence and abuse towards carers is examined in health and medical-focused studies. Reflecting on the work in the field of elder abuse and adult protection, there are clear and somewhat problematic links between the concept of illness and patient-hood and a state of vulnerability (Dixon, Biggs, Stevens, Manthorpe & Tinker, 2013). With this comes a release from responsibility for individual action in most legal or moral understandings of these terms. As a result, this shifts attention from the person carrying out the violence or abusive behaviour, to a critical focus being directed onto the carer. For example: are they caring in the best or right way, do they understand the illness well enough, how will this affect the way they care in the future? These implicit and explicit questions in many of the dementia-focused studies in the review reflect how, in focusing on carers' responses, their needs – arising from their experiences of harmful or abusive behaviour - can be overlooked. Thus, the issue of violence and abusive behaviour towards carers can become 'lost' in concerns about medication regimes, the adequacy of training and education of carers and the potential need for tailored emotional and social support for affected families.

The review findings indicate that some carers experience extreme, regular violence and life with their family member is characterized by its unpredictable and volatile nature. Moreover, carers may also lack agency or the resources needed to change this situation, often feeling that 'leaving' is not an option and that learning to 'cope with' violence and/ or distress is their only moral and pragmatic option. This raises further critical questions about whether it is

appropriate to assume that the older person/ ill person is in a static and constant state of vulnerability in relation to the person caring for them (Daniel & Bowes, 2010). Practices of power in adult relationships are complex and subtle and people do not necessarily hold power 'over' or 'against' another person in an absolute way. More often, power is developed through action and inaction and is constantly negotiated and mediated. Indeed, disrupted power relationships are more likely during times of transition, loss, crisis, and change in long-term intimate and family adult relationship (Biggs & Haapala, 2010). Thus, even when illness appears to be an appropriate and valid way of understanding violent and abusive behaviour, the impact on the family carer should not be obscured or minimized, as is the case in several of the studies included in this review.

Turning to the qualitative literature, this small group of studies has made an important contribution in developing knowledge about this complex and hidden phenomenon. Nevertheless further empirical study is needed. For example, there is minimal reference to, or engagement with, the (neuro)-biological nature of illness and how this may shape what violence and abuse 'looks like' and 'feels like' as compared to behaviour taking place when illness is not a dominant dimension of an intimate relationship. In addition, most of the sample populations were made up exclusively of women and there is limited discussion about the particular or different needs of men experiencing violence and abuse as carers. More starkly, perhaps, there is little qualitative research either with families in which violence and abuse did not precede illness, or with families where violence and abuse is more fluid, complex and ambiguous when it does occur.

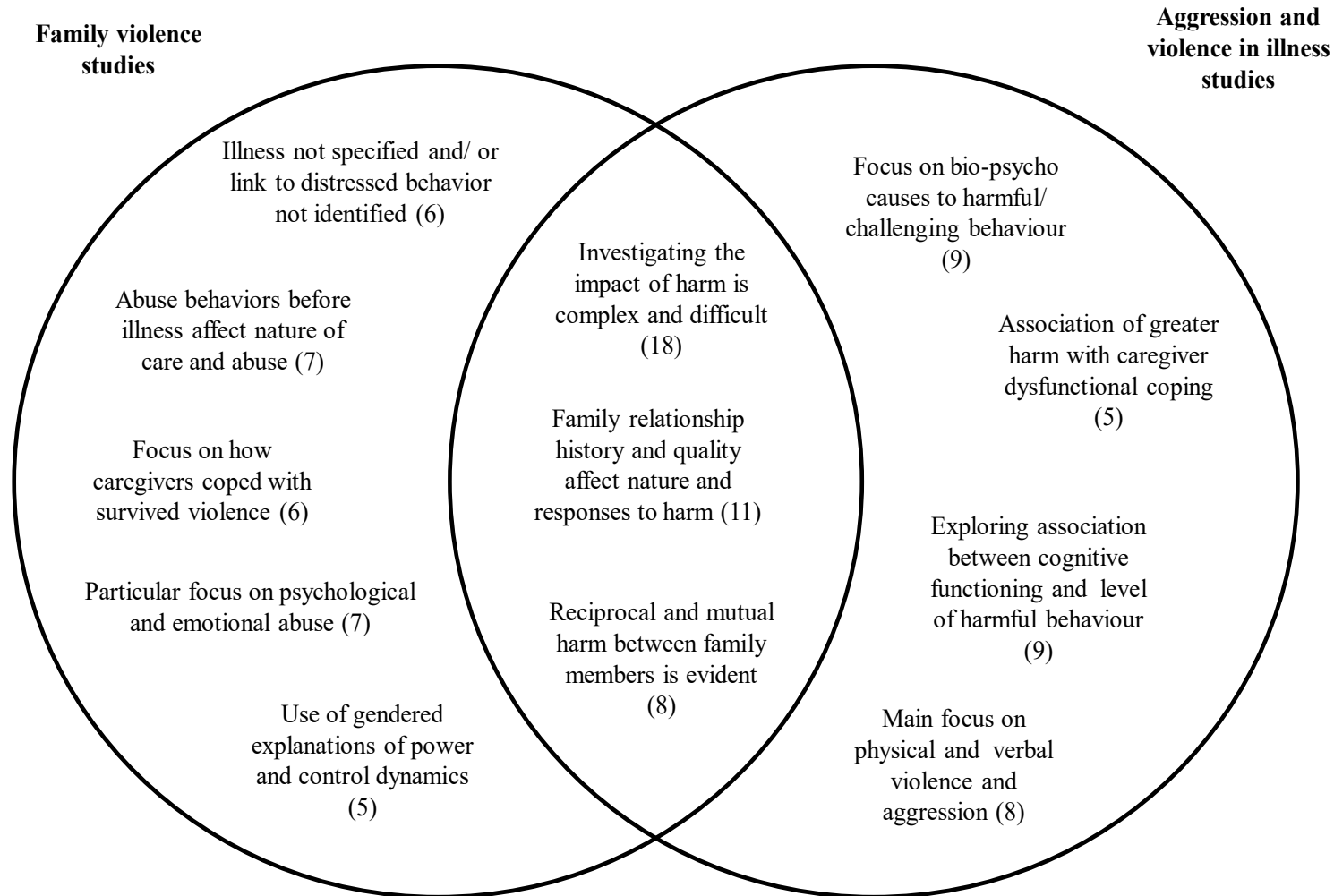


Figure
Note: I

Limitations

This review has three principal methodological limitations. Firstly, studies were included based on specific inclusion criteria (see Table 1) and none were excluded on the grounds of methodological quality. Consequently, the quality of evidence reviewed is not consistent or sufficiently robust to underpin a definitive explanatory conceptual or theoretical model. However, the review was guided by decisions about how best to examine an area in which there is limited empirical work and little conceptual development, so inclusion of studies irrespective of quality was deemed appropriate. Secondly, the analysis is likely to reflect choices about what is relevant and useful based on professional and personal worldviews of my supervisors and I. In addition, the review included only English-language papers and so did not engage with all the available international literature. This limits the scope of the review as well as the transferability of its findings. It is also likely to minimise or obscure comparison of how cultural and geographical differences shape the rate and nature of violent and harmful behaviour towards family carers. A further significant limitation of this review is that I searched for studies using predominately social science, applied health and clinical databases. The gaps in the literature that have been identified reflect gaps specifically within these disciplinary areas and their associated methodological fields. However, notwithstanding these limitations, this review is the first comprehensive synthesis of contemporary theory and evidence about family carers who experience violent, abusive or harmful behaviour by the older person for whom they care.

Conclusions

This chapter reports the findings of the first systematic literature review focused specifically on identifying and integrating knowledge about family carers who experience violent, abusive or harmful behaviours from the older person for whom they care. It highlights the

complex and multi-dimensional nature of the phenomenon and shows how problematic it can be to define when difficult and harmful behaviour is and is not abusive. Also, identifying what causes it and in what ways it affects individuals and families was also found to be empirically and conceptually challenging. The topic also raises uncomfortable questions about how culpability, inter-dependency and psychological abuse are understood in family relationships. Considering the review findings, my supervisors and I identified that there was a clear rationale for carrying out further empirical research. The next chapter sets out the technical and methodological decisions that underpinned the empirical phases of the study.

Chapter 3: Methodology and methods

Chapter overview

In this chapter, I discuss the central epistemological and methodological decisions underpinning this study. To begin, I outline the primary characteristics and criticisms of social constructionism and my rationale for adopting it as an epistemic orientation. I then draw on Bradbury-Jones, Breckenridge, Clarke, Herber, Wagstaff and Taylor's (2017) Qualitative Research – Level of Alignment Wheel (QR-LAW) model to demonstrate how social constructionism 'threads' through the design, techniques and analytic approaches used in this study. Following this, I discuss to what extent this study constituted 'sensitive' research and discuss the role of reflective and reflexive practice in qualitative research and this thesis. In the subsequent section of the chapter, I explain my reasons for co-designing the empirical stages of the project with an advisory network and using semi-structured interviews and focus groups to explore carers' and professionals' perspectives. Lastly, I report how I analysed the empirical data, drawing on a thematic and a theory-driven perspective.

Ontology and epistemology in health and social research

1. What it is and why it matters

Ontology and epistemology are commonly characterised as the scaffolding or starting point of social science inquiry (Carter & Little, 2007). Ontological questions explore claims and assumptions about the nature of social reality whilst epistemological questions focus on the nature of our knowledge (Tuli, 2011). When developing research and theory, identifying ontological and epistemological assumptions – of the investigating researcher and/ or research methodology - helps to surface assumptions about what, how and why knowledge is being developed in certain ways and to consider the relative strengths and limitations of a

given approach. Identifying these choices and influences can help to identify the forms of logic and heuristic concepts that underpin a study's findings. Qualitative researchers are widely encouraged to articulate their ontological and epistemological position and demonstrate how it 'fits' with their choice of theory, methodology and methods (Grix, 2002; Kelly, 2009). Nevertheless, this process is sometimes complicated by the confusing array of terminology and the tendency of disciplines to "argue past one another" when discussing the relative strengths, limitations and relevance of different ontological and epistemological perspectives (Grix, 2002, pp. 175). In addition, there are concerns that ontology and epistemology are not always well understood or applied with enough critical awareness. As a result, this undermines the quality and intellectual claims made by qualitative researchers and highlights a potential 'gap' between what researchers say they do and what they 'really' do (Sandlewski, 2000; Bradbury-Jones, Herber & Taylor, 2014).

Critically constructing a 'coherent' research study

To address such concerns, there has been a concerted effort to establish greater consensus within the qualitative research community about what 'good' qualitative research looks like and how researchers should engage with questions of epistemology and ontology in their work (Tuli, 2011). For example, it is important that researchers are clear and consistent about how and why they have adopted a given philosophical orientation and that they demonstrate understanding of its origins and central concepts. Perhaps more importantly, it is incumbent on researchers to demonstrate that they can think critically about how their epistemological orientation shapes, and is shaped by, the other constituent parts of the study (Carter & Little, 2007). For example, whether it is compatible with the aims of the study, the methods used to collect or develop data and the analytic approaches used to interpret the data. There needs to

be coherence between different aspects of the project and the nature and strength of these ‘internal’ connections need to be made visible (Kelly, 2009).

Qualitative researchers are also encouraged to think about the degree to which personal taste and disciplinary convention affect what theories, philosophies and research they are drawn to and what this says about their ‘personal’ epistemology (Sandleowski, 2015; Carter & Little, 2007; Ward, Hoare & Gott, 2015). This is likely to require reflective and critical effort; however, it will enhance the transparency and rigour of their work because it makes explicit the rationale for their analytical approach. In addition, although some research projects are designed using a clear, pre-determined methodological framework, many qualitative studies require a degree of flexibility to respond to the ethical, empirical or theoretical challenges that emerge during the work (Agee, 2009). Aymer and Okitikpi (2000) characterise the process of engaging with epistemology and ontology as one of building ‘conceptual bridges’ because it requires researchers to move between the theoretical, philosophical, ethical and practical aspects of their work all the while focused on the empirical foci of investigation. Puig, Koro-Ljungberg and Echevarria-Doan (2008) and Fetherstone (2000) similarly characterise the relationship between ontology, epistemology and theory as iterative. In a subsequent chapter of this thesis, ‘methodological reflections’, I critically explore the dynamic and evolving nature of my engagement with these central issues during this study. In the following section, I rehearse the central tenets of a social constructionist epistemological position and some critiques of this philosophical orientation. I then justify the need for a social constructionist stance to underpin this study.

Adopting a social constructionist epistemology

1. Background and origins of social constructionism

The constructionist movement developed in the 1960s at a time of moral and intellectual concern about the operation of institutional and cultural power and a growing scepticism towards received ways of knowing and ordering social life (Schmidt, 2001). In a radical departure from the then ascendant positive epistemology underpinning empirical science, constructionists argued that there is no single way of knowing or understanding the ‘social world’, but rather a plurality of alternative and equivalent perspectives: a position broadly characterised as anti-essentialist or anti-foundational. From this perspective, the concept of objectivity and claims of objective knowledge, i.e. knowledge that is independent of the subject who perceives, processes or interprets it, is treated critically if not entirely rejected. Instead, social constructionists suggest that knowledge develops as part of a dynamic interaction between subject and object (Burr, 1998). This means that individuals play an important role shaping how and what they know because they have interpretive agency and are constantly engaged in processes of reflection, communication and social association (Berger and Luckmann, 1967). Moreover, human interpretive activity finds expression, through the conventions of language, culture and different forms of socialization and interaction and these are foregrounded in the norms, expectations and material realities of their social and historical circumstances (Puig et al, 2008). Thus, language is a useful but not the only tool to understand and engage with human meaning and experience (Gergen, 2001).

Example of social constructionist-informed research

Ideas about harm, risk and violence are in large part shaped by a complex range of factors and processes specific to social-historical contexts (Eisikovits, Koren & Band-Winterstein, 2013). Perhaps unsurprisingly then, there is an established tradition of social researchers

adopting a constructionist perspective to explore issues such as violence and abuse (Pilgrim, 2017). Jo Woodiwiss (2014), for example, locates her narrative analysis of sixteen interviews with women who experienced childhood sexual abuse in a (feminist) constructionist epistemology. This foregrounds her argument that the dominant, contemporary social understanding of sexual abuse ‘victims’ – that characterises them as sexually innocent, passive and inevitably damaged – shapes how participants in her study understood and talked about their experiences (Woodiwiss, 2014). In another example, Morrow and Smith (1995) used a grounded theory approach to explore adult women’s strategies for coping with the effects of childhood experiences of sexual abuse. Analysis of the data from eleven individual interviews and ten focus groups, identified 160 distinct coping strategies used by survivor-participants. Orientated within a constructionist epistemological stance, the researchers then developed a conceptual schema that synthesised and contextualised these strategies, considering the way the women shared this information as well as their unique interpretations and socially-situated understanding of ‘survival’ and ‘coping’ (Morrow & Smith, 1995). In this thesis, I take as axiomatic that the way carer harm is ‘constructed’ is shaped, in part, by social, cultural and inter-personal factors. I explore the implications of this position in subsequent chapters and, in particular, in the theory-informed analysis of the synthesised data.

Critiques of social constructionism

1. Social constructionism and ontology: “a bewildering array of realities”

As an epistemological approach, social constructionism is sometimes associated with a relativist ontological position. Relativists emphasise the centrality of subjective perceptions and cognition as the primary ways of knowing (Burr, 1998). They question the basis of knowledge claims that consider social and natural phenomena as stable and fixed in nature,

i.e. that take little or no consideration of the perceptive and interpretive processes of individuals. Taken to its logical conclusion, relativism can result in a rejection of material reality because we cannot ever be sure that knowledge exists ‘outside’ of our perceptions and conceptual faculties, (Potter, 1996). From this perspective, there is only a “bewildering array of alternative realities” (Burr, 1998) and no meaningful way of identifying which types of knowledge – be they empirical, theoretical or tacit – are more relevant or useful than another. Critics therefore argue that constructionism results in a solipsistic perspective because all we ‘really’ know is our own interpretations and experiences (Hacking, 1999; Nightingale & Cromby, 2001).

In response, constructionists highlight that many of its scholars repudiate this relativist position and recognise that there is a meaningful sense in which ‘truth’ and ‘rationality’ exist (Burr, 1998; Gergen, 2001). Indeed, most constructionists align their work with an anti-realist rather than an anti-realivist perspective (Burr, 1998). Anti-realism emphasises the contingent, fluid and multiple types of social ‘reality’ that exist and the inherently subjective filter that human cognition and perception imposes. Moreover, anti-realism does not refute the material dimension of reality. Nor does it question that some forms of knowing are more valuable or relevant than others. These seemingly subtle distinctions become particularly important when social constructionism is used in the context of applied social research.

Difficulties applying social constructionism to ‘real life’ social problems

According to its critics, constructionism is concerned only with analytical, abstract processes whose fruits are rarefied and displaced from social issues and human lives. It is also argued that constructionist scholars privilege interpretations and realities that are anti-conventional or anti-establishment over and above ‘everyday’ ways of thinking (Schmidt, 2001). For

example, in his review of constructionist research and theory on child sexual abuse, Pilgrim (2017) suggests that there is too much focus on abstract and non-empirical analysis. This results in an overriding focus on how ‘moral panics’ and ‘perpetrators’ are constructed, rather than investigating the lived experience of childhood sexual abuse. In some cases, this approach has led to an epistemic denial of the ‘reality’ of this abuse and insufficient focus on affected children’s views and needs (Pilgrim, 2017). The constructionist critique of mental illness faces a similar charge. By focusing only on the socially constructed ways that mental health diagnosis is experienced, there is a risk that the neurological, emotional and psychic aspects of these conditions are under-valued and, in more extreme cases, ignored (Hacking, 1999). This does little to respect people’s experiential knowledge of mental health distress and crisis (Houston, 2001). At best, critics suggest, a relentless or exclusive focus on ‘deconstruction’ can be an unhelpful and narrow approach to interpreting the social world. At worst, critics argue that it is ethically irresponsible because it undermines individuals’ interpretive agency and the material and embodied dimensions of social problems (Houston, 2001; Nightingale & Cromby, 2001; Elder-Vas, 2012).

In response, constructionists argue that by drawing attention to the inter-subjective, contextual and relational nature of some types of knowledge, they are not refuting or denying the existence of knowledge based on different forms of evidence, experience or reasoning. Recognising the contingent, socially constructed of some types of knowledge is valuable, they suggest, because it helps to identify and critically examine some of the latent assumptions affecting what is known and considered credible as well as what is considered unimportant and not given credence. It also helps to unravel the complex and contingent nature of knowledge and the influence of social and temporal factors and this in itself can confer practical value to people seeking new and alternative ways of understanding aspects of

their social world (Burr, 1998; Michailakis and Schirmer, 2014). Most constructionists are not therefore suggesting that a constructionist lens is the most appropriate or the only way to build knowledge about the social world (Gergen, 2001). It is from this perspective that I adopted a social constructionist epistemic approach. In the following section, I identify three of the central ways this orientation shaped and was shaped by the aims and methodological scope of this study.

The central ‘threads’ of social constructionism in this study

I adopt the QR-LAW (Bradbury-Jones et al, 2017) to illustrate some of the connections and areas of ‘coherence’ between different methodological, technical and practical aspects of this study. Responding to concerns about the inconsistent ways that researchers locate their work within certain philosophical and methodological contexts, the model helps researchers (particularly novices) to identify the orientation and techniques underpinning their work and consider how the constituent dimensions of their project ‘align’ and ‘deviate’ from one another (Bradbury-Jones et al. 2017). With this in mind, I used the model (see Figure 3) to map out the constituent epistemological, methodological and methods-focused aspects of my study and to consider the credibility and appropriateness of their inter-connections. As a novice researcher, the model was particularly valuable in retaining a sense of the overall analytical and philosophical structure of the project during a period where many of its technical and ethical aspects were dynamic.

1. An anti-essentialist orientation: multiple perspectives and ways of knowing.

From the outset of this study, I was aware that how people understood and talked about harmful behaviour towards family carers varied considerably. Analysing and synthesising the findings of the literature review underscored the need to appreciate the plural and overlapping

nature of such viewpoints (see literature review chapter for details). For example, the way that harmful behaviour was understood as either an ‘act of abuse’ or a ‘symptom of illness’, depending on scholars’ methodological or disciplinary perspective. The review findings also highlighted the need to consider how certain issues and ways of knowing were ‘hidden’ and ‘potentially irreconcilable’. The study therefore took as its starting point that there are multiple ways of understanding and experiencing harmful behaviour and that these viewpoints have unique and relative meaning to different carers, as well as researchers and practitioners (Rasmussen, Muir-Cochran & Henderson, 2015).

Language and human communication as interpretive resources

Developing knowledge about harmful behaviour, I considered it to be of central importance to explore the subjective and experiential knowledge of carers and health and social care professionals. This reflects a social constructionist emphasis on the value and ability of humans to interpret and ‘make meaning’ (i.e. knowledge) of their experiences and social circumstances (Gergen, 2001; Puig et al, 2008). Thus, I elected to use in-depth, semi-structured interviews to explore carers’ understanding of harmful and abusive behaviour and reflective, vignette-based focus groups to explore practitioners’ knowledge and understanding of the issue. Analysing the empirical data, I carried out two, parallel approaches: one informed by a thematic approach and the aim of which was to develop a rich, primarily inductive interpretation that explored patterns, differences and latent meanings in participants’ verbal accounts. Carrying out the second phase of analysis, I drew on Miranda Fricker’s theory of epistemic injustice to develop a theoretically-informed analysis and synthesis of the data. This helped me to locate and explore the accounts from a wider social and historical perspective, as be-fitting a social constructionist approach.

An ethical commitment to co-construct aspects of the study

I wanted to ensure that the needs and views of people with personal insight about caring and/or family violence were central to my initial decisions about the scope and purpose of the study. Given the under-developed empirical and theoretical landscape and the challenges involved in researching this sensitive issue, their experiential knowledge of caring and/or family violence was valuable and necessary. Indeed, working with the advisory network was of critical value in terms of anticipating some of the practical and ethical issues that could arise in the course of interviewing participants (both carers and professionals) about a complex and ‘sensitive’ issue. It was also congruent with the social constructionist epistemology underpinning this study because, in practical and philosophical terms, soliciting and ‘taking’ advice from people outside the research team demonstrated a commitment to share knowledge and decision-making: in short, to actively co-construct some aspects of the project (Edvardsson, Tronvoll & Gruber, 2011; Charmaz, 2011). In view of this, I established an advisory network to work with during the design and initial development of the study. A more detailed description of the network is provided in the following section and, subsequently, in the chapter ‘methodological reflections’.

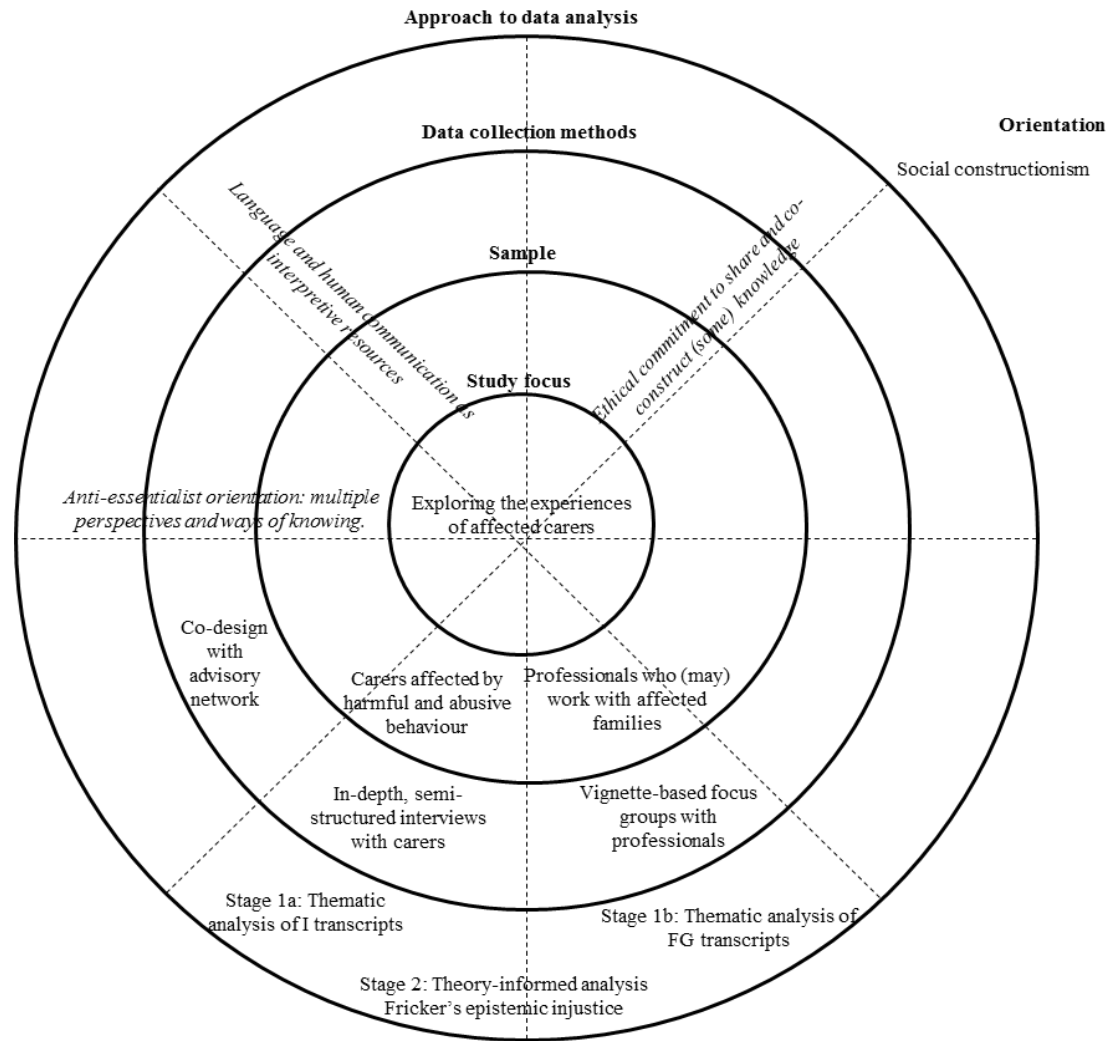


Figure 3: Three central 'threads' of a social constructionist epistemology, as mapped onto the Qualitative Research – Level of Alignment Wheel (Bradbury-Jones et al, 2017)

Methodological notes

In the following section, I discuss two central issues that shaped many of the methodological and methods-related decisions of this study: that of ‘sensitive’ research and reflexivity.

These concepts are explored throughout the thesis. For example, in the justification of the study’s empirical design and discussions about the ethical complexities involved in investigating this topic. Thus, the following is an introduction to these two important areas of qualitative research.

A note on ‘sensitive’ research

1. What is ‘sensitive’ research?

Sensitive research is an umbrella term for studies that investigate emotive topics that are often personal in nature (Dempsey, Dowling, Larkin, & Murphy, 2016). Common examples include research on death, abuse, intimate relationships and sexuality. These topics can be difficult to talk about because of their complexity or because of social and historical norms about the permissibility and capacity of people to share their experiences, particularly if they are considered atypical or taboo (Dickson-Swift, Kippen, & Liamputtong, 2007). Over the past ten to fifteen years, there has been increased interest in ‘sensitive’ research topics in the applied and theoretical social sciences. This has opened up new directions in empirical inquiry, notably the rise in ‘emotions’ research, feminist inquiry and studies investigating people’s experiences of social marginalisation (Evans, Ribbens-McCarthy, Bowlby, Wouango & Kébé, 2017; Turner & Almack, 2016). Concomitantly, the methodological literature on sensitive research has expanded and diversified (McCarry, 2012; Vaswani, 2018; Wilson, Kenny & Dickson-Swift, 2018).

Seeking to make hidden experiences visible and to explain complex, often troubling social situations and individual circumstances, there is often an association between sensitive research and research about and with people who may be ‘vulnerable’ (Serrant-Green, 2011). In addition, much sensitive research is underpinned by an ethical and intellectual commitment to develop new forms of knowledge that challenge traditional ways of knowing and exercising power, thereby giving credence to marginalised experiences and enabling hidden issues to be better heard and seen (Mantoura & Potvin, 2013; Bradbury-Jones & Taylor, 2015). Nevertheless, the term ‘sensitive’ should be used cautiously, taking into account the contextual and subjective understandings of what is (and is not) complex, important and contentious about an issue amongst the people whom the research is for or about (Powell, et al, 2018).

Exploring carer harm as a ‘sensitive’ research topic

In this thesis, I characterise family carers’ experiences of violent, abusive or harmful behaviour as a ‘sensitive’ topic. Informed by the literature review findings, I became aware of the potential ethical, methodological and critical challenges involved in studying this topic from an early stage. These ‘sensitivities’ were characterised in terms of the seemingly taboo nature of the topic and the feelings of shame and strategies of concealment that it reportedly engendered amongst carers (Band-Winterstein, 2012; Band-Winterstein, 2009). In addition, several studies identified that carers would be reluctant to share information about the severity of a family member’s behaviour because the carer would be deemed unable to cope with their health and behaviour needs (Cahill & Shaprio, 1993; Pillemer & Sutor, 1993; Hughes, 1997). Finally, difficulties naming and conceptualising the issue, in research and practice, reflect wider and perhaps more subtle challenges reconciling understandings about adults who are in some way ‘vulnerable’ with someone who can cause harm, intentionally or

unintentionally. Over the course of the study, I developed a more informed and critical perspective on the extent to which it was helpful to consider the issue ‘sensitive’ and ‘hidden’ (Aldridge 2014) and I discuss this in greater detail in the ‘theory-informed analysis’ and ‘methodological reflections’ chapters. Nevertheless, I think the concept of ‘sensitivity’ continues to have resonance for this topic, both from a methodological and conceptual perspective.

A note on reflection and reflexivity

1. Reflexivity in qualitative research

Across the disciplinary and theoretical spectrum, reflexivity is widely acknowledged to be an integral aspect of contemporary qualitative research (Finlay, 2002; Berger, 2015; Doyle, 2013). In a broad sense, reflexivity involves researchers thinking critically about their role shaping, or co-constructing, knowledge at any (or indeed every) layer of the research process. Probst (2015) characterises reflexivity as “gazing in two directions at the same time”. Probst describes how, when practicing in a reflexive manner, the researcher is focused on their field of investigation: for example, the process of interpreting the language, behaviour and social cues of their participants. At the same time, they are also examining how their own projections, assumptions, biases and attachments shape what they ‘see’ and how they interpret and develop meaning from these exchanges. Thus, reflexivity is “like an eye that regards itself while simultaneously seeing the world” (Probst, 2015, pp. 38). In surfacing these processes, researchers go some way to demonstrating the co-constructed, interpretive nature of analysis carried out within qualitative research. For these reasons, reflexivity has become a by-word for demonstrating quality and rigour in qualitative research (Darawsheh, 2014) and is a central tenet of social constructionist inquiry (Puig et al, 2008).

There are nevertheless concerns within the qualitative research community that, just as some researchers do not demonstrate understanding and appropriate use of the concepts of epistemology and ontology, reflexive approaches are not always used in a consistent manner. For example, there is a relative paucity of published work by researchers demonstrating *how* they engage in reflexive practice and the impact this has on the type of knowledge they go on to develop (Gringeri, Barusch & Cambron, 2013; Berger, 2015). This gap may be in part attributable to publication bias, which tends to value empirical and theoretical contributions in preference to reflexive accounts, which can tend towards the descriptive and personal. In addition, researchers often do not specify whether they are adopting a particular type of reflexive practice – for example one underpinned by feminist, psychoanalytic or postmodern theory – or whether they use the term to highlight, in a more generic sense, a process of consideration and learning (Berger, 2015). Finally, reflexive practice can be emotionally and intellectually demanding. Without established mechanisms for peer and organisational support, researchers may feel burdened by the responsibility and more prone to engage in “personal emoting and interminable deconstructions of deconstructions” (Finlay, 2002, pp. 226). This can foster a type of reflexivity that primarily explores the thoughts and feelings of the researcher. Whilst this type of subjective knowledge can be valuable, researchers need to make critical connections between their epistemic and reflective ‘journeys’ and the way they capture, interpret and present their findings or theorising for it to have practical or ethical value for others (Sky, 2016; Ward, Hoare & Gott, 2015).

Approaches to reflection and reflexivity in this thesis

With these debates in mind, I return to the concept of reflexivity throughout this thesis. Drawing on Sarah Banks’ (2013; 2016) concept of ‘everyday ethics’, I present a reflexive account of some of the ethical, practical and epistemic issues that arose when recruiting and

interviewing participants in the chapter ‘methodological reflections’. Yet, whilst this reflexive piece is explicitly orientated around a conceptual framework, there are other aspects of reflection and reflexive thinking in this thesis that are not. In the same chapter, for example, I present a reflective account of engaging with the advisory network and this forms the basis of a published manuscript (Isham, Bradbury-Jones & Hewison, 2018). In addition, I include two accounts of analytic decisions taken in the process of interpreting the interview and focus group data and I draw on diary notes, diagrams and coding excerpts to illustrate the gradual but creative nature of my reflexive approach (see appendices for details). Lastly, I include a series of reflective notes and observations within several chapters: for example, in this methods chapter, in the empirical findings and the discussion. These reflective notes demonstrate some of the ‘conceptual bridges’ (Aymer & Okitiikip, 2000) between the empirical, ethical, epistemic and practical aspects of the project. Taken together, this illustrates a commitment to reflective and, at times, critically reflexive research practice. When constructing this thesis, I was mindful of Berger’s (2015) concern that despite the high methodological value placed on reflexivity, often it is a case of “now you see it, now you don’t”. In this thesis, I have endeavoured to make it as visible and consistent as the empirical and analytical-focused content.

Methods

In the following section, I present some of the central issues and debates pertaining to: working with lay advisors, conducting interviews, and carrying out focus groups in the context of sensitive research. I also explain the rationale for adopting these methods. As indicated previously, I engage in a more detailed discussion about the ethical and methodological issues that I encountered using them in the chapter ‘methodological reflections’ (chapter 7).

Working with an advisory network

1. Lay involvement and participation in health and social research

In the last twenty years, involving non-academic stakeholders in research has moved from being a specialist to mainstream practice in health and social research (World Health Organization, 2015; INVOLVE, 2015; Coulter, 2011). There are often overlapping reasons for involving participants in research and approaches vary in emphasis and degree, depending on the disciplinary context as well as the skills and outlook of the research team involved (Cornwall, 2008). In broad terms, however, working in a collaborative, respectful and inclusive way with people who use research and/ or are ‘experts by experience’ has become a cornerstone of ‘best practice’, particularly in applied health research (Brett et al., 2014). Involving different types of people in shaping decisions about how and what knowledge is developed opens a previously restricted area of professional practice to wider public scrutiny and influence. In turn, it is argued, new types of knowledge and understanding may be developed which better represent and address the needs and experiences of people who may otherwise be overlooked or marginalised (Aldridge, 2016; Nind, 2014). The different degrees of involvement have been conceptualised as a ‘ladder’ with the implication being that there are better or ‘stronger’ forms of involvement (Arnstein 1967). However, what is best for a particular project is contingent on the context and focus of the study. Thus, it is perhaps more helpful to think in terms of a continuum of involvement as judgements concerning what is the ‘best’ approach can be problematic (Nind, 2014).

Advisory fora

Advisory groups are generally fora in which people with different interests and experiences come together as a means of ensuring the research is conducted in accordance with best

practice guidelines and is managed efficiently. They are also referred to as steering or stakeholder groups. When convened specifically as a forum to advise on participant involvement in research, common activities include: providing feedback about the credibility of a research question, contributing to design and development decisions, and, critically reviewing ethical issues and procedures to ensure participant welfare.

The advisory network

In planning this project, I wanted to ensure that the needs and views of people with personal insight about caring and/ or family violence were central to decisions about the scope and purpose of the study. The network played an active role in terms of recruitment of interview participants, suggesting amendments to materials and questioning decisions about the project's chronology and methodology. For example, advisors made a significant contribution to the development of the project website and strategy for online communication (see appendices). They also raised critical questions about how to frame violence, abusive, or harmful behaviour in participant-orientated materials and exchanges: indeed, this was a central and re-occurring point of discussion and debate with advisors. Thus, there were similarities in the activities of the network to that of a 'traditional' advisory group (Lewis, et al. 2008; Porter, et al. 2006), particularly in terms of shaping study recruitment and engagement strategies. The network also helped to create a reflective space to discuss the purpose, justification, and conduct of the research project.

Semi-structured interviews

1. Interviews in sensitive research

Interviews are the most commonly used method in qualitative inquiry and their popularity extends to the field of sensitive research. Often characterised as an exchange or a process,

research interviews provide a forum to develop (and test) relational dynamics between researcher and researched. Attending to social cues and non-verbal communication is often pivotal in building a sense of trust and rapport between people that may in turn facilitate conversation about complex or emotionally-charged topics (Dickson-Swift, James, Kippen & Liamputtoing, 2007). When discussing difficult issues such as trauma and abuse, it is particularly important that the researcher conveys a willingness and ability to listen to potentially upsetting, intimate information in an attentive and professional manner (Aadnanes & Gulbrandsen, 2017). This may decrease participants' feelings of unease or shame. Perhaps more importantly, researchers need to be cognisant of potential signs of distress or discomfort and explore these with participants so that their psychological welfare is protected, and their individual social and emotional needs are met (Decker, Naugle, Carter-Visscher, Bell, & Seifert, 2011). Thus, the behaviour and social skills of the investigating researcher play a critical role in shaping the conduct of the interview as well as interpreting the transcripts or field notes that record the talk and interactions that go on within it.

Yet with the rise of sensitive research has come a concomitant rise in ethical and methodological debate about researchers' remit and capacity to protect participants from harm in the research encounter. It is questionable, for example, whether researchers are blurring the line between therapeutic and research interviews. Because researchers rarely have a relationship with participants following the study's end, this limits their ability to support participants to process the potentially negative thoughts, feelings and memories that talking about difficult topics may have evoked (Chan, Teram, & Shaw, 2017). In addition, because researchers are unlikely to have undergone specialist training in human psychology and counselling techniques they may fail to pick up on more subtle signs of distress and discomfort (Tyldum, 2012). This is particularly important in the context of research about

violence and abuse, as a poorly-managed or premature disclosure could affect participants' longer-term recovery and rehabilitation (Appollis, Lund, de Vries, & Mathews, 2015). In addition, researchers and therapeutic practitioners tend to have different motivations for talking about difficult subjects. Although both are likely to stress the emotional and social benefits of talk and meaning-making, researchers often derive professional benefit from analysing and sharing these exchanges whereas the practitioners' focus lies with the growth and recovery of their client or patient (Chan et al, 2017).

Nevertheless, participants can, and often do, benefit in some ways when taking part in sensitive inquiry and have different motivations for research involvement. Developing meaning through talk and raising awareness about a taboo or hidden issue (for the benefit of others) are common explanations cited by participants (Appollis et al., 2015; Clark, 2010). For some participants, having their expertise and views valued can be a positive and sometimes cathartic experience. This may be more significant if participants have experienced feelings of disenfranchisement and marginalisation in the past, particularly in interactions with professionals or in institutional contexts (Buchanan & Wendt, 2017).

The use of interviews in this study

I chose to use semi-structured, one-to-one interviews as the primary research method to explore family carers' experiences of violent, abusive and harmful behaviour. For the reasons detailed earlier, this seemed an appropriate way of exploring emotive and complex issues with participants and to find a space for them to consider and express their views and feelings about carer harm. I also hoped that the interview context would provide participants with a degree of choice and control about what they shared. Conducting and analysing interviews was also congruent with the social constructionist orientation of this project and its emphasis

on social interaction and language as central mechanisms by which subjective and social meaning is developed. For more details about the interview participants and interview process, including ethical considerations, please see the chapters ‘interview findings’ (chapter 4) and ‘methodological reflections’ (chapter 7). However, at this stage, it is important to note that I sought to recruit both male and female carers to take part in the study.

Focus groups

1. Focus groups in sensitive research

Focus groups are commonly characterised as a discussion between individuals that is ‘focused’ on a topic and facilitated by the convening researcher (Robinson, 1999). Focus groups are associated with producing rich, often complex, data about points of comparison, contrast, and consensus between members of a group (Kitzinger, 1994). In addition, the group environment can help people talk about ‘difficult’ topics because it facilitates exploration of latent, shared social meanings that can otherwise be difficult to name or describe to ‘outsiders’ (Bradbury-Jones, Taylor & Herber, 2014). Focus groups can also provide a reflective and structured space for people to share views that they may feel uncomfortable or hesitant to do in a one-to-one encounter. This is because group members may feel more confident to speak out, tacitly given ‘permission’, about controversial or difficult issues once they have been raised by other, perhaps more confident, or experienced, members of the group (Brondani, MacEntee, Bryant, & O'Neill, 2008). Because there is less attention to or detailed exploration of the views of any one individual, group members are also likely to feel that they have more discretion over if, and when, they share their views or experiences. In turn, this may enhance their sense of control and comfort when taking part in the research process.

There are nevertheless limitations to consider when using focus groups. Although they provide a useful way of generating discussions that encompass a range of people's views, they can at times develop breadth of data at the expense of depth of discussion. When investigating contentious or sensitive issues, this can prevent exploration of ethically complex issues or opportunities to gain an informed understanding about issues participants find difficult to articulate in the group space: for example, because they raise powerful or uncomfortable emotions (Brondani et al, 2008). Furthermore, in the case of pre-formed groups, participants may derive little comfort from assurances from the research team concerning anonymity and confidentiality (Kitzinger, 1994). This is because whatever takes place within the focus group sessions will be heard, witnessed or responded to by people with whom participants have ongoing relationships. This can increase the chance that tensions may surface and that the group perpetuates normative discourses (Smithson, 2000). People taking part in groups that are created and then dissolved as part of the research process may feel more comfortable expressing their views to relative strangers. However, a lack of trust and reciprocity between participants can curtail exploratory and 'deep' discussions, particularly those relating to seemingly 'difficult' issues.

The use of focus groups in this study

Given the limited research on professionals' views about harmful behaviour towards carers, I considered that focus groups would provide a useful forum to begin to map professionals' attitudes and experiences. To stimulate discussion amongst group members, I used vignettes - adapted from extracts of the interview data - alongside a short semi-structured topic guide. Vignettes can help to root focus group discussions in 'real life' examples. They also enable participants to talk about issues from a hypothetical or third-party perspective if they do not wish to share examples from their own practice (Bradbury-Jones, Taylor, & Herber, 2014). I

considered these to be strengths of the vignette method given the potential sensitivities involved in talking about carer harm coupled with the limited research or practice guidance about the topic. As discussed in the focus group findings chapter, the vignettes proved to a powerful way of engaging practitioners in conversations about both the example ‘cases’ and as acting as a spur for reflections on their practice experiences working with people in similar situations.

From an epistemological perspective, focus groups are well-suited to social constructionist inquiry because they provide an inter-personal, social ‘system’ in which to explore social dynamics through the medium of observed behaviour and use of language (Puig et al, 2008). This is because, depending on the nature of the discussion, members may search for points of association and difference to explore and explain their ‘position’ on a topic. This can be useful when exploring points of contrast and comparison between defined groups, such as members of a profession or workers in an organisation (Robinson, 1999). In the field of adult protection and safeguarding, there is limited research about how health and social care professionals construct and manage the often emotionally and ethically demanding aspects of their work (Band-Winterstein, Goldblatt, & Alon, 2014; Bourassa, 2012). Thus, I considered that the use of vignette-based focused groups might prove a valuable way of enriching knowledge about practitioners’ needs and views.

Finally, on a practical note, focus groups are an expedient way of capturing a range of views and ideas in a short space of time. The relatively time-limited nature of the group event means participants are less inconvenienced than other more resource-intensive research methods. Given my position as an ‘outside’ researcher, this was an important consideration when seeking access to the professional groups and I was cognisant of the concerns that their

employing organisation may face when deciding to allocate time to research rather than service-user focused activities (Clark, 2011). I attempted to mitigate these concerns by organising the groups well in advance and carrying them out during lunch-times or at the end of the working day to minimise interruption to practitioners' busy schedules. I also held initial, exploratory discussions with senior managers and highlighted how the sessions were intended to provide a reflective space for practitioners to share their views and experiences as a group. As a result, participation in the groups was advertised as an opportunity to take part in research *and* to engage in continuing professional development (CPD), thus meeting some of the needs and objectives of the host organisation. On a practical point, I provided drinks and snacks during the focus group sessions. This gesture was a small way of indicating my gratitude to participating practitioners and welcoming them to join in an exploratory, confidential discussion.

The following extract is taken from the ethical approval letter (see appendix 1) from the local authority research ethics committee that approved the application to carry out focus groups with practitioners. I share it here as an indication that the study's design was recognised to be practical and sensitive to practitioners' needs.

We agreed this is an extremely well prepared application and a potentially a very useful study of an under-researched area. Consent forms and information sheets are well written and clear and the vignettes are ones that will, we think, lead to some interesting and productive debates within the proposed focus groups. The design and methods reflect a good understanding of the operational pressures facing Adult Social Care Departments these days and set out to consciously minimise the impact of the

study on busy working lives. The study is achievable within available timescales and resources. Research ethics committee (local authority)

Management of potential harm

Given that the groups consisted of practitioners, I anticipated that participants would be used to talking about ethical and ‘sensitive’ issues. However, I recognised that carer harm may raise practical and ethical dilemmas for focus group participants and that professionals may be affected by this issue in their personal lives. As a result, I used the group session to develop a reflective, confidential space in which professionals could discuss the issue of harmful behaviour toward carers in a spirit of learning and support amongst peers. This included facilitating the discussion in a way that minimised the domination of any one group member. In part by establishing ground rules at the beginning of the session to encourage sensitivity to other people’s potentially different views and experiences. For further details of the focus groups sessions and participant characteristics, please see the chapter ‘focus group findings’ (chapter 5).

Analysis of the interview and focus groups transcripts

In the following short section, the two, parallel approaches I adopted to analyse and synthesise the carers’ accounts and the professionals’ group discussions are described. I interpreted both data sets using Braun and Clarke’s (2006) approach to thematic analysis. The theory of epistemic injustice and the concept of ‘hermeneutic injustice’ (Fricker, 2007) informed a ‘deeper’, theory-informed synthesis of the accounts. Here I explain the rationale for taking this hybrid approach and reflect on some of the opportunities and limitations it afforded.

Thematic analysis

1. Background

Thematic analysis is a systematic and rigorous method used to organise and interpret qualitative data (Braun & Clarke, 2006). Over the past fifteen years, thematic analysis has become a well-established approach and its popularity is evident amongst applied and theoretical disciplines, as well as novice and experienced researchers. This has been in part a result of a developing consensus amongst the academic community about how to carry out as well as teach thematic analysis (Clarke & Braun, 2012; Braun & Clarke, 2014). So too are there clear and well-established criteria about how to evaluate thematic analysis for evidence of rigour, consistency and authenticity, akin to other approaches in the qualitative canon (Fereday & Muir-Cochrane, 2006; Braun & Clarke, 2006; Boyatzis, 1998).

Because thematic analysis is an analytical technique, rather than a methodological approach, it is not aligned with any one theoretical or epistemological position. It is therefore compatible with the ‘full spectrum’ of philosophical positions: from realist/ essentialist views to symbolic interactionism and social constructionism (Vaismoradi et al, 2013; Boyatzis, 1998). This flexibility means that the technique can be used by a wide range of researchers from different intellectual disciplines. In addition, the type of analysis being carried out can ‘look’ different, depending on the researchers’ theoretical and disciplinary orientation. Joffe (2012) suggests that thematic analysis encompasses a set of “core methodological skills” required of all analysts. Looking for patterns and associations across a data set is, for example, a common aspect of many analytical approaches in qualitative research. So too is there an expectation that researchers stay ‘close’ to their empirical data, developing accurate and descriptive interpretations that remain authentic to participants’ intended meaning (Koch, 2006; Pope & Mays, 2009).

Used widely and across different disciplinary contexts, the ‘quality’ of thematic analysis nevertheless varies. Moreover, thematic analysis is not considered by some to be a comparable or equivalent approach to those of more-established academic traditions, such as grounded theory, phenomenological or narrative approaches to inquiry (Clarke & Braun, 2014; Vaismoradi, et al, 2013). This is in large part a result of the view that it is a simple, rudimentary process. Joffe (2012) suggests there are likely to be cultural reasons underpinning this stereotype that are “in part, a residue” of the approach’s early association with realist epistemological traditions, now largely eschewed by contemporary social scientists. One of the paradoxes of the flexibility and broad application of the approach is that it does not ‘belong’ to any one discipline or intellectual tradition and therefore seems to sit outside of the academic lineage of other analytic methods and methodologies (Boyatzis, 1998; Joffe, 2012). This is evident in the relative paucity of critical or reflective literature about how researchers use and apply thematic analysis in their work, aside from some notable exceptions (Frith & Glesson, 2004; Tuckett, 2005).

Braun and Clarke’s model

Adopting the model set out by Braun and Clarke (2006), thematic analysis involves six stages. Although the phases are presented in a tabular form (see Table 1), they do not progress in a strictly linear fashion; rather, there is a significant recursive dimension to the process of interpretation as well as a sustained intellectual, and often time-intensive, commitment involved (Boyatzis, 1998; Clarke & Braun, 2013; Tuckett, 2005). Braun and Clarke (2006) suggest that analytic transparency can be developed through a range of measures, including: reflective writing, textual description, visual representations of

developing ideas, annotated excerpts of the data, and, draft versions of the definitions, summaries and diagrams that make up the final conceptual schema.

	Stage	Description
1	Familiarisation	Initial and detailed engagement with all of the dataset. Often, this will be done through the process of transcription of audio-recording and/ or preparation of other textual materials. Researchers are encouraged to read and re-read all of the data before they begin initial coding.
2	Generating initial codes	At this initial stage, researchers are encouraged to code broadly, encompassing latent and manifest interpretations. They should also use multiple codes (i.e. to preserve the potential richness and diversity of the data) and code all data. This can be a time-consuming and intellectually-intensive process.
3	Searching for themes	Researchers should make decisions about what ‘counts’ as a theme and/ or what types of themes they are seeking to identify. Sometimes, the frequency of a theme can mean that it is highly relevant and central to any interpretive account.
4	Reviewing themes	At this point, the researcher needs to check for the coherence, accuracy and breadth of the conceptual schema. This may involve re-coding some sections of the data to reflect the more refined codes that have developed in the latter stages of the analysis. Nevertheless, it is important that researchers do not continually re-code and re-organise the thematic content of their data.
5	Defining and naming themes	This stage is characterised as the “define and refine” phase. The researcher should now be honing their conceptual themes and checking that they are congruent, but not overlapping, with one another. Themes should be described in concise terms and should be understood by the general reader.
6	Producing the report	The presentation of the final analysis involves developing a narrative about the data that both describes and seeks to explain it (or significant parts of it). This should be developed with the intended audience in mind and with the aim of making the narrative clear and engaging.

Table 3: Braun and Clarke’s (2006) phases of thematic analysis

Thematic analysis of the carers’ and practitioners’ accounts

I chose to use thematic analysis as the primary analytic method to code, interpret and synthesise the transcripts of the carers’ interviews. Retaining a focus on descriptive meaning can be particularly useful when exploring an under-researched topic because it helps to map

new areas of emerging knowledge and meaning (Braun & Clarke, 2006). It can also help to retain the ‘descriptive power’ of the accounts (Sandleowski, 2000) and to produce an interpretation that is recognisable to participants, who had trusted that their stories would be treated with integrity and respect (Koch, 2006; Lewis, 2010). Nevertheless, I was cognisant that I was not giving a ‘voice’ to participants in a way that meaningfully challenged the inherent power asymmetries in our exchange and my privileged position of ‘making meaning’ from the experiences they shared during our encounters (Nind, 2014; Serrant-Green, 2011). Adopting a thematic approach also enabled me to explore some of the more symbolic and latent meanings expressed by the carers. This in turn helped me to draw connections between my empirical data, and conceptual, theoretical and empirical work in the wider field: an established and well-recognised approach in qualitative inquiry (Braun & Clarke, 2006; Clarke & Braun, 2013).

As discussed, appendices 3 and 4 contain two reflective, step-by-step accounts of my work analysing the carers’ accounts and the group discussions with health and social care practitioners. These accounts are shared with the aim of making more transparent the decision-making and reflective and interpretive processes that contributed to my use of Braun & Clarke’s (2006) approach to thematic analysis. Furthermore, by making these sources available, readers can check as well as critique the consistency and rigour of my interpretive choices and technique (Seale, 1999; Mays & Pope, 2009). I have placed these notes in the appendices because they are intended as supplementary, contextual material to the empirical findings which, for ethical and methodological reasons, take priority in terms of reporting and discussion. However, this placement does not infer that analysis is less important; rather, that it is a necessary foundation on which ‘good quality’ data are built.

Developing a theoretically-informed analysis of the data

1. The role of theory in qualitative research

Theory can play a central role guiding, informing and strengthening qualitative health and social research. Often rooted in a disciplinary tradition, a theoretical framework can provide a means of organising key concepts which in turn can guide the analysis. In many cases, this lays a strong foundation on which to build more in-depth or informed interpretations (Kelly, 2010). As with ontological and epistemological claims, it is important that researchers are clear and consistent about how and why they are using a given theoretical approach.

Moreover, theoretical frameworks need to be rooted in a clearly-articulated epistemological context and be compatible with the methods and techniques used to develop empirical data (Carter & Little, 2007; Bradbury-Jones et al, 2017). Perhaps most importantly, researchers need to be honest about their level of knowledge and experience of using a given theory, recognising that it is not theory that enriches the interpretation of data, but rather the ability of the researcher to understand and apply theory. Reflecting on the choice, as well as the limitations of a given theory may therefore render the analysis more rigorous and help the wider audience ‘follow’ the analytical process (Featherstone, 2000).

Applying Miranda Fricker’s theory of epistemic injustice

In the process of carrying out the thematic analysis, I became increasingly cognisant of the limitations of adopting this approach in isolation. Over time, I came to notice the constraints of relying solely on the descriptions and reflections of participants to explain and explore the complexity of their emotional experiences, aspects of which might not be possible to ‘put into words’. I also recognised that although the empirical data was rich and valuable, it encompassed the views and experiences of a limited number of people. Clearly, there were gaps and silences in the data: people, in short, who may be affected by the issues that the

project raised but whose voices, for manifold reasons, had not been heard (Lewis, 2010; Serrant-Green, 2011). Thus, I considered it valuable to orientate my analysis within a framework that took explicit account of social factors and processes that might affect how carers and professionals ‘constructed’ our discussions. Taking these emerging critical and methodological reflections into account, I came to learn about Fricker’s theory of epistemic injustice and decided to use it to guide further analysis of the interview and focus group data. My ‘discovery’ of her work was serendipitous, and, it opened a way to develop a ‘deeper’ approach to analysing the carers’ accounts. I will discuss in greater critical depth the rationale and limitations of adopting this theoretically-informed approach in the relevant analysis chapter. In the following chapter, I present the findings of my thematic analysis of the carers’ accounts.

Chapter 4: Interview findings

Chapter overview

In this chapter, I present a thematic analysis of the transcripts of the carer-participants accounts. I first provide an outline of who took part in the study and reflect on how the interview exchanges were established. The findings are then presented as four, inter-related themes: 1. Participants' views and experiences of caring as a 'natural' role borne out of circumstance and duty. 2. Participants' experiences of harmful behaviour, as instigated (but not necessarily intended) by the older person for whom they cared. 3. How participants managed, minimised and found meaning in the context of caring *and* harmful behaviour: a position I characterise as 'paradoxical intimacy'. 4. Participants' reflections on how their experiences were often 'hidden' from others, both in terms of remaining unknown as well as not meaningfully understood.

The participants

I carried out twelve in-depth interviews with female carers who identified as having experienced violent, harmful or abusive behaviour, as instigated by the older person for whom they cared. In terms of their relationship with their family member, six women identified as spouses, four as adult daughters, one as a sister and one as a niece. Ten participants cared for a male partner, father or brother whilst one woman cared for her elderly mother and one woman cared for her elderly aunt. In terms of ethnicity, two women identified as British-Asian, two as British-Caribbean and seven women identified as white-British. One woman was of non-British, European heritage.

All of the interviews were face-to-face meetings and they lasted approximately 1.5 hours. Eight women elected to be interviewed in their home, and I met four women in a private

room at a public location. Three interviews were held at a university and one in a local library. I audio-recorded 11 of the interviews and transcribed the files verbatim. One interview was conducted over a series of meetings: one two-hour face-to-face meeting and, three one-hour phone conversations. During these sessions, the participant and I co-developed a written account of the experiences she wanted to share. A fuller, critical account of this work is included in the chapter ‘methodological reflections’. In the process of transcribing or collating the accounts, each woman was assigned a pseudonym and these names are used consistently in the following chapter. The chosen names seek to preserve some sensitivity to the individual’s gender, age and ethnic background, whilst maintaining their anonymity. Table 4 outlines each participant’s caring situation at the time of interview.

Participant name	Relationship to family member	Co-resident with family member during caring?	Current or former carer at time of interview
Asrah	Daughter	Yes	Former carer
Megan	Wife	Yes	Former carer
Mary	Wife	Yes	Former carer
Anna	Sister	Yes*	Former carer
Dorris	Daughter	No	Former carer
Jane	Daughter	No	Currently caring
Sally	Wife	Yes	Currently caring
Janice	Daughter	No	Currently caring
Rose	Wife	Yes	Currently caring
Sarah	Wife	Yes	Currently caring
Anita	Niece	Yes	Currently caring
Christine	Wife	Yes	Currently caring

Table 4: Interview participant characteristics

*Anna lived with her brother for many years, both as a child and young adult. As an older adult, she was no longer co-resident with her brother however she had, for many years, continued her role as a carer.

Presentation of the thematic analysis

Table 5 provides an overview of the central themes and sub-themes developed during the process of analysing the participants' accounts. In the process of developing this analysis, I drew on the wider literature. Such an approach is congruent with the social constructionist orientation of this project and its qualitative methodology (Braun & Clarke, 2006). It helped to situate the accounts temporally, socially and conceptually and to consider critically some of the social processes and factors that affected how the carers (and I) 'constructed' our discussions. Nevertheless, decisions about what literature was considered relevant and valuable are necessarily interpretive and partial, as are my choices about which themes were privileged and developed from the data (Sandelowski, 2015). For more details of the analytic approach and method, please see the methodology and methods chapter and appendix 2.

Organising theme	Central sub-themes
Becoming a carer: a 'natural' and inevitable role	Over-arching theme
Identifying and experiencing harm	<ul style="list-style-type: none">• Feeling manipulated and controlled• The threat and incidence of physical and sexual violence• 'Witnessing' distress and constant change
Caring and coping in the context of paradoxical intimacy	<ul style="list-style-type: none">• Managing and minimising harm• Dilemmas and decisions: transition and separation
Hiding and feeling hidden	Over-arching theme

Table 5: Central thematic findings of the interview data

Becoming a carer: a 'natural' and inevitable role

Participants consistently talked about caring as a 'natural' or inevitable role and one they sought to fulfil to the best of their ability. In addition, participants talked about how it was assumed by other family members and sometimes by professionals they would take on the role as the sole or primary carer for their partner or family member. Nevertheless, the circumstances in which participants became carers varied considerably. For some women, caring had been a part of their life for many years. In these situations, their family member's illness was chronic in nature and their role as a carer had changed and adapted over time. This didn't mean that these carers felt more prepared or better equipped to manage their role; however, they were, perhaps, more familiar with it and the norms that it engendered. Sally, for example, describes how she became a carer for her husband early on in their marriage:

My husband had a car accident twenty-one years ago and had top-to-toe injuries. Physical and mental: his brain was damaged as well. I became a carer from the moment he had the accident. Sally

Mary knew that her husband was in poor health before they married. Over time, his health deteriorated and he developed more complex physical and mental health issues. Looking back on that period, Mary reflected that she did not anticipate the challenges that lay ahead.

I knew that he (husband) was a diabetic when we got married. What I didn't understand was that the professionals made it all sound very easy. That if you did all the right things then everything would be OK. It didn't take me long to realise that that wasn't going to be the case. Mary

Both Sally and Mary talked about how unprepared they had been to understand the challenges involved in combining the roles of wife and carer for their partner. Over time, they had become attuned to their needs and taken on the primary role providing their medical care and acting as an advocate for their family member. This transition took place during their

early years of marriage and during a time when both women were parenting their young children. As older adults, aspects of their role had changed. Nevertheless, there was also a sense of continuity as their partner's illness remained the central organising foci of family life and their shared domestic space, as it had throughout their adult lives together.

Although many participants became carers later in life, three women had taken on a caring role as children or young adults. Here, Anna describes how she felt habituated to the role of a 'young carer' for her brother and mother, both of whom had serious mental health problems. Anna reflected that she could not remember a time when caring was not part of her life. She drew on a powerful example to illustrate her view that being a carer meant learning "not to notice" her own needs or feelings.

I became aware very young of the fact that nobody was in charge. So, it felt like my duty to listen, to support, to help in whatever way I could and certainly not to put any pressure on them (brother and mother). I had an abortion when I was young because I was raped when I was young but nobody knows about that and in fact that is the first time that I have said that to anyone... It's just a good example to show that, you know, nobody is going to be there for you. You keep everything for yourself... You know, you keep everything for yourself. Anna

Echoing Anna's comments about being attuned to the suffering and needs of her family members, many carers characterised caring as an expression of identities, commitments and feelings forged across the life-course, rather than a personal choice (Fine & Glendenning, 2005; Lloyd, 2000; Forbat, 2005).

I think, caring is... it's something that you do for somebody else that is over and above what you would normally do for them. So, what I do for my husband who is ill... is over and above what anybody else would normally do for a husband...I don't see that I have any choice, maybe I do. Sally

I don't think it's really a choice. It's part of my culture, isn't it? ... It's the way we are. We have to look after our parents and, you know, our family. You have to show respect. I think that that's what I'm keeping with me. Because she's my aunty. What

can I do? That's why you can't tell them. That's why you have to bottle it up for yourself. Anita

Asrah and Megan reflected that they too felt a significant sense of responsibility to care for their family members. They drew a comparison between caring and parenting to illustrate the similarities between providing personal care for an older person and parenting care for a baby or young child. This association highlights that there was, in some important ways, an asymmetric dynamic to their relationship, at least in terms of how they felt depended on.

I think that that feeling that I have had, if anything, it's just kinda grown over the number of years that I have been a carer for him (father). And I don't know how it's happened... It was kind of like as if I had taken on the parent role. Because of the things that I was doing for him, so kind of like making sure that he was bathed, changed, fed: things like a parent would do for a child. And because he was, I wouldn't say he was vulnerable... but the fact that his whole personality as a result of his stroke, had changed in the sense that he became so carefree... It was like this role reversal that we had. He was the child and I was the parent. Asrah

The first time (he went 'wandering') I thought "right, you're going to have to be really vigilant here". Social services came out to see if there was anything they could do like getting an alarm on the bed to alert us when he was getting up. They thought he was too far gone. But I never slept properly anyway because it was like having a baby because you sleep with one eye and one ear open, listening. Megan

On this theme of transition and recalibration in the relationship, several women talked about their family member's illness as a process or event that marked a stage of loss. It appeared that they were coming to terms with the significant changes in their family member's personality and behaviour, as well as what it meant to be their carer *and* their wife. Bury's (1982) concept of 'biographical disruption' – when (chronic) illness disrupts one's sense of self and requires new material and cognitive resources to adjust, both physically and socially – may be important here. Indeed, a number of scholars have demonstrated how families, including family carers, are actively involved in co-constructing new understandings of illness and family life (Radcliffe, Lowton & Morgan, 2013; Adamson & Donovan, 2005). In the following extracts, Rose and Sarah reflect that they had few opportunities to process

recent and significant changes in their husbands' health. Here they talk about how this lack of time and, perhaps, emotional space, limited their ability to grieve for the person and relationship that was, seemingly, changing beyond recognition.

I cannot explain how much loss I have experienced since my husband became unwell and I became his carer.... Our life is almost unrecognisable now and I feel like there has been no time to reflect on what has happened and to grieve for this loss. I sometimes think about how different my life would have been had my husband not become ill. I never had a choice about becoming his carer or having my life change in such a fundamental way. Rose

You don't have time to even grieve for it, because effectively I have lost my husband. And I don't mean that in a ... but he's not a husband anymore, he's not a partner any more... Now there is nothing, nothing at all. So, effectively you are single but not only that but you have this massive responsibility for someone else's health, welfare and safety. And you have to think for them. I have to anticipate almost his every need. Sarah

Touching on the need to respond and adapt to changing circumstances, Jane – a carer for her two elderly parents – described some of the practical changes that this new role had engendered. The need to be geographically close was real and pressing for Jane, as both her parents' health was deteriorating rapidly at the time of our discussion and her mother had almost died several times in the preceding year. It was also difficult to navigate these new and increasing responsibilities, she explained, because her husband resented her spending this additional time with her parents and being away from their marital home.

So, it's a strain. I want to do my best by them. And I want to, you know, the hours I do - when they are in real strife - I go over at least five times a week, which is two buses from where I live, because my husband needs the car to go to work and so that causes all sorts of troubles. When I leave at the end of my stint I try and coax myself to believe that I have done enough; that I can't do any more than I have done. I have vacuumed, I have washed up, I have been to the local shops for shopping, made sure that they have been fed. So, everybody is doing as much as they can but I still feel bad for walking away. So, that pulls, pulls at my heart strings. Jane

Jane's comment about her heart strings being "pulled" touches on a common thread running through the carers' accounts: that of the emotional and unique, relational reasoning that

underpinned women's caring practices (Pickard, 2010). For many of the women, managing difficult decisions and feelings was done with limited support from others. Indeed, all the women taking part in this study were, or had been for a significant period, the sole or primary carer for their family member. For those participants who shared aspects of their caring role with other family members, the involvement of other people was, in the main, limited. There was thus a recurring theme of participants feeling isolated and that this sense of being alone was compounded, if not caused, by the constraints that arose from their family member's illness. Several women, for example, discussed how family members had struggled to recognise and to respond to their family member's changing needs. This could result in them feeling uncomfortable or becoming hesitant about doing the 'wrong thing' and as a result, seeing someone less often. Women also talked about how there were not many other people who lived close enough, or who had a sufficiently close relationship, with their family member. Sometimes, their family member's past behaviour also contributed to the limited willingness of other people to visit or support them, as discussed by Christine and Mary:

People can't always cope. I remember a very old friend of my husband's, his wife said to me "Sam can't cope with David (husband): he can't bear to see him, what's happened to him, from the person he knew". Mary

There just isn't anyone else. He sort-of... he doesn't actually drive them away but they just sort-of get fed up of being cancelled or ignored... All his friends, they weren't friends, they were just people that drank with him. Christine

Understanding caring as a relational and emotional practice may go some way to explaining why many carers feel ambivalence about the term and associated identity of 'being a carer'. This was certainly an important point for many of the women taking part in this study, as they reflected on their feelings of discomfort when using the term. This may have been because the term is understood to imply a professional arrangement and a dynamic of partial or total dependency by a 'vulnerable' person on another adult (McGovern, 2011). Such associations

can devalue the normative dimension of caring and tend to obscure the non-caring related aspects of the relationship (Molyneaux, Butchard, Simpson & Murray, 2011). These issues were discussed by several participants:

I didn't recognise myself as a carer initially... but once I got into a pattern of dealing with his needs and everything... I'd actually identified myself, that not only am I his daughter and doing it from my love for my dad, I'm also falling under this category of a carer and I think that that identity, I really struggled with at that time because I didn't recognise myself as a carer. I just saw myself as a daughter and I'm just doing this anyway... but then having to come round to identifying myself as a carer because I had to become a carer in order to access some of the support. Asrah

The GP actually said at the end of the conversation, 'oh, OK, so we'll reclassify you as a carer'. And that was a bit gob-smacking to me because I had never even thought of that word... I was his wife and I looked after him. You know? And I thought that carers were people who worked in nursing homes. Do you know what I mean? And I sometimes think that sometimes the word is a bit derogatory... I mean, it's because carers do horrible things to older people in nursing homes and it all gets filmed. Christine

Several other participants echoed Christine's comment about the "horrible things" that formal (paid) carers do to older people. These women talked about their distrust of care staff and their concern that their family member would experience neglect or abuse in a residential or nursing home setting.

So, I said to them – my daughter had told me about some of the medication that we could get to help my mother. I said, I think we need to have her (mother) sedated, yes, yes... We think that she will either be heavily sedated or that she will be abused, if she is in a care home. So, the best place for her is home with somebody coming in. Janice

You hear horror stories out in the press and everything about home carers and them coming in and doing the things that they were doing. I didn't really want to be in that position if something was to happen. Because that would be an extra pressure in terms of my siblings or family members who would say "well, you sorted out this care package for him and look what's happened". So that, if anything, put me off telling people what was going on. Asrah

There were many other reasons why the women wanted their family member to remain at home, not least because they thought this would ensure a better quality of life for them and

because they felt it was their duty to care for them within their home environment for as long as possible. Their comments touch on many of the distinctions between the practices of formal and informal care and the inherent sense that care provided by a loved one was of a qualitatively different and superior nature (Lynch, 2007). As a corollary of this, several of the participants appeared to have low expectations of formal carers and the ability or willingness of government to uphold consistent standards of dignity and safety in nursing and care home environments. It is possible that the women's concerns were exacerbated by recent high-profile cases exposing poor care in residential and nursing homes, contributing further to the sector's 'broken image' (Hockley, Harrison, Watson, Randall & Murray, 2016; Jönson, 2016). Coupled with their position of relative isolation - and the 'natural', often normative way that the women understood their role as a carer - this could result in them feeling that they needed to care for their family member until they could, practically and often psychologically, do no more. Although this meant different things to different women, I would suggest it was a central factor shaping their understanding of and response to harmful or abusive behaviour.

Identifying and experiencing harmful behaviour

This theme explores participants' accounts of what harmful behaviour 'meant' and 'looked like' to them. As highlighted by the literature review, there are few empirical or theoretical studies which have investigated the experiences and views of family carers affected by abusive, violent or harmful behaviour by the older person for whom they care. Thus, sharing and analysing the women's accounts makes a small but valuable contribution to developing knowledge about the challenges and issues they face. It also contributes to the growing body of empirical work that explores adults' views and experiences of issues of abuse, neglect and 'vulnerability' (Abley, Bond & Robinson, 2011; Lonbay, 2018; Naughton, Drennan, Lyons &

Lafferty, 2013; Morbey, 2002). In the following section, I will draw on this literature, as well as my own thematic and primarily inductive, analysis of the carers' accounts.

1. Feeling manipulated and controlled

The feeling of having limited or no meaningful agency was a pervading theme throughout the participants' accounts. Although this sense of powerlessness had different causes and contexts, it reflected a pervading sense of feeling trapped and constrained. For example, women talked about needing to monitor their reactions and responses to the family member for whom they cared and having little influence about the expectations placed on them as carers. The women also talked about feeling that some or many aspects of their interaction with their family members were, or could quickly become, unequal and sometimes asymmetric in terms of the control and power being exercised or withheld (Daniel & Bowes, 2010). For some carers, this sense of feeling trapped was closely related to their discomfort in taking on the role of carer and the limited choice they experienced in setting any of the terms of this arrangement. For Jane, for example, her father's refusal to accept professional carers looking after him was particularly uncomfortable, given the complicated and difficult relationship she had had with him throughout her life.

Dad was refusing all care. He would only accept it off me: I was his little carer! I helped him get through his finances, now I help him because his mobility is going down. And I am changing Dad's pyjamas because he won't change them himself. I didn't want to do that! But otherwise it's leaving Dad in the same clothes for weeks and weeks... Or, I help him change. I'm thinking, I shouldn't be down here! It's my father, I don't want to! But I need to, to help him because he won't accept that help from anyone else... He will not have it from the carers, only me. Jane

For Asrah, she expressed an inability to challenge her father's expectations that she would care for him and that he refused all "outside help". Caring for her father in her twenties and

thirties, Asrah delayed getting married, going to university and eventually stopped working, in order to look after her father.

Dad had become so dependent on us, when it came to getting outside help or support, he became resistant in accessing that support. He didn't really see the need of accessing that support. And I think that the fact that we never really discussed how challenging he was and how hard it was for us to look after him, he didn't really see the need as to why he would need outside help because we're supporting him as a family. He would say 'what was the need of bringing someone else from outside?'
Asrah

Several carers talked about feeling manipulated and controlled by their family member in a more direct way. For example, when their family member sought to dominate situations or acted in a threatening or aggressive manner so that they were more likely to 'get their way'. Several carers talked about how their family member would 'use' their illness to exert this control: either by placing themselves in position of potential vulnerability or danger, or by calling on their illness as the reason for them behaving in an unreasonable way. This included acting out feelings of resentment or displeasure, if carers did not do the 'right' thing.

Christine, for example, talked about several distressing experiences when her husband had attempted suicide and ensured that she found him following the suicide attempt. Christine said that on many occasions this had happened after they had had a disagreement, or when she had not done what she was 'told' to do. As her husband Rob's mental and physical health needs continued to increase, so too did his harmful behaviour. This resulted in Christine making the decision that Rob would be better cared for in a nearby specialist residential home. However, Rob demanded that Christine visited him for at least four hours a day, every day, in the residential home. Here she describes his response when she tried to go away for a weekend.

So, I go every day and I have to make, I have to tell a lie, to get a day off... He will find a way for it not to happen. The carers (in the residential home) will find him on the floor and I will get a phone call saying that I'm needed... I was away recently, trying to have a breath of fresh air and get my head together and the carers found him on the floor and he said that he had banged his head. So, it will always be that way. I know it will. Christine

In the following extract, Anita talked about how her aunt sought to keep her close, in a literal, physical sense.

There is shouting and screaming. Yeah, she likes to get one over on me. It's attention, I think. Because I might be in the other room and sometimes she might do something because I have left the room. Sometimes she pretends that she has fallen down. Anita

Anticipating family members' changing moods often required a significant amount of emotional energy. Many of the women talked about the need to be responsive to their family member throughout the day and, in several cases, throughout the night. Clearly, this made it difficult to spend time away from them. For other women, they were wary of their family member's unpredictable and often violent behaviour and the likelihood that they would be blamed for their outbursts or feelings of anxiety or low mood. This meant that the women felt a sense of responsibility for their family member's behaviour and they often went to considerable lengths to ensure that it did not escalate. In the following excerpts, Sarah and Anna describe how their family members frequently saw them as the cause of their negative feelings.

Luke (husband) just freaked out. As soon as my brother had gone he just freaked out on me. He was thundering around the house, threatening me. He was telling me that he hadn't eaten for five days and that nobody was looking after him and he was, you know, he was alone. How could I do that? There was this massive thing because I had left him. Sarah

He was so manipulative, to such a degree, with such intent and tension in the background that you think, surely, it can't just be the illness... But, who knows? Anna

For some women, being worried about and attentive toward their family members' needs was intimately bound up with feeling controlled and constrained by them too. Christine and Rose talked about living in the shadow of their husbands' serious mental health problems. One of the effects of their husbands' repeated suicide attempts was that they became increasingly cautious in their interactions with them, concerned that saying or doing the 'wrong' thing would result in another attempt. For Rose this meant feeling "controlled" by her husband's illness and the harmful behaviour it engendered.

I have often felt that my husband, or my husband's illness, is controlling of me and of us. My husband can be demanding and difficult. There are lots of rules and things that I can and can't do. I have to respond to him day-by-day, hour-by-hour. At the same time, I feel that my husband is controlled by his illness. He is powerless too. He doesn't want to act in the way that he does. Rose

Christine made a similar observation about the cyclical and somewhat predictable nature of her husband's suicide attempts. Because he would require more support and care, she felt drawn back to help him, irrespective of his behaviour towards her.

When it (suicide attempt) happens for the twelfth time, you suddenly realise that it's a behaviour that he thinks will grab him the attention. You know, however distant we were up to the time when he did it, you know, the minute that he is taken into hospital because of an overdose, he knows that I'm going to be there and all will be forgiven and that we will be back to square one, at least for a little while, until his behaviour becomes unmanageable again. And there have been so many times when he has done this. It's a real pattern, yes. Christine

The women's accounts illustrate that although the older people in this study often depended on their family to play a critical role in meeting their physical, emotional and psychological needs, they were not without power or the ability to exert influence. They also underline the fluid, sometimes rapid, nature of changes in family members' relational dynamics. These findings thus add to the growing literature, highlighting the complex and dynamic nature of

power in adult relationships and the need to move beyond binary distinctions between ‘victims’ and ‘perpetrators’ of abuse and neglect (Dixon et al, 2013; Wydall & Zerk, 2013; Daniel & Bowes, 2010).

The threat and incidence of physical and sexual violence

The threat and incidence of physical violence was a common aspect of many carers’ descriptions of what harmful behaviour ‘meant’ or ‘looked like’. Physical violence was often understood to be an expression of distress and/ or loss of control on the part of their family member. For those women who cared for someone with a chronic condition that fluctuated over time, violence could also be a sign of deterioration of their health. However, violence was more frequently characterised as being a normal or accepted part of domestic life. Collectively, the participants described a wide range of behaviours that varied in their severity, ranging from acts of physical protest and overt physical gestures, to the threat and acting out of violence that was extreme and sometimes repetitive in nature. In the following section, I present some of the incidents and patterns that the women described.

There was an implicit understanding demonstrated in several participants’ accounts that their family member didn’t mean to cause harm and the term ‘abuse’ was rarely used to describe physical (or any other type) of harm. Several women also made a distinction between being hit and other types of physical threat and/ or physical violence. In these encounters it seemed the participants wanted to make it clear that although they may have experienced, or been threatened with, violence it was a different type of violence than that which characterised domestic abuse. Christine and Anita, for example, drew a clear distinction between being hit and being threatened with being hit.

He has never hit me but he has thrown things at me. When he is frustrated, his hands are pumping, and he will pick up his mobile phone or the television remote control or something like that. Christine

When she does stuff like bang on the table. And when that doesn't work, she throws things at you. And, you know, you're at the receiving end. Anita

Women also shared their experiences of 'near misses' and times when they had felt unsafe and threatened by the physical behaviour and presence of their family member.

Towards the end, he would, he would threaten, well, me... he would go to attack me. He never actually did. He never actually hit me mainly because Alex (adult son) would come on the scene. It was when we tried to stop him going out... And then, he got violent with that as well. When I'm saying violent: aggressive. And yes, I think he would have hit me if Alex wasn't there. Megan

Later in our conversation, Megan described how there was a pattern of increasingly threatening incidents as her husband's dementia worsened and that this had culminated in a 'crisis' situation where he had attempted to strangle her. Following the incident described below, Megan's husband was detained under the Mental Health Act.

I think that if he (husband) hadn't gone into care when he had... because he had me pinned up against that door one day; he had his hands by my throat there (indicates this, hands around throat), umm, because I was stopping him from going out. I think that I would have ended up with quite a few bruises. Megan

Mary also emphasised that her husband, David, had never hit her. However, she was fearful that he would become violent towards her and that there was a precedent for this behaviour. This was a concern shared by David's psychiatrist, who suggested that Mary lock herself in her bedroom when he was "going haywire".

There were things that went awry which nobody ever spoke to me about which was when he was put into a separate room and a psychiatrist was called. So, I assume he was violent on the ward because he could lose his temper at any time, on the streets, at home, all over the place; at anytime, anywhere. He was just going haywire... And the psychiatrist told me to put a lock on the door... The point is, is that he would have just come in and bashed the door down. Mary

Dorris expressed concern about the potential threat that her father, Stan, posed to her physical safety and that of others. Her primary concern was that he might use a dangerous weapon. At a time when Stan's behaviour was becoming increasingly unpredictable and verbally abusive, Dorris had become worried about her father and frightened for her own safety when caring for him alone. I asked Dorris to tell me more about why she was frightened.

He said those dammed people (social workers) are coming in here and they are bothering me, they are bothering me! And he had a little brown pen knife..., he had it in his pocket... And where I found that, that was upstairs, he had it upstairs. So, whenever I was going in there, I had to be careful. Dorris

Over the coming months, Stan became more distressed and increasingly hostile towards Dorris. Struggling to come to a decision about how to carry on caring for him, Dorris identified a clear turning point:

Well... he had a machete. And when he went to bed at night it was by his bedhead because he claimed that when he goes to bed at night people are going to come in and steal his stuff. Dorris

On discovering the machete, Dorris explained that she knew it was no longer safe for her father to stay at home or for her, or any other carers, to care for him alone. Stan continued to ask about the machete's whereabouts long after he had moved to a residential home and talked about wanting to use it against people. Listening to Dorris's account, I was struck by the feeling of threat and trepidation that characterised her interactions with Stan. The presence of weapons in the house reflected and reinforced a mutual sense of fear and powerlessness by them both. This, unsurprisingly, increased as Stan's illness progressed and Dorris felt unable to meet his needs without additional support.

For some women, however, it was not always possible to prevent physical violence and this meant that the threat and incidence of violence had become interwoven into their daily lives.

In the following excerpts, Rose and Sarah describe acts of regular physical violence instigated by their husbands.

I have experienced physical violence many times. I have been hit and pushed and kicked. There was one awful time when my husband tried to strangle me. He had his hands around my neck and he was squeezing my neck so hard and he wouldn't let go. I fell to the ground and he held me down against the floor so that I couldn't breathe and I couldn't move. I didn't know what was going to happen or how it was going to stop. I thought that I was going to die. It was so terrifying. Eventually, I was able to make a little sound and this alerted him to what he was doing and he stopped. Rose

We had another incident earlier in the year where he had thrown something at me. And I said 'don't!' It was stupid, it was a dishcloth. And instinctively I threw it back, like that (gestures). I passed it back. And then he turned around and his eyes were open wide and his hands came up and he literally launched at me. And he turned around like that (gestures) and he pushed me onto the worktop and I think I bruised my ribs, because obviously they just hit the edge of the work-top... and he dragged me around and he put his fist like that (indicating with hands)... and he punched me. And although it wasn't as hard it could be, he has such a lot of strength that it cut across my mouth and the inside of my mouth... And I don't really bruise that easily so thankfully there wasn't too much to show. Sarah

In addition, four women described experiencing sexually harmful or sexually violent behaviour. In three cases, these were recent occurrences. In an echo of other women's accounts of physical violence or 'difficult' behaviour, Sally believed her husband Paul's sexual advances were a way of seeking attention and exerting control.

Yeah, I can tell that it is sort-of intentional. You know? A lot of it is intentional, to get a rise. He does this, he likes to, he grabs my breast or my bottom, which is horrible. You know? And I know personally that I don't like it... I see it as.... I find it.... Abusive, demeaning, offensive, inappropriate. There is nothing I like about it. Sally

Because Paul persisted with this behaviour, Sally felt increasingly upset by its re-occurrence. This, she said, had become a source of tension and sadness for her. Furthermore, because the situation remained unresolved, it was something she had to distance herself from to avoid further conflict, particularly within the routines and spaces of their daily life and shared home.

I tell him not to do it. I occasionally, I think that I have said that I'm not a piece of meat and those sorts of things. But I just say no, and he'll push his hand away, or whatever, I don't know, I don't know. It's one of those things that I just haven't got the energy to do anything about it. Sally

Rose also described experiencing the sexually harmful behaviour of her husband. This was a source of distress for her husband as well as for herself.

When he was very ill, my husband would sometimes act in a difficult way towards me in our personal relations. I had to stop that. Now we both have to be very careful. My husband is horrified about this. He is scared about what he can do and he doesn't want to be this way. The last thing he wants is to hurt me. Rose

For Sarah, too, it was critical to emphasise that her husband Luke's behaviour was not the "real" him, but rather a manifestation of his increasing ill health and vulnerability, caused by his dementia. She explained how Luke's illness was developing and changing at a rapid and often unpredictable pace, particularly over the past year. This had resulted in a series of physically and sexually violent incidents.

I think that what people have to understand is that the risk from dementia, for the carer, it comes in many forms. It isn't just physical. It is also mental... But I think, you know, the one particular occasion that sticks in my mind, is when he literally dragged me out of the bed by my legs and dragged me across the floor. And I slipped a disk in my back. And that's still, coming up to nearly twelve months in the summer, and that's the legacy I have now. Because my back is a constant source of pain and I'm trying to have treatment for it. But it's a constant reminder... And on that particular night it was because I said no. So I learnt my lesson then: to never say no. Sarah

The women's experiences of both physical and sexual violence underscore some of the ways that harm and danger can develop within relationships of care and caring. Sometimes, the trajectory of a family member's illness contributed to their disinhibition, disorientation or distress which in turn resulted in physical, sexual and psychologically harmful behaviour towards their family member. At other times, the causes of this behaviour were less clear.

Given that an increasing number of people are living with complex, multi-morbidities for many years in later life, it is important that those caring for them are supported and equipped to address a wider spectrum of emotional and behavioural needs. Although there are signs that this need is being recognised in the context of institutional settings and interactions between nursing staff and patients (Enmarker, Olsen & Hellzen, 2011; Duxbury, Pulsford, Hadi & Sykes, 2013; Bows & Westmarland, 2015), the women's accounts underline that such behaviours are, unsurprisingly, also taking place in domestic spaces and within intimate and familial relationships. Yet the potentially serious and negative impact of violence and harm in this context is yet to be meaningfully understood or addressed.

Witnessing and responding to unpredictability and distress

The participants' descriptions of harmful behaviour focused on identifiable physical and sexual harm and acts of overt verbal abuse or 'manipulative' behaviour. However, they also talked about their experience in broader terms, touching on some of its psychological and emotional aspects. This included watching or 'witnessing' their family member 'lose control'. Such accounts often included participants' descriptions of living in a constant state of uncertainty and unpredictability. In the following excerpt, Megan describes her difficulty knowing how to respond to her husband's distressed behaviour: how to protect him, herself and her grandchildren.

So, one night, he had come back from the day centre and I could see that he was really agitated and he said, "are we going out?" And I said "no, you can't, you can't go out without one of us". And I had the grandchildren here, cooking at teatime. I said, "well, you can't go out now". And it just went from bad to worse. He knocked everything off the windowsill and he was trying to climb out of the windows. In the bedroom, he ran in there, and he was trying to get out there. That was the night that he had me pinned up against the doorframe. So... people don't know what to do. I didn't know what to do. Megan

This sense of ‘not knowing’ surfaced in participants’ descriptions of feeling that they constantly needed to respond to new and unfolding circumstances. For Rose, Mary and Sarah, this resulted in their developing a highly-attuned sense of their family members’ needs, as well as habituating themselves to the potential for future violence or distressed behaviour.

My husband’s behaviour is very unpredictable. I never know what will happen next and who he will be. As a result of his illness, it can seem like he is many different people: in some ways he is many different people. Even when things appear calm and he seems well, I am constantly worried that things will change again, quickly and without warning. Rose

It was, I guess, it was more or less continual. Actually, that’s the point, it’s when it becomes the norm. This continual walking on hot coals: you don’t know what’s going to happen from moment to moment... You might be having a reasonable conversation one minute and the next minute he’s changed. I think I used to live, well, I used to call it the Sword of Damocles, I lived under the Sword. You never knew, from moment to moment, what was going to happen! And that went on for decades... For decades! I never, never knew what he was going to do next. Mary

You lived by the hour. Because he could wake up in quite a good, in seemingly quite a good mood. And he has this morning routine which I can’t interfere in because the second that I do, then it goes. And that’s really basic... And then something would go wrong and he would just become in a rage. So, you really just didn’t know from hour-to-hour. Sarah

Sally also talked about needing to anticipate how her husband might become stressed or upset and her efforts to plan their routine and home life to minimise this happening.

Other times, it begins, something starts off and he almost, he’s out of control and he has to keep going in that direction. He can’t turn around. Do you know what I mean? It’s almost as if he’s got on a train and he can’t get it off it. You know? He can’t stop. Sally

Remembering and recovering from traumatic events in the recent past was also critical to Christine and Rose. Both women, were in a state of fear and trepidation about the unpredictable nature of their husbands’ mental health needs, and their sense, sometimes, of powerlessness navigating this difficult situation.

Sometimes I have had to lock him out of the house to keep myself safe and from him becoming even more out-of-control. Then my husband has gone in the shed and I worry about how he will cope. I worry that he will get more distressed. He has told me before that he wants to end his life. In the past and he has said that he would hang himself in the shed. I don't know what to do. I worry that whatever I decide will put him in danger. I constantly check on him and wait for things to change. Most of the time there is nothing that I can do but wait. Rose

I think that we have come a long way, but I know that it's not over. It might be quiet at the moment and he might be taking his medication at the moment, but, it's going to come again... Yes, absolutely, it's always there... Yeah, and I don't think that there is anything that anyone can do in this situation. Christine

Taken together with the theme 'feeling manipulated and controlled', the women's accounts of 'witnessing' violence and distress underline the importance of understanding the lived experience of harmful behaviour in relation to both the relationship between carer and cared for, and its emotional and psychological dimensions (Stark, 2009a; Myhill, 2017). It seems credible to suggest that experience of past trauma also shaped carers' ways of coping, tolerating and feeling safe in relation to current patterns of harmful or violent behaviour. Their accounts also underline that even if a person is not the 'direct' victim or recipient of violence, they are likely to be affected by living and/ or caring in a situation in which violence is seen, heard and accepted. Thus, it may be helpful to consider the impact of both caring for and responding to someone who exhibits harmful behaviour as active rather than passive in nature.

Caring and coping in a situation of paradoxical intimacy

In the following section, I explore some of ways that the women talked about responding to situations of harm and the type of dilemmas and difficult decisions they experienced. A pattern emerged of women feeling their needs were less of a priority than their family member because of their needs and 'vulnerabilities'. This was the context in which the

participants made decisions about how to tolerate, ignore and/or challenge harmful behaviour.

1. Managing and minimising harmful behaviour

Noticing signs of potential frustration and anxiety was a common way that the respondents sought to prevent and minimise the impact of violent or distressing behaviour. Picking up on subtle cues about their family member's emotional state, as well as being aware and vigilant of their health needs, were common ways of achieving this. Moreover, when difficulties arose, women were often careful to manage their responses to prevent further inflaming and complicating the situation. Such strategies were usually informed by their own experiential learning. However, some women talked about how advice from family or professionals had been a valuable source of help.

One strategy used by several women was to remove themselves from escalating situations, particularly when physical violence had taken place or was likely to take place. In the following accounts, Rose, Sarah and Christine talk about times when they left a situation to prevent further harm to themselves or to their family member. They also discuss some of the concerns that such decisions evoked and whether this was the 'right thing' to do for their family member and for their own safety and well-being. Frequently, however, it was difficult to find a way of reconciling these two, seemingly incompatible needs.

It is very frightening to see my husband become ill and to be the only one with him and caring for him during these times. I have had to lock myself in rooms to keep myself safe. He has damaged doors before, trying to get in although he has not hurt me in this way. A lot of the time, I am worried about him hurting himself and what it is like to experience the level of pain and distress that he does. Rose

I thought that I needed to stay there and take it until he got it out of his system and then he would calm down. Because I'm sure that walking out, all it does, is make him even

more enraged... But, really, he can't do anything about it except sit down and calm down. There is no one there to yell at or to throw things at. Christine

Now I know that there is a change there, so I don't say anything. I just pass it to him, whatever he is looking for. And you have to learn how to deal with that. Because before, he literally just got up and tipped the table up and all the crockery and food was on the floor. And he smashed glasses and everything...And I have obviously just learnt to get out of the way now; to get out of the way and out of his sight. Sarah

Anita, Mary and Dorris also talked about how they occasionally stepped away from their caring role – physically and emotionally – to help defuse a difficult situation, or to help manage their own feelings of threat and anxiety. These women felt it was ‘safe enough’ to leave their family member, although this could be only done for a short period of time.

You have just got to have patience. You have to have patience. Yeah, it's that. Although sometimes I just walk out of the room. Just to get a break. I have just had enough. I need a bit of space for myself. Anita

In an earlier excerpt, Mary shared her frustration that her husband's psychiatrist had told her to lock herself in an upstairs room when he was “going haywire”. However, she also talked about times when he was in a less distressed state where she sought to put distance between herself and her husband. In the following passage, Mary described her response when her husband “lost it” (his temper) when they were out shopping one weekend.

He just completely lost it and I have to admit, I walked the three miles home. I couldn't take any more. I mean, this is when you don't know what the cause is. If you know what the cause is, then you can do something about it, or you might be able to do something about it. But when it's just someone completely losing their temper and it's extremely embarrassing. I just had to get away. Mary

For Sally it was important to avoid conflict and tension by carefully considering the possible consequences of saying or doing the ‘wrong’ thing, at all times, when engaging with her husband.

I might, I mean, I'm always honest with him but occasionally I might delay telling him or saying something bad to him because I know his reaction is going to be bad and I will wait until he's in a better mood. But I suppose we all do that with relationships? If you know somebody is really crabby at that time, you're not going to tell them bad news. You know, that sort-of thing. Sally

As Sally points out, being aware of what might upset or affect a partner or family member is a 'normal' and, perhaps even necessary, part of maintaining a close relationship. So too, it could be suggested, is anticipating someone's needs an integral skill when caring for them. There is nothing harmful *per se* about developing an attuned and attentive relationship and many participants highlighted how important this was in the process of caring for their family member (Barnes, 2011). However, what was striking was their limited discussion about how appropriate or reasonable it was to adopt this responsive, empathic position, even when they felt unsafe and threatened. Yet, because these containment strategies had practical value – i.e. they helped to calm, soothe or minimise harmful or violent behaviour on the part of their family member – it was very difficult for women to revoke them (Spencer, Funk & Heron, 2018).

As some of the excerpts above illustrate, it was not always possible to avoid or prevent violent or distressed behaviour. Indeed, several carers talked about 'stepping in' or taking control of situations because they were acting in what they believed to be in their family member's best interests, as illustrated by Megan and Mary's comments:

He didn't want to be here. Because he would say, "I'll go through on a morning". And he would put his shoes and his coat on. And he had five pairs of shoes at the ready all of the time. Just so that he could grab a pair of shoes, like we were holding him prisoner - which I guess he thought we were in a way we were but for his own safety. Megan

He never felt that I was helping. Or, never admitted to me that anything I was doing was of any help to him at all. He never, I was never, no. That was what I was supposed to do. It just didn't happen... The people that it (illness) is happening to, they just don't

know it. And it's far worse for the people watching and I don't think that that's taken on board. Mary

As Megan and Mary's accounts demonstrate, carers found themselves in the uncomfortable and somewhat disorientating position of taking on both a protective role for their family member at the same time as becoming more 'vulnerable' to verbal or physical violence by them. This involved a complex process of exercising and ceding different types of safety and power within the relationship: one that is also reported by mothers of adolescents who act in a violent or abusive way towards them (Jackson, 2003). However, for the women taking part in this study, their decisions were further complicated by their family member's lack of recognition of the impact of their behaviour. This tended to intensify carers' feelings of being isolated and alone and I discuss the implications of this 'hidden' form of harm in greater detail in theory-informed analysis chapter.

Dilemmas and decisions: the spectre of transition and separation

Carers talked about facing difficult decisions as they sought to minimise and manage their family member's harmful or violent behaviour. These decisions were complicated further because the outcome of taking or not taking action was often unclear, in part because carers felt like they had limited or insufficient knowledge to make informed choices. They also found it difficult to explain what could, and perhaps should, be tolerated and what felt safe and manageable, and what did not. One common area of difficult decision-making was whether or not a family member should be prescribed medication to reduce instances of aggressive or violent behaviour. For Sarah, the psychiatrist's recommendation to prescribe her husband anti-psychotic medication was a source of considerable concern. She was worried about his physical health and the potentially life-limiting impact of the drugs. She

also recognised that they could (and did) have a positive effect on his mood and significantly decreased the incidence of violent and aggressive behaviour.

He's on that new tablet and it is making a massive difference. He has his sense of humour back, we can have a bit of banter... So the medication works. But, obviously, there is a massive risk with stroke and Parkinson's and you know, shortening of life and all of this... So the guilt you feel about imposing that drug on him. And I would say that that (decision) is probably the first time that I had put myself first. Sarah

For Megan, however, the prescription of drugs that “sedated” and “calmed” her husband was a necessary and relatively unproblematic choice. In the passage below, Megan talks about her changing attitude to her husband’s medication following a deterioration in his health after he had left the family home and was receiving full-time nursing care.

I gave up asking. At first, I was asking “what medication is he on, why are you giving him that?” And then it got to the stage when Bob was really just a shell. I thought, “what does it matter? What's the point?” As long as they keep him calm (pauses). I mean, to me, his pupils are so tiny. They are like pinpricks. I mean, that must be limiting his vision as well. It's the drugs but what else can they do? It's the only way they have to keep him calm. Megan

Megan’s account touches on a second common source of difficult decisions: deciding if and when a family member should be cared for by formal carers, either in a hospital or a nursing or residential home. Many participants talked in detail about the ambivalent and often powerful emotions they experienced making choices about whether to relinquish care and for whose benefit this was being done. This was made more difficult because there was rarely an opportunity to make these decisions in partnership with their family member due either to their diminished cognitive abilities or because they had limited insight into their needs and the impact of their behaviour.

Perhaps unsurprisingly, for those participants who had cared for their family member from childhood, they had developed different ways of coping and their decisions were shaped as

much by past harm as by problems in the present. Anna and Jane, for example, talked about the need to be attuned and attentive to their family member to avoid conflict and upset, as discussed earlier, and these strategies were subsequently adapted to minimise the chance of repeated or increased harm now their family member was older.

There were just loads and loads of details that I could never work out that made it impossible to live a normal life. So, in that sense, that was my brother's norm so that was my norm. And then when he was more unwell he would, you know, there would be the threat of suicide, of violence, and also the control of not being able to see people ... So now, for the first time I have now stopped seeing him, stopped listening to him.

Anna

Now Dad's shown that he is willing to be physical towards carers, it has crossed my mind that he would be physical with Mum and with me. Because Dad showed his temper to me when I was two years old I developed an anxiety about it. So, when I go in I know I'm feeling anxious when I'm interacting with Dad. So, in a sense, I'm soft-peddalling, so I don't see that anger surface.

Jane

For Anna and Jane, there was a connection between how the memory and witnessing of violence in the past continued to shape their feelings and responses to their family member now. As discussed in the literature review chapter, Band-Winterstein (2012) found that past experiences of domestic violence were sometimes a reason cited by participants to take up caring duties who sought a last chance to 'draw closer'. In addition, Koeing, Rinfrette & Lutz's (2006) reported how, during therapeutic work, carers found new ways to recalibrate their relationship with a partner who had been violent towards them in the past because it provided an opportunity for 'healing' and an altered power dynamic. Nevertheless, for many women who have experienced life-long intimate partner violence, evidence suggests that victim-survivors tend to accept and habituate themselves to continuing violence, relying on pathogenic coping mechanisms and often suffering serious negative social and health outcomes in the process (Lazenbatt, Devaney & Gildea, 2013). This is important to consider, because although the majority of participants in this study did not identify as having experienced domestic or intimate partner abuse, the literature suggests that this group may be

amongst the most likely to 'stay' with their partner and become their carer, irrespective of whether levels of violence and abuse change (Band-Winterstein, 2012).

Explaining why they sought to cope with and tolerate harmful behaviour, several participants referred to their marital vows. Indeed, the unique nature of the marital relationship appeared to be a significant factor that underpinned many women's accounts of the way they explained why harmful, abusive and violent behaviour was different from domestic abuse (Morbey, 2002).

In the past they have sent me to things for people suffering domestic abuse. They have even offered me a place in a refuge before. In some ways this is domestic abuse. But it is also very different. My husband can't help how he is. He has no control over his behaviour and how he feels. So I didn't feel like this was the right place to be. I needed to be able to help my husband and to stay with him. Rose

Similarly, Mary was asked and encouraged, on several occasions, to leave her husband because of his unpredictable and controlling behaviour. During our meeting, Mary talked about how this suggestion was not a course of action she could really consider:

People don't understand if something can just become the norm, it becomes normal behaviour, well it is. And, I knew, well, someone would say to me "well, perhaps you should leave him". But the responsibility, who is going to take responsibility if I don't? Mary

Sally also talked about how people questioned why she remained in a relationship with her husband in light of his behaviour. She argued that the situation was "complex" and bound up with her duty as a wife. Sally also emphasised that she needed to protect and promote her husband's needs, as a person experiencing illness who was more vulnerable than herself.

I made the choice. I know that it's really stupid of me, to make my bed and lie in it. But to me, it shows strength: stupid strength. That I can get through it, that I can survive it and I chose it. That he's the father of my kids. You know? And actually there is just a

lot of me that is scared. The actual practicalities of leaving him, you know, like, what would he do? You know? I would be fine. I would be fine. Sally

Sarah reflected on her situation in similar terms, referring to the importance of marriage vows and the marital relationship as one of unconditional commitment and as the primary reason to support and withstand, in her case, extreme and repeated harmful behaviour. Sarah talked about her love and feelings of protection and care towards her husband many times in the interview. However, as the following excerpt illustrates, she also discussed the considerable harmful impact that caring was having on her.

I'm completely trapped. You know, I love him and I would give my right arm for him... and isn't that awful thing to say... but I am trapped (crying)...But it's sickness and health and it sounds awful but, but.... Sarah

The nature of the difficult decisions that the women made varied, perhaps unsurprisingly given their different circumstances and relational contexts and there was no pattern to what women found most difficult about coping and making sense of harmful behaviour within their caring and family relationship. Seemingly, participants had different and unique ways of minimising harmful behaviour as well as different 'red lines' about what could be tolerated. Further complicating this was an anxiety that other people or outside events would take these decisions away, leaving carers with a lack of agency and sense of responding to events beyond their control. This is because losing control could mean both a change in their current situation as well as a potential loss of autonomy to make decisions about the nature of their relationship with their family member in the future.

Hiding and feeling hidden

The 'hidden' nature of caring was a consistent theme running through the women's accounts. For many carers, hesitancy about sharing their experiences was underpinned by fear of the

consequences of ‘exposing’ their family member. Carers also talked about feeling ignored or misunderstood because people could not or would not acknowledge and engage with the seriousness or complexity of their situation. This was another way their experiences were marginalised or overlooked. For several respondents, this led to a sense of alienation and disenfranchisement. It also acted as a spur for some carers to seek change, often by developing new relationships with peers or developing a role to advocate on behalf of others.

There were multiple reasons for women exercising caution about how much to reveal to other people about their experiences of caring and harmful behaviour. These were also identified in the literature review. For example, the ‘sensitive’ and seemingly taboo nature of the topic engendered feelings of shame and fostered strategies of concealment and withholding of information (Band-Winterstein, 2012; Band-Winterstein, 2009). Also, that sharing information about the severity of a family member’s behaviour could lead to them being taken into statutory care because the carer would be deemed unable to cope with their health and behaviour needs (Cahill & Shaprio, 1993; Pillemer & Sutor, 1993; Hughes, 1997). Yet the women’s accounts identified other reasons: for example, a concern about facing people’s responses that would be either dismissive or unhelpful. In these circumstances, carers tended to exercise considerable caution determining what and if they would share with other people about the nature and impact of their family member’s harmful behaviour.

It’s very hard to tell other people too. They’re not going to believe that she is violent... I feel like I can’t tell anyone, you know, because they would think that that can’t be the case. Because if you don’t know the ins and outs of dementia then you don’t understand; if you don’t care for someone at the same level then you don’t understand.
Anita

I have had some lovely friends over the years and some of them you keep and some of them you lose as things move on, but I can say without exception that they think I’m mental not to walk away and divorce him. They do... And they say, have you seen Rob today? And I say, ‘yeah, I went over and I cooked him a meal’. You know? And I will leave it at that. Christine

Asrah and Megan also found that after years of limited contact with their family members, they felt it was no longer helpful to keep the lines of communication open with people who did not try hard enough to understand their situation. When there had been a pattern of poor or limited communication and relational support in the past, it was hard, unsurprisingly, for some women to find a way of reaching out at a point of crisis. Instead, these women felt that it was more appropriate and, in some ways, ‘easier’ to address the situation alone.

I told them all the way through. I would say, “well, this has happened today” So I kept them informed all of the time. And then because they didn’t respond to anything when he (husband) dipped, when this happened (violence and admission to nursing home), I didn’t tell them. I thought why should I? Because you haven’t been here at all. Why tell you now? What can you do now? It’s too late. It’s too late to see him now. Megan

So it got to the stage where I just stopped asking other people if they could do things and I just thought it will just make my life so much easier if I do this for myself. Asrah

Feelings of embarrassment and shame were also cited by Rose and Sarah as reasons for not sharing their experiences of violence and distress with family and professionals. The intimate and complex nature of the harmful behaviour they experienced may have made it particularly difficult to share their experiences.

I used to feel shame and embarrassment about going out after there had been lots of shouting and violence. I was worried about what the neighbours would think. I stayed inside; I wanted to stay hidden. You take on the shame of your loved one’s behaviour because you know that people don’t understand why they are acting in a difficult or upsetting way. You also worry that people blame you and hold you responsible. There are so many layers to how this affects your life. Rose

I feel embarrassment. I mean, I had never told anybody what I told you about not wanting to, you know, have sex. Because it’s very embarrassing. I think that... but I did say to the psychiatrist when he interviewed me, because I had to explain that there was a risk of sexual violence. Sarah

Again, it is worth reiterating that for Rose and Sarah, as with all of the women, their caution about sharing their experiences was shaped by a range of factors. For women who had experienced difficult and strained encounters seeking help for their family member, there was a sense of feeling let down by health and social services. This meant they lost confidence in the statutory services and were reluctant to ask for support. Mary, for example, talked about a long-term struggle to gain appropriate support and recognition of her husband's complex physical and mental health problems. In our meeting, Mary talked about times when she felt professionals knew that she was at risk of violence, yet they did not take proactive steps to help. In the following excerpt, Mary describes how professionals were unwilling to admit that they did not know, or did not know enough to diagnose and treat her husband's condition.

Because obviously something was very wrong in a way but nobody knew what it was. I didn't know what it was. Because, you see, if it is a medical thing you can go to the doctor's. But if it's purely behaviour?... I didn't know what to do... We had a procession of different people that we saw and we got nowhere. I had no idea. Mary

Some participants' mistrust of professionals meant that they felt compelled to take on a role as an advocate and protector for their husband whilst tolerating and coping with increasingly distressed and harmful behaviour at home. It also highlighted the women's desire (and need) to be asked about their experiences *as well* as having meaningful opportunities to talk and develop shared understanding with professionals about experiences of care and harm. This raises an important question about why different people, particularly professionals, might struggle to conceptualise and name harmful and abusive behaviour instigated by older people with care needs. I will return to these questions in the following chapter, which explores the professionals' accounts, and again, in the theory-informed analysis chapter.

Summary

Analysis of the interview data found that carers' experience of harm varied in its severity, chronicity and impact and it encompassed physical, verbal, psychological and sexual harm and violence; in some instances, participants shared experiences of abuse. Moreover, carers talked about the isolating and complex processes required to manage, cope and tolerate harm; for example, through strategies of emotional containment, by minimising contact and interactions with their family member and by focusing on the ethical and relational value of protecting and caring for their family members, however difficult the circumstances. The accounts suggest not only that harm took place in 'private' spaces but that it was difficult to 'see'. This is because harmful behaviour could be emotional and psychological in nature and its impact was often cumulative. Moreover, it could be difficult to share and to 'make sense' of experiences of harm for reasons of shame, taboo and fear of unintended consequences. In the following chapter, I analyse health and social care professionals' responses to vignettes developed from the carers' interviews. This provides a vantage point to explore how they 'see', understand and respond to harmful behaviour experienced by family carers.

Chapter 5: Focus group findings

Chapter overview

This chapter presents the first stage in my analysis of the practitioners' group discussions. Employing a thematic approach (Braun & Clarke, 2006), I identified three central and intersecting themes: 1. Practitioners understood harmful behaviour as a 'live' and complex issue that could arise in the context of illness and/ or domestic abuse. 2. Practitioners sought to develop choices and contingency plans with affected carers; however, there were limitations and constraints that arose from working in a 'crisis' orientated system. 3. Naming and responding to 'carer harm' was considered a complex and 'sensitive' process and many practitioners were cautious about when (if at all) harmful behaviour could be considered 'abusive' behaviour.

The focus groups

The five focus groups took place between November 2017 and June 2018 in the West Midlands region of England. Thirty-eight practitioners took part in the discussions. In this chapter, I use the term 'practitioner' synonymously with 'focus group participant'. All practitioners worked with older people and their families. Four of the groups worked, predominantly, in the community and this included direct work with families in their homes. The fifth group was made up of adult social workers who co-ordinated the care of older adults requiring residential or nursing home support. As a result, their contact with family members, who were often former carers, only came about when a formal assessment or review was undertaken. In addition, two groups specialised in work with older adults affected by dementia illnesses: The Admiral Nurses and the Dementia advisors. The three groups of local authority (statutory) social workers worked primarily but not exclusively with older adults. An overview of the composition of each group is summarised in Table 6.

In four groups, vignettes were used to stimulate reflective discussions in conjunction with a short question guide, see ‘methods and methodology’ chapter for more details. The vignettes were not used with Group 5; instead, I facilitated a discussion session, exploring practitioners’ knowledge and views about the topic. As will be discussed in greater detail in this chapter, this practitioner group appeared to have significantly less direct contact with, and therefore understanding of, families affected by harm and abuse. In the following section of this chapter, I present the three vignettes used to stimulate discussions with the practitioner groups.

As discussed in the interview findings chapter, in the process of developing this thematic analysis, I drew on the wider literature. Please see appendix 3 for a step-by-step, reflective account of the analytic process. Finally, please note that, to protect participants’ anonymity, all names in the following chapter are pseudonyms.

Group	Practitioner group	Focus/ specialism of work	No. of participants
1	Admiral Nurses	Specialist dementia nursing	10
2	Adult social workers	Safeguarding and care coordination	5
3	Adult social workers	Safeguarding and care coordination	6
4	Dementia advisors (N)	Community dementia support/ advice	10
5	Adult social workers (N)	Care coordination (nursing/ residential care)	7

Table 6: Focus group characteristics

Question guides and vignettes

1. Questions/ points of discussion

- What are your thoughts about the situation that Rose/ Sarah/ Megan describe?
- Could these situations be considered ‘abusive’? Please can you tell me a bit more about what does/ does not make the situation ‘abusive’?
- For a practitioner working with the family, what might be some of the challenges and limitations that a practitioner might encounter?
- For a practitioner working with the family, how might they make a positive difference to the situation and what would enable them to do this?

The vignettes

Rose: It is very frightening to see my husband become ill and to be the only one with him and caring for him during these times. I have had to lock myself in rooms to keep myself safe. He has damaged doors before, trying to get in although he has not hurt me in this way. A lot of the time, I am worried about him hurting himself and what it is like to experience the level of pain and distress that he does. Sometimes I have had to lock him out of the house to keep myself safe and to stop him becoming even more out-of-control. Then my husband has gone in the shed and I worry about how he will cope. I worry that he will get more distressed. He has told me before that he wants to end his life. In the past he has said that he would hang himself in the shed. I don't know what to do. I worry that whatever I decide will put him in danger. I constantly check on him and wait for thing to change. Most of the time there is nothing that I can do but wait.

Sarah: I think that what people have to understand is that risk from dementia, for the carer, it comes in many forms. It isn't just physical. It is also mental... And, obviously, the last thing I want at night is that... because you are so anxious, you know... because quite often there have been issues through the day and you know that it is building up... So, that's obviously the last thing. But I think, you know, the one particular occasion that sticks in my mind, is when he literally dragged me out of the bed by my legs and dragged me across the floor. And I slipped a disc in my back. And that's still... coming up to nearly twelve months in the summer, and that's the legacy I have now... Because my back is a constant source of pain and I'm trying to have treatment for it. But it's a constant reminder... And, umm, on that particular night it was because I said no. So, you know, then I learnt my lesson that night. Never say no. Because otherwise, you know, the frustration will build up and you will pay in another way. So, in that respect it is mental sexual violence. Do you know what I mean?

Megan: You do just give up to an extent. And I'm not going to lie, I did used to think, "Oh, I'm sick of this". It's like a bad dream and you think you're going to wake up and think "Ee, this was all a joke; you've been kidding me". And he would suddenly be all right. I don't know. But at the end, I used to lie in bed and think I would think "What's going to happen, what's going to happen, when will this end?" And I didn't want it to end but I didn't want it to carry on the way it was. So, one night, he had come back from the day centre and I could see that he was really agitated and he said, "Are we going out?" And I said "No, you can't, you can't go out without one of us". And I had the grandchildren here, cooking at teatime. I said, "Well, you can't go out now". And it just went from bad to worse. He knocked everything off the windowsill and he was trying to climb out of the windows. In the bedroom, he ran in there, and he was trying to get out there. That was the night that he had be pinned up against the doorframe. So... people don't what to do. I didn't know what to do.

Harm as a proxy for dilemmas, difficulties and distress

Practitioners identified harmful behaviour towards carers as a ‘live’ issue that they encountered in varying degrees of frequency and severity. At the same time, they were cognisant that the issue was ‘hidden’ and attributed this to the challenges that families experienced naming and sharing their experiences. Practitioners were sensitive to carers’ feelings of shame and fear about being seen to not cope and/or to precipitate their family member being ‘removed’ or ‘placed’ in a care setting outside of the family home.

Practitioners also recognised that for some families it was not safe or desirable to continue caring in the context of harm, particularly if there was a history of abuse and violence. Thus, many of the practitioners drew attention to the ethical dilemmas and social expectations that carers were likely to face in responding to harm in the context of an intimate relationship.

1. The practical, emotional and ethical dimensions of experiencing harm

When responding to the vignettes about carer harm, there was little surprise or discomfort expressed by the practitioners. Indeed, participants engaged readily and empathically with the vignettes and there was consensus that carer harm was a complex and difficult issue facing families. Most of the practitioners’ direct experience involved supporting carers affected by, or at risk of experiencing, physical violence, rather than emotional or sexual harm. Furthermore, because carers’ experiences played out at home, practitioners talked about the ‘hidden’ nature of the problem. Several practitioners suggested this could lead to additional challenges, including the loss of home as a place of physical and emotional security. In addition, harm could herald the unwelcome recalibration of important adult relationships that shaped an individual’s identity and psychological well-being. Thus, although practitioners tended to associate harm with physical or verbal violence, they also

talked about its consequences in terms of its emotional and relational impact (Barnes, 2011; Held, 2010). It represented not only a ‘loss’ of someone to illness, but a profound change in carers’ sense of self and sense of physical safety: echoing a central theme in the participants’ accounts.

I think that we tend to view home as a safe place, but you get a sense from this that she has lost that security of home. Wendy (Admiral Nurse, Group 1), on Rose’ vignette

What upsets a lot of the families that I see is that, and they are often older ladies - white ladies – it is about the language. They say, “he never used that word before”. And that seems to upset them more than any other sort of violence. Because it seems so strange for them, knowing their character, to be like that. Cathy (Dementia advisor, Group 4)

It’s about that contrast, from that one person who used to build you up, who used to be your rock, they are the person who sees you as you are and now all of a sudden they are swearing at you, they are telling you that you’re incompetent and they’re telling you that you’re the worst thing in the world. It’s that relationship crash. And I mean, where do you go? Where do you go for your support now? David (Adult social worker, Group 1)

Practitioners’ frequent references to the “dilemmas” and “difficult choices” that carers were likely to face reinforced how important it was, in their view, to understand carers’ experiences in relation to their feelings of love, loyalty and responsibility towards their family member. Practitioners emphasised that it was not possible or desirable to separate the act and immediate impact of harmful behaviour from these relational bonds and obligations. In addition, participants discussed that because family members may not intentionally seek to cause harm and/ or because they were ‘vulnerable’ in some way, the situation was complex. This echoed carer participants’ talk about the biographical disruption caused by their family member’s illness and their transition to the dual role of carer *and* wife, daughter, sister, etc. (Chamberlayne & King, 1997). This perspective is evident in the following excerpts:

I think that if I was the wife and I had a husband saying that he was going to hang himself in the shed, then you would feel this massive sense of responsibility. And you would feel this massive sense of guilt that if he was to do something then would it be my

neglect or lack of care or something that I didn't do right? Sue (Admiral Nurse, Group 1) on Rose's vignette

What a conflict for her, in her mind, especially if she is saying no, for lots of different reasons, I'm sure. How awful for her. She might feel guilt, but then she also has to protect herself. Because so often as a carer people put their own needs as secondary. You know? The cared-for becomes the absolute priority. And then she is saying no and then she is being assaulted. The complexities are just massive. Angie (Adult social worker, Group 3) on Sarah's vignette

I feel that dilemma for her. That questioning of when it is going to end and willing it to end but knowing that really the only way that this is going to end is when that person passes away. That guilt must be awful: willing it to be over but not wanting that person to be gone. That must be so hard... Katrina (Senior social worker, Group 3), on Megan's vignette

Echoing the carers' accounts, practitioners recognised the emotional and ethical dimensions of carers' choices when responding to harmful or abusive behaviour. They emphasised that feelings of guilt frequently shaped carers' responses and that this in turn engendered difficulties for them assessing the situation in a more 'objective' manner. Indeed, Nancy (Admiral Nurse) described managing feelings of carer guilt as "running through our work like a stick of rock". Nevertheless, by focusing on the subjective and personal challenges that harmful behaviour evoked, practitioners subtly and consistently located this issue as a 'private' matter and one that was affected by the quality and stability of the relationships between carers and their family members (Lynch, 2007).

Relational history and histories of abuse and violence

Practitioners emphasised the importance of developing an understanding of families' unique circumstances and past relationships. Practitioners recognised that many people became carers in ambivalent and often constrained circumstances and that this could be a contributory factor to carer 'breakdown' and carer-initiated abuse (Cooper, Seelwood & Livingston, 2008; Momtaz, Hamid & Ibrahim, 2013). Practitioners also talked about the intersection between families with a history of domestic violence or childhood abuse and the experience of harm in

later life (Band-Winterstein, 2012; McGarry & Simpson, 2011). Within the focus groups, many practitioners explored these connections and talked about their work with families affected by domestic abuse in later life. For example, several practitioners highlighted how perceptions of what was permissible and tolerable behaviour varied greatly between families and that people could, and did, habituate themselves to a range of difficult and abusive circumstances.

Whether or not someone is going to disclose, is again so complex. For all we know she has got a lifetime of abuse. I mean we know from our work how people normalise things and come to accept all types of harm because they normalise things. Angie (Adult social worker, Group 3), on Sarah's vignette

I think we develop ways of coping with really awful situations. I mean, you think of things like Stockholm Syndrome. You know, that's what we do, we learn to adapt and to adjust. I get the feeling that they have developed this way of coping over a long time. John (Admiral Nurse, Group 1), on Roses' vignette

Practitioners also talked about how illness was sometimes deployed as an 'excuse' or explanation for violent or manipulative behaviour. Practitioners cited examples of this tactic used by both the cared-for and the carer. In the latter case, it was widely considered a coping or distancing strategy that helped carers continue to care, irrespective of the nature of violence and harm they faced.

We come across people who have capacity but use dementia as an excuse to be violent and to do what they would have done anyway. Unfortunately, we do come across that. Katrina (Senior social worker, Group 2)

You do get some who blame it on the dementia and then when you dig a bit further and ask "so this wasn't their personality before?" then they say "oh yes, they have always been like this". Cathy (Dementia advisor, Group 4)

If you have people who have been in abusive relationships and they have often learnt ways to be canny enough to do it without getting caught. But when that first line of filter comes off and, yeah, I have had quite a few cases like that, when you get the disclosure, and someone says, actually, this is not that uncommon. It's just that now he doesn't have the wit to mask it. To time it, you know, when no one is there or to time it when it can be done covertly. David (Adult social worker, Group 2)

In addition, some practitioners shared accounts of working with carers affected by harmful or abusive behaviour that was long-term and entrenched in nature.

She (carer) had gone through this historical abuse and then her husband was diagnosed with dementia but the abuse continued. It only came out because of his dementia. Once he went into residential care, his behaviour was excused because of his dementia. And then she was sat with all of this. She was saying that she needed support, she needed counselling, because she had had to live with this for all these years and she had just become detached from this person who she had spent most of her life with. Kate (Student social worker, Group 5)

Well, I've got a lady at the moment and she cares for her husband: he has frontal-temporal dementia. And we have put a panic button in there because there is quite a high risk of domestic violence. They had split up but then they had got back together because they couldn't afford to sell the house. So this lady is trapped. But she feels a sense of duty to look after him. Sally-Anne (Admiral Nurse, Group 1)

We have got something going on with a couple that we are working with. They don't have any children and he has been abusive all of his life. She is caring for him but she also had a stroke a few years ago and needs support. But he still hits her. We have had safeguarding coming in but then she drops it. She says "no, I would rather stay here..." Suresh (Dementia advisor, Group 4)

Many participants made a clear connection between 'carer harm' and domestic abuse in older age: a potentially noteworthy finding given the relative paucity of empirical or theoretical literature, or practice-orientated guidance, about this domestic abuse in older age (Wydall & Zerk, 2017; McGarry & Simpson, 2011). This illustrates that practitioners recognised that illness was not necessarily the cause of violent or harmful behaviour and that, in fact, illness could be used to disguise longer-term patterns of domestic abuse. In the following section, I explore the reasons put forward by practitioners to explain the 'hidden' nature of this complex problem.

A 'hidden' issue: Challenges and barriers seeking support

As identified in the previous chapter, carers talked about the challenges of talking about their experiences of harmful and abusive behaviour. Thus, I purposefully wanted to explore

practitioners' views about what barriers carers might face seeking support and to consider how they compared and contrasted with the carers' accounts. Practitioners in each of the groups identified how feelings of loyalty and guilt were likely to be significant inhibiting factors. In turn, it was identified by practitioners that carers were likely to be implicitly (as well as more directly) pressured to carry on caring when their family members' behaviour was becoming more serious or complex in nature.

You're not going to speak up about these issues in a public arena. That's just a kind of thing. It is just behind closed doors. It's a cultural thing, you know, the shame from the community. Needhi (Dementia advisor, Group 4)

I think, for me, one of the issues is about people not being able to admit that they can't cope. You know, acknowledging to the outside world that they need help. And asking for that can be such a huge step for people. And feeling that they have failed someone can be such a huge hurdle to get across. Sally-Anne (Admiral nurse, Group 1)

These comments also touch on the idea of concealment: that carers would consciously try to limit other people seeing and knowing about their situation. This draws a parallel with the carers' accounts, particularly those who feared that intervention by health and social care practitioners would lead to the 'removal' of their family member from their care.

Nevertheless, practitioners also reflected on situations where carers were not always in a good position to recognise the extent and severity of their situation and that this prevented them from seeking support. The following extracts are examples of practitioners' views about the nature and quality of choices available to carers as presented in the vignettes.

Constantly on guard, isn't she? She comes across as quite helpless as well, hopeless really. Eleanor (Admiral nurse, Group 1) on Roses' vignette

I mean, this woman, in my mind, has been raped and I'm sure that there will be other women out there who have been raped. They might not look at it that way themselves, which might be a blessing, but they would know that it is something wrong and they may well feel shame as a result and for that reason alone wouldn't speak to me (as a social worker) about it. Jan (Adult social worker, Group 3), on Sarah's vignette

I think that often people do see the situation is getting worse but what they tend not to do is acknowledge that their ability to manage the situation is getting less and less and I think that comes back to the thing that a lot of the time carers don't acknowledge or see themselves as carers... So, they see it happening, but they just carry on because that is what they have always done. Emily (Social care coordinator, Group 2)

Several participants also talked about how the isolated and often intense nature of caring relationships could lead to a further challenge of acknowledging and naming harmful behaviour. There were several discussions, for example, about how patients/ service users might express feelings of distress and fear only with people with whom they felt 'safe' (i.e. their family carer). Practitioners' awareness of this issue may have come as a surprise to those carer-participants who talked about feeling blamed for their family member's behaviour and who felt they would not be (and had not been) taken seriously when raising concerns about their family members' deteriorating health and/ or harmful behaviour.

I think that some of the traits (of some mental health conditions) is that from an outsider's perspective, they can seem very difficult. Sometimes people can be very manipulative as a result of them. They can mask very well. They can present very well publicly... I think that with the presence of manipulative behaviours in particular, I think that that can be something that is really difficult for other people to see. John (Admiral Nurse, Group 1)

She (carer) says that when they are away from the group then it's an absolute nightmare. Because he (husband with dementia) is just chip, chip, chipping away at her. The language, she says it's abusive. When she goes to buy anything, do anything, then he is always questioning her. She says that it is just constant, constant, constant. And then he sees somebody else and his whole way of being just changes again. Maggie (Dementia advisor, Group 4)

Sometimes when we put homecare in, sometimes (family) carers will come back and say that they don't behave that way with the (paid) carers. That they don't shout at those carers. It's just me. They are completely different. And I think that we all conclude that it is because they feel so comfortable with their partner or their son or daughter who is caring for them. Katrina (Senior social worker, Group 2)

Thus, practitioners recognised that there were myriad reasons why carer harm could be difficult to identify. These discussions encompassed practical as well as social factors,

drawing parallels with the carers' accounts and the limited literature on this topic to date (see literature review). However, participants also recognised that some carers faced challenges being believed and taken seriously because the experience was 'hidden' from view and because they were more likely to be exposed to the more extreme and intense expressions of their family member's harmful, violent or abusive behaviour.

Practitioners' responses, roles and working relationships

The vignettes stimulated discussions about how practitioners worked with families, in the course of their current work which was broadly characterised as supporting individuals and families at times of crisis and loss. Practitioners identified that crisis situations tended to dislodge or even tear away the protective shields and distancing strategies that carers had built up to cope with and to contain experiences of harmful behaviour. Reflecting on this point opened wider discussions amongst the different practitioner groups about the approaches, values and strengths that the different practitioner groups associated with their work. Often, these centred on developing relationships, informing decisions and supporting people to manage and minimise (often unspecified) risks. In four of the groups, there was consistent reference to understanding people holistically and working in a 'person-centred' and/ or 'family-focused' way. Because Group 5 practitioners' work was review and assessment focused, they tended to interact with families more sporadically and it was not in the remit of their role to carry out therapeutic or systemic interventions. Thus, perhaps unsurprisingly, this group made less explicit reference to holistic and family-orientated approaches. Practitioners also highlighted some of the limitations and constraints on their role working in a crisis-orientated system and some of the tensions and difficulties working with other practitioner groups who had different values and priorities about when and how to

support families in 'crisis'. The following theme explores some of the goals and beliefs that practitioners highlighted as being integral to their work with families.

1. Responsive and relational support

Practitioners talked about different types of support and help that they strove to provide to carers experiencing harmful behaviour. Several practitioners talked about the importance of building contingency plans with families which included practical measures about how to mitigate violence, as well as longer-term planning about when to relinquish care. Participants also emphasised their role supporting carers to develop awareness and ownership of the choices available to them as a way of increasing safety and minimising risk.

I think that the work that we can do is preparatory sometimes. In terms of strategies but also in terms of contingency plans and practical issues about how somebody can keep themselves safe in a risky situation... You know, sometimes it can be as simple as... you know, has this lady talked about where is her safe space? Where do you take yourself? Where is your means of escape? Rita (Admiral Nurse, Group 1), on Rose's vignette

We would help to explain her choices. Even if she doesn't want to do anything right now then our door will be open: so, just being sure that she knew her options. That she knew about that empowering side. Jan (Adult social worker, Group 3), on Sarah and Megan's vignettes

Practitioners highlighted that working with families could be complex and required a responsive and relational approach. This reflected practitioners' sense that disclosing abuse and harm was likely to be a difficult process for carers, shaped by ethical, inter-personal and social factors. Thus, it was important to build bridges through trusting and positive working relationships in safe and opportune spaces to facilitate disclosures of harm and abuse (Bradbury-Jones, Taylor, Kroll & Duncan, 2014). The following excerpts illustrate the participants' sensitivity to the importance of attending to inter-personal dynamics when exploring and facilitating disclosure of harm and abuse.

Although I could see that he was going to need permanent care (service user acting in a harmful way), it took her a while to get there, to see it. Because of guilt, because she needed a sounding board – which was me but could have been someone else – to reflect back to her that this is the situation as I see it. You know, this is your lived experience, but this is how I see it. And that was when things started to change in her mind. Angie (Adult social worker, Group 3)

You have to spend time with the individual to see something, or you have to spend time talking about it. After the information hits the table then the body language begins to move and the couple are looking at each other, and that one is now looking at that one, you know? Or one starts crying... So, you pick up on the dynamics. Maggie (Dementia advisor, Group 4)

I think that yeah, I mean it's just that key social work thing of the customer and social worker actually just sitting down and taking away those roles and just sitting down and talking to one another and not necessarily trying to find solutions. It's not necessarily about services. David (Adult social worker, Group 3)

Thus, practitioners talked about the role of professionals in bringing about positive changes to support families in illness and later life. This is consistent with policy and practice exhortations to respect adults' self-determination and the ability to make choices about their needs (Cooper & Bruin, 2017). They also reflect a more recent emphasis in adult social care and safeguarding, on working with individuals in a therapeutic and relational manner. This requires practitioners to be both critically reflective as well as emotionally responsive to the complex and unique circumstance of individuals and families (Butler & Manthrophe, 2016). Underpinned by a growing evidence base, this shift toward relationship-based and holistic practice complements a drive to reject process-driven and task-centric approaches thus reclaiming the ethical orientation and judgement-based nature of the 'helping' professions (Trevithick, 2014). Yet there remain concerns about how well-equipped and how well-prepared some health and social care organisations are to provide the time, space and supervisory structures to enable practitioners to work provide this type of support in a consistent and meaningful way (Ash, 2015; MacKay, 2017; Sawbridge & Hewison, 2013). I

return to this point in the theory-informed analysis chapter and the concluding chapter of this thesis.

Working within a system orientated towards crisis and health need

Despite practitioners' emphasis on the importance of timely and bespoke support, several reported that it was sometimes difficult responding to carers affected by harmful and abusive behaviour. This was a recurrent topic of conversation in the focus group meeting of statutory social workers. As a result, carers were often left "sitting with" or "sitting in" – phrases used by several practitioners in the focus groups – situations that were violent, traumatic or distressing up until their family member was placed in residential or nursing home care. Practitioners' felt that because carers were coping with, tolerating and 'masking' the needs of their family member, they often encountered services only when they could no longer cope and/ or the situation, as illustrated by the comments below.

Most of the time it has to be residential dementia and you think well, what we are providing there is a large building with several members of staff... and then you reflect, well, one person on their own has been providing what we now think needs specialist nursing and many staff to manage. David (Adult social worker, Group 2)

I think that the focus is mainly on the person who has got the illness... So, OK, they might hear about the situation but along with that situation is a whole other scenario around, about how it occurred and why. Because if you take the carer out, then OK, the person who has got the illness is obviously magnified but the carers are always buffering that: they are covering up that situation. Amanda (Dementia advisor, Group 4)

In the following excerpts, Jan and Lucy reflect on the difficulties they believed carers were likely to experience when talking about a sensitive, emotive topic such as harmful behaviour. They highlighted some of the potential limitations engendered by the organisation of front-line services and the need to 'screen' people before they could access social workers and/ or

specialist safeguarding teams. This resulted, they suggested, in a situation where violence or abuse would be discussed only if the carer initiated the conversation.

We don't ask that question, we don't even ask.... Well, it's not even about just sexual harm and violence, it's about any type of harm or violence. If we just left it open at any sort of violence within an intimate relationship, we just don't pose that question. We would be asking her about her carer support needs. I don't know what Duty (initial assessment team) would do. They might sign her off because I don't think that they would even let her through the door. I don't think that they would start exploring with her. They wouldn't start to explore with her about violence in her relationship. It's not part of the script. Jan (Adult social worker, Group 3), on Sarah's vignette

A similar comment was made by Lucy, a social worker, who questioned her colleagues' suggestions that they would "explore all the options" and "take as long as was needed" with carers who might be experiencing harm or abuse.

We forget that we are a stranger. We all know that we are from the safeguarding team and know what we can and can't do, but they don't know that... We expect people to listen to us and accept what we say. And then just tell us all the most horrific things that have ever happened to them without even seeing anybody. Lucy (Adult social worker, Group 3)

Jan and Lucy identified some of the potential barriers that prevent carers' disclosing their experiences. On a related point, Emily and Gill discussed their concerns about the limited support available for carers to help them recover from harmful or abusive experiences and to adjust to the loss of their role and way of life once their family member was placed in a nursing or residential home. It was difficult to meet these needs because the provision of care and support was determined almost exclusively by the health and social needs of carers' family members.

I think one of the things that this (focus group discussion) brings up for me is a concern about when things like this do come up, like on duty, about how we react to those things. Because it is often when things are at a crisis point... I think that the perception is that when we have removed that person (causing harm) then everything is fine now... But I just don't think we push to actually support the carer. We just remove the risk, essentially, but we don't actually follow it up. I mean that is what definitely alarms me

from all of this... We're constantly fire-fighting. Emily (Social care coordinator, Group 2)

The carers always get forgotten about because we don't offer any services once the cared-for have gone into a home. It's as if, well, there you go! But they are dealing with a whole raft of emotions. And like I was saying, it can be a few years down the line. And I am always conscious of that. You know, what can I offer? Well, it's not a lot. Gill (Adult social worker, Group 5)

Whilst these discussions highlight some of the constraints that statutory social workers experienced, the two groups of dementia specialist (and non-statutory) workers also talked about difficulties working with families affected by harm. Practitioners talked about their feelings of frustration that they were unable to do more for families until their needs met a certain level or threshold. As discussed, considerable emphasis was placed on the ethical and therapeutic value of working in an exploratory and relationship-focused way with families. However, members of both non-statutory groups also highlighted that this approach was sometimes borne from pragmatic considerations too. Although there is not necessarily anything inconsistent between these different rationales, several practitioners talked about the limitations and adaptive nature of their role.

Sometimes we are just waiting for a crisis because we know that people don't want us. You know, they have capacity so until it hits crisis we can't intervene... Although we can see the issues and we want to intervene. We can't because of... constraints. Jenny (Admiral Nurse, Group 1)

We try to, we try to explore how much they are willing to put up with. But the frustrating point is that we don't really have any other options to give them at that stage. Usually, they (family member) just has to go away, which is the exact thing that they want to avoid most of the time. Cathy (Dementia advisor, Group 4)

There were also tensions between practitioners who had different perceptions and ways of working with 'risk' and determining what constituted a 'crisis'. Both groups of non-statutory workers reflected on their difficulties working with statutory services.

We try to support families to think about where that disclosure (of harm or abuse) then takes them. Particularly if it then exposes them to the statutory services who will work with them in a different way and not necessarily be supportive in terms of finding resolutions but will be bound by protocols and procedures... We work with people in a very different way. And actually when you start working with people and we put our head above the parapet, we open ourselves up to other practitioners, to other views, and we have to think about the impact that that might have on a couple. And there will maybe be that sense of things being taken out of our control. Rita (Admiral nurse, Group 1)

They opened up completely to me, explained what had been happening for years regarding the abuse – and obviously, as part of my duty of care to them, I had to think about safeguarding – and that is exactly what I did. And as soon as safeguarding got involved, they just said “I don’t know what you’re talking about”. But then that same carer then backed off me because then that trust is gone. Jo (Dementia advisor, Group 4)

In trying to navigate how best to protect and empower the families whom they worked with, Rita and Jo touched on their concerns that statutory social work intervention can be a sign or even cause of crisis and result in a loss of control (and trust) for the individuals concerned. More subtly, their comments perhaps also reflect their own feelings of disempowerment and loss of control when ‘giving up’ or ‘reporting’ families, thereby ‘losing’ their relationship and way of working with a family. The difficulties navigating inter-practitioner systems can stem from a host of issues, including tensions and perceived differences between practitioner values or ethical codes (Hewison & Sim, 1998); differences in practitioner terminology and heuristics (Munro, 2005), competing priorities, and a lack of time to develop mechanisms for robust inter-practitioner working and reflection (Abley, Bond & Robinson, 2011; McLaughlin, Robbins, Bellamy, Banks, & Thackray, 2018). The fragmented and diffuse nature of service provision and recording systems further compounds these problems in UK adult safeguarding (Ash, 2011). With these structural and contextual factors in mind, it can be difficult for practitioners to share and develop meaningful and timely knowledge about and with families affected by harmful behaviour. In turn, this can result in their needs being overlooked or given low priority in anything other than ‘crisis’ situations.

Inter-personal dimensions

In the following section, I highlight some of the comments made regarding gender, race and ethnicity. I then reflect on how these issues might shape the way some practitioners talked about and understood harmful behaviour towards carers. Of the 38 participants, only five were male, with one man in each of the five groups. Three of the male participants highlighted that gender was an important consideration that they felt was over-looked in the discussions. The male workers highlighted the potential difficulties of male workers supporting carers affected by sexually harmful or abusive behaviour. Underpinning these comments was an assumption that sexual harm is more likely (if not exclusively) likely to affect female carers.

You know, you just said that you would never ask that question (about abuse) but I have to admit that I would feel quite awkward asking that question of a female carer as a social worker.

Yes, yes... I don't think that you would ever ask that question Geoff and I agree that that would just feel very inappropriate. If you were sitting with an older woman and you started asking her about her sexual activity with her partner, I mean no, no you couldn't. Geoff and Jan (Adult social workers, Group 3)

I think gender is important here because as a man going into this situation with a female carer, they would be a lot less likely, understandably, to disclose this sort of thing. So that comes to mind as well. I think there is probably a lot going on that we don't know about. Andy (Dementia advisor, Group 4), on Sarah's vignette

It is perhaps unsurprising that practitioners expressed feelings of discomfort and unfamiliarity discussing issues around sexual abuse and harm of and by older people. Shaped in part by the 'real rape' stereotype that sexual violence is an expression of desire or attraction (Bows & Westmarland, 2015), there remains limited research or practice literature about how sexual violence and harm affect older people. Moreover, until 2015, there was no official recording of reported sexual violence against any one aged 60 years and older, thus perpetuating the myth that sexual harm is an issue that only younger adults experience and implicitly

legitimising the paucity of bespoke criminal, health and social support for survivors (Bows, 2018). Indeed, several (female) participants talked about their surprise that this issue had surfaced in the study.

I had never really thought about this scenario. When I think about domestic abuse as the result of cognitive impairment then I think about the physical side and the emotional side. I had never really considered the sexual side and I guess, with that label of people being older on top of that, that it is just not something that I had really thought about. Lucy (Adult social worker, Group 3)

I do think that there is something, when you are looking at the terminology, I think that gender has something to do with it. I think that as a female, when you hear anything about sexual... that to me is the ultimate thing, that is the worst thing that could happen. So, when I hear that, it automatically triggers something that is deep down inside of me. So I wonder, what do other people think of that? Do other people have that reaction, I don't know. Emily (Social care coordinator, Group 2)

We're not supposed to comply with stereotypes... and we know that sexual activity occurs, because the nursing homes tell us it does. Yet I have never ever asked anybody about this. They talk about all manner of challenges that they are having keeping their partner clean, fed and safe but I have never talked about night-time in terms of sexual intimacy. Jan (Adult social worker, Group 3)

Some practitioners also highlighted issues of race, culture and ethnicity. At this point I want to clarify that I did not ask participants to self-identify their race or ethnicity. Thus, the brief observations that I make here are made with caution and critical awareness that they tend towards generalisation. However, I was struck that in four of the five groups, there was no discussion about issues of culture, race or ethnicity and that amongst these groups there appeared to be only a small number of people from an ethnic minority (in terms of appearance, language, name, etc.). However, in one group, where the participants discussed their experiences as workers from minority and non-European ethnic backgrounds openly, race and culture were identified as important factors affecting people's views, values and reactions when caring in the context of harm. These issues were described as: the perceived reluctance of many ethnic minority families (particularly those with roots in collectivist societies) to initiate or accept support from 'outside' agencies without understanding their

responsibilities that workers had to disclose concerns about harm and abuse. Practitioners also highlighted the racial verbal abuse that workers experienced from older people, and sometimes their family members, when working with them.

I know certainly that when you go into African-Caribbean communities – and I’m not saying all, but some – and then you walk in and sit down and there is this natural thing that you just get – which is “keep your mouth shut, I’m telling you”. And you’re trying to communicate with them to say that that is not as easy as you would like it to be. So, you have to almost guide them to say, “if you tell me this, then I’m going to have to do this”. But there is a great sense of risk that you pick up on as you go along. Maggie (Dementia advisor, Group 4)

These comments point to the complex nature of developing ‘shared’ understanding or ‘safe’ spaces to disclose abuse and/ or seek help for carers. They also indicate that social and cultural factors shape the nature of communication between practitioners and carers (Eisikovitis, Koren & Band-Winterstein, 2013). Without formal guidance and with limited discussion or visibility of the issue in law and policy, the data suggest that practitioners are more likely to draw on personal and experiential knowledge when brokering (and perhaps sometimes unintentionally avoiding) these difficult conversations.

Responding to ‘carer harm’: reflections on naming practices

To conclude, this third unifying theme explores practitioners’ discussions about the extent to which harmful behaviour could or should be considered a form of abuse. Many practitioners emphasised the importance of honouring carers’ subjective understanding of their situation and their ability to make choices about how to understand and manage the practical and ethical issues engendered by their family’s member’s harmful behaviour. They also raised concerns about whether it was appropriate or useful to frame ‘carer harm’ as a type of abuse. From an organisational perspective, participants talked about some of the difficulties this conceptualisation might engender in terms of how to identify and respond to affected

families. From a more personal perspective, participants expressed their reluctance to situate this type of harm and distress in the context of ‘abuse’ and ‘abusive relationships’.

Many practitioners identified the potentially emotive and visceral connotations of the word ‘abuse’ and suggested that use of the terms would have an adverse effect developing trusting and open relationship with families. This is consistent with Ayres and Woddis’s (2000) recommendation that the term abuse does not adequately capture the nature and impact of harm and violence that can occur within caring relationships. Focus group participants highlighted that individuals had different interpretations of what ‘abuse’ looked and felt like and these interpretations were shaped by a host of intersecting factors (e.g. previous experiences, severity of violence, degree of social support). As a result, it was difficult to characterise harm to carers in a broad-brush manner. This note of caution is evident in Rita and David’s comments:

I mean, abuse is a very emotive word... And I think that how people respond to that is unique. About what that would look like for them. Rita (Admiral Nurse, Group 1)

I mean abuse is just so subjective, its so much about perception and the experience of the individual. And you would probably find that people in the same room would manage different kinds of abuse in different ways and build up coping mechanisms whilst others can’t. So, yeah, it’s a very, very broad thing, I think. It is just an incredibly broad term. David (Adult social worker, Group 2)

The practitioners felt that it was important to respectfully engage with the way people talked about and understood their experiences. Failing to do this was likely to impede meaningful communication between professionals and families. Given the emphasis placed on exploratory and relationship-based practice by four of the five groups, it is perhaps unsurprising these participants placed a high value on sensitivity to language in the context of developing good inter-personal dynamics with service users and carers. It also echoes research findings that demonstrate the powerful role of generational and cultural norms in

shaping how older people talk about abuse and harm, with attendant implications for how they understand what, if any, options they have for engaging with services ‘outside’ of their family network (Naughton, Drennan, Lyons & Laferty, 2013; Wydall & Zerk, 2013; McGarry et al, 2014). Participants in this study appeared to be attuned to the different and additional challenges involved in talking about abuse and harm with older people and family members and they stressed that making the ‘wrong’ move could result in a premature severing of their working relationship.

Sometimes when you are working with someone and something develops as part of the case, during the time that you have that practitioner relationship with them, then using the word abuse might not be helpful, it might make them back away. What might be useful is to just ask them, to ask how they feel and what they want to call it. If they say that they felt this or that, you can then just ask them what they want to do with that pain. Sometimes that helps. Sue (Adult social worker, Group 3)

I mean I do think it is quite a loaded word and at times people can switch off very quickly with certain words. So, if you use a particular word, they can shut down... I mean, I feel awkward talking about abuse. You know? And I’m the advisor. I mean, I will do it but it’s not something that I particularly like talking about. So, I can’t imagine what the person on the receiving end would feel like. Andy (Dementia advisor, Group 4)

Participants also identified that the terminology surrounding ‘abuse’ was problematic because of the associated implications that the person instigating the behaviour was doing so intentionally. They also expressed caution about using a term that could lead to blaming or stigmatising the older person with care needs and/ or experiencing mental illness (Solomon et al, 2005).

I think... some of it is about capacity. You know, does this gentleman fully understand the impact of his behaviour? You know, is this behaviour used as an element of control? Is he having his needs met? What is driving this behaviour? These are important questions. Leah, on Rose’s vignette (Admiral Nurse, Group 1)

Reflecting on the findings of the literature review, it is credible to suggest that participants and carers alike were highly attuned to criminal and legal conceptualisations of abuse. That

is, they recognised it as an incident or pattern of behaviour that an individual enacted despite knowing – or having the emotional and cognitive capacity to know – that it would hurt or constrain another person (Biggs et al, 2013). This meant that it was difficult to know how to name or to ‘formalise’ responses to ‘carer harm’.

Even though it is a case of us giving them the information about what they could do, they would rather protect their loved and one and they be the one that sits with the abuse rather than risk somebody else abusing their loved one. So, how do you formalise that? To say, basically, get help as soon as you can, because this is still all about love. Amanda (Dementia advisor, Group 5)

From a more practical perspective, several focus group participants talked about how the labelling of behaviours (or people) as ‘abusive’ also had implications for the type of support and help that a family would receive. Recounting a joint visit to an older woman who was experiencing serious and ongoing violence by her husband, Angie highlighted some of the evident tensions between her approach, as a social worker, and that of the independent domestic violence worker.

And this worker was like, ‘now, this, is the King of the Castle and this, THIS IS ABUSE’. Ahh, God... I thought, this lady loves her husband, she does still love her husband... I just thought, woahhh! She (worker) was just so in your face. She was so de-sensitised in a way, just launching in like that, talking about abuse. I just thought, no, that is so unhelpful... So I stepped in to turn things round. Angie (Adult social worker, Group 3)

On a separate but related point, several participants also noted that the way carers named and understood their experiences was not the only (or most reliable) indicator of harm and abuse. Thus, although there was a consistent emphasis on working in a person-centred and empathic manner, practitioners highlighted that it was sometimes helpful and necessary for people ‘outside’ of the situation to assess the severity and nature of the harm taking place. These discussions reflected the evident tensions between balancing individuals’ rights and capacity to ‘choose to live with harm’ and the role of people working in adult social care and

safeguarding to actively manage and mitigate this harm (McKay, 2017). Indeed, several practitioners suggested that a carer's choice to 'tolerate' harm could in fact reflect a misunderstanding (and neglect) of the severity of their family member's needs. This touched on concerns about 'retaliatory' abuse (Koeing et al, 2006; Band-Winterstein, 2012) and the effect of 'poor' care on the older person if both carer and cared-for were living in a 'chaotic' environment, as illustrated by the following comments.

In a way, she is depriving him of shelter, warmth, comfort... So it could be a bit of both, really. And, what does she perceive to be a risk and aggression? I mean, he might have just slammed his fist on the table and she has ran off to a room because she feels threatened. But he could just be letting off some steam. Because there might be abuse on both sides. Lyn (Admiral Nurse, Group 1) on Roses' vignette

I think that if you screened that then, I don't know, it depends who did it, you might be inclined to, well, you might be inclined to pick it up and look at it as a potential safeguarding issue for him because he wasn't able to get out, he was driven to do that... So, you would be looking at those aspects of it as well. So, as well as her having to deal with that then she might also be looked at as a perpetrator of abuse, which is really difficult as well. Katrina (Senior social worker, Group 2) on Megan's vignette

We also need to think about when it is time to let someone go. And that might be because their level of need is now so much that it is unsustainable for them to remain at home. And then actually, a wish for a family carer to want them to stay at home, in itself that can become abusive, because they are actually denying somebody the opportunity to have care that would better meet their needs. Rita (Admiral Nurse, Group 1)

The difficulties involved in naming 'carer harm' as a form of 'carer abuse' engendered conversations about practitioners' professional and ethical responsibilities and the difficulties of meeting the (often complex and dynamic) needs of individuals with different needs and vulnerabilities. Furthermore, given participants' comments about working in a crisis-orientated system, it is also possible that the conversations with families tended to come about when there were multiple and evident signs of carer and family 'breakdown'. Arguably, these circumstances made it necessary and thus permissible for practitioners to talk directly about dimensions of carer harm. This

suggests that ‘carer harm’ is a complex form of harm and that there are similar as well as additional challenges involved in identifying and responding to it in comparison to other, better-recognised, ‘types’ of familial and intimate partner violence.

Summary

Many practitioners were sensitive to the needs of carers who experienced harmful and abusive behaviour by the older person for whom they cared. Reflecting on the vignettes and discussing examples from their own practice, they highlighted how they would respond to affected carers, often emphasising the need to build trust, develop strong working relationships, and support carers to make ‘difficult’ choices about their situation.

Nevertheless, practitioners also discussed the constraints and contradictions that they faced (or would face) carrying out such work, however much they knew about or empathised with the difficulties they faced. Working in a system orientated towards crisis response and the protection and care of ‘vulnerable’ people, some practitioners felt they were not able to explore and prevent harm taking place or offer rehabilitative support when it had already happened. Yet practitioners also talked about more immediate difficulties, knowing what to ‘call’ the type of harmful behaviour and knowing who could and should support affected families given, they stressed, that this was not ‘like’ domestic abuse. In the following chapter, I will explore how additional structural and ‘epistemic’ inequalities may have shaped the way practitioners, and carers talk and think about, and respond to, harmful behaviour by older people with care needs.

Chapter 6: Theory-informed analysis of the carer and practitioner accounts

Chapter overview

In order to develop the thematic, mainly inductive analysis of the carers' and practitioners' accounts further, I drew on Fricker's theory of epistemic injustice to develop a theoretically-informed interpretation of the empirical data (Fricker, 2006; 2007; 2010). Using Fricker's theory enabled me to foreground my analysis in concepts that were sensitive to the interpersonal power differentials and structural inequalities that were latent in the carers' and practitioner participants' accounts; in turn, this enriched the critical depth of my analysis and fed into the recommendations I set out for future practice, policy and research in the concluding chapter of this thesis. In the first section of this chapter, I outline the background and central concepts of Fricker's theory, including her characterisation of testimonial and hermeneutic injustice. This section includes two reflective notes on my 'discovery' of Fricker's work and on the rationale for adopting it to explore the synthesised accounts of the carers and practitioners. In the third part of the chapter I make the case that carers' attempts to understand and talk about their experiences of harmful behaviour are affected by conditions of testimonial and hermeneutic injustice. Thus, the theory of epistemic injustice affords valuable insights into some important aspects of how carer harm is constructed, responded to and, at times, rejected. It also goes some way to explaining why some carers may be more likely to be 'silenced' than others.

Fricker's theory of epistemic injustice

Fricker argues that there are two different types of epistemic injustice - testimonial and hermeneutic – and these can cause 'harm' to individuals or groups whose knowledge is disregarded. Fricker describes the aim of her work as identifying the ethical aspects of everyday epistemic practices – for example, how we share and communicate knowledge and

how we develop understanding about our social experiences. She argues that there is a close and inherent connection between the “operation of social power in epistemic interactions” and this gives them an ethical dimension (Fricker, 2007, pp.2). This means that social injustices – that often have a material, political and cultural dimension – will find expression in and are compounded by, epistemic injustices, which tend to be social, inter-personal and psychological in nature. Acknowledging the inter and intra-personal dimensions of epistemic injustice is critical to Fricker’s argument that epistemic harm is likely to have negative psychological effects including feelings of being silenced, mistrusted, and confused (Fricker, 2007). Furthermore, because being considered an equal and rational ‘knower’ is the central tenet of social belonging and identity, experiencing epistemic injustice may also affect how people engage with their social and political community (Fricker, 2006).

1. Philosophical method: the ‘failure-first’ approach

Fricker first set out her ideas about epistemic injustice at a time when post-modernist and constructivist approaches were in the ascendancy in western intellectual thought.

Acknowledging their value and contribution to philosophy and the social sciences, she argues their focus on social power and rational action only partially accounted for the complexities of how social justice (and injustice) develop (Fricker, 2006; Fricker, 2007). Something is lost, she argues, if language and knowledge are understood only in terms of explanations of individual or institutional power. Furthermore, Fricker suggests that political and moral philosophy may be limited when they explore only ‘ideal’ scenarios: be this the cultivation of positive virtues such as compassion, courage and justice, or, the development of ‘transcendental’ political structures to uphold the principles of justice and the fair distribution of resources (Sen, 2011). Fricker argues that experiences of injustice and inequality are prevalent, problematic and real, whilst the experience of perfect justice and social equality

are not. As a result, questions of moral philosophy should be foregrounded in the imperfections and complexities of ‘real life’ (Fricker, 2007; Fricker, 2015). This allows us to “trace some of the interdependencies of power, reason, and epistemic authority”, which in turn deepens our awareness of how dominant groups exercise and hold on to their epistemic resources (Fricker, 2007, pp. 4). Adopting this reflective, context-sensitive perspective also helps us become more conscious of our own epistemic habit which enables us to see how our epistemic practices can become more rational and more morally just (Fricker, 2007).

The ‘rise’ of epistemic injustice

Over the past decade, the concept of epistemic injustice has been taken up by a number of scholars working outside of Philosophy and its sub-disciplines. Initially adopted by political and feminist scholars – exploring epistemic injustice in the context of gender and racial inequalities - the concept has been critically developed in the fields of applied social science and bioethics. Although there are several scholars who have contributed to the critical development of the concept, Fricker’s work has perhaps made the most noteworthy, unique contribution. Riggs characterises her work as a “marvellously detailed exploration of a phenomenon that is important to both epistemology and ethics” (Riggs, 2012, pp 150) whilst Sherman describes Fricker’s theory as making an “important contribution” to a hitherto overlooked and “important sort of moral and intellectual wrong-doing” (Sherman, 2016, pp 229).

Fricker’s framework has been used as a sensitising concept to explore the accounts of individuals who have experienced marginalisation and oppression in the context of encounters with institutions and their representatives (examples include, Buchman, Ho & Goldberg, 2017; Kurs & Grinshpoon, 2018; Bell, 2014; Blease et al, 2016). Kidd and Carel (2017), for example, explore how Myalgic Encephalomyelitis (M.E.) patients’ testimonies

about their psychological symptoms are frequently given low credibility in the context of encounters with clinicians. Kidd and Carel (2017) also discuss how diagnostic practices – that provide limited time for patient-clinician interactions and are predicated on forms of knowing that are validated by empirical evidence and bio-medical concepts - make it difficult for this patient group to explain their social and psychological symptoms, thus compounding the fractured and sometime fraught nature of communication between the two groups.

Epistemic injustice has also been used to explore the structural, social and inter-personal conditions that foster oppression and discrimination – much of it implicit and difficult to locate – of groups who have atypical ways of communicating or who belong to a ‘group’ with low or contested status (Dotson, 2011; Kalman, 2016; Steyn, 2012). Steyn (2012), for example, argues that so deeply ingrained were discriminatory attitudes in the political, cultural and social systems of apartheid South Africa, they gave rise to a collective epistemic ignorance that made it difficult to recognise, let alone challenge, the deep and complex nature of inequality between white, and black and mixed-race individuals following the legal dismantling of the apartheid state.

Fricker’s ‘failure-first’ approach to tackling ethical questions thus offers a valuable conceptual bridge between the abstract and the lived dimensions of some forms of injustice and marginalisation. It helps to surface new, critical issues for those investigating and seeking to effect change in the distribution of contemporary social and epistemic resources and can help to explain social processes and dynamics that are often subtle or so embedded in the social fabric that they have become ‘invisible’. Furthermore, over the past decade there has, in some areas of public life, been a greater focus on the ‘politics’ of identity and the operation of unconscious bias within institutional as well as inter-personal spaces (Medina, 2013; Pohlhaus, 2012). Thus, it is perhaps unsurprising that Fricker’s work has been

advocated as one valuable way of working through these complex debates and their associated politics.

Reflective note: My ‘discovery’ of epistemic injustice

I first encountered Fricker’s work at a time when I was reflecting on (and trying to write about) my experiences working with the advisory network (see the chapter ‘methodological reflections’ for further details). By this point, I had also completed the literature review and carried out most of the interviews with the carers. Exploring work about the inherent power dynamics and inequities of collaborative and participatory research, I reviewed two papers that drew on the theory of epistemic injustice. My ‘discovery’ of Fricker could therefore be considered serendipitous. However, I think it more likely reflects the iterative, reflective and sometimes disjointed nature of developing knowledge in qualitative research (Probst, 2015; Finlay, 2002).

As a novice researcher, my ability to identify themes and connections between different parts of the study and the wider literature was bound up in my own learning and familiarisation with the role of theory in social science research (Ward et al, 2015). To this end, reflective discussions with my supervisors played an invaluable role in shaping my decision to ‘go deeper’ and to engage with Fricker’s theory. This helped me to make an informed decision about the use of theory within the project and the degree to which it ‘aligned’ with the research topic, epistemological orientation and methodological decisions that had been adopted earlier in the study (Carter & Little, 2007; Kelly, 2009).

I started to consider how the theory of epistemic injustice might be useful in explaining aspects of carers’ experiences and narratives of violent, abusive and harmful behaviour.

Throughout the project, the ‘hidden’ and ‘sensitive’ nature of the topic had been apparent. I had experienced considerable challenges, for example, developing space and time to talk about the topic with professionals and carers (Isham, et al 2018). Similarly, there was an evident ‘gap’ in the research literature that indicated the issue was under-explored and that there were limited conceptual and linguistic tools with which to explore it (Isham et al, 2017). Indeed, by this point in the project, I too had come to characterise the topic as ‘hidden’ when talking and writing about it. This is noticeable in the various applications for ethical approval made during the project and the recruitment materials that I designed (see appendix 1 and 2). On reflection, I may have unconsciously done this as a way of drawing attention to the issue and legitimating the need - and therefore my role - for the research.

Until this point, however, I had not considered the epistemic or analytical implications of what being ‘hidden’ meant, nor had I explored the issue with a focus on the processes of telling, sharing and co-constructing knowledge between individuals. These questions became increasingly pertinent as, in the process of carrying out thematic analysis of the carers’ and practitioners’ accounts, I became cognisant of the limitations of adopting this interpretive approach in isolation. I noticed, for example, the constraints of relying solely on the descriptions and reflections of participants to explain and explore the complexity of their emotional experiences, aspects of which might not be possible to ‘put into words’. I also recognised that although the empirical data was rich and valuable, it encompassed the views and experiences of a small number of people. Clearly, there were gaps and silences in the data: people, in short, who may be affected by the issues that the project raised but whose voices, for manifold reasons, had not been heard (Lewis, 2010; Serrant-Green, 2011).

Thus, I considered it valuable to orientate my analysis within a framework that took explicit account of social factors and processes that might affect how carers and professionals

‘constructed’ our discussions. Fricker’s theory also helped me think more critically about issues of social injustice and marginalisation and the degree to which these were helpful concepts when exploring the experiences and needs of carers affected by harmful behaviour. It is in this context that I began a process of familiarisation with Fricker’s work and engagement with the critical debates and empirical work that it has engendered. In the following section, I outline some of the central concepts that underpin Fricker’s theory of epistemic injustice and the two types of epistemic injustice she identifies.

Central concepts and types of epistemic injustice

1. Epistemic resources

Epistemic resources are used to communicate and develop knowledge about our individual and social experiences. They are also the tools with which we develop trust and credibility with others. When we lack shared epistemic resources, we may find it difficult to build understanding with someone and to feel heard. This in turn limits our capacity to create social bonds and relationships. Examples of epistemic resources include mastery of written and verbal language, and the use of non-verbal communication. They also include how we listen, convey understanding and build epistemic connections with others, drawing on aspects of social performance and role identity. Origgi (2012) suggests that epistemic resources are a “complex set of judgements, heuristics, biased social perceptions and previous commitments” (pp. 223). They include knowledge based on inferences about a subject’s rationality, emotional reactions and our moral or political commitments to other people or institutions (Origgi, 2012). Epistemic resources therefore encompass a wide range of skills and attributes that are shaped by our access and exposure to different ways of communicating and knowing.

Crucially, for Fricker, the nature and distribution of epistemic resources is shaped to a significant degree by social and structural factors. Fricker argues that there is an iterative and reinforcing relationship between the unequal distribution of epistemic and social resources, because “unequal epistemic participation is one of the key modes in which unequal relationships and statuses of other kinds tend to express themselves” (2015, pp. 7). These structural dynamics underpin both ‘informational’ exchanges where information is shared, as well as ‘interpretive’ ones when understanding is conveyed or developed in a more implicit manner (Fricker, 2010; Hookway, 2010). In short, individuals who exercise social power – and belong to dominant social groups - are likely to have greater or more varied epistemic resources. This could include: being able to assume a universality to one’s experience; enjoying access to social, economic and political spaces without recognising how and why this entry takes place; and, not recognising what it means to be socially or politically silenced (Medina, 2013). Individuals who do not belong to social groups that exercise power or dominance or do so only in very limited and contingent ways, may in turn, develop new or alternative epistemic resources that ‘speak to’ their experiences and ‘make sense’ of the world as they experience it.

The credibility economy

Epistemic resources play an important role in Fricker’s credibility economy. Having what one knows, and the way one communicates this knowledge, considered to be legitimate by others provides leverage within the credibility economy. Similarly, if other people do not recognise what and how you know, you may be excluded from certain areas of exchange. Although Fricker uses the term credibility economy as a global concept, she identifies that different ‘rules of exchange’ will operate in different areas of social life and people who may enjoy a great deal of legitimacy in one area may not in another. Social identity and

performance play a central role shaping the creation and distribution of credibility; however, it is also shaped by the views, choices and understanding of the individuals involved and the nature of their inter-personal interaction. Children, for example, possess legal rights and, in many societies, moral and social capital that require adults to protect and to promote their needs. However, when children present knowledge that challenges adult expectations and practices, or, indeed appears to be ‘unbelievable’, they are often stripped of their epistemic credibility and find it difficult to contest the more ‘reliable’ and ‘rational’ account of an adult (Carel & Györffy, 2014; Murriss, 2013). In the context of child welfare and child protection practice, Knezevic (2017) found that when adults implicitly constructed children’s actions (and hence, the children) as immoral or disloyal, this served to reinforce their contention that the children’s testimony should not be taken as seriously as that of an adult’s. This example highlights that whilst credibility can be fostered, and the imbalance between people’s social status addressed it is possible for an individual (or group) to dismantle this somewhat fragile consensus if it is no longer in their interests to consider a less powerful person (or group) equal (Polihaus, 2012; Fricker, 2015).

Fricker argues that when a person’s knowledge is mistrusted or overlooked – without good reason – they are likely to suffer a credibility ‘deficit’. This deficit often stems from identity prejudices and/or unfamiliarity with the type of knowledge the person is sharing or the way they are communicating. Similarly, credibility ‘surpluses’ can build up, when a person’s knowledge is given undue status and regard without examination of its provenance and relevance to the matter at hand. Surpluses tend to develop when a person already enjoys a position of social status or power that engenders deference, respect or fear. Although it is not difficult to identify how suffering a credibility deficit may be a negative experience, it is plausible that a credibility surplus can also be harmful: for example, when a person is left to

make a decision without adequate resources because their opinion is, mistakenly, given such high credence. Fricker gives the example of a family placing trust in a doctor to treat their sick relative, even though the doctor lacks the relevant training and experience of treating people with the condition. In this case, both the family and doctor suffer from the misplacement of credibility and, in a practical sense, this could result in poor or inadequate care for the individual who is unwell. This example also highlights how exchanges within the credibility economy are often shaped by implicit forms of knowledge about how we relate to and develop trust with individuals and groups in different social contexts. Fricker argues that it is therefore necessary to examine how our systems of belief and judgement develop if we are to address systemic imbalances in the credibility economy.

Identity prejudice

Identity prejudice refers to the assumptions, negative stereotypes and unchecked and implicit knowledge that confers certain characteristics or explanations about a person based on one or several aspects of their social appearance. Fricker suggests that prejudice can be conscious and deliberate; however, it is often more subtle and implicit. She draws on the psychological concepts of dissonance and unconscious bias to explain how there is often a 'gap' between people's conscious, stated, beliefs and their behavioural and emotional responses (Fricker, 2007). She suggests that human behaviour is largely 'incoherent' (non-rational) and that this is sustained by 'psychological compartmentalisation' and the tendency to place 'epistemic trust' in established social norms, rather than adjusting perceptions to take on board new, empirical, evidence (Fricker, 2007). Crucially, identity prejudices play a significant role in shaping epistemic encounters. For example, they may lead to certain knowers being given less time and attention, or, their testimony being taken less seriously. Identity prejudice may come to shape how people think about their own knowledge, thereby affecting how they

come to know and communicate their private and psychic world. Above all, Fricker emphasises the systemic nature of identity prejudice and argues that it is particularly pernicious because it ‘tracks’ a person, sometimes across their life-course and often throughout their interactions in different social spaces. The cumulative experience of identity prejudice is often serious and long lasting. Moreover, it is compounded if individuals cannot access a ‘community of knowers’ who share their experiences and who can, implicitly and explicitly, challenge the way that other people prejudicially judge them (Fricker, 2006; Kidd & Carel, 2017).

Two types of epistemic injustice

1. Testimonial injustice

Testimonial injustice is characterised as when a ‘speaker’ (someone who is communicating) is not heard (meaningfully listened to) because how and what they are saying are not given appropriate credibility and respect. It can occur on an incidental as well as a systematic basis and the degree of harm caused is likely to reflect the frequency and severity with which this form of epistemic injustice takes place. Fricker argues that testimonial injustice is harmful to the speaker ethically and psychologically. It is an attack on their status as a rational and equal member of a social community because the failure to hear them reflects the epistemic (and social) prejudices of the listener that what and how the speaker communicates are of less value. This is harmful, she argues, because being valued as a knower is a ‘basic’ condition for human flourishing as well as a ‘basic’ tenet of reciprocity and social association between individuals (Fricker, 2015). In addition, testimonial injustice can have practical ‘secondary’ effects that include experiencing psychological distress, loss of social status, and feelings of confusion and uncertainty about their own rationality and knowledge.

In her 2007 work, Fricker draws on the example of a woman in the 1920s, whose information and insights about a murder were not given due regard by an older male relative. She is considered ‘hysterical’ and to be acting in an overly-emotional way, thus impairing her ability to provide rational and objective knowledge. As a result of this testimonial injustice, Fricker argues that the woman is likely to suffer harm. She may feel censured and suffer some degree of psychological stress or grievance. If this incident is a common occurrence – part of a cumulative and repeated experience of testimonial injustice – then the woman may come to have less confidence and belief in her own ability to know and/ or to expect to be treated with credibility. In both cases, the individual is harmed and so other people lose the opportunity to hear and engage with her views and experiences.

Underpinned by negative identity prejudices about women’s ability to act and think in situations of stress and complexity, Fricker suggests that the male relative’s actions are largely the result of implicit and contemporary attitudes in the 1920s. This does not mean that his reaction is inevitable: another man may respond to the woman’s testimony in an entirely different way, considering it credible and useful and incorporating this into his own developing understanding of the situation at hand. In this case, however, Fricker emphasises that because negative gender stereotypes were prevalent, the male relative’s response is best understood as being the result of both identity prejudices and structural imbalances of power between them (Fricker, 2007). This, then, is a case of testimonial injustice because the woman’s knowledge is given less credibility and regard without reason or due process. Her attempts to ‘tell’ are systemically impaired by gender prejudices, but not necessarily caused by the deliberate action or inaction of her male relative.

Hermeneutic injustice

Hermeneutic injustice is the second type of epistemic injustice explored by Fricker. This takes place when significant parts of a person's social experience are obscured from understanding owing to prejudicial flaws in shared resources for social interpretation (Fricker, 2007). This results in a 'lacuna' where neither knower nor hearer can understand the other and, in some cases, the knower is unable to meaningfully define and describe an important aspect of their own experiences to themselves (Fricker 2006). At an individual level, hermeneutic injustice may happen when a person lacks the skills and, crucially, motivation or willingness to listen and engage with people who think and communicate in a different way from them; or, perhaps, in a way they perceive as threatening or irrelevant. At a structural level, hermeneutic injustice often reflects the failure of a community to accommodate and incorporate new and plural ways of knowing, thereby leading to the exclusion and marginalisation of some individuals and groups (Steyn, 2012).

Fricker gives the example of the changing status of sexual harassment in western societies to illustrate the conditions of hermeneutic injustice (Fricker, 2006; 2007). Prior to the political and legislative changes of recent decades, there was limited recognition or consensus about anything other than extreme and violent sexual crimes against women by men. Even then, this behaviour was often considered to be relevant only in the public realm - i.e. no legal recognition of the act of rape by a husband of his wife – and this led to cases of sexual assault and harassment going unaddressed by the legal and criminal justice system and being 'hidden' or minimised within social and cultural discourses. However, in the 1960s and 1970s, political campaigning, alongside social education efforts, helped to increase visibility of women's lived experience and impact of sexual harassment and challenged dominant narratives about the rights and actions of men (Dotson, 2011). This in turn developed

epistemic resources – alongside legal rights and a more developed public lexicon - that helped people to explain both their experiences to themselves and others. Thus, it is possible to identify shifts in the hermeneutic landscape that confer an expanded set of shared epistemic resources – about some issues, amongst some people, at certain points in time.

Nevertheless, it takes considerable time and effort to dismantle and re-construct hermeneutic structures and the cultural norms and institutional practices on which they rest (Steyn, 2012). Exploring how sexual assault victims were negatively treated when giving testimony in court, Tuerkheimer (2017) for example, found that women consistently encountered an “enduring system of disbelief” that found their accounts to fall below the expected standard of ‘perfect’ witnesses and/ or robust evidence. Despite considerable changes in statute to protect and promote the rights of victims of sexual violence, this attitude of deep scepticism has, she argues, moved from the area of formal to informal practices that are deeply embedded in the U.S. legal system. This example illustrates the subtle but critical way that inconsistencies between different epistemic ‘systems’ operate and the silencing effect that they can have on individuals.

Fricker argues that the harm caused by hermeneutic injustices is multi-faceted and affects people at an individual and group level. However, for those knowers who cannot explain or understand important parts of their own experience to themselves, the harm is likely to be particularly pernicious and psychological. It may result in a form of psychological dissonance, as they seek to minimise, ignore or find alternative explanations for their experiences and feelings without sufficient internal or external epistemic resources (Fricker, 2007). Depending on one’s disciplinary perspective, this effort to develop understanding – when your experiences or feelings are not easily understood or in accordance with one

another – is described as coping, being in ‘denial’, or using a different set of heuristics (such as social or moral codes) to explain a situation (Origgi, 2012). Fricker emphasises that the hermeneutic context is constantly changing, because “our collective resources for social interpretation are not a fixed set of meanings, but rather a hive of hermeneutical potential, only some of which is communicatively realised at any given time” (Fricker, 2010 pp. 169). This fluidity, she argues, is a cause for hope and a motivation to work towards fairer and more transparent epistemic practices. It is also a reminder that people can shape, challenge and adapt their thinking and behaviour and that in turn affects the distribution of social power and resources.

Reflective note: Adopting and adapting Fricker’s theory

Fricker’s theory places the experience of individuals at its heart and seeks to uncover the complex nature of social experience. This is consistent with the approach I adopted during this project: to explore participants’ lived experiences of harmful behaviour whilst taking account of the inter-personal and social circumstances that shaped how they talked about and made sense of them. Moreover, Fricker challenges the idea that injustice only arises when prescribed rules are broken and an individual can be considered culpable for their behaviour. She illustrates how inaction, misinterpretation and ignorance - often arising as the result of social inequalities and structures - can cause harm at the individual and collective level. This ‘failure-first’ approach offers, I think, a way of cutting through the important but potentially unresolvable questions about the extent to which carer harm should be seen either as a ‘symptom of illness’ or an ‘act of abuse’.

There are nevertheless limitations and potential challenges in employing Fricker’s theory. Primarily, her work is a philosophical exploration of conceptual issues: it is not based on

empirical inquiry nor does it present a methodological approach to analysing empirical data. In addition, it is not a theory that will elicit or help to explain several, important features of the carers' accounts. For example, considerations of gender in the context of care, or inter-personal dynamics in family, intimate and abusive relationships. This could potentially undermine the descriptive power of the accounts and the valuable contribution of empirical, not just theoretically-informed knowledge (Thorne, 2010). Furthermore, Fricker's work focuses, primarily, on the experiences of individuals. She does not consider the epistemic practices and harms that arise within intimate and familial relationships and their attendant ethical norms and behaviour systems.

With this in mind, there are limitations to my analysis and different but similarly valuable approaches could have been adopted. Moreover, I am not arguing that epistemic injustice is the sole or even central form of harm that affected the women taking part in this study. As outlined in the interview findings chapter, the harm that they experienced related, primarily, to: feeling manipulated and controlled by their family member and was a result of experiencing the threat and incidence of physical and sexual violence, and, frequently 'witnessing' distressed behaviour and unpredictability when alone. However, Fricker's theory offers a robust conceptual approach to explore how and why carers may have felt 'hidden' and why other people were sometimes not able to see and hear their experiences well.

Application of the theory to the empirical data

In the following section, I draw connections between the carers' and practitioners' accounts and some of the central concepts in Fricker's theory of epistemic injustice. This is with the aim of surfacing some of the particular epistemic issues faced by carers in identifying, talking

about and understanding their experience of harmful behaviour: both to themselves and to other people. This foregrounds a discussion about some of the hitherto under-explored ways that harmful behaviour affects carers and how the theory of epistemic injustice helps to identify what carers need in the process of disclosing, exploring and recovering from experiences of harmful and abusive behaviour. To begin this discussion, I briefly discuss some aspects of the contemporary hermeneutic context that may shape the way ‘knowers’ and ‘listeners’ respond to accounts of ‘carer harm’.

1. Reconciling patient-hood, vulnerability and the intention to cause harm

As discussed in the literature review, because there is a link between the concepts of illness and patient-hood there is also a subtle but pervasive assumption that people who are ill or vulnerable in some way cannot instigate violence or abuse intentionally (Dixon et al, 2013). With this comes a release from responsibility for individual action in most legal or moral understandings of these terms. In the context of caring relationships, this implicit assumption makes it difficult to recognise the complex and fluid nature of power between adults. Rather it closely positions those with (any) care needs as having less power than those on whom they rely on for care (McDonald & Thomas, 2013). Yet understanding ‘vulnerability’ as an innate, stable characteristic can obscure considerations about how needs and risks vary over time, as well as in different social and inter-personal contexts (McDonald & Thomas, 2013).

This perspective on vulnerability – reinforced by legal and policy frameworks as well as cultural attitudes – may fail to recognise the relational and temporal nature of issues such as co-dependency and intimacy in adult relationships over the life-course (Daniel & Bowes, 2010; Dunn, Clare & Holland, 2008). It may also overlook subjective experiences of harm and abuse and the unique, highly individual ways that people cope and adapt to distress and

difficulty later in life (McKay, 2017): for example, when older adults choose to stay within a familial or social network that is both a source of comfort and meaning as well as a potential source of stress and exploitative or unequal relationships (Local Government Association, 2015). Critically, in the context of this study, the coupling of vulnerability and health and care need obfuscates consideration of how people can be both vulnerable and also have the capacity - intentionally and unintentionally - to instigate violence and to cause harm to another person.

Challenges putting harmful experience ‘into words’

All the carer-participants talked about their difficulties sharing their experiences of harmful behaviour. One of the central inhibiting factors was fear of being seen not to meet their family members’ needs and this would in turn warrant unwanted intervention of health and social care services. Acting on behalf of the state, professionals were widely understood to hold considerable decision-making power over what would happen to their family member including whether they should be ‘removed’ from the family home. Focus group participants were also cognisant of carers’ concerns about sharing ‘difficult’ information and the need to foster trust and to demonstrate empathic understanding to make carers more at ease sharing their experiences and exploring their options. Touching on a central theme in the research literature, carers also talked about the ‘sensitivities’ of sharing their experience because doing so evoked feelings of embarrassment, complicated feelings of disloyalty and a severing of relational trust. This highlights the importance of considering the emotional and relational heuristics that shape how people develop understanding and the ways in which they communicate, as illustrated by the following excerpt from Sarah’s account.

I feel disloyal talking about this... That’s the feeling that you have to understand (crying). That’s the feeling that inhibits you know, it inhibits you, because you feel guilty. Sarah

For some carers, however, it was simply difficult to ‘make sense’ of their experiences of harm. This difficulty was particularly evident amongst carer-participants whose caring experiences were either recent or current. In the context of the wider interview findings, it is credible to suggest that the sometimes chaotic, sometimes overwhelming nature of the caring experience contributed to participants’ difficulties explaining and reflecting on harmful behaviour. In short, it was not always possible, or perhaps even desirable, to ‘put into words’ the complex nature of caring and relational transition they were experiencing.

I mean I have never really gotten over the fact that he would rather kill himself than be with me... And no matter how logical and sensible I try and be, it's still there, it really is. I can't make sense of it, I can't talk about it. Christine

In addition, many carers were sensitive to the seemingly emotive and loaded connotations of the word ‘abuse’ and the predicating assumption that abuse took place only when a person intended to cause harm: this concern was also raised by the focus group participants. As discussed in the interview findings chapter, several carers talked about how their experiences were ‘not like’ domestic abuse. Instead they tended to focus, instead, on illness-orientated explanations for their family members’ behaviour and to highlight the moral imperative affecting their decisions about how and why they cared in the context of harm. Irrespective of the conceptual integrity of this reasoning, this nevertheless meant that language was a real and problematic issue when it came to talk about ‘carer harm’, as illustrated in the following comments by Sally and Mary.

So, do I fit into your box?... You see, this is my control thing. That you have this little box that I need to tick.... Whether I'm abused or mistreated; I guess I am, yeah but then, like I say, is it his fault? I don't know. I don't know. Sally

You can't, you can't... can you be critical of someone who is ill. It's not the illness but it is the effect that it has on you and I think that we need a word to describe the effect

on the person, on the care-giver, rather than then the service user being an 'abuser'. That's what I would like to try and find. Mary

Analysis of the carer-participants' accounts also found that their reasons for withholding information were because they were unlikely to be believed or taken seriously in the sense that carers recognised that being harmed by a person with care and support needs was an unusual if not improbable circumstance and did not 'fit' with ideas about older people, particularly those who were in some way ill or 'vulnerable'. In this way, they were sensitive to the paucity of conceptual or linguistic resources to describe the problem and reacted to this gap in knowledge by concealing and limiting what they said, as illustrated by Anita and Rose's comments:

And you think, I can't do it anymore but I can't say anything to her because she won't understand. I can't say anything to anyone, because if I told someone else then they would probably think that I was more abusing her than she was abusing me! Anita

Sometimes it is hard for me to talk about what has happened without becoming upset. Sometimes it surprises me how I react when I talk about things because I know them all so well. I think that I have to bury them, to hide them, so deeply that can be hard to know how it will be when I can share them. Rose

Reflecting on the carers' accounts, it is evident that there were myriad factors that made it difficult and uncomfortable, to communicate their thoughts, feelings and decisions about the harm they experienced. Indeed, it is striking that many of these factors were subtle and implicit, rooted in carers' expectations about how their testimony would be heard and their experiences, more generally, of being a female carer. This suggests that carers can be disadvantaged in both 'informational' and 'interpretive' exchanges about their family member's harmful behaviour. It also suggests that their epistemic practices were sensitised to their hermeneutic context; i.e. they were cognisant of the paucity of conceptual and linguistic resources they could employ to communicate their experiences and they recognised that this impaired other people's ability to understand their needs and circumstances. Fricker suggests

that hermeneutic injustice takes place when a significant part of a person's social experience is obscured from understanding owing to prejudicial flaws in shared resources for social interpretation (Fricker, 2007). This, according to Fricker, is likely to have had a negative psychological impact on individuals because it can compound feelings of confusion, anxiety and isolation. Furthermore, when individuals experience hermeneutic disadvantages, they may find it difficult to form meaningful associations with other people who have similar experiences and may be a source of social, emotional or political support (Fricker, 2006). Thus, hermeneutic disadvantages can impede the creation of epistemic communities which, in turn, contribute to feelings of isolation and social marginalisation: factors that may have affected carers at an individual level – compounding, perhaps, feelings of ambivalence and hesitation to self-identity as a carer - as well as mitigated against them sharing their experiences with peers and in more public fora.

Limited epistemic resources and opportunities within 'private' spaces

Several recent studies have utilised the concept of epistemic injustice to explore the way that people affected by illness can be disadvantaged and marginalised. For example, highlighting the systematic and implicit prejudices that make it difficult for people to explain non-observable symptoms (Blease, Carel & Gerharty, 2016), the complex nature of some types of psychiatric illness (Kyratsous & Sanati, 2016) and intellectual impairment (Kalman, Lövgren, & Sauer, 2016). These studies highlight how atypical epistemic practices are often misunderstood and can result in negative stereotyping and subtle processes of social marginalisation. Their focus is on the epistemic harm suffered by the person who exhibits these alternative epistemic practices: a trend mirrored in the literature reporting studies using epistemic injustice as a framework to understand gender, racial and cultural biases (Medina, 2013; Freeman, 2015). Reflecting, on the carers' accounts however, there may be a missing

dimension here: that of the people with whom illness is lived and navigated together. For those people who, in Rose's words are the "only witness" to their behaviour and, often, the main 'translator' and advocate for their needs.

In considering the epistemic dimensions of these interactions, carer-participants' accounts of feeling manipulated and controlled reveal the subtle operation of emotional and symbolic power and that this is an often-overlooked dimension of caring relationships. The participants talked about a range of behaviours that were experienced as controlling because they had a significant impact on how the women cared and how they lived: for example, because they had to closely monitor what they said and how they behaved or because they felt unable to negotiate or reason with their family member. Often, the interactions were subtle in nature; however, because they were cumulative and repetitive, participants identified that they led to feeling constrained or with limited agency. As the excerpts demonstrate, some types of manipulative behaviour were more explicit and extreme. Nevertheless, what these examples demonstrate is the misuse of emotional and symbolic power – whether intentionally-initiated or not – was a consistent feature of participants' narratives of feeling harmed. This type of subtle power was arguably complicated by the fact that family members were not able to remember when they were violent or abusive or to reflect or atone for their behaviour, as illustrated by the following excerpts:

There are times when he has grabbed me by the neck and held me down. And you can see his eyes are looking.... And he's trying to compute, is this the right thing? It doesn't stop him doing it but he does back off. And then, of course, it's always screaming at you. You know, it's your fault: you make me like this! Sarah

He will never say sorry that he did it. He will only say sorry that he was unwell. And he doesn't remember what he did but he remembers that he did something. But no, he's not good at sorry at all. It's the illness. Christine

As discussed in the interview findings chapter, for several carers, it was not clear why their family member struggled to discuss, acknowledge or reflect on their behaviour. Indeed, some carers questioned whether illness was sometimes used as an ‘excuse’ or a way of exerting control. Nevertheless, although this point was raised by several participants, they erred towards understanding their family member’s behaviour as being affected by their illness, as discussed by Jane and Anna:

I am in conflict in regards to Dad’s behaviour towards me. I know that there’s tension; I know that I’m anxious that he will go ‘vvvvoof’! Like he used to. But now Dad is being physical with carers, with strangers. So, I’m thinking I can’t be there to witness it and if I was there would Dad do that, would Dad be physical? Would the carers’ behaviour be different?... You know, I need some cameras in the room to see what’s going because I don’t know. Jane

There were just loads and loads of details that I could never work out that made it impossible to live a normal life...I don’t know any more. I’ve lost the sense, I’ve completely lost the capacity to see my brother and to see how much is illness and how much is part of his character. I guess I still choose to think that it’s completely the illness but I’m not sure. Anna

Jane and Anna’s comments touch on a theme that ran throughout the carers’ accounts, that of feeling uncertain about their ability to explain and ‘make sense’ of their family member’s behaviour. They also reveal the difficulties some carers faced reconciling their role as an advocate and protector for their family members with that of being the sole witness to acts and patterns of behaviour that few other people were in a position to see or to understand. From an epistemic perspective, this raises question about what kind of spaces – be they social, emotional or political – carers were afforded to think about and express their needs.

This lack of space and opportunity may account for why carers accounts tended to draw on ethical and relational heuristics (Origgi, 2012). Illness-orientated explanations may have helped carers to psychologically disengage from abuse and harm that was deliberate and/ or controllable because they helped to de-personalise the experience of violent or controlling

behaviour (Jackson, 2003). Similarly, by positioning themselves as advocates and protectors – carrying out a moral and personal duty – carers may have been less prone to feelings of powerlessness and that they were a victim of violence. On a related point, illness-orientated explanations are also likely to have reinforced gendered and socially-sanctioned ideas about the role of women to care and love in an unconditional manner (Morbey, 2002). Lastly, from a hermeneutic perspective, this reinforces the expectation that the needs of people who are ‘vulnerable’ in some way should be prioritised because, implicitly, people without health and social needs can (and should) be able to look after themselves.

Application of the concept of epistemic injustice to the data may provide alternative and valuable routes to understanding why illness-orientated experiences characterised the carer and practitioner accounts. It reveals that there may be a gap between how different types of harm and violence are recognised and this depends, in large part, on where they take place as well as who are the apparent ‘victims’ and ‘perpetrators’. Indeed, analysis of the carers’ accounts suggests that by failing to engage with the unique nature of epistemic spaces within people homes and intimate relationships (Lyon, 2007; Kittay, 2011), we may serve to further entrench the private and isolated nature of caring in the context of harm. This is because if people are not equipped to understand the cumulative and often psychological nature of harm – dimensions that are difficult to observe and to articulate - it may be difficult to appreciate the impact of caring for someone who engages in controlling or manipulative behaviour (Myhill, 2017). Similarly it may be difficult to understand the impact of living in a chronically unstable and distressed emotional environment: to understand, in short, the nature of living in a state of paradoxical intimacy. The gendered inequalities that underpin expectations that women adopt formal and informal caring roles (Barnes, 2011) *and* make them more likely to be victims of domestic violence and abuse mean that seeing and

understanding ‘carer harm’ requires challenging implicit assumptions about family life and the division between ‘private’ and ‘public’ spaces (Held, 2010; Kelly & Westmarland, 2016). This requires re-considering how carers’ testimony is heard and what resources health and social care practitioners can access in their encounters with carers and families.

Experiences of contingent and contested credibility

Feeling credible requires that a person is taken seriously and responded to in a meaningful way. Moreover, developing and maintaining credibility is a highly social and often performative process that is shaped by inter-personal as well as social-cultural factors (Fricker, 2007). Reflecting on the carers’ accounts, it is evident that a common source of tension and difficulty were their relationships and interactions with health and social care professionals. Some carers talked about needing to ‘fight’ and ‘battle’ to gain access to resources and to advocate on behalf of their family. They also talked about their feelings of frustration and anger at not being taken seriously and being ‘left’ to cope and to care with limited support, as illustrated by the following comments by Dorris and Rose:

He (Dad) had started to walk around with a knife in his pocket. And I’m telling them, the social workers, ‘no, this is not going to work! It’s not going to work for someone to be living here with him, it’s not safe!’ And then they (social workers) decided to come and they said about putting him in the respite for two weeks and I had to say, ‘no, no, no, that is not enough, two weeks is not enough to do an assessment!’ Dorris

I thought that they (professionals) would see what was happening and that they would acknowledge how difficult things were and try and help. But they didn’t do that. They didn’t believe us and they pushed us away. We kept going back for help but they kept pushing us away.... I felt so small and so frightened that they wouldn’t listen to me and couldn’t see how scared we were and that something awful, something that took one of our lives, might happen at any time. Rose

Other carer-participants characterised their interactions with professionals as being fleeting and fragile. They talked about not wanting professional support and facing difficulties accessing it when, they felt, it was most needed. In addition, several carers talked about

feeling that they were on the periphery of conversations and decision-making about their family members' care, as illustrated by Jane and Asrah's comments:

I'm floundering to establish relationships with all these transient personalities and their effects and all the energies that they bring in. So I'm trying to keep everything as calm and as collected as possible for my parents...and try to relate to people who are virtual strangers to me; respect them as professionals but know that I know my parents better than they do; not make waves but explain reality as it is in our house – not theirs'; and ending up, just so jangled up. I just don't know which emotion to feel for the best! Jane

It was always a case of people coming from the outside and saying "you're doing a really, really fantastic job, you're all kind muddling together and looking after him: fantastic, great work that you're doing". And that was it. They would just leave. And no one actually asked the question, "are you coping?" And that just made things so much difficult because that just was affirmation, particularly in my Dad's mind that "well, we're doing fine... I don't need that outside support". Asrah

Furthermore, the practitioners' accounts underline that they too recognised that there were challenges for them working with families affected by carer harm. As discussed in the focus group findings chapter, practitioners highlighted carers' reluctance to disclose 'sensitive' information; they also talked about being reluctant to initiate conversations about this topic, in part because they did not think the word 'abuse' was appropriate and in part because they were not always in a position to do something about problems that were brought to their attention. This was attributed, in part, to an absence of clear policy or practice guidance and, more generally, inadequate resources to support and engage with carers.

There is no formal guidance or accepted procedure for what we do to help keep carers safe. And I have had this concept in my mind before, when I have been on duty. And I have said, bloody hell, this person could be dead tomorrow but there is nothing there, there is no safety net. Jan (Adult social worker, Group 3)

I think that looking after carers, it is the biggest thing that we don't do well... by a long chalk. I think that we are good at a lot of thing... but I think that our thinking is limited. I wouldn't even ask my manager for certain things (for carers) because, well, it's almost unfair to ask her because you know that she will feel rotten by having to say no, we can't do that. Andy (Adult social worker, Group 2)

Andy's comment about how his thinking about carers was "limited" touches on another, more implicit, barrier to thinking and talking about carer harm: that of the organisational and inter-agency systems that shaped practitioners' ability to identify and respond to the needs of affected families. Analysis of the practitioner accounts identified that it was difficult for participants to work with carers in a supportive and timely way in a system orientated towards crisis intervention and predicated on meeting patient, rather than family, needs. Furthermore, practitioners recognised that carers could find themselves with limited power in interactions with health and social care services. For example, when an older person's needs were becoming increasingly complex and demanding yet did not meet the threshold for enhanced social care or continuing healthcare funding. Or, when a carer felt unable to disclose the full extent of the harm they were suffering because of fears about unwanted interventions and the loss of agency over how their family member would be cared for, and, perhaps where they would live until the end of their life. The professionals also highlighted how they felt constrained in their practice and were often waiting for and anticipating such situations before they could 'step in' and/ or support families. Professionals talked about how this meant they had to wait until situations escalated before they could intervene, despite 'knowing' or sensing that harmful behaviour was taking place.

While we're seeing a display of violence now, he (carer) had been seeing it build up for years. And now we're seeing what he has been experiencing for a long time but he was worried about saying anything because of the backlash from the community. He kept it all within him, because of the circumstances. I mean, I know that there were friends of his who started to see... When they were at the house one of them went to the bathroom with her (wife) and she attacked them, she was screaming at them and they said that they had never seen anything like it. But he just kept saying "leave her, leave her!"
Maggie (Dementia advisor, Group 4)

We have to screen things, as you can imagine, we have to prioritise. And we will say 'how are you? Can you wait for respite? How are you feeling? Can you wait two weeks for an assessment?' And if they say yes then they will be waiting for two weeks because there will be another person who has stomped their feet and said that they need a visit there and then. And that person who had agreed to wait two weeks will be constantly put back because they keep agreeing to be put back while other people jump

ahead until it gets to crisis point, which is really difficult. Katrina (Adult social worker, Group 2)

Maggie and Katrina's comments underline that knowing about 'carer harm' is a necessary but not sufficient condition for practitioners to identify and respond to affected families.

Moreover, although carers' relationships with professionals varied in their quality and consistency, carers had fewer opportunities to make decisions, to offer explanations and to be considered: in short to be systematically, rather than incidentally, considered a 'credible' knower. This epistemic disadvantage is all the more noteworthy given that carers are, by virtue of government policy and campaign efforts by a number of carer organisations, entitled to have their individual needs assessed and to be considered an 'equal partner' in decision-making about their family members' care and support (Department of Health and Social Care, 2018; Carers UK, 2015). That this does appear to be the case highlights that although carers' testimony is trusted and valued in some contexts, their needs are not consistently protected and addressed (Larkin et al, 2018). This is likely, Fricker would suggest, to compound distrust between individual carers and practitioners and to increase carers' feelings of fear and trepidation communicating their experiences (Fricker, 2006; 2007). Above all, it suggests the unequal and complex nature of the credibility economy in which practitioners and carers are likely to interact but not necessarily be able to listen meaningfully to one another.

Discussion: recognising and responding to epistemic injustice

The aim of focusing on the issue of being and feeling 'hidden' – a central, but by no means the most important aspect, in the carers' accounts – was to develop a better understanding of the ways in which carer harm may be more readily surfaced. Fricker highlights that developing understanding among people - particularly if they have different and unequal

social status - requires more than a common language. Rather, an epistemic environment in which trust, reciprocity, and shared meaning are developed is needed. This underlines the importance of conceptualising disclosure and help-seeking as processes rather than as events, significantly shaped by the quality and nature of the inter-personal dynamics between those who are 'telling' and 'listening' (Bradbury-Jones et al, 2015).

For the women in this study, experiences of harm were inseparable from those of care and later life. They were tied up with decision-making about residential and nursing home care, as well as anxieties about planning for the end of life. In short, they were imbued with relational and ethical meaning to the extent that these factors could overlay carers' ability to recognise – or communicate – the nature and impact of harmful or abusive behaviour instigated by their family member. This suggests that by sensitively opening spaces in which harmful behaviour can be explored, it may be possible to better understand the priorities, worries and the lived experience of care and illness in older age. Making it more visible, may in turn help to surface other, pressing, questions about how to better prevent situations of crisis and experiences of harmful, as well as abusive and neglectful behaviour.

Analysis of the practitioners' accounts also raises important questions about what epistemic resources other people have to see and hear carers' experiences. If they have irregular and limited contact, that this may inhibit the development of trusting relationships in which 'difficult conversations' can take place. Similarly, if people have partial knowledge or understanding of the psychological and emotional impact of caring and/ or the effects of violent or abusive behaviour, it is more likely that they will overlook indicators of harm in their early stages. Although practitioners' conceptualisation of carer harm as a private and moral issue was congruent and, in some ways, strikingly similar to that of the carers,

application of the theory of epistemic injustice to the data underscores the serious and negative unintended consequences of practitioners failing to question whether there are alternative and additional ways of engaging with the issue. Interpreting violent behaviour with reference to limited knowledge and conceptual alternatives has been found to circumscribe how practitioners think about and respond to domestic abuse (Mahon, Devaney & Lazenbatt, 2009) and it is reasonable to suggest that this is also the case in the context of carer harm. Furthermore, although the problem was recognised as a real and complex issue by practitioner-participants – i.e. it was not ‘hidden’ - they also identified constraints and limitations on their ability and opportunity to identify and respond, particularly in terms of carrying out preventative or rehabilitative work. These challenges were further exacerbated by the absence of formal guidance and were frequently impaired by lack of time and resources to work with families.

Interpreting the study data with reference to the theory of epistemic injustice highlights the critical role hermeneutic factors play in shaping individual and collective expectations about whether we will be believed, understood and protected by others and, in the case of health and social care professionals, the institutions they represent. Thus, it is critical that if we are to improve responses to carer harm, we need to do more than raise awareness of the issue amongst individuals who work in health and social care services. Responses need to take into account the legal, economic and organisational resources that make it possible for practitioners to see and to respond to ‘carer harm’ in a meaningful and timely way for affected families: in short, there needs to be consistency and clarity between legal, economic and organisational parts of the social and epistemic ‘system’ (Hooker, Small, Humphreys, Hegarty & Taft, 2015).

Furthermore, by drawing on Fricker's theory of epistemic injustice, it is evident that the framing of carer harm as a private, moral issue may reinforce the view that if adults have the cognitive capacity to make decisions, then they are free to do so. This elevates the status of logic and privileges the idea of individual autonomy in a way that is congruent with contemporary legal constructions of domestic and familial violence but may not attend to the emotional, relational and ethical heuristics that carers (and practitioners) deploy to talk about caring *and* harmful behaviour within caring relationships (Kittay, 2011; Barnes, 2012). Thus, improving responses to carers' needs requires an unravelling of some of the central concepts in contemporary law and policy relating to 'vulnerable' adults and the determination of capacity and choice in the context of harm and abuse, irrespective of its cause. Fricker's theory of epistemic injustice underlines the powerful role that inter-personal encounters can play in challenging social norms and alleviating some aspects of marginalised individuals' suffering: this offers hope and direction about ways to identify and respond to carer harm and these are discussed in more detail in the concluding chapter of this thesis.

Chapter 7: Methodological reflections

Chapter overview

The aim of the first section of this chapter is to identify, reflect on, and critically consider how, why and with what implications this study's work with an advisory network, as a form of participant involvement, played out. These reflections are shared in view of the limited guidance and lack of evidence about the role and operationalisation of advisory fora, despite their prevalence and popularity. I co-wrote a methodological paper with my supervisors on this topic (Isham et al, 2018) and the content of the first section of this chapter forms a substantial part of the published manuscript (see appendix 7). The second section of the chapter considers the ethical and methodological challenges and issues that arose in the process of recruiting and carrying out interviews with carer-participants about their experiences of harmful behaviour. This latter discussion is foregrounded in Sarah Banks' conceptualisation of 'everyday ethics', as pertaining to social work research and practice.

Engaging with the advisory network

1. Advisory practice as under-reported and under-explored

Across a range of disciplines, advisory groups are a common way of including people in research although there has been little critical discussion of their role (Mathie et al, 2014) beyond some notable examples in the field of children's research (McCarry, 2012; Moore, Noble-Carr & McArthur, 2016) and adult learning disability research (Porter, Parsons & Robertson, 2006; Lewis et al, 2008). Because advisors are not generally involved directly in decision-making with research collaborators, they do not have significant responsibilities or ownership of the research data and outcomes (Nind, 2014). Instead, advisors are understood to 'influence' decisions made by the research team. Moreover, although research proposals often indicate that an advisory group will work with a given researcher or research team, the

work they do is rarely subject to ethical or regulatory review. This indicates that advisory work is implicitly conceptualised as ‘outside’ or ‘additional to’ the research process (Gooberman-Hill, 2014). For several reasons, then, the work of advisory fora is often obscured from institutional and peer scrutiny (Mathie et al, 2014). This paucity of critical attention seems at odds with the investment and attention now directed towards more conventional forms of participatory and collaborative research practice. Yet, this is the most common type of involvement work and it is influential in shaping research questions, designs and outcomes (Mathie et al, 2014). Therefore, by making visible what this type of work ‘looks like’ – and being prepared to address the questions this raises about its value and role – knowledge and practice can be shared and developed.

Sensitive research and the inclusive research agenda

It is perhaps unsurprising that there is a close association between sensitive research and more ‘radical’ forms of involvement and collaboration. Broadly, ‘stronger’ or ‘radical’ participatory approaches conceptualise the experiential knowledge and subjective insights of lay people as equivalent, and sometimes more important than, knowledge developed by scientific or theoretical methods (Beresford, 2000). In such circumstances, the central, if not the only, purpose of the research is to develop knowledge that is driven by and useful to, stakeholders (sometimes called co-researchers or experts by experience). Thus, such approaches are intended to redress (to some degree) the inherent power asymmetry between academic and non-academic researchers in the design and conduct of research. Participatory approaches also emphasise conducting research with, rather than on or for, a group. One example is action research: the development of knowledge by members of a community about issues that are important to them and who benefit from carrying out research, either by developing skills and/or effecting practical change (Fals Boreda, 2001). Another example is

co-production research, where different stakeholders from different groups or communities collaboratively develop knowledge to address shared and clear objectives (Ramierz, 1999; Hewison, Gale & Shapiro, 2012). Broadly, then, participatory and co-production research seek to support, and sometimes empower, co-researchers to express their views and to have an equal role in decision-making pertaining to the aims and outcomes of research (Catalani & Minkler, 2010; Conrad, 2004 and Israel, Schulz, Parker & Becker, 2001).

Nevertheless, as the research community has developed more experience in involving participants in research, an informed, critical, agenda to improve it has also emerged. This is particularly the case in areas of sensitive research where ethical and methodological considerations are closely intertwined. For example, Bourke (2009) argues that it is overly simplistic to assume that power can be meaningfully recalibrated simply by sharing or devolving research tasks or processes. These seemingly benign practices may obscure wider power inequalities in terms of who benefits from and owns the knowledge produced by research. This raises further, potentially uncomfortable questions about how appropriate and meaningful some participatory projects are for those involved (McCarry, 2012). Moreover, it challenges us to consider how much their rapid rise is underpinned by a political and cultural requirement to appear ‘authentic’ rather than being methodologically coherent and responsive to the needs and objectives of participants and co-researchers (Gristy, 2015). In response, there have been calls to re-examine the ethical and methodological rationale of participatory and collaborative research. Nind (2014) for example, challenges the assertion that ‘more radical’ approaches are ‘more ethical’ and encourages researchers to consider whether other forms of participation are as, or more appropriate. Nind (2014) also suggests that practices along the involvement continuum have different strengths and limitations and that it is

incumbent on researchers to think critically and carefully about their use on a case-by-case basis.

In the following section, I discuss: 1) How the network evolved in response to ethical and pragmatic considerations 2) Challenges involved in discussing sensitive issues ‘outside’ of the participatory or participant context and, 3) Practical and epistemic issues involved in (not) ‘taking’ advice.

Engaging with the network

1. Establishing the network

Over a period of six-months eight people became actively involved in the network. Six advisors identified themselves as carers or ex-carers, one advisor identified herself as needing and receiving care and one advisor worked as a professional in older people’s health services. There were six women and two men in the network. I communicated with advisors on a one-to-one basis, by telephone, email, video-call and sometimes by meeting in person. The members of the network did not meet all together at any point. In terms of recording our actions, I made detailed notes of conversations and compiled a reflective diary about interactions and work with network members. Work with the network was also discussed regularly in meetings with my supervisors.

Summary of central characteristics
<ul style="list-style-type: none"> • Communication between advisors and the research team was asynchronous and flexible, according to the needs of each advisor. • The network ‘met’ using tele-conferencing or online fora. I shared feedback about the project anonymously between participants. • Advisors provided advice and/or shared experiences in a private and confidential space. I was responsible for identifying and recording points of consensus and difference. • As a result of the recruitment strategy and advisors’ access to communication technology, advisors came from a wide geographical area.

Text box 1: Central characteristics of the advisory network

Balancing pragmatic and ethical considerations

From the outset, I emphasised the confidential nature of taking part in the project and many advisors took the decision to use telephone and virtual communication as their methods of choice for liaising with one another and with me. Advisors may have felt that non-direct contact (e.g. email and phone calls) afforded time and space to consider how and when they engaged and that this in turn this may have increased feelings of confidence and comfort when communicating with me and other members of the network. In addition, for most members, it was not possible to travel or to commit time to attend face-to-face meetings regularly. This was due to advisors’ significant and ongoing caring commitments for family members. The advisors reported that the flexible, asynchronous nature of online communication, coupled with the ability to set up (and rearrange) when, how often, and in what way they communicated with me was a helpful aspect of working in a network. Given that caring for people with fluctuating, complex needs is demanding of time, emotional energy and is uncertain and stressful I decided that it was essential to facilitate practical ways of taking part in the project that took account of these pressures on carers (Horrell, 2015). Underpinned by principles of cooperation and partnership, it seemed axiomatic that advisors needed to have a meaningful degree of choice and control in how they worked and engaged

with the network. In addition, because advisors were located across the country (in part due to online recruitment) this raised challenges for me, in terms of setting up face-to-face meetings, as used in the more conventional advisory 'group' model. Similarly, although I offered to remunerate advisors for any expenses they incurred (e.g. for travelling), this was not enough in and of itself to mitigate the time commitment needed to attend such meetings. It became evident that coordinating an advisory network could be an appropriate, and perhaps even necessary, way of working with advisors.

Reflecting on the initial development of the network, I recognise that there are considerable advantages of drawing on more direct forms of engagement – such as holding group discussions or group exercises – in fostering creativity, critical dialogue and co-production of joint work. Indeed, these are all advantages identified by other researchers working with advisory groups (Lewis, 2008; Porter et al, 2006; Moore et al, 2016). The group environment can confer benefits when researching topics of considerable social or emotional complexity. With this in mind it is relevant to ask if, in using a network rather than a group approach, I forfeited an opportunity to develop 'deeper' discussions that may have enabled us to better identify the emotional and social needs of advisors. Certainly, I faced time and resource limitations that inhibited my ability to build the relationships that can support and empower some people to take part in 'sensitive' research (Dickson-Swift, Kippen & Liamputtong, 2007) and for some potential 'gatekeepers' to build trust in me as a researcher with 'outsider' status (Clarke, 2011). Nevertheless, the network evolved in response to the needs, preferences and social situations of the carers who wanted, and were willing to take part, in this study. As Aldridge (2014) suggests, social research with vulnerable groups – that explores issues of social sensitivity or complexity – presents ethical issues by "default and design". Thus, there was a balance to be struck between adapting the way advice was sought

and acted on – to promote inclusiveness and increase the comfort and control of advisors and participating organisations – without resorting to surface or tokenistic engagement that would undermine the ethical and intellectual rationale of the project.

Discussing sensitive issues ‘outside’ of the participant space

Because the research topic evoked potentially uncomfortable and emotive questions, it was important to take time to unravel (and re-consider) the words and concepts I used to talk about carers’ needs and experiences with advisors. I also needed to make clear why I was seeking to explore the lived experience (and subjective meanings) of carers affected by harmful behaviour and to assuage concerns that I was not seeking to hold either carers, or the older person for whom they cared, responsible for any violence, abuse or distress that had taken place. Thus, I sought to create a space to explore and understand advisors’ views and subjective understandings, as is congruent with the social constructionist epistemology underpinning this study. In addition, to ensure there was clarity about my responsibilities, I spoke with advisors about this issue several times and provided comprehensive written and electronic information about the project’s aims and scope, and their role (see appendix).

In terms of their input, some advisors focused on the technical and specific issues of research ethics and others were more concerned with issues of harm, violence, and caring. Those who offered valuable insights on both areas perhaps unsurprisingly tended to be more active members of the network, working with the project more directly. However, several advisors shared historic personal experiences of violent and abusive behaviour and/ or witnessing difficult and distressing behaviour on the part of close family or friends. The advisors concerned shared this information with me openly and unprompted at an early stage. Echoing research findings about the motivations of participants in sensitive research projects,

advisors said that they were taking part in the study because of these experiences, motivated by their concern that there was limited recognition of, and support for affected families (Clarke, 2010; McClinton Appollis et al. 2015). I was surprised by the candid and personal nature of these accounts and I was grateful to advisors for the emotional risk they took in sharing them. Nevertheless, I remained cognisant of my role, informing advisors about the likely outcomes and limitations of the research process, a point discussed in more detail later.

For some people, it is possible that taking part in the advisory network was preferable to becoming a research participant. Indeed, advisors may have been protecting themselves from being in a socially or emotionally vulnerable position by limiting the way they talked about their personal experiences (Gabb, 2010). However, although advisors initiated these discussions about their experiences willingly, I was mindful that talking about sensitive and personal topics had the potential to trigger negative emotions and that advisors may not have anticipated the impact of this (Newton, 2017). Working with research participants, there is an expectation that researchers inform people of the potential benefits and risks of taking part and check their understanding: indeed, this is integral to the process of obtaining and maintaining participants' consent (Wiles, Crow, Heath, & Charles, 2008). Moreover, there is an expectation that researchers can anticipate and address the risks of disclosure and respond to emotional and behavioural cues to minimise unnecessary distress or discomfort (McClinton Appollis, Lund, de Vries, & Matthews, 2015). Yet there is no clear guidance for how such issues should be managed with advisors. In this project, I sought to recognise and support advisors' welfare needs, when appropriate, by drawing on skills in reflective listening and attention to non-verbal cues and emotion-focused communication, developed in large part during previous employment as a case worker and social worker. I also discussed any

concerns about advisors' needs and the nature of their involvement in supervision meetings regularly.

Reflecting on how advisors sought to share, disclose and sometimes limit how and what they talked about in relation to harmful behaviour, I could perhaps have anticipated that some people would share personal experiences. Indeed, the lack of formal guidance or reporting about advisors' potential welfare needs may indicate that most researchers – particularly those who have expertise researching sensitive or complex social issues – manage these issues subtly and intuitively. They draw, in effect, on their knowledge and skills working with participants. It may therefore seem unnecessarily prescriptive, perhaps even pedantic, to call into question whether there is a need for critical and practical guidance for researchers working with advisors.

Nevertheless, this lack of attention reflects the wider point that because the work of advisory fora is infrequently recorded or analysed, it receives less scrutiny and is afforded less practical and symbolic value. In addition, there is likely to be a wide range of researchers – from novice to expert-, from different social and health-related disciplines – who are working with advisors as part of sensitive research projects. In the contemporary literature, it is difficult to assess what the advisory fora landscape is, the complexity of ethical or welfare issues involved and how frequently they arise. This makes it difficult to ascertain how researchers go about identifying and supporting advisors and the extent to which this work overlaps with the more visible and formalised practices of working with research participants or co-advisors, particularly those with complex or additional needs. Relying on the researcher's integrity and 'intuition' may mean that advisors do not always benefit from the same level of protection and support that participants in research are afforded.

Taking advice: managing different views and interpretations

I wanted advisors to express their views and ideas, particularly if they differed from my own. Indeed, it was of great practical and intellectual benefit to have the time to discuss and consider the project with advisors. Their contribution was vital in challenging my thinking and informing practical amendments to the project. Advisors also surfaced critical questions about the proposed approach to engaging with participants, as well as some of my latent assumptions about carers' understanding of issues such as confidentiality and anonymity. For example, advisors emphasised that people would be discouraged from taking part if there was a perceived risk that their participation might lead to the involvement of statutory health or social care services in their life. Although I had considered this issue, I had not anticipated the degree to which the prospect of intervention by statutory services - and the threat of having a loved one 'removed' from the family home – would be an ethical and practical issue. Cognisant of this pressing concern, I took time to explore and explain the rationale and limitations of confidentiality with advisors and to communicate this clearly in the participant-focused literature.

Advisors also challenged my aptitude to assess participants' suitability for involvement in the project and the level of follow-up support available for participants if they experienced negative effects after taking part in an interview. In fact, on the matter of participant welfare, the advisors scrutinised the proposals in more detail than the formal research ethics review panel. I believe advisors' experiential knowledge, combined with the proxy role of advocate they assumed, conferred a degree of symbolic capital and prescience on their advice, particularly in matters of participants' welfare (Locock, Boylan, Snow & Staniszewska, 2016). Rightly or wrongly, many advisors identified themselves as being similar to, or able to talk for, potential participants: in short, they identified themselves as part of a social group

or community, however displaced and tentative, of family carers or people who knew about the needs of family carers. This highlights how concepts of ‘vulnerability’, ‘and ‘being marginalised’ can be shaped in a range of research (Aldridge, 2014). In turn, it may be helpful for researchers to consider how they will seek to capture, and manage, different types of contribution – be they foregrounded in experiential, subjective or empirical understanding – on such matters (Bray & McDonnell, 2012).

There were some differences of opinion between the advisors and me about the focus and impact of the project. This raised questions about how I could best identify and address the expectations and needs of network members. For example, several advisors rejected the suggestion that older people who were unwell could be abusive or harmful in their behaviour. These advisors suggested that the project’s focus should be on investigating the causes of carer breakdown and stress and, in particular, how inadequate or inappropriate support from health and social care services was the ‘real’ issue at hand, not harmful behaviour by the individual older person. In addition, some advisors reported they wanted to have the ‘truth’ told and to speak up for other carers in light of their own negative and distressing experiences with health and social care services. I became concerned that some advisors had unrealistic expectations about what the project could achieve and that this was the motivation for their involvement. This was at odds with my own more modest expectations about the study’s likely impact. To address this, I had discussions with advisors about the probable outcomes of the project. This involved being open about the fact that the impact of research on practice and policy is often more limited than the public assume, and researchers would like it to be (Nicolini, Powell, Conville, & Martinez-Solano, 2008). I learned from this episode that open discussion of objectives at an early stage of the project may have played a more central part

in developing a shared agenda for working with advisors, including explanation of the type and nature of knowledge being developed.

I acknowledge it could be questioned how confident advisors felt to challenge me on key issues in the study, given my role (and power) as a ‘professional’ researcher (Porter, et al., 2006; Aldridge, 2016). However much I sought to address this in my interactions with advisors and commitment to partnership working, I recognise that these inter-personal dynamics are relatively superficial in terms of recalibrating decision-making power and ownership of research outcomes (Karnieli-Miller, Strier & Pessach, 2009). If anything, the asymmetry between symbolic and decision-making power is particularly significant in advisory group fora given that there is no formal expectation that the work of the network will be shared and reported publicly. I also accept that some of these tensions touched on fundamental differences about what knowledge is and what is valuable to know – i.e. they had an epistemic dimension. How to reconcile these issues is a long-held and important area of debate in co-production and involvement research, particularly when working with ‘vulnerable’ or marginalised populations (Bray & McDonnell, 2012). It overlaps with questions about who ‘owns’ and influences the outcomes of research, and the attendant power dynamics such distinctions or partnerships can engender. However, such philosophical and ethical issues are another under-explored dimension of debate and reporting on advisory fora.

Discussion

Although sensitive research is generally aligned with more ‘radical’ forms of participatory and collaborative practice, advisory fora – and, specifically advisory networks - offer a useful and sometimes more appropriate form of inclusion and engagement for some advisors and for some types of research study. This is not to suggest that advisory networks are a more

appropriate way of soliciting feedback and evoking discussion than advisory groups, or any other form of involvement practice. Rather, advisory networks offer an alternative approach that can be used alone or in conjunction with other mechanisms for feedback, fieldwork, and co-produced activities. They are one way of facilitating participant involvement.

When investigating ‘sensitive’ issues and working with vulnerable or marginalised groups, carving out meaningful opportunities to reflect, learn and collaborate is of practical, ethical and conceptual value. It takes time to build enough trust to foster relationships between researchers, individuals and groups, particularly if these interactions and encounters are shaped by structural imbalances in social power and status. It was my experience that working with advisors using a network approach offered some helpful ways of addressing these issues. For example, the asynchronous nature of communication between researchers and advisors made it possible for a range of people from different social backgrounds to participate in the research project. This created opportunities for personal disclosures and reflective discussions. Moreover, the iterative nature of exchange between advisors and me was a catalyst for practical and conceptual adjustments to the project. This helped to bring about new ways of collaborating in the design and development of the study. The network approach may also provide a practical way to carve out confidential, less formal, spaces in which people feel more comfortable to contribute to sensitive, often ‘hidden’, research topics.

In addition, when investigating under-explored social phenomena, researchers need to remain open to nuance and detail: to idiosyncratic themes and ideas that may, when integrated with other information and theory, have interpretive meaning. Taking time to notice and attend to small, often subtle details about how people talk and understand an issue, as well as to step back and notice what is not said or expressed, can help to identify some of the ways that

sensitive issues become or remain hidden. In turn, this means that researchers may need to tolerate uncertainty to make more informed methodological, design, and analytical decisions that better reflect and attend to the complexities of the phenomena under investigation. In short, field work, collaborative discussion and exploratory design work tends to take longer but can be valuable in shaping the aims and agenda of the resulting research study (Vaswani, 2018). Working with advisors in a network forum can create useful opportunities for this type of respectfully curious work. The relationships and interactions in the network developed over time and the shifting roles raised some ethical questions, however they also underscored the different types of advice that people ‘gave’ and the need for me to adopt different ways of ‘taking’ their contributions on board. This underlines how context-specific advisory roles depend on the nature of the research project (Cornwall, 2008). It also highlights the importance of researchers carefully considering their approach (including their conceptualisation of advice as knowledge) when establishing and reporting on work with advisory fora in a sensitive research context.

Despite the benefits, there are several limitations of the advisory network approach. One key concern is whether non-direct communication methods are adequate – when used alone – to foster a relational and emotional context that fosters ‘deep’ discussion of sensitive issues, albeit with a focus on research design. In addition, working mainly through one-to-one exchanges reduces opportunities for advisors to engage in collective discussion that may be more organic, socially stimulating and potentially affirming or empowering. These are important ethical considerations, particularly when considering the needs of people who are in some way ‘vulnerable’ or marginalised from some forms of social participation and inclusion. Researchers therefore need to be cognisant of the balance to be struck between ensuring a responsive approach to advisors’ individual needs - based on their preferences and

wish for anonymity - with that of creating a disjointed and solitary experience for them. One way of addressing this is to establish mechanisms for both individual and group contact from the outset. Because my early efforts were focussed on recruiting advisors to work in ways that were acceptable to them, I gave less attention to establishing mechanisms for group interaction. In addition, and on a practical point, because the network relied on online, telephone and video-call communication methods, it may have excluded people without the means or inclination to use these technologies. In turn, this may have compounded age and educational biases about who takes part in and who shapes research. Although there has been a considerable shift in access to and familiarity with these communication methods – that foster greater opportunity for advisory networks than a decade ago – the needs of potential advisors must always be the key factor determining which approaches are used.

Perhaps one of the most important considerations about the future relevance and development of the advisory network approach is whether researchers (and advisors) can begin to shift the cultural expectations about what is considered valuable and worthy of reporting. This will be difficult to achieve if the development and presentation of empirical and theoretical findings remains the main element of research that is reported (Gooberman-Hill, 2014; Gillard, 2012). This serves to obscure the contribution of those involved in the work and the under-reported and ‘hidden’ realm of work of advisory fora. Moreover, these limitations restrict the impact of research on sensitive or complex social issues, for the reasons discussed already.

Reflections on future directions

There were limitations and problems working with an advisory network and I hope that by sharing them in this chapter, other researchers will be able to build on our learning (see Text Box 2). The network played a central role in shaping the research project and it seemed

important to meaningfully acknowledge the contribution of its members whilst maintaining their anonymity in accordance with assurances given. I recognise that by sharing the experiences of one network and one study, the recommendations put forward are tentative. Moreover, the relevance of the network approach will vary from study to study, depending on the research question and population from which the advisory network is drawn. This points to future opportunities for innovation of the advisory network approach and critical commentary about its methodological and ethical implications.

To this end, my supervisors and I co-wrote a methodological paper that discussed the practical changes and ethical issues raised here (see appendices for the published manuscript). The aim of which is to encourage discussion about what researchers and advisors are doing, what is working well and what needs further practical and conceptual development. We suggest that advisory networks provide opportunities for different, more iterative, types of exchange and influence between advisors and researchers during a project. This brokering of different forms of communication is the central characteristic of all types of involvement and we do not advocate that advisory networks supersede, or are incompatible with, other forms of advisory fora or participatory practice. However, we think that the network approach is of relevance and value to advisors and researchers exploring sensitive and complex social phenomena. It is one of a range of approaches on the continuum, referred to earlier, that can be used to good effect in areas of sensitive research (Nind, 2014). Nevertheless, for advisory groups and networks to be better acknowledged and more critically developed, researchers need to make time and space to think about how they describe, share, and, conceptualise their work. This echoes recent recommendations that there needs to be more consistent and critical reporting of participatory and collaborative research (Staniszewska, et al. 2017), and the role of advisory fora.

Summary of key learning points

- Advisory networks provide a flexible and appropriate space to discuss ethical or socially sensitive topics because communication with the research team is private and confidential. Critically, advisors can determine the nature and degree of their involvement with the research team. This may lead to additional or alternative forms of involvement in the wider project, as relationships between advisors and researchers develop over time.
- Advisory networks provide a means for people who cannot, or choose not to, take part in more direct and formal advisory fora to shape research design and development. This may lead to new insights and increased sensitivity to the needs of people who may benefit from, or be affected by, research on ‘hidden’ or ‘sensitive’ topics.
- If advisory networks do not include any face-to-face communication (whether online or in person), it is questionable how appropriate they are for the discussion of ‘deeper’ (emotionally or ethically sensitive) topics. Depending on the individuals involved, they may also limit advisors’ opportunities for learning and social inclusion. These are important considerations in the context of research with marginalised or ‘vulnerable’ groups.

Text box 2: Key learning points: advisory networks in the context of ‘sensitive’ research

Recruiting and interviewing carers

In this second section of the chapter, I reflect and consider critically some of the central ethical and methodological issues that arose during the process of recruiting and interviewing participants. The discussion also considers how my status as a social worker and a novice researcher influenced my decisions about the ethical, practical and methodological issues of the project.

Background

1. Ethics and reflexivity in the context of ‘sensitive’ research

As noted earlier, much sensitive research is underpinned by an ethical and intellectual commitment to develop new forms of knowledge that challenge traditional ways of knowing and exercising power, thereby giving credence to marginalised experiences and enabling hidden issues to be better heard and seen (Mantoura & Potvin, 2013; Bradbury-Jones & Taylor, 2015). From an ethical perspective, researchers need to be attentive to participants’ welfare in a holistic sense, considering their individual needs, circumstances and ability to make informed and critical decisions about the potential harms and benefits of participation. Researchers also need to be cognisant of the subtler power differentials that structure their encounters with participants (Serant-Green, 2011). This is because making time to think through, discuss and address these issues from a reflexive perspective can help develop a more reciprocal and transparent framework for participant and researcher exchange (Fawcett & Hearn, 2004). On a more pragmatic note, sensitive research often requires careful planning that can be time or resource-intensive: for example, to identify and meet the needs of participants with developmental, cognitive or physical impairments or to develop trust and rapport with ‘gate-keepers’ when researching a sensitive topic from a position of ‘outsider’

(Berger, 2015). Thus, researchers need to be mindful of the ethical implications of every aspect of the research process, from the inter-personal to technical to analytical.

The iterative and often unpredictable nature of qualitative research can make it difficult for researchers to anticipate the issues that lie ahead (Probst, 2015). This can lead to difficulties assuring research ethics and governance boards that the dynamic, creative nature of qualitative research is not a proxy for uncertainty and imprecision (Gabb, 2010). In addition, when exploring issues affecting people with additional needs, researchers' assurances of professional competence and critical discretion is, increasingly, not considered an adequate safeguard for institutions charged with protecting 'vulnerable' individuals from all forms of potential harm (Parker & Ashencaen Crabtree, 2014). Furthermore, exercising reflexivity is not in itself a sufficient measure to address the real practical and structural issues that can arise in the context of sensitive research (Pillow, 2003). Critics suggest that writing reflexively is too often mistaken for acting reflexively - i.e. making changes to the conduct of the research process *as the result of* new insights. When this critical link is absent, reflexivity is unlikely to have much social or practical value to 'vulnerable' research participants or co-researchers or do much to challenge how, and with what influence, research knowledge is developed and shared (Finlay, 2002).

'Everyday ethics' in social work practice and research

Prior to starting my PhD, I spent several years working in a sexual assault centre and a homelessness service before qualifying as a social worker and moving into the field of child protection and 'looked after' children. As a novice researcher, moving from direct to research-orientated practice, I at times struggled to recognise and articulate my epistemic approach and its relationship with the various ethical and practical challenges I faced. I also

came to recognise limitations about the extent to which this knowledge and experience was transferable to the context of research practice. In the following account, I will draw on the work of Sarah Banks, a social work practitioner and researcher to situate my methodological reflections on the interview process within a clear reflexive framework (Berger, 2015; Finlay, 2002). Banks conceptualises ethics as an ‘everyday’ practice because ethical issues are inherent in all human interaction (Banks et al., 2013; Banks, 2016). She suggests that researchers need: 1) To be sensitive to the ethically salient features of all aspects of the research process. 2) To ‘embody’ the inter-personal qualities that promote the welfare of participants and seek to minimise the asymmetric power dynamics of the research encounter and 3) To be sensitive to the social and historical context in which interactions take place. Banks also encourages researchers to share and reflect on the ethical aspects of their practice and to make greater use of case studies and contextualised examples.

In the following account, I discuss: 1) The challenges and unexpected opportunities that occurred when recruiting participants as an ‘outsider’. 2) Maintaining a responsive and participant-centred approach when engaging with participants and 3) Recognising the ethical as well as methodological dimensions of decisions about how I analysed and shared the interview (and focus group) data. Following Banks’ (2013) model, I draw on two case studies to ‘bring to life’ some of the practical, ethical and methodological challenges I encountered.

Methodological reflections

1. Recruiting participants as an ‘outsider’

Recruiting participants was a slow and challenging process, characterised by the somewhat fragmented nature of negotiating time and space to discuss the project with gatekeepers and

potential stakeholders. Interview recruitment took place over a fifteen-month period and ran concurrently, in the latter months, with designing and recruiting practitioner-participants for the third empirical stage of the study. It was therefore an example of the non-linear nature of qualitative research that tends to characterise work with so-called ‘hard-to-reach’ or ‘vulnerable’ populations (Berger, 2015; Aldridge, 2014). It also highlights that exploratory studies frequently necessitate extended periods of fieldwork - to develop working relationships and a shared agenda for engagement with stakeholders and participants and to respond to emerging critical, ethical and methodological issues - both factors that can be overlooked in debates about rigour and quality in qualitative research (Vaswani, 2018).

In the main, I contacted potential gatekeepers on an individual and unsolicited basis: for example, making telephone calls and sending emails, contacting named professional after a colleague had given permission and/ or a recommendation to do so. Initially I had considered that this might be an appropriate method of ‘reaching out’ to carers in different circumstances and from different demographic backgrounds. I posted information about the project on a national database that connects academic and clinical researchers with patients and carers who are interested in taking part in research as collaborators or participants (www.invo.org.uk). I also shared information with carers’ organisations, informal patient and carer networks, advocacy organisations and non-specialist community and voluntary agencies. In addition, I developed a suite of recruitment materials to share with people and an independent project website (see appendix 1). The aim of these actions was to offer a space for potential participants to access more detailed information about the project in a confidential manner. In total, I had discussions with approximately seventy services and networks, of which sixteen agreed to share information about the project.

Nevertheless, I had not anticipated how reluctant caring organisations would be to share recruitment materials in any face-to-face forum or for me to talk directly with prospective advisors. Many services were concerned about the potential sensitivity of raising the issue of harmful behaviour with carers and their family members. Some service representatives reported that harmful behaviour and/ or domestic abuse was not ‘within the remit’ of their service and therefore the issue never came up in their work with clients. Other services highlighted this was a ‘safeguarding issue’ that could (and perhaps in their view) should be a matter only for social services. When agencies/organisations did agree to share information about the project, they emphasised the importance of doing so discreetly. They chose, for example, to distribute recruitment materials by email or website postings or relaying information to service users through established groups or meetings, rather than putting up posters or taking up my offers to speak at meetings and events. In addition, during the last six months of the project, I also carried out recruitment with a local NHS trust. This required applying for ethical permission from the Health Research Authority (HRA) and a local NHS ethics governance board in addition to my initial University ethical approval. In turn, I sought to establish contact with six NHS teams, in the first instance, to share information about the study. Despite having ethical permission and a letter of support from the Trust, accessing NHS staff proved to be a challenging process and I recruited only one carer-participant from this organisation.

Throughout the recruitment process, I regularly discussed emerging issues and sought guidance from my supervisors. They highlighted the value of adopting multiple and concurrent recruitment methods and this gave me confidence that although there was an unpredictable and tentative nature to the recruitment process, there was a sound methodological and ethical rationale for working in this way. Thus, the recruitment process

raised my awareness of people's diverse views about the status and value of research and the difficulties of establishing working relationships without a shared understanding of different parties' roles and objectives. Regardless of how willing I was to engage in discussions or to provide additional (written) information about the project, I had to obtain permission to do so in a relatively ad hoc and opportunistic manner. Perhaps more importantly, I needed to do this on a continuing basis. In practical terms, negotiation and compromise characterised my initial encounters with gatekeepers and I quickly came to realise that I had little influence on decisions about whether and how I could share information about the project with potential participants (Roesch-Marsch, Gadd and Smith (2012).

My position as an 'outsider' placed me in new, valuable spaces on the peripheries between academia and practice and helped me to see the issues of harmful behaviour from different vantage points. For example, I began to consider how structural and contextual factors shape how some types of distress and suffering are visible (or not) in public and 'private' spaces. It also highlighted the existence of 'gaps' and tensions between different forms of knowing and knowledge from a research, practice and participant/ service-user perspective.

The interview process: maintaining a participant-centred approach

Due to the ad-hoc and contingent nature of the recruitment process, potential participants contacted me independently and at a time of their choosing. In turn, the nature and duration of our communication varied considerably. In my conversations and initial meetings with participants, I took time to address what harmful behaviour might mean or 'look like'. Cognisant of the advisory network's guidance on this matter, I was aware that participants may have had concerns that disclosing harmful behaviour could be considered akin to suggesting that they needed protecting from their family member and/ or that they were

unable to manage their care needs (Ayers & Wooditi, 2001). Thus, I advised people to think about what they wanted to discuss during the interview and outlined what I would ask them. By taking time to prepare and negotiate the terms of our meeting, I hoped to minimise any sense of surprise or unfamiliarity experienced by participants and to enhance their sense of agency over what and if they took part in the project (McClinton Appollis, Lund, de Vries & Mathews, 2015). Nevertheless, I recognise that this did not significantly recalibrate or equalise our relationship as I could misuse my privilege as a listener at any point: implicitly, by failing to notice cues of distress or discomfort, or more explicitly, by encouraging emotional disclosures that result in ‘powerful’ data (Karnelli-Miller, 2009; Dickson-Swift, 2009).

Some participants chose to meet in person before the interview. On meeting, some people took the time to show me around their homes and shared photographs of family members. It was my impression that for some of these participants, understanding their home environment was part of sharing their experiences. It may also have been a way of communicating important information about the place in which harmful incidents had played out and aspects of their current and past family life (Gabb, 2010). Other people did not want, or could not afford, to develop this degree of familiarity before the interview and several participants approached me with a clear account of their reasons for taking part in the project. From the outset, these women identified what they would talk about during the interview and that their reason for doing so was to help others in a similar situation, as do many research participants (Clarke, 2010; Newton, 2017). In addition, such a strategy may have helped participants limit the risks of ‘over-disclosure’. Thus, I was often unsure about how exchanges with participants would develop: how long they would last, how often I would meet and talk with them and, critically, what would be discussed (Newton, 2017). Indeed, five potential

participants – with whom I spoke and met several times – chose not to take part in an audio-recorded interview. Having spoken as much about their experiences of harmful behaviour and distressing care as they wanted and/ or felt able to, they perhaps no longer had need or motivation to revisit these discussions in a recorded interview.

This sense of ‘not knowing’ and needing to adopt a responsive, participant-led approach required a degree of time and critical attention that may be less common in ‘non-sensitive’ qualitative interviews. On reflection, I think that my experience of working with so-called ‘hard-to-reach’ clients helped me to feel relatively comfortable in this role (Drake, 2014). Drawing on principles of motivational interviewing and strengths-based therapy, I recognised the importance of ‘leaning in’ and ‘listening afresh’ to signs of emotional and relational meaning, that might not be expressed through verbal communication (Béres, 2017). Drawing a parallel with skills in sensitive research, this requires a blend of both reflexive and non-verbal communication skills (Dickson-Swift, et al, 2007). Indeed, Miller and Rollnick, the originators of motivational interviewing, conceptualise their work with clients as one of a ‘dance’ in which the practitioner takes neither the lead nor the role of follower (Miller & Rollnick, 2012). Rather, it is critical that both people are in-step with one another. This expresses a willingness to cede conventional forms of professional autonomy and ‘expertise’. It can also help to foster trust and rapport between client and practitioner that enables potentially uncomfortable, distressing or difficult issues and feelings to be explored and, to this end, the therapeutic and research process share common ground. Nevertheless, as discussed, in the research context, interviewers need to be aware of the time-limited nature of their exchange and the extent to which they should ‘open up’ issues that they are not able to support participants to manage and explore beyond the research encounter (Chan et al, 2017).

In the following section, I share two examples of engaging with interview participants – Asrah and Rose – to illustrate some of the challenges and benefits of adopting a responsive approach (Banks, 2013) in the context of carrying out research on a ‘sensitive’ topic. Just as Asrah and Rose’s needs and circumstances were unique, so too of course, were each of the seventeen people whom I engaged with who identified as experiencing harmful or abusive behaviour, twelve of whom went on to take part in a recorded interview. Given the complications and practical demands involved in establishing contact, trust and a shared professional agenda with NHS, local authority and voluntary sector organisations - in their capacity as recruitment ‘gatekeepers’ - and with study advisors, the following case studies are another example of the iterative, careful nature of engagement that ran through the different ‘layers’ of the study, prior to the development of empirical data.

Case studies

Asrah

Asrah contacted me by email, expressing an interest in taking part in an interview. I asked if she would like to talk on the phone or to meet in person to discuss what taking part would involve and to find out some basic details about her personal circumstances. Asrah was keen to meet in person and to do so soon. When we met, she seemed to have a good understanding of the project, indicating that she had read the participant materials and, perhaps, the website. Asrah was an academic staff member at a university and clearly had a detailed understanding of research methods and ethics.

When we met, Asrah talked in detail about her relationship and experiences of caring for her father. However, Asrah said that she wasn’t sure if she ‘fit the box’ of harmful behaviour and that it would be useful to talk about her situation. I suggested that it might be difficult to talk

about these issues now and again in the interview. However, Asrah said that she found it helpful to talk things through and reiterated her worries about not being the ‘right’ kind of participant. During our discussion, Asrah said that she had felt manipulated and controlled by her father and at the same time felt guilty and conflicted for saying so, as she understood her father’s behaviour to be the result of his illness and without intention to harm her. Asrah said that she had been ‘very frightened’ about her father harming himself and that she felt compelled to do ‘whatever he wanted’ and to continue to be his primary carer despite changes and competing demands in her personal life over many years. Asrah described how she had felt both hurt and harmed during her caring experiences.

I was concerned that that this was an emotionally tiring and troubling conversation for Asrah. I suggested that I write up the conversation and that she could add or edit it accordingly. Asrah was clear that she wanted to take part in a ‘proper’ (recorded) interview. Given what I knew about Asrah’s circumstances and her presentation, I considered that it was her decision to make. When we met for the second time, we talked for two hours whilst the recorder was on, and about an hour afterwards. This time, Asrah talked very little about harmful behaviour and didn’t repeat the examples that she had shared before. Her focus was on exploring the difficulties navigating the complex dynamics in her family and her feelings of sadness that fewer members of the family had recognised the stress and dilemmas that she has experienced. It was my opinion that, for Asrah, talking about her experiences as a carer – on that day, with me – had taken a new or additional focus and that thinking about ‘harmful behaviour’ was not a particularly useful or meaningful exercise for her and I drew only on this second account in the process of analysis. Nevertheless, I was conscious I could not forget what Asrah had told me previously and that this may have shaped the way I interpreted and explored her second account. It also underlined the contingent nature of the interviews.

They were valuable but partial representations of the women's feeling, thoughts and understanding about their experiences of care and harmful behaviour.

Rose

I met Rose during a group meeting with a carer advocacy organisation. Rose introduced herself to me and asked if we could speak privately. Rose seemed surprised about the idea of our conversation being recorded and it was my view that she had no or limited understanding about what taking part in an interview entailed and the possible implications of doing so. Although Rose said that she agreed to the interview being recorded, I felt uncomfortable about whether she had had the time and information to make a considered decision. It later transpired that she had read all of the participant information.

I decided during those, initial moments that it was not appropriate to record and that consent could not be meaningful in this situation. Although I said this to Rose, she continued to talk about her experiences of caring and of harmful behaviour with great clarity and emotion. I began to realise that Rose wanted to talk about these issues, whatever the status of this conversation, whoever she thought I was. Rose went on to disclose experiences of psychological harm and sexually aggressive and inappropriate behaviour by her husband. She also talked at length about the challenges she faced getting professional recognition and support to manage her husband's complex needs.

Almost as soon as I left this meeting, I doubted my decision not to record my conversation with Rose and to accept at face value her indication that she was comfortable with it being recorded. Discussing the issue with my supervisors, I reflected that Rose came to meet me knowing that I was carrying out a research project and to talk to me about her experiences of

harmful behaviour. In turn, I began to question whether my decision reflected an emotional response on my part: an anxiety borne from not feeling prepared to hear Rose. I also considered whether I had confused Rose's emotional distress with signs of emotionally vulnerability. Perhaps, it is reasonable to say that I couldn't make an informed assessment of the nature of her consent to take part, particularly without knowing more about Rose's personal circumstances and history.

My supervisors encouraged me to think more critically about the tacit and fluid ways that consent is 'given' and brokered on an ongoing basis rather than as a discrete or one-off event. This helped me to recognise that although a clear indication of 'full' consent was not present at the outset of my meeting with Rose, our subsequent conversation illustrated that this circumstance may have changed. We discussed that it was only possible to make such a judgement in partnership with Rose. Thus, I contacted Rose and asked her how she wanted her account to be heard.

I was hesitant about the idea of holding a second interview and instead suggested developing a written summary of the conversation that Rose could review and edit. When I contacted Rose, she welcomed this idea. We spent the next six weeks talking and co-editing an extended written account of her experience as a carer and as a carer affected by harmful behaviour. The account was in large part based on our conversation; however, Rose was keen to add information and played a lead role ensuring that the tone and message of the account was as she wished it be. As the weeks passed, I was left in little doubt as to Rose's capacity and informed consent to take part in the project. Nevertheless, the experience also raised critical questions, for me, about the different types and, perhaps, 'depth' or 'quality' of

consent that researchers develop with participants and the extent to which this shapes the information that is shared and developed between them.

Analysing the data during a process of ‘epistemic awakening’

In contrast to meeting and talking with participants, the contemplative intensity and critical attention required of the analytic process was new and somewhat uncomfortable (Dickson-Swift et al, 2009). Looking back on this period, I think I was struggling to unravel different technical, philosophical and ethical issues about how and which ‘voices’ would be heard in this study (Lewis, 2010). In the initial phases of the project I was particularly concerned that I did not have enough knowledge (in terms of data and understanding) about the views and experiences of participants to represent them accurately. For a more detailed discussion about these issues, please see the ‘reflective notes’ in the theory-informed analysis chapter and the ‘methods and methodologies’ chapter. I was also concerned about whether the thematic analysis was congruent with participants’ intended meaning and reasons for taking part in the project (Serrnt-Green, 2011). These different technical and ethical issues were difficult to disentangle because they were abstract in nature and inextricably linked with personal feelings about my role and contribution in social work and research and making the transition between the two. At a time when my ‘epistemic consciousness’ (Staller, 2013) was in its infancy, I initially found it difficult to understand how theory could provide a deeper level of analysis. I was concerned that it might rarify and complicate interpretation of the participants’ accounts, giving me what seemed like licence to impose what I found interesting and intellectually compelling about them, rather than thinking about what is valuable from an ethical and service user perspective (Thorne, 2011; Smith, Bekker & Cheater, 2011; Hardy, 2016).

Through an iterative process of writing and talking about these disparate but connected issues with my supervisors, my understanding of theoretical and epistemic sensitivity developed. So too did my appreciation of the different role, and value, of considering different types of knowledge – experiential, tacit, empirical or theoretical – in developing insight and understanding about complex social issues. Indeed, there is a small but growing literature from novice researchers about the challenges and opportunities that practice-orientated research and theorising can present (Sky, 2016; Ward, Hoard & Gott, 2015; Smith, 2016). I began to recognise the value of orientating my analysis within a framework that accounted for social factors and processes that might affect how carers and professionals ‘constructed’ our discussions. This helped me to draw a connection with social work values and ethics (Shaw, 2008) to develop a ‘deeper’ and alternative way of exploring and thinking about the implications of the carers’ accounts.

Discussion

Navigating the changes engendered by my status and role as a novice researcher was sometimes a source of personal discomfort and practical difficulty. The need to continually re-establish and re-consider how I engaged with people, as gatekeepers and participants, required a concerted degree of practical and critical effort (Roesch-Marsh et al, 2012). Some aspects of this felt more familiar than others, for example, in negotiating contact and spaces for ‘deep’ talk with people about difficult issues. Focusing on points of intersection between my work in research and practice was initially helpful, particularly in terms of designing the empirical stages of the study. It also meant I could anticipate and recognise that the project would require a degree of emotional ‘work’ in terms of supporting participants to share their accounts and to engage with the important often troubling questions and issues they raised (Dickson-Swift, 2009; Newton, 2017). However, the seriousness of the participants’

accounts, combined with my observations about the isolated and complex nature of their experiences and ability to be meaningfully ‘heard’, was sobering and difficult, at times, to process and explain – to myself and to others.

I came to recognise differences in the way that ethical issues are identified and responded to in research and practice. For example, as a practitioner, I strove to be aware of various forms of power that I embodied and exercised and to address this through adopting an anti-oppressive practice perspective (Ruch, Turney & Ward, 2010). However, in the practice context, I had a clear ethical orientation that this power was contingent on acting in a way that promoted the welfare of children and adults and protected them from immediate or future harm. I lacked such moral clarity as a researcher and thus although ethical issues were less immediate and risk-focused, they often felt more complex and abstract. I also came to consider the concept of ‘sensitivity’ in a more critical way. This in turn led me to question how I ‘heard’ the carers’ accounts and whether I was likely to exhibit de-sensitisation or interpretive bias. As evidenced throughout this thesis, I have tried to account for, explain and justify my work and to consider the needs and views of the gatekeepers, advisors and participants.

Finally, I draw attention to some of the methodological limitations of recruiting and interviewing participants. The experience of caring and of experiencing violence and abuse have multiple gendered dimensions (Barnes, 2011; Kittay, 2011). Nevertheless, it is important to note that no male carers agreed to participate in the study. This was despite circulating recruitment information for advisors and interview participants widely and using a range of platforms and materials (see pages 171-174 and Appendix 1).

The ‘absence’ of men in the project may stem from the way I constructed and presented the project in my participant-focused recruitment materials and discussion with gatekeepers. In addition, my social appearance may have negatively affected men’s willingness to take part, in part because they may have considered that I would have fewer points of shared cultural or experiential understanding: both critical factors when identifying and exploring ‘sensitive’ issues (Dickson et al, 2009).

Nevertheless, it is noteworthy that two members of the advisory network were men who reviewed all the participant-facing materials and engaged in discussions about my proposed recruitment processes. Neither advisor indicated that they were unappealing to men.

Furthermore, one man did come forward to be interviewed during the course of the study. He was not included in the final sample because, as the interview progressed, it emerged he was caring for a younger family member rather than an older person and therefore did not fit the study criteria for interview participants.

In the context of this study, the lack of male participants may indicate that male carers who experience violent, abusive or harmful behaviour by the person for whom they care may constitute a hidden group ‘within’ a hidden group. That is, there may be additional and in some respects different social and psychological factors that facilitate and inhibit disclosure and exploration of their needs (Sorsoli, Kia-Keating, & Grossman, 2008; Tsui, Cheung, & Leung, 2010).. Affected male cares may also be less likely to be identified by professionals who come into contact with the family because their experiences are considered particularly atypical or taboo (Lab, Feigenbaum, & De Silva, 2000). These considerations highlight the need for future research that explores male carers’ views and needs (Fisher, 1994). They also indicate a responsive and relational approach should not be confused with a more intimate or

familiar on (Serrant-Green, 2011) and that in-depth interviewing may not always be the most suitable or appropriate way of researching sensitive issues.

In this chapter I have shared some of the ethical and methodological challenges that arose when engaging with advisors, ‘gatekeepers’ and participants. As with many areas of research, particularly that in the ‘sensitive’ canon, there are inherent and perhaps irreconcilable questions about the practice of power and the value and ownership of people’s testimony. Despite this, taking part in the interviews and advisory group may have provided some people a limited space to reflect and to be heard about seemingly ‘difficult’ issues and such an opportunity to share experiences of isolation and silencing has also been found to be of value to the participants in other studies (Appollis et al, 2015; Newton, 2017). For many participants, sharing their experiences was not necessarily about taking part in research but about raising awareness of an often sensitive and sometimes deeply painful issue and as a way of contributing to positive change for others. This highlights how assumptions about ‘vulnerability’ and ‘sensitivity’ need to be engaged with critically so as not to exclude and limit opportunities for research participation (Powell et al, 2018). This is critical if we are to develop knowledge to better support carers, like those who took part in this study, who are experiencing violent, harmful or abusive behaviour. In the following chapter, I reflect on the study’s findings and set out recommendations about how future practice, policy and research could be better foregrounded to affected carers and families’ needs.

Chapter 8: Concluding discussion and study recommendations

Chapter overview

As discussed in the introductory chapter of this thesis, in the context of a globally ageing population, there is evidence that rates of elder and domestic abuse is rising. A recent large-scale systematic literature review estimated that internationally 141 million people, or one in six older adults (aged 60 years and over), are affected by abuse or neglect (Yon et al, 2017). In the UK, in the reporting year 2016-17, 109,145 individuals were considered to be ‘at risk’ and made subject to a safeguarding enquiry, representing a 6% rise from the previous reporting year. During the same period, 364, 605 separate safeguarding concerns were made to local authorities, which equates to approximately 1000 referrals a day. Moreover, analysis of national data identified that the “location of risk” in 44% of enquiries was the adult’s home environment (NHS Digital, 2017) and that the majority of referrals related to adults aged over 64 years old (NHS Digital, 2017).

These statistics highlight that, for a growing number of families, the experience of illness, abuse and neglect in older age are shaped in part by the quality and nature of their intimate relationships and play out within their home environment. This raises questions about how and when the state intervenes in families’ ‘private’ lives and whether contemporary legislative, policy and organisational responses are meeting the increasingly complex needs of the ageing population. It is against this backdrop that this chapter synthesises the findings of the study and discusses its principal implications for policy and practice. Because the process of naming and conceptualising harmful behaviour is intimately bound up with practices of talking, thinking about, and relating to affected families, I discuss to what extent it is valuable and appropriate to consider it as a ‘type’ of abuse, as defined and operationalised under the Care Act (2014), hereafter referred to as the Act.

This chapter is intended to initiate a conversation about how research evidence can inform, and be informed by, policy and legislation to improve identification and responses to carer harm. It recognises that the relationship between research, practice and policy is a contested area, characterised by mutual as well as distinct interests, skills and objectives (Locock & Boaz, 2004). It also takes as axiomatic that the process of knowledge transfer and dissemination is frequently iterative (Kothari, MacLean & Edwards, 2009) and that it is shaped by social factors, such as the role of powerful stakeholders and the mobilising of networks of influence (Lewis, 2006). The chapter is an exploratory, reflective discussion, rather than a systematic or theory-informed analysis of policy and practice guidance. It draws on the study's empirical findings to structure the discussion and it concludes by outlining recommendations to better address carer harm. To begin, I set out the central conceptual and structural changes that have occurred in the field of adult safeguarding since the Act was passed.

The Care Act (2014)

1. A new practice framework for responding to abuse and harm

Coming into effect on April 1st 2015, the Care Act 2014 marked a significant shift in the way adults with care and support needs are recognised and their rights and needs enshrined in law and policy. The period of implementation coincided with the period of this study and this has, serendipitously, provided a vantage point from which to explore contemporary debates and shifting practices in adult care and safeguarding. For the purpose of this chapter, I will discuss only those sections of the Act relating to adult safeguarding and adult protection.

The Care Act ushered in a series of organisational and policy reforms to some parts of the English health and social care system. Preston-Shoot and Cooper (2015) suggest that many of these changes were considered long overdue and, broadly, welcomed by a number of major stakeholders in practice and academic communities. The Care Act reforms are restricted to England as adult safeguarding in Scotland and Wales is the responsibility of the respective devolved governments which have their own legislation: the Adult Support and Protection (Scotland) Bill (2007) and the Social Services and Well-being (Wales) Act (2017). There is no specific legislation relating to adult safeguarding in Northern Ireland. However, there are a range of policies and procedures to support practitioners working with individuals and families 'at risk' of harm and abuse and there are currently no plans to reform this system. Montgomery and McKee (2017) suggest that this less formalised approach suits the social and cultural needs of Northern Irish society. Nevertheless, in England, one of the principal aims of the Care Act (2014) was to provide a clearer, legislative framework to address adult care and safeguarding issues.

The Act sets out detailed recommendations for establishing inter-agency fora to improve communication and shared decision-making between partner agencies: for example, when carrying out reviews into unexpected or avoidable deaths of adults with care needs.

Nevertheless, the majority of the Act's recommendations relate to local authorities. This includes establishing and managing a local, multi-agency Safeguarding Adult Board, whose principal responsibilities include overseeing the implementation of the Act and reviewing the quality of safeguarding practices. In addition, the Act places a statutory duty (known as a Section 42 enquiry) on all local authorities to make enquiries about any adult with care or support needs who is suspected of being abused or neglected. Concerns can be raised by professionals or by the public and must be followed up by the local authority when an adult:

1. *Has needs for care and support (whether or not the local authority is meeting any of those needs)*
2. *Is experiencing, or at risk of, abuse or neglect*
3. *As a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect (whether they have mental capacity or not)*

The Act also recognises different forms of harm and abuse that were not previously considered to fall within the remit of adult safeguarding. These include: modern slavery, human trafficking, organisational abuse and self-neglect. The Act also, for the first time, recognises domestic violence and abuse (DVA) as a form of harm to adults that may require a safeguarding response. This change is broadly welcomed by the domestic abuse sector because it provides additional legal and policy tools to address DVA; symbolically, it also goes some way to giving this important issues ‘parity of esteem’ with other types of harm and abuse (Safe Lives, 2016). Nevertheless, there remains a concern that there is an “ideological gulf” between domestic abuse and safeguarding approaches and that in practice this continues to hamper effective joint-working and decision-making (Safe Lives, 2016).

A new approach: thinking critically about what constitutes abuse and neglect

One of the central changes brought about by the Act is its shift in ethos and approach. The Act emphasises the importance of a strengths-based and person-centred way of working and this echoes principles set out in each of the devolved countries’ safeguarding policies. In this vein, the Act’s guidance characterises safeguarding enquiries as engaging people in a conversation in a way that “enhances involvement, choice and control as well as improving quality of life, wellbeing and safety” (Department of Health and Social Care, 2018, point 14.15). This should be done under the remit of the Making Safeguarding Personal (MSP) agenda, which is underpinned by the Act’s six ‘safeguarding principles’: empowerment, prevention, proportionality, protection, partnership and accountability. According to the

Act's guidance, practitioners should think critically and carefully about what harm and abuse mean to different individuals and be cognisant of the additional disadvantages and vulnerabilities of some groups when accessing support. For example, older women experiencing domestic violence, people from minority groups who may have different cultural or social needs and people with complex health issues and disabilities. This emphasis on choice, person-centred solutions and partnership working contrasts sharply with the investigative, risk-focused and sometimes punitive approach of previous safeguarding practices and policies (Pritchard-Jones, 2018). A recent evaluation of MSP found that local authority practitioners welcomed the shift towards a more relationship-based and exploratory approach to carrying out safeguarding enquiries. However, participants also voiced concerns that the MSP training was not being rolled across partner agencies and that without a clear and shared agenda, efforts to work in a holistic and exploratory manner would face practical challenges (Butler & Manthorpe, 2016).

Guidance to the Act stresses the importance of practitioners considering the circumstances in which abuse occurs and being alert to patterns as well as incidents of abuse within long-term and inter-generational partner relationships. It emphasises the complex nature of familial and intimate relationships and how adult attachments affect people's understanding of, and response to, experiences of abuse and harm:

Practitioners... must recognise that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear or unrealistic about their personal circumstances... People have complex lives and being safe is only one of the things they want for themselves. Professionals should work with the adult to establish what being safe means to them and how that can be best achieved. Department of Health and Social Care, 2018, point 14.7

It is in this context that accompanying Local Government guidance direct practitioners to engage in systemic and family-focused practices, including family group conferences,

mediation and counselling (Local Government Association, 2015; 2017). Furthermore, the Act's guidance document acknowledges that many people wish to retain a positive, if not co-resident, relationship with the person who is acting in a harmful or abusive manner towards them. These wishes should be upheld when a person has cognitive capacity to make this decision, so long as the risk of harm is not immediate or life-threatening. This principle corresponds with recent research highlighting that service users prioritise "feeling safe" and being supported to maintain "key relationships" with people, even if the people concerned have or continue to harm or abuse them (Butler & Manthorpe, 2016; Storey & Perka, 2018; Wydall & Zerk, 2017). Nevertheless, there is limited specific guidance in the Act about how practitioners can address these complex, potentially countervailing, issues amongst adults, particularly when one or more person has fluctuating mental capacity (Parkinson, Pollock & Edwards, 2018).

Carers and safeguarding

Guidance to the Care Act (2014) acknowledges that carers can act in an abusive or neglectful way towards adults with care and support needs. This can take place within formal (professional) settings and in informal (family) homes and relationships. Unlike the No Secrets (2000) policy, the 2014 Act explicitly acknowledges that family carers can experience harmful or violent behaviour by the person for whom they care and that this type of abuse can be intentional or unintentional in nature.

"A carer may experience intentional or unintentional harm from the adult they are trying to support or from professionals and organisations they are in contact with... (and) a carer may unintentionally or intentionally harm or neglect the adult they support on their own or with others". (Department of Health and Social Care, 2018, point 14.45)

When this type of abuse is taking place, the guidance suggests that the local authority should consider whether there is available support that mitigates the risk to either or both parties and whether there is a need for independent advocacy. It encourages local authorities to consider whether “*other agencies should be involved*” and whether necessary amendments can be made to the carers’ care plan that enhance safety, “*for example, the provision of training or information or other support that minimises the stress experienced by the carer*” (Department of Health and Social Care, 2018, point 14.48). The guidance also suggests that in some circumstances it may be appropriate to contact the police if a criminal offence is suspected although there is no further detail about the ‘type’ of violence or abuse that would warrant such an intervention.

Although it is encouraging that the possibility of people harming their carers is acknowledged in the Act, there is little substantive guidance as to how best to address such harm. Indeed, the section focusing on ‘carers and safeguarding’ encompasses five short statements and one case study (less than two pages) whereas the safeguarding section of the guidance is 53 pages long and the total document is over 500 pages long. Moreover, there is no explicit mention of carers who are abused or harmed by the person for whom they care in any of the principal guides and summaries produced by local authority or government bodies (e.g. LGA, 2015; LGA, 2017; Social Care Institute of Excellence, 2016). Similarly, there is no discussion about the potential inter-relationship between older age domestic violence and abuse and carer harm. Thus, in the following section, I consider to what extent the Act offers a valuable first step in recognising carer harm as a ‘type’ of abuse and draw on data and analysis presented in this study to foreground this discussion, the principal aims of which are to consider:

1. To what extent does the Act offer a useful approach to recognising and responding to carers affected by harmful or violent behaviour as ‘type’ of abuse?
2. What are the limitations and potential difficulties involved in naming and conceptualising harmful behaviour as defined and characterised by the Act?

The case for conceptualising carer harm as a form of abuse

1. Focusing on impact rather than causation

This study’s empirical findings suggest that there is no one explanation for older people acting in a violent, harmful or abusive manner towards their family members. Moreover, in some situations it may not be possible to identify its cause. Carers and professional participants shared experiences where harmful behaviour began and developed after the onset of cognitive, mental or physical ill health. They also talked about patterns and incidents of harmful behaviour that were part of longer-term abusive, ‘strained’ or ‘complex’ relationships between intimate partners and/or family members. Furthermore, a central finding of this study was that explanations of harmful behaviour tended to be illness-orientated. As discussed throughout this thesis, this speaks to an implicit, conceptual connection between ‘not intending’ to cause harm and being unable –because a person was unwell and therefore ‘vulnerable’ - to exercise power or control over another person. As is evident from the carers’ accounts, this view obscures the complexity and dynamic nature of different forms of power and control, particularly those that are emotional and psychological in nature.

Because the Care Act (2014) states that abusive behaviour can be both intentional and unintentional, it may help practitioners to evade the conceptual cul-de-sac of placing the cause (and intent) of behaviour as the primary (or exclusive) way of understanding what

‘type’ of harm it is and, as a consequence, how it should be understood and addressed. This doesn’t mean that the cause of behaviour is not important; rather, it opens up a space for safeguarding enquiries to take account of the impact and context of behaviour *as well as* its cause. This is further reinforced by the Act’s exhortation that practitioners not “limit their view” about what constitutes abuse (Department of Health and Social Care, point 14.17).

Taking account of patterns as well as incidents of harmful behaviour

Recognising and interpreting patterns of behaviour helps us to ‘see’ how certain behaviour – particularly that which is repetitive in nature and that plays out in domestic spaces and within familial relationships – develops over time and has a cumulative effect on individuals (Stark, 2009b; Pitman, 2017). These seemingly ‘invisible’ types of harm can result in a profound loss of control and agency with attendant negative effects on a person’s psychological and emotional wellbeing (Kelly & Westmarland, 2016, pp. 125). Thinking about patterns of behaviour may be, therefore, a valuable way of identifying some of the less overt types of harmful and abusive behaviour. Indeed, such an approach is congruent with the principles and guidance set out in the Care Act (2014), which states:

“Incidents of abuse may be one-off or multiple, and affect one person or more. Professionals and others should look beyond single incidents or individuals to identify patterns of harm...” (Department of Health and Social Care, 2018, point 14.18)

As discussed in the interview findings, the experience of having limited and constrained agency was consistently raised by carer-participants. When talking about living in a situation of ‘paradoxical intimacy’, carers described feeling emotionally and physically responsive to their family member whilst at the same time threatened and fearful of them. In addition, it was apparent that feelings of being trapped or inhibited were compounded if participants felt isolated in their caring role, often because they lived with their family member and were their

sole carer. Thus, exploring patterns of behaviour within caring relationships may provide some valuable ways to better recognise the potential for abusive behaviour to take place, regardless of whether it is intentional or unintentional in origin.

On a separate but related point, it was identified in the literature review that many of the observational, cross-sectional studies measured the severity and prevalence of violent behaviour using the original and revised versions of the Conflict Tactics Scale. These are validated and widely-used instruments however they take little account of the relational and temporal nature of violence and abuse (Myhill, 2017; Walby, 2015). Thus, future research about harm and abuse to carers should draw on different or additional tools to capture the patterns as well as the incidence of violence, abuse and harm.

Analysis of the practitioner accounts also identified the challenges of ‘seeing’ and taking account of different types and patterns of carer harm. Practitioners talked, for example, about how carers often ‘masked’ the severity and complexity of their family members’ behaviour. They also talked about how the crisis-orientated and responsive nature of their work limited opportunities to ‘see’ or to meaningfully explore patterns of behaviour particularly those that were psychological or sexual in nature and that were historic in origin. Thus, there were inconsistencies, sometimes frustrations, about what professionals ‘knew’ about harm and abuse – whether intuitively or as a result of training and professional education – and how they could operationalise this knowledge in practice. Given its emphasis on recognising patterns of behaviour and different, intersecting forms of harm, it is possible that as the concepts and ethos of the Care Act (2014) become embedded in different disciplinary practice cultures, some of these inconsistencies may be reduced and the ‘invisible’ dimensions of carers’ experiences of harm will be more readily and routinely surfaced.

Recognising and exploring ethical and relational issues

This study found that carers experienced considerable difficulties feeling safe enough to share and to explore their experiences of harm. Analysis of the carer-participant accounts found that most participants understood their experiences of abusive and violent behaviour as being qualitatively different from domestic abuse because of the relational context in which it played out. In short, the meaning and value that carers placed on honouring explicit and implicit commitments to protect and care for their family members was central to how they ‘made sense’ of their experiences of harm. It also shaped what they considered to be harmful, the dilemmas they grappled with and the ‘lines’ they drew (and re-drew) around what they could and could not tolerate.

Thus, the exploratory, empowerment-focused approach of the Act may serve as a valuable orientating ethos for practitioners working with carers. As discussed, the Act’s guidance emphasises the importance of a relational approach and acknowledges that ‘difficult’ conversations require time and skill. Such work is likely to be particularly important when developing knowledge about an issue that can all too often evoke feelings of shame and embarrassment like carer harm. Furthermore, because the Act promotes a systemic, family-focused approach to safeguarding, this may help carers to share and develop plans about how to manage situations of harm. A systemic and family-focused approach is likely to be valuable because it lends itself to working with individuals in a way that recognises and potentially prioritises subjective experiences and concepts of safety. The Care Act (2014) may facilitate a way to recognise that carers can and do experience harm and abuse, without curtailing their ability to determine if and how they should care. This person-centred, empowerment focused approach appears to be consistent with the concerns and wishes of many of the carers and advisors who took part in this study.

The case against conceptualising harmful behaviour as a form of abuse

1. Limited empirical or theoretical development

There is good reason to suggest that attempts to name or locate harmful behaviour towards carers within a specific policy or legislative context may be premature. There is a paucity of research about carer harm and the empirical landscape can be characterised as being divided by two conceptually diverse approaches: one that identifies harmful, violent and abusive behaviour as a ‘symptom of an illness’ and one that considers it as an ‘act (or pattern) of abuse’ (Isham et al, 2017). There is also a wide and diverse range of opinion amongst professionals and carers about what constitutes harm and when it does (not) overlap with abuse, as demonstrated by this study’s interview and focus group findings.

Thus, although it is noteworthy that carer harm is recognised in the Act – marking a departure from previous safeguarding legislation and policy – the guidance alone does not provide a clear or comprehensive blueprint for what this work will ‘look like’. As a result, there may be areas of contradiction and inconsistency that require further attention. There is no detail, for example, about the potential intersection between domestic abuse and carer harm. Neither is there information about in what circumstances ‘challenging’ or ‘distressed’ behaviour would be legitimately considered (unintentionally) ‘abusive’. In addition, given the institutional and hermeneutic structures that reinforce the positioning of people with care needs as being the ‘priority’ and ‘coming first’, there may be a tension between what choice and empowerment mean to an older person and their carer and a likelihood that in most circumstances the needs and views of the former will take precedence (Daniel & Bowes, 2010). Finally, notwithstanding clearer guidance, a systemic and family-focused approach may place too much responsibility on families and individuals to determine their care and safety needs (Parkinson, Pollock & Edwards, 2018). As several participants in this study

reported, it became increasingly difficult to recognise what was “normal” after years of living in the context of harm and care and thus resulted in them ‘tolerating’ and ‘coping’ with serious and repetitive experiences of violence and harm until a point of crisis.

Aspects of discordance with the carers’ and professionals’ accounts

This study found that the majority of carer and professional participants rejected or cautioned against using the term ‘abuse’ to describe carer harm. As discussed in the two findings chapters, there may be several important reasons why so many people questioned the comparison between domestic abuse and harmful behaviour towards carers: for example, because it was unfamiliar and disrupted implicit ideas about what ‘victims’ and ‘perpetrators’ of abuse ‘look like’; or, because it seemed inappropriate and simplistic, from an ethical perspective, not to consider the cause and context of behaviour, particularly when it developed in the course of illness. Whilst it seems appropriate to consider the degree to which implicit biases (relating to age and gender) and structural inequalities affect the way carers and professionals ‘constructed’ their accounts of harmful behaviour, caution needs to be exercised about whose voice and interpretive power is being privileged in such an exercise.

The way carer harm is named raises questions that echo a small but growing body of work that questions whether domestic violence and adult safeguarding services are sufficiently sensitive to the ways older people name, think about and respond to abuse and neglect (Crockett, Cooper & Brandl, 2018; Wydall & Zerk, 2017; Storey & Perka, 2018; Safe Lives, 2016). These studies reinforce the message that intimate relationships and concepts of home have a unique and powerful meaning for many older people and these factors affect how they think about ‘leaving’ a relationship or home environment (Crockett et al, 2018; Wydall & Zerk, 2017; Storey & Perka, 2018; Safe Lives, 2016). Thus, whilst there may be some

conceptual merit in naming and locating harm as a form of abuse, attention needs to be paid to the wider social-historical context in which conversations, ideas and the imagery of abuse exist (Eisikovits, et al, 2013). Otherwise such efforts are unlikely to have the desired outcome of raising the visibility of this issue. At best, they will result in discussions about terminology that have limited application outside academic and policy spheres. At worst, they risk further constricting the spaces in which carers feel comfortable to share and explore their experiences.

Financial and organisational constraints affecting the Act's implementation

Although many practitioners and academics have welcomed the laudable aims and shift in ethos set out in the revised Care Act (2014), there are concerns that financial and organisational constraints will limit its impact. The National Audit Office estimates that central government funding to local authorities, charged with delivering adult social care and safeguarding functions, has reduced by 49.1% between 2010-11 and 2017-18. During the same time period, demand on services has increased (National Audit Office, 2018) leading Aileen Murphie, Director of Local Government at the Audit Office to warn that: *“A financial model based on dwindling reserves and difficulties delivering savings, or use of non-recurrent savings, is not financially sustainable over the medium term”* (Room151, 2018). It is against this backdrop that the eligibility for local authority support and care services have become narrower. Only those with the most complex and immediate needs are now receiving support and only when they are financially eligible. Reduced funding curtails opportunities for preventative and rehabilitative safeguarding support (Higgs & Hafford-Letchfield, 2018; Tanner, Ward & Ray, 2018). It also has implications for the monitoring of the quality and consistency of care and support provided to adults, particularly those at risk of harm and abuse.

Reflecting on interviews with participants, many carers talked about ambivalent or distant relationships with practitioners, often fostered by and limited to contexts of crisis. This could lead to carers' feeling that they had contingent credibility when interacting with professionals and making decisions about their family member's care and support (see theory-driven analysis of the data for a more detailed discussion). Thus, if there are fewer staff working in an increasingly complex environment it is reasonable to suggest that the dynamics of this knowledge economy may not have changed for the benefit of carers affected by harm and abuse – at least not since the inception of the Care Act. Not only may it be more difficult to carve out time and space to explore affected families' needs, it may also be difficult to maintain consistent communication with multi-agency partners. This has an effect on the quality and consistency of holistic care and support offered to all adults, whether carers or cared-for.

Reflecting on the contemporary issues facing local authorities re-surfaces questions about how well 'positioned' practitioners are to identify and intervene when they suspect harm and abuse, specifically, when directed towards family carers. It also underlines how naming and recognising the issue will only have practical benefit for affected families if practitioners are equipped with the requisite time, skills and emotional resources. If not, it is likely that practitioners will struggle to 'see' and to engage with affected carers in a way that consistently prevents or protects them from harmful or abusive behaviour.

Study limitations

In each of the previous chapters, I have outlined the principal limitations and challenges that developed in the course of the project. For example, in relation to the disciplinary reach of the literature review, the difficulties recruiting participants and the ethical complexities that became apparent working with the advisory network. With these issues in mind, I think the project would have benefitted from a longer period of co-design and development work, establishing relationships with potential gatekeepers and even co-researchers in NHS and local authority settings. From a practical perspective, this may have lessened some of the challenges of recruiting from an ‘outsider’ position. It may also have facilitated a more cooperative and iterative process of knowledge development that was driven as much if not more by the needs of practice as by the limitations and gaps in the research literature.

In previous chapters I have also discussed the principal limitations of my methodological and methods-orientated decisions: for example, regarding the epistemic framework and analytical approaches used when interpreting the empirical data or in regard to the relatively small sample size of the interviews and focus groups. As with all qualitative studies, it is not possible to claim generalisability or representativeness; however, this study’s limited empirical output means that the identification of patterns, congruence and dissimilarity in the data could only be carried out to a limited extent. I have tried to address these limitations in empirical breadth by strengthening the interpretive and critical depth of my analysis.

Nevertheless, that these were decisions available to me highlights the considerable practical and interpretive power of the primary researcher in qualitative research (Berger, 2015).

Furthermore, the interpretive agency that I exercised underlines that this study could have taken different directions in terms of the methods used, the analytic techniques deployed and the disciplinary and conceptual context in which its aims and outcomes were foregrounded.

This means that there are alternative approaches and topics that could be explored in the future and that would have equal validity and relevance if carried out in a rigorous way. Given there remains a paucity of conceptual and empirical development about this topic, such work is to be welcomed.

Recommendations

The following set of recommendations is intended to serve as a series of orientating points to guide future work, critical discussion and theorising about carer harm. They focus on: peer and social support, health and social care practice, theory and research and policy. Clearly, there are links between these areas and I highlight these where appropriate. In-keeping with the methodological and ethical principles of this study, these recommendations are foregrounded in comments and suggestions made by carer and practitioner participants about how to improve recognition and efforts to address carer harm.

1. Peer and social support

Although feeling misunderstood, ignored or unseen were common and often damaging experiences for carer-participants, several people identified the ways they had sought information and support about their situation. Friendship and meaningful relationships with professionals could play an important role in making some aspects of their experience more visible and less isolating. Women talked, for example, about the value of having time away from their caring role to talk and reflect on the situation. Practical advice and sharing knowledge was also highly prized, especially when it came from peers with first-hand experience of caring and of illness.

I have found it useful talking with people who have similar experiences... Before this time, I hadn't met anyone with this illness. It felt like it was only my husband who suffered from it. All these people have been so good and kind and normal. You would

not know that they suffered from mental illness. I think that this is one of the difficult things about mental illness, that it is hidden and that there is much difficulty being open about it. Rose

Well, I think a lot, what has helped me has been having friends to talk to and a few people, one or two of them, worked in hospitals and with people with dementia. So, they were able to explain to me what to expect and things like that. Dorris

I think that my coping strategy was my husband and my close friends who I had the opportunity to offload. And I found that they were my support network. They understood where I was coming from; they knew how challenging things were. Asrah

I have accessed counselling a few times in my life. And I think that always the biggest thing is that it's completely anonymous and you can say whatever you like. Even if, well not that it's not true, but even if it's only true in that moment. You know? Yes, you can say you hate your husband, or whatever, and literally you can say whatever you're thinking, whatever you're feeling and not be judged. No one is going to come back and say you said this or you said that. So, it's safe, it's secure, it's yours. It's nobody else's and there's no right or wrong. Sally

Anna, Asrah and Christine also talked about the importance of having a person who stood 'outside' the situation: someone who was not enmeshed in the daily routine and relational dynamics involved in care and caring and who could, as a result, be better positioned to support both the carer and person with illness.

I think it would be helpful to have someone who sits, not necessarily someone who steps in when I go out, but just like someone who sits in the middle, someone who looks at them and looks at me and listens to both of us. So, that would probably make things better. Not necessarily someone who steps in when I go out, like when I'm here or something. Who takes my job. But someone who understands what I'm going through and what they're going through. Anita

I mean, Joan (friend), was and is still an amazing person and has given me so much unbelievable support just by listening and helping me to learn to be the observer instead of being sucked into things. You become the observer and then you can deal with the guilt, to deal with that thought that 'oh, perhaps I don't need to be responsible for everyone in the world' and all of that kind of stuff. Anna

Some carers nevertheless expressed doubts about the feasibility of providing effective services or education for carers, given the unique nature of each family's circumstances.

Christine, for example, reflected on the practical and ethical difficulties of offering advice in

crisis situations, such as suicide interventions. Nonetheless, Christine also suggested that there was a role for an informed ‘outsider’ when supporting carers. As the excerpts above indicate, maintaining a relational, perhaps even systemic perspective on harmful behaviour was an important issue for many of the carers.

If people haven't got someone to talk to... I think that some sort of buddy system would be quite nice... Even if it's just texting, you know, 'what sort of day have you had? Mine has been vile!' You know, that sort of thing? Sometimes, you do just want someone in the outside world to know. You know, just 'I had a horrible day today' or 'I got away today', you know? That sort of thing. But I don't think that there is. I mean, there is no training for being a carer. Christine

With the carer-participants’ recommendations in mind, one way of improving identification and responses to carer harm is to consider in what ways ‘safe’ and supportive spaces can be opened up for affected carers to disclose, explore and make decisions about their situation. As discussed in the theory-informed analysis, the ability to relate to and talk about one’s experiences – particularly when they are negative, atypical and marginalised by dominant political and social discourse – can be valuable in alleviating individuals’ sense of isolation and stress (Fricker, 2006; 2007). From an epistemic perspective, such opportunities can help to shift the balance of epistemic resources and thus enable some individuals find a collective voice; however mediated this may be by other forms of social and political disadvantage (Pohlhaus, 2012).

As a ‘sensitive’ topic, there may thus be some practical ways that the visibility and permissibility of talking about carer harm can shift, as it has with other seemingly taboo or ‘difficult’ topics. In the context of end-of-life care and death and dying, for example, there has been a discernible shift in research, practice and public fora to make this once ‘private’ matter part of routine, open conversations with patients and their families (Emanuel, Fairclough, Wolfe & Emanuel, 2004) and to lessen the stigma around violent and traumatic

death (Chapple, Zieblan & Hawton, 2015). In addition, the ‘Dying Matters’ campaign publicises social events relating to death and bereavement, provides information and resources for patients and families and shares practical tools to support ‘difficult’ conversations between family members (www.dyingmatters.org). With this in mind, it may be valuable for carers’ organisations to initiate discussions about carer harm in the context of peer and facilitator-led support meetings and to provide advice and guidance about the issue. Similarly, it may be helpful to begin conversations using online fora and to provide guidance and support using a range of media, so that carers who are more isolated and/or who choose not to take part in groups of formal events can also hear and participate in discussions about carer harm. In Fricker’s terms, this may help to develop a ‘community of knowers’ and, more practically, to lessen the epistemic and social harm many carer currently experience.

Health and social care practice

Given the social, ethical and practical ‘sensitivities’ that can impede carers sharing their experiences, it would be helpful to consider if and how we can re-distribute epistemic resources in a way that facilitates ‘deeper’ and different types of communication about harmful and abusive behaviour. Health and social care practitioners are well-positioned – perhaps uniquely so - to engage with carers, particularly those who are isolated and socially marginalised. They work within domestic spaces and engage with intimate and ‘private’ issues on a routine basis. This engenders opportunities for carers to share their experiences and explore their needs. It also means that knowledge developed in the practice context could helpfully guide research and policy innovation.

Disclosure of abuse is rarely an event, but rather a process that is shaped by social and interpersonal factors (Bradbury-Jones, et al, 2015). It often requires time and relational trust,

although this can ‘look’ and mean different things to different people. With this in mind, it is important to emphasise that the identification of harmful behaviour is likely to be only the first step in developing responses and informing decisions about how to mitigate or prevent its occurrence. Practitioners may need to re-visit the issue on an ongoing basis. Given what we know about the challenges facing older victim-survivors of domestic abuse and mothers affected by violence or abuse by their children (Wydall & Zerk, 2017; Crockett et al, 2018; Miles & Condry, 2015) it may be helpful to make clear that ‘separation’ or criminal prosecution is not a necessary or inevitable aspect of seeking help and support to address carer harm. In addition, responding to carer harm is likely to require systemic or dyadic solutions: for example, identifying the support and care needs of the older person instigating harmful behaviour as well as those of their family carer (Ayres & Woddti, 2001; Herron & Wrathall, 2018).

With these issues in mind, it may be helpful for practitioners to ask clear and focused questions about if, and in what ways, harmful and abusive behaviour is taking place. Drawing on practical and practice-focused guidelines for nurses (Bradbury-Jones & Clarke, 2016) this could include, for example, asking carers whether they ever feel unsafe in their caring role and, if so, in what ways and how often. Or, asking them if they feel harmed by their family member’s behaviour and if so what this ‘means’ or ‘looks like’ to them. It may also be helpful for practitioners to initiate sharing knowledge about harmful behaviour as this may make it more permissible to talk about the issue and mitigate potential feelings of shame and social taboo. In turn, this could play a role in shifting their expectations about what could and should be tolerated. I discuss the challenges that practitioners may face carrying out such work in the following section of the chapter.

The above recommendations draw on and reiterate those made by practitioners who took part in the focus groups. Several practitioners emphasised the need, for example, to create more opportunities for carers to safely disclose and explore their options. Reflecting on the limited opportunities for carers to disclose and explore their experiences, Kate and Andy suggested that practitioners could play a greater role facilitating ‘difficult’ conversations about harmful behaviour and its impact.

So, I think that care homes need to be really vigilant and really on the ball with that – with asking those questions and not to be afraid to ask that question, that when there is violent behaviour, has this been going on for a long time and do you need support with this? Kate (Student social worker, Group 5)

So, I don't know if there is room for any sort-of formal mechanism? Whether that is in the information that we provide on the first visits, or as part of our dementia awareness work... So I think it is that permission aspect. How do we allow people permission to feel that they can talk about this? Andy (Dementia advisor, Group 4)

In addition, Geoff and Maggie reflected on potential changes and innovations to services that might help them to better recognise and support carers experiencing harm.

I'm just wondering whether there could be a merger, a sort of link worker, between somewhere like refuge and carer support. They could actually get things together and offer bespoke support for people who are in violent situations or such. It could be advertised as something for people who are in this situation, who are caring. Geoff (Adult social worker, Group 3)

I don't know if this is already in place, but maybe there could be an anonymous line that people could call. Maybe that is there already. You know, sometimes when people are on their own at two o'clock in the morning and something isn't right, then they need someone to talk to: to assess that situation or to help you to assess that situation. Maggie (Dementia advisor, Group 4)

The development of bespoke practice guidelines may support practitioners to hold ‘difficult’ conversations with families affected by carer harm and co-production of such resources may increase their acceptability and uptake for frontline staff (Sohal et al, 2018). However, it is also important that other stakeholders, such as commissioners, policy-makers and people in

senior leadership roles, are also involved in this process. This is because, regardless of the conceptual integrity or acceptability of guidelines to practice communities, their successful implementation requires embedded organisational support, in particular clear leadership (Mulla, Hewison & Shapiro, 2014). This study found that a critical and consistent issue was that of practitioners having adequate time to work with families and to follow up and respond to the relational, tacit knowledge that they often have about their needs and experiences. Thus, practitioners need to be supported to carry out work that may be ethically complex and emotionally-demanding and this requires commitment to systems that promote practitioner well-being and foster a culture of reflection and peer support (Hooker et al, 2015; Hewison & Sawbridge & Hewison, 2016). Without these mechanisms, it is likely that practitioner responses will remain ad hoc and reactive, dependent primarily on the aptitude, capacity and willingness of individual practitioners to identify and respond to carer harm. This study's findings demonstrate the undue responsibility this can put on practitioners and the gaps that this opens up in terms of service provision for carers and families with complex needs.

Theory and research

Since carrying out and publishing the findings of this literature review, I have continued to engage with the empirical and theoretical literature relating to elder abuse, domestic violence in older age and caring and I have identified two recently-published studies that meet the inclusion criteria for this review (Herron & Rosenberg, 2017; Spencer, Funk, Herron & Dansereau, 2018). Both studies focus on carers of older people with dementia who exhibit physically or verbally violent behaviour. They adopt a qualitative approach to explore how family carers narrate and construct understanding about their families' members' behaviour. It is noteworthy that neither study adopts a feminist analytic lens to interpret participants' accounts, thus marking a shift in the conceptual and theoretical orientation of papers in the

review sample. Nevertheless, echoing a principal thematic finding of this study's literature review, both papers characterise the issue as 'hidden' and 'invisible' because it has hitherto received scant attention in research or policy and because it engenders feelings of shame and taboo for many affected families (Spencer et al. 2018; Herron & Rosenberg, 2017).

Spencer et al (2018) find that carers develop defensive coping strategies that either: minimise their interactions with their family member and seek to contain and hide their emotions, or, develop internalised ways of defending themselves that tend to result in hostile or antagonistic care practices and interactions. Heron and Rosenberg (2017) find that carers' vulnerability is poorly recognised because there is limited understanding of the interpersonal and structural contexts of violence by health and social care providers. Again, echoing aspects of this study's literature review findings (Isham et al, 2017), Heron and Rosenberg (2017) find that participants' narratives suggest that "the stigma associated with reactive behaviours made talking about and naming them very challenging for the majority of participants" (pp.5) and that this was in part perpetuated by the lack of opportunities to share and explore their experiences.

Reflecting on these recent papers and the findings of the literature review it is evident that theory and research can make an important contribution to raising awareness of carer harm. There is a need for innovation and development from a range of perspectives: for example, focusing on different population groups, taking different theoretical perspectives, exploring cross-cultural contexts, and so on. Longitudinal studies may help build understanding about how patterns of caring, conflict and harm develop within families. In addition, by refining and developing the way violence is captured and measured, observational studies could play a valuable role in mapping and developing more accurate prevalence estimates of carer harm.

I now turn to focus, in more detail, on the future of qualitative research and its potential contribution to developing understanding about carer harm. As noted in the literature review chapter, the concepts of gender inequality and structural models of violence and ‘power and control’ (and the attendant division of roles into ‘perpetrator’ and ‘abuser’) were central in the analysis and discussion of findings of many of the reviewed qualitative papers. This reflects dominant paradigms in IPV and gender violence work over the past thirty (and more) years as well as the more recent shift to conceptualising these issues of public health and legal concern. Nevertheless, there may be other factors that are helpful in explaining people’s understanding of care and violence. Turning to the literature on formal carers, studies have used a range of analytic lenses. For example, exploring responses by examining spatial and environmental factors (Herron & Wrathall, 2018), recognising the inherent and tense relationship between violence and care or the process by which violent behaviours are ‘pathologized’ and constructed as ‘challenging’ (Dupuis, Wiersma & Loiselle, 2012). These are among several potential and alternative lines of enquiry that may be relevant to understanding care and relational dynamics in the informal care context. In addition, perhaps one of the principal limitations of current conceptualisation of harm and abuse towards carers is that there is limited explicit discussion of when ‘challenging’ behaviour ‘becomes’ abusive and to what degree factors such as intent, impact and relational context could and should shape such distinctions.

Finally, there are areas for future application and development of Fricker’s theory of epistemic injustice. Using her theory to carry out a ‘deeper’ layer of analysis brought to light structural, hermeneutic and social factors that were less evident in the thematic analysis. Given that the theme of ‘invisibility’ is a consistent theme in pan-caring scholarship and

activism, there may be merit in applying Fricker's work to analyse or conceptualise other areas of caring research and practice (Larkin et al, 2018). In addition, this study identified some potential limitations of the theory that need further investigation. For example, exploring how women who live in the epistemic sphere of someone with impaired or atypical communication skills can experience different but powerful forms of epistemic silencing and marginalisation.

Policy

As discussed, it is noteworthy that the Care Act (2014) identifies – and makes some recommendations about how to address – carer harm. This recognition may help commissioners, people in leadership roles and practitioners to direct resources and attention to the issue in a way that was less possible when the problem lacked any identification in policy. Nevertheless, there is little substantive guidance as to how best to address carer harm and, as this study identifies, unresolved issues about the appropriateness of characterising it as a 'type' of abuse. Thus, there is a need for policy development. It may be helpful, for example, to consider whether the concept of carer harm could be usefully embedded in other areas of policy, such as domestic violence and older people care (Safe Lives, 2016; Zerk & Wydall, 2017; Crockett et al, 2018). In addition, this study found that some of the principles and service structures that underpin the organisation of adult care may also contribute to the marginalisation and 'hiding' of carers' experiences: for example, the practical difficulties of working in a systemic manner, the challenges of multi-agency communication and the ability to reconcile the needs of individuals with complex and potentially competing needs (Daniel & Bowes, 2010; Parkinson et al, 2018). Future policy development would benefit from paying closer attention to these issues and making explicit how the Care Act's ambitious aims

– for practitioners to work in a person-centred, relational way – will be operationalised in the context of cases of carer harm.

Concluding reflections

As discussed at the outset of this study, the globally ageing population raises pressing questions about how a growing number of families will cope and care for older partners and relatives. Because more people experience chronic and co-morbid illness in later life, ‘informal’ care often requires people to develop considerable skills and knowledge to manage the complex and dynamic nature of their family member’s health needs in older age (World Health Organization, 2015; Pinquart, & Sörensen, 2011). Caring affects employment status, financial security and physical health. It can also engender considerable ethical, emotional and relational changes in the context of becoming and moving on from caring and cared-for experiences. Thus, experiences of illness and care in older age frequently re-structure how time is spent, relationships are fostered and domestic space used in the context of familial and intimate life (Pin & Spini, 2016).

Taking account of these issues is critical when we think about what is different (as well as similar) between abuse and harm that takes place in institutional settings and ‘formal’ care interactions and those in familial and intimate relationships. Clearly, there are areas of overlap between these two spaces in terms of the potential asymmetry in power between those who provide and those who are in need of care (Wharton & Ford, 2014). In addition, when violent or ‘challenging’ behaviour is precipitated by cognitive or physical illness, it may ‘look’ similar and be addressed by drawing on skills and techniques that are relevant to the formal as well as informal care context. Thus, it is encouraging that over the past ten years, recognition of the challenges faced by nursing and care home staff has increased and

that this has spurred innovation and practice learning about how to better identify and manage the violent and distressed behaviour of older people with care needs (Duxbury, Pulsford, Hadi & Sykes, 2013; Enmarker, Olsen & Hellzen, 2011; Rosen, Lachs, & Pillemer, 2010).

Nevertheless, a key finding of this study is that the impact and context of harmful and abusive behaviour towards family carers is different and the causes of it are more complex and ambiguous. This is not currently accounted for in the literature and guidance relating to ‘challenging’ behaviour or domestic violence in older age. Furthermore, this study’s findings suggest that, to better identify and respond to carer harm, we need to do the following: look for patterns (rather than incidents) of harm and abuse; recognise that there are unique temporal and spatial factors to consider when harm takes place in intimate and familial relationships; and, develop a more nuanced way of exploring the co-dependent and dynamic nature of adult relationships, particularly those in later life. In addition, structural factors and inequalities – relating, for example, to gender, race and socio-economic disadvantage – are likely to shape the nature and duration of people’s caring relationships and these too need to be better understood in the context of harm and abuse. With all this in mind, it is time to move the debate on from considering *whether* abuse to carers happens, and instead concentrate on ways to improve how we identify and respond to it when it does occur.

Throughout this thesis, I have sought to explore the intersecting practical, ethical and conceptual factors that make it difficult to talk and think about harmful or abusive behaviour towards family carers. ‘Deconstructing’ the social factors that underpin people’s reluctance to use certain words and images indicates that future work, be it research, practice or policy-orientated needs to be context-sensitive and carried out in an exploratory and collaborative manner if it is to have practical value. It is vital to foreground responses in the language and

intended meaning of people who have personal and professional knowledge about the issue and to consider this of equal value to empirical and theoretical insights.

It is evident that there is no panacea when it comes to developing understanding about, and improving responses to, carers and families affected by harmful behaviour. However, there is a role to play for us all in examining why we might not want, or struggle to, consider the issue of harmful and abusive behaviour towards carers. Carer harm can be uncomfortable, perhaps even overwhelming to consider. Yet, when we re-frame this issue as one of familial disruption and transition, we more clearly see that there are myriad opportunities for hope and change; for harm to be lessened or prevented and for new relational and ethical meanings to be developed in the context and aftermath of harm and abuse. By developing empirical knowledge about carers and practitioners' experiences and by exploring the different ways this sensitive issue is hidden, we can develop informed research, policy and practice recommendations about how we can make it more visible and in turn support the individuals and families whom it affects. Set against the backdrop of a sparse research landscape, replete with conceptual ambiguities and ethical questions, this study makes an important contribution to the limited knowledge about carer harm. It also goes some way to challenging the idea that carer harm is too sensitive or complex an issue to be researched in a meaningful way and, more importantly, to questioning the latent assumption that carers either do not want to talk about the issue or to affect change for themselves and for carers in similar circumstances.

References

- Aadnanes, M., & Gulbrandsen, L. M. (2018). Young people and young adults' experiences with child abuse and maltreatment: Meaning making, conceptualizations, and dealing with violence. *Qualitative Social Work*, 17(4), 594–610.
<https://doi.org/10.1177/1473325016683245>
- Abley, C., Bond, J. & Robinson, L. (2011) Improving interprofessional practice for vulnerable older people: gaining a better understanding of vulnerability, *Journal of Interprofessional Care*, 25:5, 359-365, DOI: 10.3109/13561820.2011.579195
- Adamson, J., & Donovan, J. (2005). 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK. *Social Science & Medicine*, 60(1), 37-48. doi.org/10.1016/j.socscimed.2004.05.002
- Age, U. K., & Carers, U. K. (2016). Walking the Tightrope. The Challenges of Combining Work and Care in Later Life. Age UK, London. Retrieved from:
https://www.dataplan.info/img_upload/5c84ed46aa0abfec4ac40610dde11285/walking_the_tightrope_report_2016.pdf
- Agee, J. (2009) Developing qualitative research questions: a reflective process, *International Journal of Qualitative Studies in Education*, 22:4, 431-447,
doi.org/10.1080/09518390902736512
- Aldridge, J. (2014). Working with vulnerable groups in social research: dilemmas by default and design. *Qualitative Research*, 14(1), 112-130. doi.org/10.1177/1468794112455041
- Aldridge, J. (2016). Participatory research: Working with vulnerable groups in research and practice. Policy Press: Bristol.
- Appollis, T. M., Lund, C., de Vries, P.,J., & Mathews, C. (2015). Adolescents' and adults' experiences of being surveyed about violence and abuse: A systematic review of harms, benefits, and regrets. *American Journal of Public Health*, 105(2), doi: 10.2105/AJPH.2014.302293
- Arnstein, S. R. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35(4), 216-224. doi.org/10.1080/01944366908977225
- Ash, A. (2011). A cognitive mask? Camouflaging dilemmas in street-level policy implementation to safeguard older people from abuse. *British Journal of Social Work*, 43(1), 99-115. doi.org/10.1093/bjsw/bcr161
- Ash, A. (2015). Safeguarding older people from abuse: Critical contexts to policy and practice. Policy Press.
- Aymer, C., & Okitikpi, T. (2000). Epistemology, ontology and methodology: What's that got to do with social work? *Social Work Education*, 19(1), 67-75.
doi.org/10.1080/026154700114667
- Ayres, M. M., & Woodtli, A. (2001). Concept analysis: abuse of ageing carers by elderly care recipients. *Journal of Advanced Nursing*, 35(3), 326-334. doi: 10.1046/j.1365-2648.2001.01849.x

- Band-Winterstein, T. (2012). Narratives of aging in intimate partner violence: The double lens of violence and old age. *Journal of Aging Studies*, 26(4), doi: 504-514. 10.1016/j.jaging.2012.07.003
- Band-Winterstein, T. (2014). The impact of lifelong exposure to IPV on adult children and their aging parents. *Journal of family issues*, 35(4), 439-461, doi.org/10.1177/0192513X12472657
- Band-Winterstein, T. A., & Eisikovits, Z. (2014). *Intimate Violence Across the Lifespan*. Springer New York.
- Band-Winterstein, T., & Eisikovits, Z. (2009). "Aging Out" of Violence: The Multiple Faces of Intimate Violence Over the Life Span. *Qualitative Health Research*, 19(2), 164-180, doi.org/10.1177/1049732308329305
- Band-Winterstein, T., Goldblatt, H., & Alon, S. (2014). Giving voice to 'age at the edge'—A challenge for social workers intervening with elder abuse and neglect. *Journal of Family Violence*, 29(7), 797-807, doi.org/10.1007/s10896-014-9627-0
- Banks, S. (2016). Everyday ethics in professional life: social work as ethics work. *Ethics and Social Welfare*, 10(1), 35-52. <https://doi.org/10.1080/17496535.2015.1126623>
- Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., ...& Moore, N. (2013). Everyday ethics in community-based participatory research. *Contemporary Social Science*, 8(3), 263-277, doi.org/10.1080/21582041.2013.769618
- Barnes, M. (2008). Is the personal no longer political? *Soundings*, (39), 152, doi:10.3898/136266208786879227
- Barnes, M. (2011). Abandoning care? A critical perspective on personalisation from an ethic of care. *Ethics and Social Welfare*, 5(2), 153-167, doi.org/10.1080/17496535.2010.484265
- Barnes, M. (2012). *Care in everyday life: An ethic of care in practice*. Policy Press.
- Beaulaurier, R. L., Seff, L. R., Newman, F. L., & Dunlop, B. (2006). Internal Barriers to Help Seeking for Middle-Aged and Older Women Who Experience Intimate Partner Violence. *Journal of Elder Abuse & Neglect*, 17(3), 53-74. doi:10.1300/J084v17n03_04
- Bell, K. (2014). Exploring Epistemic Injustice through Feminist Social Work Research. *Affilia*, 29(2), 165-177. doi:10.1177/0886109913516457
- Béres, L. (2017). Maintaining the ability to be unsettled and learn afresh: what philosophy contributes to our understanding of 'reflection' and 'experience'. *Reflective Practice*, 18(2), 280-290, doi: doi.org/10.1080/14623943.2016.1269003
- Beresford, P. (2000). Service users' knowledges and social work theory: conflict or collaboration? *The British Journal of Social Work*, 30(4), 489-503. Retrieved from <http://www.jstor.org/stable/23716149>
- Berger, P. L., & Luckmann, T. (1967). *The social construction of reality*. New York: Anchor.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, 15(2), 219-234, doi.org/10.1177/1468794112468475

- Biggs, S., & Haapala, I. (2010). Theoretical Development and Elder Mistreatment: Spreading Awareness and Conceptual Complexity in Examining the Management of Socio-Emotional Boundaries. *Ageing International*, 35(3), 171-184. doi: 10.1007/s12126-010-9064-1
- Blease, C., Carel, H., & Geraghty, K. (2016). Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome. *Journal of Medical Ethics*. doi:10.1136/medethics-2016-103691
- Bourassa, D. (2012). Examining self-protection measures guarding adult protective services social workers against compassion fatigue. *Journal of interpersonal violence*, 27(9), 1699-1715, doi.org/10.1177/0886260511430388
- Bourke, L. (2009). Reflections on doing participatory research in health: participation, method and power. *International Journal of Social Research Methodology*, 12(5), 457-474. doi:10.1080/13645570802373676
- Bows, H. (2018). Practitioner views on the impacts, challenges, and barriers in supporting older survivors of sexual violence. *Violence against women*, 24(9), 1070-1090, doi.org/10.1177/1077801217732348
- Bows, H., & Westmarland, N. (2015). Rape of older people in the United Kingdom: Challenging the 'real-rape' stereotype. *British Journal of Criminology*, 57(1), 1-17, doi.org/10.1093/bjc/azv116
- Boyatzis, R. E. (1998). Thematic analysis and code development: Transforming qualitative information.
- Bradbury-Jones, C., & Clark, M. (2016). Intimate partner violence and the role of community nurses. *Primary Health Care* (2014+), 26(9), 42.
- Bradbury-Jones, C., & Taylor, J. (2015). Engaging with children as co-researchers: challenges, counter-challenges and solutions. *International Journal of Social Research Methodology*, 18(2), 161-173. doi:10.1080/13645579.2013.864589
- Bradbury-Jones, C., Breckenridge, J., Clark, M. T., Herber, O. R., Wagstaff, C., & Taylor, J. (2017). The state of qualitative research in health and social science literature: a focused mapping review and synthesis. *International Journal of Social Research Methodology*, 1-19. doi.org/10.1080/13645579.2016.1270583
- Bradbury-Jones, C., Taylor, J., & Herber, O. R. (2014). Vignette development and administration: a framework for protecting research participants. *International Journal of Social Research Methodology*, 17(4), 427-440, doi.org/10.1080/13645579.2012.750833
- Bradbury-Jones, C., Taylor, J., Kroll, T., & Duncan, F. (2014). Domestic abuse awareness and recognition among primary healthcare practitioners and abused women: a qualitative investigation. *Journal of clinical nursing*, 23(21-22), 3057-3068, doi.org/10.1111/jocn.12534
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101, doi: 10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-being*, 9, doi: 10.3402/qhw.v9.26152

- Braye, S., & McDonnell, L. (2013). Balancing powers: university researchers thinking critically about participatory research with young fathers. *Qualitative Research*, 13(3), 265-284. doi:10.1177/1468794112451012
- Brett, J., Staniszevska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities. *The Patient - Patient-Centered Outcomes Research*, 7(4), 387-395, doi.org/10.1111/j.1369-7625.2012.00795.x
- Brondani, M. A., MacEntee, M. I., Bryant, S. R., & O'Neill, B. (2008). Using Written Vignettes in Focus Groups Among Older Adults to Discuss Oral Health as a Sensitive Topic. *Qualitative Health Research*, 18(8), 1145-1153, doi.org/10.1177/1049732308320114
- Brossoie, N., & Roberto, K. A. (2015). Community professionals' response to intimate partner violence against rural older women. *Journal of elder abuse & neglect*, 27(4-5), 470-488, doi.org/10.1177/1077801213517564
- Brown, H. (2011). The role of emotion in decision-making. *The Journal of Adult Protection*, 13(4), 194-202, doi.org/10.1108/14668201111177932
- Buchanan, F., & Wendt, S. (2018). Opening doors: Women's participation in feminist studies about domestic violence. *Qualitative social work*, 17(6), 762-777, doi.org/10.1177/1473325017694081
- Buchman, D. Z., Ho, A., & Goldberg, D. S. (2017). Investigating trust, expertise, and epistemic injustice in chronic pain. *Journal of bioethical inquiry*, 14(1), 31-42, doi.org/10.1007/s11673-016-9761-x
- Burr, V. (1998). Overview: Realism, relativism, social constructionism and discourse. *Social constructionism, discourse and realism*, 13-26
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182, doi.org/10.1111/1467-9566.ep11339939
- Butler, L., & Manthorpe, J. (2016). Putting people at the centre: facilitating Making Safeguarding Personal approaches in the context of the Care Act 2014. *The Journal of Adult Protection*, 18(4), 204-213, doi.org/10.1108/JAP-03-2016-0003
- Cahill, S., & Shapiro, M. (1993). 'I think he might have hit me once': Aggression towards caregivers in dementia care. *Australian Journal on Ageing*, 12(4), 10-15. Retrieved from: <https://www.researchgate.net/>
- Carel, H., & Györfy, G. (2014). Seen but not heard: children and epistemic injustice. *The Lancet*, 384(9950), 1256-1257, doi.org/10.1016/S0140-6736(14)61759-1
- Carmichael, F., & Ercolani, M. G. (2016). Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes. *Social Science & Medicine*, 156, 1-11, doi.org/10.1016/j.socscimed.2016.03.020
- Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative health research*, 17(10), 1316-1328 doi: 10.1177/1049732307306927
- Catalani, C., & Minkler, M. (2010). Photovoice: A Review of the Literature in Health and Public Health. *Health Education & Behavior*, 37(3), 424-451. doi:10.1177/1090198109342084

- Chamberlayne, P., & King, A. (1997). The biographical challenge of caring. *Sociology of Health & Illness*, 19(5), 601-621, doi.org/10.1111/j.1467-9566.1997.tb00422.x
- Chan, T. S., Teram, E., & Shaw, I. (2017). Balancing methodological rigor and the needs of research participants: A debate on alternative approaches to sensitive research. *Qualitative health research*, 27(2), 260-270, doi.org/10.1177/1049732315605272
- Chapple, A., Ziebland, S., & Hawton, K. (2015). Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death. *Sociology of health & illness*, 37(4), 610-625, doi.org/10.1111/1467-9566.12224
- Charmaz, K. (2011). Grounded theory methods in social justice research. *The Sage handbook of qualitative research*, 4(1), 359-380
- Clark, T. (2010). On 'being researched': why do people engage with qualitative research? *Qualitative Research*, 10(4), 399-419, doi.org/10.1177/1468794110366796
- Clark, T. (2011). Gaining and Maintaining Access: Exploring the Mechanisms that Support and Challenge the Relationship between Gatekeepers and Researchers. *Qualitative Social Work*, 10(4), 485-502. doi:10.1177/1473325009358228
- Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, 26(2), 120-123, retrieved from: <http://eprints.uwe.ac.uk/21155>
- Cohen, D. (2004). Violent Deaths and Dementia. *Journal of Mental Health and Aging*, 10(2), 83-86.
- Cooper, A., & Bruin, C. (2017). Adult safeguarding and the Care Act (2014)—the impacts on partnerships and practice. *The Journal of Adult Protection*, 19(4), 209-219, doi.org/10.1108/JAP-03-2017-0009
- Cooper, A., Briggs, M., Lawson, J., Hodson, B., Wilson, M., Belderson, P., ... & Cocker, R. (2016). Making Safeguarding Personal: Temperature Check 2016. Association of Directors of Adult Social Services, retrieved from: <https://www.adass.org.uk/media/5453/making-safeguarding-personal-temperature-check-2016.pdf>
- Cooper, C., Selwood, A., & Livingston, G. (2008). The prevalence of elder abuse and neglect: a systematic review. *Age and Ageing*, 37(2), 151-160. doi:10.1093/ageing/afm194
- Cooper, C., Selwood, A., Blanchard, M., & Livingston, G. (2010). Abusive behavior experienced by family carers from people with dementia: the CARD (caring for relatives with dementia) study. *Journal of Neurology, Neurosurgery & Psychiatry*, 81(6), 592-596. doi: 10.1136/jnnp.2009.190934
- Cornwall, A. (2008). Unpacking 'Participation': models, meanings and practices. *Community Development Journal*, 43(3), 269-283, doi.org/10.1093/cdj/bsn010
- Cornwall, A. (2008). Unpacking 'Participation': models, meanings and practices. *Community Development Journal*, 43(3), 269-283. doi:10.1093/cdj/bsn010
- Coulter, A. (2011). *Engaging patients in healthcare*. Maidenhead: Open University Press.
- Coyne, A., Reichamn, W. & Berbig, L. (1993) The relationship between dementia and elder abuse. *The American Journal of Psychiatry*, 150(4), 643. Retrieved from: <http://ajp.psychiatryonline.org/loi/loi/ajp>

Critical Appraisal Skills Programme (CASP), Ten questions to help you make sense of qualitative research. Retrieved from:

http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf.

Crockett, C., Cooper, B., & Brandl, B. (2018). Intersectional Stigma and Late-Life Intimate-Partner and Sexual Violence: How Social Workers Can Bolster Safety and Healing for Older Survivors. *British Journal of Social Work*, 48(4), 1000-1013, doi.org/10.1093/bjsw/bcy049

Daniel, B., & Bowes, A. (2010). Re-Thinking Harm and Abuse: Insights from a Lifespan Perspective. *British Journal of Social Work*. doi: 10.1093/bjsw/bcq116

Darawsheh, W. (2014). Reflexivity in research: Promoting rigour, reliability and validity in qualitative research. *International Journal of Therapy and Rehabilitation*, 21(12), 560-568, doi.org/10.12968/ijtr.2014.21.12.560

Decker, S., Naugle, A., Carter-Visscher, R., Bell, K., & Seifert, A. (2011). Ethical Issues in Research on Sensitive Topics: Participants' Experiences of Distress and Benefit. *Journal of Empirical Research on Human Research Ethics: An International Journal*, 6(3), 54-64, doi: 10.1525/jer.2011.6.3.55

Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in nursing & health*, 39(6), 480-490, doi.org/10.1002/nur.21743

Department of Health and Social Care (2016) Factsheet 7: Protection adults from abuse and neglect. Retrieved from: <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-7-protecting-adults-from-abuse-or-neglect>

Department of Health and Social Care (2018) Care and support statutory guidance. Retrieved from: <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1>

Department of Health. (2000). No secrets. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/194272/No_secrets_guidance_on_developing_and_implementing_multi-agency_policies_and_procedures_to_protect_vulnerable_adults_from_abuse.pdf

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral Disturbance in Dementia. *Current Psychiatry Reports*, 14(4), 298-309. doi:10.1007/s11920-012-0288-5.

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2009). Researching sensitive topics: qualitative research as emotion work. *Qualitative Research*, 9(1), 61-79. doi:10.1177/1468794108098031

Dixon, J., Biggs, S., Stevens, M., Manthorpe, J., & Tinker, A. (2013). Defining the "perpetrator": abuse, neglect and dignity in care. *The Journal of Adult Protection*, 15(1), 5-14. doi: doi:10.1108/14668201311299872

Dotson, K. (2011). Tracking Epistemic Violence, Tracking Practices of Silencing. *Hypatia*, 26(2), 236-257. doi:10.1111/j.1527-2001.2011.01177.x

Doyle, S. (2013). Reflexivity and the capacity to think. *Qualitative Health Research*, 23(2), 248-255, doi.org/10.1177/1049732312467854

- Drake, G. (2014). The ethical and methodological challenges of social work research with participants who fear retribution: To 'do no harm'. *Qualitative Social Work*, 13(2), 304-319, doi.org/10.1177/1473325012473499
- Dunn, M. C., Clare, I. C., & Holland, A. J. (2008). To empower or to protect? Constructing the 'vulnerable adult' in English law and public policy. *Legal Studies*, 28(2), 234-253
- Dupuis, S. L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies*, 26(2), 162-173, doi, 10.1016/j.jaging.2011.12.001
- Duxbury, J., Pulsford, D., Hadi, M., & Sykes, S. (2013). Staff and relatives' perspectives on the aggressive behavior of older people with dementia in residential care: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 20(9), 792-800. doi:10.1111/jpm.12018.
- Edvardsson, B., Tronvoll, B., & Gruber, T. (2011). Expanding understanding of service exchange and value co-creation: a social construction approach. *Journal of the Academy of Marketing Science*, 39(2), 327-339, doi.org/10.1007/s11747-010-0200-y
- Eisikovits, Z., Koren, C., & Band-Winterstein, T. (2013). The social construction of social problems: the case of elder abuse and neglect. *International psychogeriatrics*, 25(8), 1291-1298, doi.org/10.1017/S1041610213000495
- Elder-Vass, D. (2012). Towards a realist social constructionism. *Sociologia, problemas e práticas*, (70), 5-24., retrieved from: <http://www.scielo.mec.pt/pdf/spp/n70/n70a01.pdf>
- Emanuel, E. J., Fairclough, D. L., Wolfe, P., & Emanuel, L. L. (2004). Talking with terminally ill patients and their caregivers about death, dying, and bereavement: is it stressful? Is it helpful?. *Archives of internal medicine*, 164(18), 1999-2004, doi:10.1001/archinte.164.18.1999
- Enmarker, I., Olsen, R., & Hellzen, O. (2011). Management of person with dementia with aggressive and violent behavior: a systematic literature review. *International Journal of Older People Nursing*, 6(2), 153-162. doi:10.1111/j.1748-3743.2010.00235.x.
- Evans, R., Ribbens McCarthy, J., Bowlby, S., Wouango, J., & Kébé, F. (2017). Producing emotionally sensed knowledge? Reflexivity and emotions in researching responses to death. *International Journal of Social Research Methodology*, 20(6), 585-598, doi.org/10.1080/13645579.2016.1257679
- FalsBorda, O. (2001). Participatory (action) research in social theory: Origins and challenges, pp. 27-37, in Reason, P., & Bradbury, H. (Eds.). (2001). *Handbook of action research: Participative inquiry and practice*. Sage
- Fawcett, B., & Hearn, J. (2004). Researching others: epistemology, experience, standpoints and participation. *International Journal of Social Research Methodology*, 7(3), 201-218, doi.org/10.1080/13645570210163989
- Featherstone, B. (2000). Researching into mothers' violence: Some thoughts on the process, in Fawcett, B. et al, *Practice and Research in Social Work: Postmodern Feminist Perspectives*, pp. 10 – 35, London: Routledge.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods*, 5(1), 80-92, doi.org/10.1177/160940690600500107

- Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & society*, 25(4), 601-621, doi.org/10.1017/S0144686X05003600
- Finfgeld-Connett, D. (2014). Intimate Partner Abuse Among Older Women: Qualitative Systematic Review. *Clinical Nursing Research*, 23(6), 664-683. doi: 10.1177/1054773813500301
- Finlay, L. (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative research*, 2(2), 209-230, doi.org/10.1177/146879410200200205
- Fisher, M. (1994). Man-made care: Community care and older male carers. *The British Journal of Social Work*, 24(6), 659-680, retrieved from: <https://www.jstor.org/stable/pdf/23709738.pdf>
- Fook, J. (2002). Theorizing from practice: Towards an inclusive approach for social work research. *Qualitative Social Work*, 1(1), 79-95. <https://doi.org/10.1177/147332500200100106>
- Forbat, L. (2005). Talking about care: Two sides to the story. Policy Press.
- Freeman, L. (2015). Confronting Diminished Epistemic Privilege and Epistemic Injustice in Pregnancy by Challenging a "Panoptics of the Womb". *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 40(1), 44-68. doi:10.1093/jmp/jhu046
- Fricker, M. (2006). Powerlessness and social interpretation. *Episteme*, 3(1-2), 96-108. doi.org/10.3366/epi.2006.3.1-2.96
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*: Oxford University Press.
- Fricker, M. (2010). Replies to Alcoff, Goldberg, and Hookway on epistemic injustice. *Episteme*, 7(2), 164-178. doi.org/10.3366/E1742360010000894
- Fricker, M. (2015). Epistemic Contribution as a Central Human Capability in, Mills, C.,
- Frith, H., & Gleeson, K. (2004). Clothing and Embodiment: Men Managing Body Image and Appearance. *Psychology of Men & Masculinity*, 5(1), 40. DOI: 10.1037/1524-9220.5.1.40
- Gabb, J. (2010). Home truths: ethical issues in family research. *Qualitative Research*, 10(4), 461-478. doi: 10.1177/1468794110366807
- Gergen, K. (2001). *Constructionism and realism: a necessary collision*. Social construction in context. London: Sage.
- Gooberman-Hill, R. (2014). Defining evidence: Involvement and participatory approaches in applied health research. *Anthropology in Action*, 21(2), 31-36. doi: <http://dx.doi.org/10.3167/aia.2014.210205>
- Gormley, N., Lyons, D., & Howard, R. (2001). Behavioral management of aggression in dementia: a randomized controlled trial. *Age and Ageing*, 30(2), 141-145. doi:10.1093/ageing/30.2.141
- Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26(2), 91-108. doi: 10.1111/j.1471-1842.2009.00848.x

Gringeri, C., Barusch, A., & Cambron, C. (2013). Epistemology in qualitative social work research: A review of published articles, 2008–2010. *Social work research*, 37(1), 55-63, doi.org/10.1093/swr/svs032

Gristy, C. (2015). Engaging with and moving on from participatory research: A personal reflection. *International Journal of Research & Method in Education*, 38(4), 371-387. doi:10.1080/1743727X.2014.940306

Grix, J. (2002). Introducing Students to the Generic Terminology of Social Research. *Politics*, 22(3), 175-186, doi.org/10.1111/1467-9256.00173

Hacking, I. (1999). *The social construction of what?* : Harvard university press.

Hamel, M., Gold, D. P., Andres, D., Reis, M., Dastoor, D., Grauer, H., & Bergman, H. (1990). Predictors and Consequences of Aggressive Behavior by Community-Based Dementia Patients. *The Gerontologist*, 30(2), 206-211. doi: 10.1093/geront/30.2.206

Hannes, K., & Macaitis, K. (2012). A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qualitative Research*, 12(4), 402-442. doi: 10.1177/1468794111432992

Harden, A. (2010). Mixed-methods systematic reviews: Integrating quantitative and qualitative findings. *Focus: A Publication of the National Center for the Dissemination of Disability Research (NCDDR) Technical Brief*, (25), retrieved from: http://ktddr.org/ktlibrary/articles_pubs/ncddrwork/focus/focus25/Focus25.pdf

Hardy, M. (2016). 'I know what I like and I like what I know': Epistemology in practice and theory and practice again. *Qualitative Social Work*, 15(5-6), 762-778, retrieved from: doi.org/10.1177/1473325016654962

Held, V. (2010). Can the ethics of care handle violence? *Ethics and Social Welfare*, 4(2), 115-129, doi.org/10.1080/17496535.2010.484256

Herron, R. V., & Rosenberg, M. W. (2017). Responding to aggression and reactive behaviours in the home. *Dementia*, 1471301217699676, doi.org/10.1177/1471301217699676

Hewison, A., & Sawbridge, Y. (Eds.). (2016). *Compassion in Nursing: Theory, Evidence and Practice*. Macmillan International Higher Education.

Hewison, A., & Sim, J. (1998). Managing interpractitioner working: using codes of ethics as a foundation. *Journal of Interpractitioner Care*, 12(3), 309-321, doi.org/10.3109/13561829809014122

Hewison, A., Gale, N., & Shapiro, J. (2012). Co-production in research: some reflections on the experience of engaging practitioners in health research. *Public Money & Management*, 32(4), 297-302. doi:10.1080/09540962.2012.691311

Higgs, A., & Hafford-Letchfield, T. (2018). 'At what cost? the impact of UK long-term care funding policies on social work practice with older people': a literature review. *Ethics and Social Welfare*, 1-15, doi.org/10.1080/17496535.2018.1505931

Hockley, J., Harrison, J. K., Watson, J., Randall, M., & Murray, S. (2016). Fixing the broken image of care homes could a 'care home innovation centre' be the answer?. *Age and ageing*, 46(2), 175-178, doi.org/10.1093/ageing/afw154

- Hooker, L., Small, R., Humphreys, C., Hegarty, K., & Taft, A. (2015). Applying normalization process theory to understand implementation of a family violence screening and care model in maternal and child health nursing practice: a mixed method process evaluation of a randomised controlled trial. *Implementation science*, 10(1), 39, doi.org/10.1186/s13012-015-0230-4
- Hookway, C. (2010). Some varieties of epistemic injustice: Reflections on Fricker. *Episteme*, 7(2), 151-163. doi.org/10.3366/E1742360010000882
- Horrell, B., Stephens, C., & Breheny, M. (2015). Online Research with Informal Caregivers: Opportunities and Challenges. *Qualitative Research in Psychology*, 12(3), 258-271. doi:10.1080/14780887.2015.1040318
- Houston, S. (2001). Beyond social constructionism: Critical realism and social work. *British Journal of Social Work*, 31(6), 845-861, retrieved from: <https://www.jstor.org/stable/pdf/23716466.pdf>
- Hsu, M.-C., & Tu, C.-H. (2014). Adult patients with schizophrenia using violence towards their parents: a phenomenological study of views and experiences of violence in parent-child dyads. *Journal of Advanced Nursing*, 70(2), 336-349. doi:10.1111/jan.12194
- Huang, H.-L., Shyu, Y.-I. L., Chen, S.-T., & Hsu, W.-C. (2009). Carer self-efficacy for managing behavioral problems of older people with dementia in Taiwan correlates with care receivers' behavioral problems. *Journal of Clinical Nursing*, 18(18), 2588-2595. doi: 10.1111/j.1365-2702.2008.02547.x
- Hughes, M. (1997). "That Triggers Me Right Off": Factors Influencing Abuse and Violence in Older People's Care-giving Relationships. *Australian Journal on Ageing*, 16(2), 53-60. doi: 10.1111/j.1741-6612.1997.tb01027.x
- INVOLVE, National Institute of Health Research (2015). Public involvement in research: Values and principles framework. Retrieved from <http://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf>
- Isham, L., Bradbury-Jones, C., & Hewison, A. (2018). Reflections on engaging with an advisory network in the context of a 'sensitive' research study. *International Journal of Social Research Methodology*, 1-13, retrieved from: doi.org/10.1080/13645579.2018.1494971
- Isham, L., Hewison, A., & Bradbury-Jones, C. (2017). When older people are violent or abusive toward their family caregiver: a review of mixed-methods research, *Trauma, Violence, & Abuse*, 1524838017726425
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: policy recommendations for promoting a partnership approach in health research. *Education for health*, 14(2), 182-197, retrieved from: https://depts.washington.edu/ccph/pdf_files/EducforHealthIsrael.pdf
- Jackson, D. (2003). Broadening constructions of family violence: mothers' perspectives of aggression from their children. *Child & Family Social Work*, 8(4), 321-329. doi:10.1046/j.1365-2206.2003.00298.x
- Joanna Briggs Institute, University of Adelaide (2014) The Joanna Briggs Institute Reviewers' Manual 2014: JBI methodology for mixed-methods systematic reviews, University of Adelaide. Retrieved from:

http://joannabriggs.org/assets/docs/sumari/ReviewersManual_Mixed-Methods-Review-Methods-2014-ch1.pdf

Joffe, H. (2012). Thematic analysis, in *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*, edited by David Harper and Andrew Thompson, Chichester: Wiley-Blackwell, 2012, pp. 209-223

Jönson, H. (2016). Framing scandalous nursing home care: what is the problem?. *Ageing & Society*, 36(2), 400-419, doi.org/10.1017/S0144686X14001287

Jorm, A. F. (2015). Using the Delphi expert consensus method in mental health research. *Australian & New Zealand Journal of Psychiatry*, 49(10), 887-897, doi.org/10.1177/0004867415600891

Kalman, H., Lövgren, V., & Sauer, L. (2016). Epistemic injustice and conditioned experience: the case of intellectual disability. *Wagadu: a Journal of Transnational Women's and Gender Studies*, 15, 63-81, retrieved from: http://www.academia.edu/34954804/Epistemic_Injustice_in_Practice_Special_Issue_in_Wagadu._A_Journal_of_Transnational_Women_s_and_Gender_Studies_H._15_2016_http_webhost1.cortland.edu_wagadu

Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power Relations in Qualitative Research. *Qualitative Health Research*, 19(2), 279-289, retrieved from: doi.org/10.1177/1049732308329306

Kelly, L., & Westmarland, N. (2016). Naming and defining 'domestic violence': Lessons from research with violent men. *Feminist review*, 112(1), 113-127, doi.org/10.1057/fr.2015.52

Kelly, M. (2009). The role of theory in qualitative health research. *Family Practice*, 27(3), 285-290. doi.org/10.1093/fampra/cmp077

Kidd, I. J., & Carel, H. (2017). Epistemic Injustice and Illness. *Journal of Applied Philosophy*, 34(2), 172-190. doi:10.1111/japp.12172

Kittay, E. F. (2009). The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy*, 40(3-4), 606-627, retrieved from: <https://www.jstor.org/stable/pdf/24439804.pdf>

Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), 49-58, doi.org/10.1111/j.1467-9337.2010.00473.x

Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of health & illness*, 16(1), 103-121, doi.org/10.1111/1467-9566.ep11347023

Koch, T. (2006). Establishing rigour in qualitative research: the decision trail. *Journal of advanced nursing*, 53(1), 91-100, doi.org/10.1111/j.1365-2648.2006.03681.x

Koenig, T. L., Rinfrette, E. S., & Lutz, W. A. (2006). Female carers' reflections on ethical-decision making: the intersection of domestic violence and elder care, *Clinical Social Work Journal*, 34(3), 361-372. doi: 10.1007/s10615-005-0023-3

Kothari, A., MacLean, L., & Edwards, N. (2009). Increasing capacity for knowledge translation: understanding how some researchers engage policy makers. *Evidence & Policy: A Journal of Research, Debate and Practice*, 5(1), 33-51, doi:10.1332/174426409X395402

- Knezevic, Z. (2017). Amoral, im/moral and dis/loyal: Children's moral status in child welfare. *Childhood*, 24(4), 470-484, doi.org/10.1177/0907568217711742
- Kurs, R., & Grinshpoon, A. (2018). Vulnerability of individuals with mental disorders to epistemic injustice in both clinical and social domains. *Ethics & Behavior*, 28(4), 336-34, doi.org/10.1080/10508422.2017.1365302
- Kyratsous, M., & Sanati, A. (2017). Epistemic injustice and responsibility in borderline personality disorder. *Journal of evaluation in clinical practice*, 23(5), 974-980.
- Lab, D. D., Feigenbaum, J. D., & De Silva, P. (2000). Mental health professionals' attitudes and practices towards male childhood sexual abuse. *Child abuse & neglect*, 24(3), 391-409, doi.org/10.1016/S0145-2134(99)00152-0
- Larkin, M., & Milne, A. (2014). Carers and Empowerment in the UK: A Critical Reflection. *Social Policy and Society*, 13(1), 25-38. doi:10.1017/S1474746413000262
- Larkin, M., Henwood, M., & Milne, A. (2018). Carer-related research and knowledge: Findings from a scoping review. *Health & social care in the community*, doi.org/10.1111/hsc.12586
- Lazenbatt, A., Devaney, J., & Gildea, A. (2013). Older women living and coping with domestic violence. *Community practitioner*, 86(2).
- Lewis, A. (2010). Silence in the context of 'child voice'. *Children & Society*, 24(1), 14-23, doi.org/10.1111/j.1099-0860.2008.00200.x
- Lewis, A., Parsons, S., Robertson, C., Feiler, A., Tarleton, B., Watson, D., . . . Marvin, C. (2008). Participation in research: Reference, or advisory, groups involving disabled people: reflections from three contrasting research projects. *British Journal of Special Education*, 35(2), 78-84. doi:10.1111/j.1467-8578.2008.00376.x
- Lewis, J. M. (2006). Being around and knowing the players: networks of influence in health policy. *Social science & medicine*, 62(9), 2125-2136, doi.org/10.1016/j.socscimed.2005.10.004
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P., ... & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLoS medicine*, 6(7), e1000100, doi.org/10.1371/journal.pmed.1000100
- Lloyd, L. (2000). Caring about carers: only half the picture?. *Critical Social Policy*, 20(1), 136-150, retrieved from: <https://journals.sagepub.com/doi/pdf/10.1177/026101830002000106>
- Local Government Association (2015) Making safeguarding personal: A toolkit for responses Fourth Edition January 2015. https://www.adass.org.uk/media/5142/making-safeguarding-personal_a-toolkit-for-responses_4th-edition-2015.pdf
- Local Government Association (2017) Making safeguarding personal materials, Local Government Association, London. Available from: https://www.local.gov.uk/sites/default/files/documents/25%2026%20-%20Chip_MSP%20Safeguarding%20Adults%20Boards_WEB.PDF
- Locock, L., & Boaz, A. (2004). Research, policy and practice—worlds apart?. *Social Policy and Society*, 3(4), 375-384, doi.org/10.1017/S1474746404002003

- Locock, L., Boylan, A.-M., Snow, R., & Staniszewska, S. (2016). The power of symbolic capital in patient and public involvement in health research. *Health Expectations*, doi:10.1111/hex.12519
- Lonbay, S. 'These Are Vulnerable People Who Don't Have a Voice': Exploring Constructions of Vulnerability and Ageing in the Context of Safeguarding Older People, *The British Journal of Social Work*, Volume 48, Issue 4, 1 June 2018, Pages 1033–1051, doi.org/10.1093/bjsw/bcy045
- Lundy, M., & Grossman, S. F. (2004). Elder Abuse: Spouse/Intimate Partner Abuse and Family Violence Among Elders. *Journal of Elder Abuse & Neglect*, 16(1), 85-102. doi:10.1300/J084v16n01_05
- Lynch, K. (2007). Love labour as a distinct and non-commodifiable form of care labour. *The Sociological Review*, 55(3), 550-570, doi.org/10.1111/j.1467-954X.2007.00714.x
- Mackay, K. (2017). Choosing to live with harm? A presentation of two case studies to explore the perspective of those who experienced adult safeguarding interventions. *Ethics and Social Welfare*, 11(1), 33-46, doi.org/10.1080/17496535.2017.1280069
- Mahon, M., Devaney, J., & Lazenbatt, A. (2009). The role of theory in promoting social work values and its potential effect on outcomes in work with domestically violent men. *Irish Probation Journal*, 6, 151-170, retrieved from: https://www.researchgate.net/profile/Fergus_McNeill/publication/46571626_Probation_rehabilitation_and_reparation/links/02e7e52336c256e303000000.pdf#page=154
- Mantoura, P., & Potvin, L. (2013). A realist–constructionist perspective on participatory research in health promotion. *Health Promotion International*, 28(1), 61-72. doi:10.1093/heapro/das037
- Mathie, E., Wilson, P., Poland, F., McNeilly, E., Howe, A., Staniszewska, S., . . . Goodman, C. (2014). Consumer involvement in health research: a UK scoping and survey. *International Journal of Consumer Studies*, 38(1), 35-44. doi:10.1111/ijcs.12072
- Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *BMJ*, 320(7226), 50-52, doi:10.1136/bmj.320.7226.50
- McCarry, M. (2012). Who benefits? A critical reflection of children and young people's participation in sensitive research. *International Journal of Social Research Methodology*, 15(1), 55-68, doi.org/10.1080/13645579.2011.568196
- McClinton Appollis, T., Lund, C., de Vries, P. J., & Mathews, C. (2015). Adolescents' and Adults' Experiences of Being Surveyed About Violence and Abuse: A Systematic Review of Harms, Benefits, and Regrets. *Am J Public Health*, 105(2), e31-45. doi:10.2105/ajph.2014.302293.
- McDonald, L., & Thomas, C. (2013). Elder abuse through a life course lens. *International Psychogeriatrics*, 25(8), 1235-1243. doi: 10.1017/S104161021300015X
- McGarry, J., & Simpson, C. (2011). Domestic abuse and older women: exploring the opportunities for service development and care delivery. *The Journal of Adult Protection*, 13(6), 294-301, doi.org/10.1108/14668201111194203

- McGarry, J., Simpson, C., & Hinsliff-Smith, K. (2014). An exploration of service responses to domestic abuse among older people: findings from one region of the UK. *The Journal of Adult Protection*, 16(4), 202-212, doi.org/10.1108/JAP-08-2013-0036
- McGovern, J. (2011). Couple meaning-making and dementia: Challenges to the deficit model. *Journal of Gerontological Social Work*, 54(7), 678-690, doi.org/10.1080/01634372.2011.593021
- McLaughlin, H., Robbins, R., Bellamy, C., Banks, C., & Thackray, D. (2018). Adult social work and high-risk domestic violence cases. *Journal of Social Work*, 18(3), 288-306, doi.org/10.1177/1468017316653268
- Medina, J. (2013). *The epistemology of resistance: Gender and racial oppression, epistemic injustice, and the social imagination*. Oxford University Press.
- Michailakis, D., & Schirmer, W. (2014). Social work and social problems: A contribution from systems theory and constructionism. *International journal of social welfare*, 23(4), 431-442, doi.org/10.1111/ijsw.12091
- Miles, C., & Condry, R. (2015). Responding to adolescent to parent violence: Challenges for policy and practice. *British Journal of Criminology*, 55(6), 1076-1095, doi.org/10.1080/10439463.2014.989158
- Miller, W. R., & Rollnick, S. (2012). *Motivational interviewing: Helping people change*. Guilford press.
- Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing & Society*, 31(3), 422-437. doi:10.1017/S0144686X10001066
- Momtaz, Y., Hamid, T. A., & Ibrahim, R. (2013). Theories and measures of elder abuse. *Psychogeriatrics*, 13(3), 182-188. doi:10.1111/psyg.12009
- Montgomery, L., & McKee, J. (2017). Adult safeguarding in Northern Ireland: prevention, protection, partnership. *The Journal of Adult Protection*, 19(4), 199-208, doi.org/10.1108/JAP-03-2017-0011
- Moore, T., Noble-Carr, D., & McArthur, M. (2016). Changing things for the better: the use of children and young people's reference groups in social research. *International Journal of Social Research Methodology*, 19(2), 241-256. doi:10.1080/13645579.2014.989640
- Morbey, H. (2002). Older women's understanding of elder abuse: quality relationships and the 'stresses of caregiving'. *The Journal of Adult Protection*, 4(3), 4-13. doi.org/10.1108/14668203200200017
- Morrow, S. L., & Smith, M. L. (1995). Constructions of survival and coping by women who have survived childhood sexual abuse. *Journal of Counseling Psychology*, 42(1), 24, retrieved from: https://www.researchgate.net/profile/Susan_Morrow2/publication/232457341_Constructions_of_Survival_and_Coping_by_Women_Who_Have_Survived_Childhood_Sexual_Abuse/links/541341680cf2fa878ad3d784.pdf
- Mulla, A., Hewison, A., & Shapiro, J. (2014). The importance of clinical leadership in service redesign: experience in three english national health service hospitals. *International*

Journal of Leadership in Public Services, 10(3), 126-141, doi.org/10.1108/IJLPS-03-2014-0001

Munro, E. (2005). Improving practice: Child protection as a systems problem. *Children and Youth Services Review*, 27(4), 375-391, doi.org/10.1016/j.childyouth.2004.11.006

Murris, K. (2013). The epistemic challenge of hearing child's voice. *Studies in Philosophy and Education*, 32(3), 245-259.

Myhill, A. (2017). Measuring domestic violence: context is everything. *Journal of gender-based violence*, 1(1), 33-44, doi.org/10.1332/239868017X14896674831496

National Audit Office (2018) Financial sustainability of local authorities 2018. Retrieved from: <https://www.nao.org.uk/wp-content/uploads/2018/03/Financial-sustainability-of-local-authorities-2018.pdf>

National Institute of Clinical Excellence, (NICE) (2012). Methods for the development of public health guidance: Appendix C quality appraisal guidelines. Retrieved from: <http://www.nice.org.uk/process/pmg4/chapter/introduction>.

Naughton, C., Drennan, J., Lyons, I., & Lafferty, A. (2013). The relationship between older people's awareness of the term elder abuse and actual experiences of elder abuse. *International psychogeriatrics*, 25(8), 1257-1266, doi.org/10.1017/S1041610213000513

Newton, V. L. (2017). 'It's good to be able to talk': An exploration of the complexities of participant and researcher relationships when conducting sensitive research. *Women's Studies International Forum*, 61, 93-99. doi:https://doi.org/10.1016/j.wsif.2016.11.011

NHS Digital (2017) Safeguarding Adults collection (2016-17). Retrieved from: <https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults/2016-17>

Nicolini, D., Powell, J., Conville, P., & Martinez-Solano, L. (2008). Managing knowledge in the healthcare sector. A review. *International Journal of Management Reviews*, 10(3), 245-263. doi:10.1111/j.1468-2370.2007.00219.x

Nightingale, D. J., & Cromby, J. (2002). Social Constructionism as Ontology: Exposition and Example. *Theory & Psychology*, 12(5), 701-713, doi.org/10.1177/0959354302012005901

Nind, M. (2014). What is inclusive research? London: Bloomsbury Academic.

O'Leary, D., Jyringi, D., & Sedler, M. (2005). Childhood conduct problems, stages of Alzheimer's disease, and physical aggression against carers. *International Journal of Geriatric Psychiatry*, 20(5), 401-405. doi: 10.1002/gps.1293

Origg, G. (2012). Epistemic injustice and epistemic trust. *Social Epistemology*, 26(2), 221-235. doi.org/10.1080/02691728.2011.652213

Padgett, D. K. (2016). Qualitative methods in social work research (Vol. 36). Sage Publications.

- Parker, J., & Ashencaen Crabtree, S. (2014). Covert research and adult protection and safeguarding: an ethical dilemma?. *The Journal of Adult Protection*, 16(1), 29-40, doi.org/10.1108/JAP-07-2013-0029
- Parkinson, K., Pollock, S., & Edwards, D. (2018). Family Group Conferences: An Opportunity to Re-Frame Responses to the Abuse of Older People?. *British Journal of Social Work*, 48(4), 1109-1126, doi.org/10.1093/bjsw/bcy048
- Paveza, G. J., Cohen, D., Eisdorfer, C., Freels, S., Semla, T., Ashford, J. W., Gorelick, P., Hirschman, R., Luchins, D & Levy, P. (1992). Severe Family Violence and Alzheimer's Disease: Prevalence and Risk Factors. *The Gerontologist*, 32(4), 493-497. doi: 10.1093/geront/32.4.493
- Peter, E. (2015). The ethics in qualitative health research: Special considerations. . *Ciência & Saúde Coletiva*, 20(9), 2625-2630. doi:http://dx.doi.org/10.1590/1413-81232015209.06762015.
- Phillips, L. R., de Ardon, E. T., & Briones, G. S. (2001). Abuse of Female Carers by Care Recipients: Another Form of Elder Abuse. *Journal of Elder Abuse & Neglect*, 12(3-4), 123-143. doi: 10.1300/J084v12n03_06
- Pickard, S. (2010). The 'good carer': Moral practices in late modernity. *Sociology*, 44(3), 471-487, doi.org/10.1177/0038038510362482
- Pickering, C. E. Z., Moon, A., Pieters, H. C., Menten, J. C., & Phillips, L. R. (2014). Relationship management strategies for daughters in conflicted relationships with their ageing mothers. *Journal of Advanced Nursing*, 71(3), 609-619. doi: 10.1111/jan.12547
- Pilgrim, D. (2017). The Perils of Strong Social Constructionism: The Case of Child Sexual Abuse. *Journal of Critical Realism*, 16(3), 268-283. doi.org/10.1080/14767430.2017.1303928
- Pillemer, K., & Suitor, J. J. (1992). Violence and Violent Feelings: What Causes Them Among Family Carers? *Journal of Gerontology*, 47(4), S165-S172. doi: 10.1093/geronj/47.4.S165
- Pillemer, K., Burnes, D., Riffin, C., & Lachs, M. S. (2016). Elder Abuse: Global Situation, Risk Factors, and Prevention Strategies. *Gerontologist*, 56, S194-S205. doi: 10.1093/geront/gnw004.
- Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International journal of qualitative studies in education*, 16(2), 175-196, doi.org/10.1080/0951839032000060635
- Pin, S., & Spini, D. (2016). Meeting the Needs of the Growing Very Old Population: Policy Implications for a Global Challenge. *Journal of Aging & Social Policy*, 28(3), 218-231. doi: 10.1080/08959420.2016.1181972
- Pinquart, M., & Sörensen, S. (2011). Spouses, Adult Children, and Children-in-Law as Carers of Older Adults: A Meta-Analytic Comparison. *Psychology and aging*, 26(1), 1-14. doi:10.1037/a0021863.
- Pitman, T. (2017). Living with coercive control: Trapped within a complex web of double standards, double binds and boundary violations. *The British Journal of Social Work*, 47(1), 143-161, doi.org/10.1093/bjsw/bcw002

Pluye, P., & Hong, Q. N. (2014). Combining the power of stories and the power of numbers: mixed-methods research and mixed studies reviews. *Public Health*, 35(1), 29, doi.org/10.1146/annurev-publhealth-032013-182440

Pluye, P., Gagnon, M.-P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed-methods research, and concomitantly appraising qualitative, quantitative and mixed-methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies*, 46(4), 529-546. doi: doi.org/10.1016/j.ijnurstu.2009.01.009

Pohlhaus Jr, G. (2012). Relational knowing and epistemic injustice: Toward a theory of willful hermeneutical ignorance. *Hypatia*, 27(4), 715-735, doi.org/10.1007/s11019-014-9560-2

Policastro, C., & Finn, M. A. (2015). Coercive Control and Physical Violence in Older Adults. *Journal of Interpersonal Violence*, 32(3), 311-330. doi:10.1177/0886260515585545

Pope, C., & Mays, N. (2009). Critical reflections on the rise of qualitative research. *BMJ*, 339, b3425.

Porter, J., Parsons, S., & Robertson, C. (2006). Time for review: supporting the work of an advisory group. *Journal of Research in Special Educational Needs*, 6(1), 11-16. doi:10.1111/j.1471-3802.2006.00055.x

Potter, J. (1996). *Representing reality: Discourse, rhetoric and social construction*: Sage.

Powell, M. A., McArthur, M., Chalmers, J., Graham, A., Moore, T., Spriggs, M., & Taplin, S. (2018). Sensitive topics in social research involving children. *International Journal of Social Research Methodology*, 1-14, doi.org/10.1080/13645579.2018.1462882

Preston-Shoot, M., & Cooper, A. (2015). Editorial—making safeguarding personal. *The Journal of Adult Protection*, 17(3), doi.org/10.1108/JAP-03-2015-0007

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia*, 9(1), 63-75.e62. doi:http://dx.doi.org/10.1016/j.jalz.2012.11.007.

Pritchard-Jones, L. (2018). “Adults at risk”: “vulnerability” by any other name?. *The Journal of Adult Protection*, 20(1), 47-58, doi.org/10.1108/JAP-07-2017-0029

Probst, B. (2015). The eye regards itself: Benefits and challenges of reflexivity in qualitative social work research. *Social Work Research*, 39(1), 37-48, doi.org/10.1093/swr/svu028

Puig, A., Koro-Ljungberg, M., & Echevarria-Doan, S. (2008). Social Constructionist Family Systems Research: Conceptual Considerations. *The Family Journal*, 16(2), 139-146, doi.org/10.1177/1066480707313785

Radcliffe, E., Lowton, K., & Morgan, M. (2013). Co-construction of chronic illness narratives by older stroke survivors and their spouses. *Sociology of Health & Illness*, 35(7), 993-1007, doi.org/10.1111/1467-9566.12012

Ramírez, R. (1999). Value Co-Production: Intellectual Origins and Implications for Practice and Research. *Strategic Management Journal*, 20(1), 49-65. Retrieved from <http://www.jstor.org/stable/3094231>

Rasmussen, P., Muir-Cochrane, E., & Henderson, A. (2015). Child and adolescent mental health nursing seen through a social constructionist lens. *Nurse researcher*, 23(2), 13-16,

retrieved from:

https://www.researchgate.net/profile/Philippa_Rasmussen/publication/283789322_Child_and_adolescent_mental_health_nursing_seen_through_a_social_constructionist_lens/links/5693292f08ae0f920dcda5d0.pdf

Riggs, W. (2012). Culpability for Epistemic Injustice: Deontic or Aretetic? *Social Epistemology*, 26(2), 149-162. doi.org/10.1080/02691728.2011.652210

Roberto, K. A. (2016). The Complexities of Elder Abuse. *American Psychologist*, 71(4), 302-311. doi:10.1037/a0040259

Robinson, N. (1999). The use of focus group methodology — with selected examples from sexual health research. *Journal of Advanced Nursing*, 29(4), 905-913, doi.org/10.1046/j.1365-2648.1999.00966.x

Roesch-Marsh, A., Gadda, A., & Smith, D. (2012). 'It's a tricky business!': The impact of identity work in negotiating research access. *Qualitative Social Work*, 11(3), 249-265, doi.org/10.1177/1473325011400486

Room 151 (2018) Interview with Aileen Murphie. Retrieved from: <http://www.room151.co.uk/funding/aileen-murphie-the-state-of-local-government-funding-pressures/>

Rosen, T., Lachs, M. S., & Pillemer, K. (2010). Sexual Aggression Between Residents in Nursing Homes: Literature Synthesis of an Underrecognized Problem. *Journal of the American Geriatrics Society*, 58(10), 1970-1979. doi:10.1111/j.1532-5415.2010.03064.x.

Ruch, G., Turney, D., & Ward, A. (2010). *Relationship-based practice: Getting to the heart of practice*. Jessica Kingsley, London.

Safe Lives 2016 older people and domestic abuse. Retrieved from: <http://safelives.org.uk/sites/default/files/resources/Safe%20Later%20Lives%20-%20Older%20people%20and%20domestic%20abuse.pdf>

Sandelowski, M. (2015). A matter of taste: evaluating the quality of qualitative research. *Nursing inquiry*, 22(2), 86-94. DOI: 10.1111/nin.12080

Sawbridge, Y., & Hewison, A. (2013). Thinking about the emotional labour of nursing—supporting nurses to care. *Journal of health organization and management*, 27(1), 127-133, doi.org/10.1108/14777261311311834

Schmidt, V. H. (2001). Oversocialised epistemology: A critical appraisal of constructivism. *Sociology*, 35(1), 135-157, doi.org/10.1017/S0038038501000086

Seale, C. (1999). Quality in qualitative research. *Qualitative inquiry*, 5(4), 465-478, doi.org/10.1177/107780049900500402

Sen, A. (2011). *The idea of justice*. Harvard University Press.

Serrant-Green, L. (2011). The sound of 'silence': a framework for researching sensitive issues or marginalised perspectives in health. *Journal of Research in Nursing*, 16(4), 347-360. doi: 10.1177/1744987110387741

Shaw, I. (2008). Ethics and the practice of qualitative research. *Qualitative Social Work*, 7(4), 400-414, doi.org/10.1177/1473325008097137

- Sherman, B. R. (2016). There's no (testimonial) justice: Why pursuit of a virtue is not the solution to epistemic injustice. *Social Epistemology*, 30(3), 229-250. doi.org/10.1080/02691728.2015.1031852
- Strümpel, C., & Hackl, C. (2011). The Breaking the Taboo projects—raising awareness of, and training staff in, community health and care services on violence against older women within families. *The Journal of Adult Protection*, 13(6), 323-335, doi.org/10.1108/14668201111194230
- Steyn, M. (2012). The ignorance contract: Recollections of apartheid childhoods and the construction of epistemologies of ignorance. *Identities*, 19(1), 8-25, doi.org/10.1080/1070289X.2012.672840
- Sky, I. (2016). Searching for my palm tree: Epistemological journeying of a child welfare doctoral student. *Qualitative Social Work*, 15(5-6), 619-627. doi:10.1177/1473325016652676.
- Smith, A. P. (2016). Redeeming the rejected: Curious George and evidence-based approaches. *Qualitative Social Work*, 15(5-6), 671-681. doi:10.1177/1473325016652675.
- Smith, J., Bekker, H., & Cheater, F. (2011). Theoretical versus pragmatic design in qualitative research. *Nurse researcher*, 18(2), 39-51, retrieved from: <http://usir.salford.ac.uk/18361/6/USIRDesignNResearcher.pdf>
- Smithson, J. (2000). Using and analysing focus groups: limitations and possibilities. *International journal of social research methodology*, 3(2), 103-119, doi.org/10.1080/136455700405172
- Social Care Institute for Excellence (2016) Guidance to the Care Act (2014). Retrieved from: <https://www.scie.org.uk/care-act-2014/safeguarding-adults/>
- Sohal, A. H., Pathak, N., Blake, S., Apea, V., Berry, J., Bailey, J., ... & Feder, G. (2018). Improving the healthcare response to domestic violence and abuse in sexual health clinics: feasibility study of a training, support and referral intervention. *Sex Transm Infect*, 94(2), 83-87, .doi.org/10.1136/sextrans-2016-052866
- Solomon, P. L., Cavanaugh, M. M., & Gelles, R. J. (2005). Family Violence among Adults with Severe Mental Illness: A Neglected Area of Research. *Trauma, Violence, & Abuse*, 6(1), 40-54. doi: 10.1177/1524838004272464.
- Sorsoli, L., Kia-Keating, M., & Grossman, F. K. (2008). "I keep that hush-hush": Male survivors of sexual abuse and the challenges of disclosure. *Journal of Counseling Psychology*, 55(3), 333, doi: 10.1037/0022-0167.55.3.333
- Spencer, D., Funk, L. M., Herron, R. V., Gerbrandt, E., & Dansereau, L. (2018). Fear, defensive strategies and caring for cognitively impaired family members. *Journal of gerontological social work*, 1-19, doi.org/10.1080/01634372.2018.1505796
- Staller, K. M. (2013). Epistemological boot camp: The politics of science and what every qualitative researcher needs to know to survive in the academy. *Qualitative Social Work*, 12(4), 395-413, doi.org/10.1177/1473325012450483
- Stark, E. (a) (2009). Rethinking coercive control. *Violence Against Women*, 15(12), 1509-1525, doi.org/10.1177/1077801209347452

- Stark, E. (b) (2009). *Coercive control: The entrapment of women in personal life*. Oxford University Press.
- Stewart, M., Jackson, D., Mannix, J., Wilkes, L., & Lines, K. (2005). Current state of knowledge on child-to-mother violence: A literature review. *Contemporary nurse*, 18(1-2), 199-210, doi.org/10.5172/conu.18.1-2.199
- Storey, J. E., & Perka, M. R. (2018). Reaching Out for Help: Recommendations for Practice Based on an In-Depth Analysis of an Elder Abuse Intervention Programme. *British Journal of Social Work*, 48(4), 1052-1070, doi.org/10.1093/bjsw/bcy039
- Tanner, D., Ward, L., & Ray, M. (2018). 'Paying our own way': Application of the capability approach to explore older people's experiences of self-funding social care. *Critical Social Policy*, 38(2), 262-282, doi.org/10.1177/0261018317724344
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 1-10. doi: 10.1186/1471-2288-8-45
- Thorne, S. (2011). Toward Methodological Emancipation in Applied Health Research. *Qualitative Health Research*, 21(4), 443-453. doi:10.1177/1049732310392595.
- Trevithick, P. (2014). Humanising managerialism: Reclaiming emotional reasoning, intuition, the relationship, and knowledge and skills in social work. *Journal of Social Work Practice*, 28(3), 287-311, doi.org/10.1080/02650533.2014.926868
- Tsui, V., Cheung, M., & Leung, P. (2010). Help-seeking among male victims of partner abuse: Men's hard times. *Journal of community psychology*, 38(6), 769-780. doi.org/10.1002/jcop.20394
- Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse*, 19(1-2), 75-87. doi:10.5172/conu.19.1-2.75
- Tuli, F. (2011). The basis of distinction between qualitative and quantitative research in social science: Reflection on ontological, epistemological and methodological perspectives. *Ethiopian Journal of Education and Sciences*, 6(1), doi.org/10.4314/ejesc.v6i1.65384
- Turner, N., & Almack, K. (2017). Recruiting young people to sensitive research: turning the 'wheels within wheels'. *International Journal of Social Research Methodology*, 20(5), 485-497.
- Tyldum, G. (2012). Ethics or access? Balancing informed consent against the application of institutional, economic or emotional pressures in recruiting respondents for research. *International Journal of Social Research Methodology*, 15(3), 199-210, doi.org/10.1080/13645579.2011.572675
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & health sciences*, 15(3), 398-405, doi.org/10.1111/nhs.12048
- Vandeweerd, C. V., & Paveza, G. J. (2006). Verbal Mistreatment in Older Adults: A Look at Persons with Alzheimer's Disease and Their Carers in the State of Florida. *Journal of Elder Abuse & Neglect*, 17(4), 11-30. doi: 10.1300/J084v17n04_02
- Vaswani, N. (2018). Learning from failure: are practitioner researchers the answer when conducting research on sensitive topics with vulnerable children and young people?.

International Journal of Social Research Methodology, 1-14,
doi.org/10.1080/13645579.2018.1434866

Yon, Y., Mikton, C. R., Gassoumis, Z. D., & Wilber, K. H. (2017). Elder abuse prevalence in community settings: a systematic review and meta-analysis. *The Lancet Global Health*, 5(2), e147-e156, Yon, Y., Mikton, C. R., Gassoumis, Z. D., & Wilber, K. H. (2017). Elder abuse prevalence in community settings: a systematic review and meta-analysis. *The Lancet Global Health*, 5(2), e147-e156

Walby, S., Towers, J., & Francis, B. (2015). Is violent crime increasing or decreasing? A new methodology to measure repeat attacks making visible the significance of gender and domestic relations. *British Journal of Criminology*, 56(6), 1203-1234,
doi.org/10.1093/bjc/azv131

Ward, K., Hoare, K. J., & Gott, M. (2015). Evolving from a positivist to constructionist epistemology while using grounded theory: reflections of a novice researcher. *Journal of Research in Nursing*, 20(6), 449-462. doi.org/10.1177/1744987115597731

Wharton, T. C., & Ford, B. K. (2014). What Is Known About Dementia Care Recipient Violence and Aggression Against Carers? *Journal of Gerontological Social Work*, 57(5), 460-477. doi: 10.1080/01634372.2014.882466.

Wiles, R., Crow, G., Heath, S., & Charles, V. (2008). The Management of Confidentiality and Anonymity in Social Research. *International Journal of Social Research Methodology*, 11(5), 417-428. doi:10.1080/13645570701622231

Wilks, S. E., Little, K. G., Gough, H. R., & Spurlock, W. J. (2011). Alzheimer's Aggression: Influences on Carer Coping and Resilience. *Journal of Gerontological Social Work*, 54(3), 260-275. doi: 10.1080/01634372.2010.544531

Wilson, E., Kenny, A & Dickson-Swift, V. (2018) Ethical challenges of community based participatory research: exploring researchers' experience, *International Journal of Social Research Methodology*, 21:1, 7-24, doi.org/10.1080/13645579.2017.1296714

Woodiwiss, J. (2014). Beyond a single story: The importance of separating 'harm' from 'wrongfulness' and 'sexual innocence' from 'childhood' in contemporary narratives of childhood sexual abuse. *Sexualities*, 17(1-2), 139-158. doi.org/10.1177/1363460713511104

World Health Organization (WHO), (2015). Taking a participatory approach to development and better health: Examples for the regions for health network In W. H. Organization (Ed.), WHO Regional Office for Europe Copenhagen, Denmark. Retrieved from http://www.euro.who.int/_data/assets/pdf_file/0007/294064/Taking-participatory-approach-development-health-malmo-skane.pdf

Wydall, S., & Zerk, R. (2017). Domestic abuse and older people: factors influencing help-seeking. *The Journal of Adult Protection*, 19(5), 247-260, doi.org/10.1108/JAP-03-2017-0010

Zink, T., Regan, S., Jacobson, C. J., & Pabst, S. (2003). Cohort, Period, and Aging Effects: A Qualitative Study of Older Women's Reasons for Remaining in Abusive Relationships. *Violence Against Women*, 9(12), 1429-1441. doi: 10.1177/1077801203259231

Appendix 1: Recruitment materials

Screen-shots of project website and online recruitment

Image 1: Project website home page

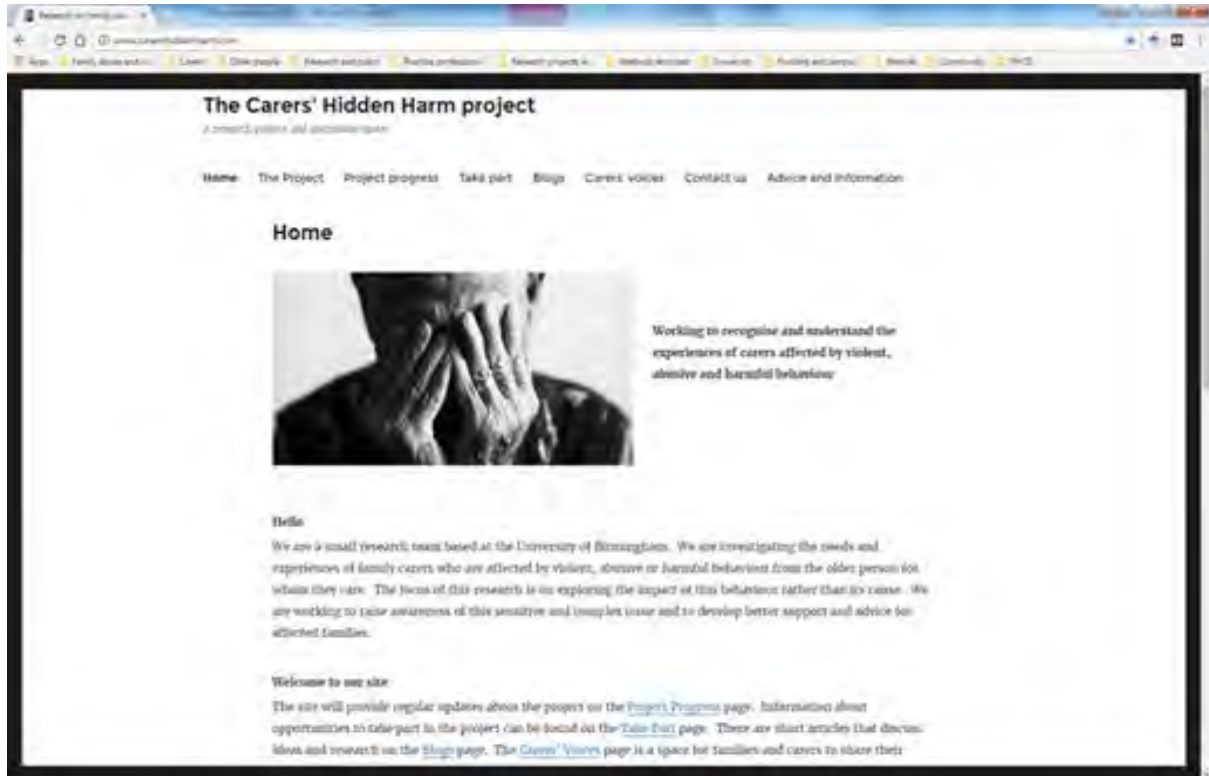


Image 2: Participant-focused information, from project website

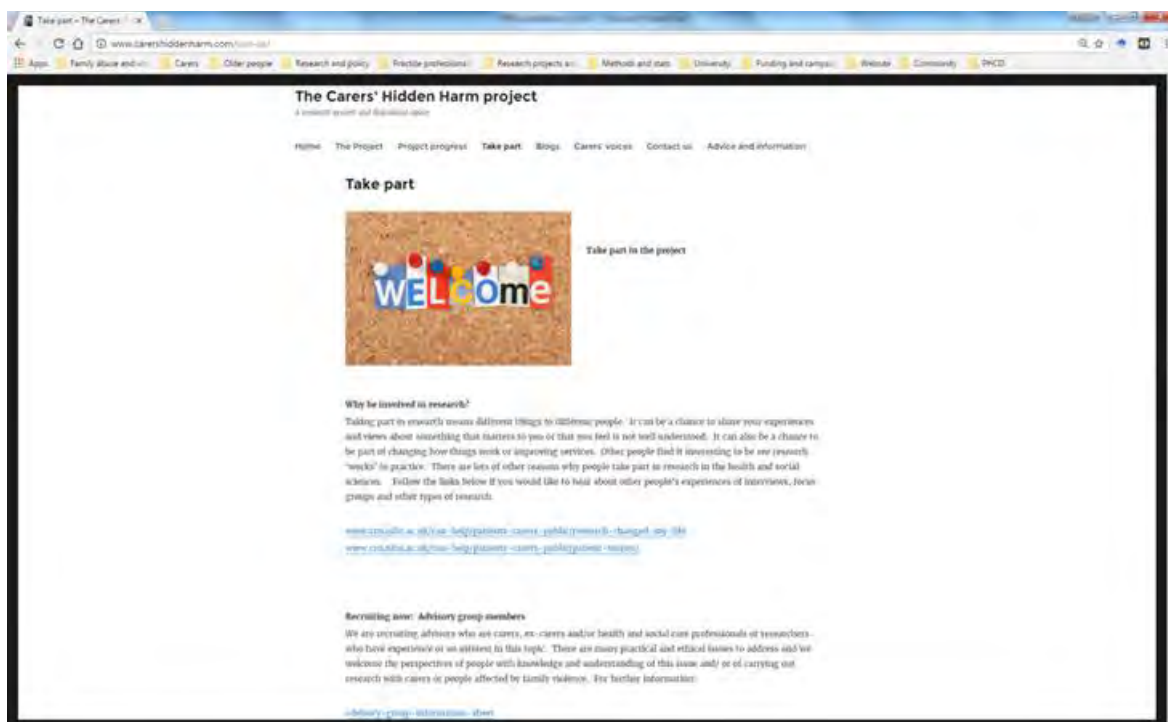
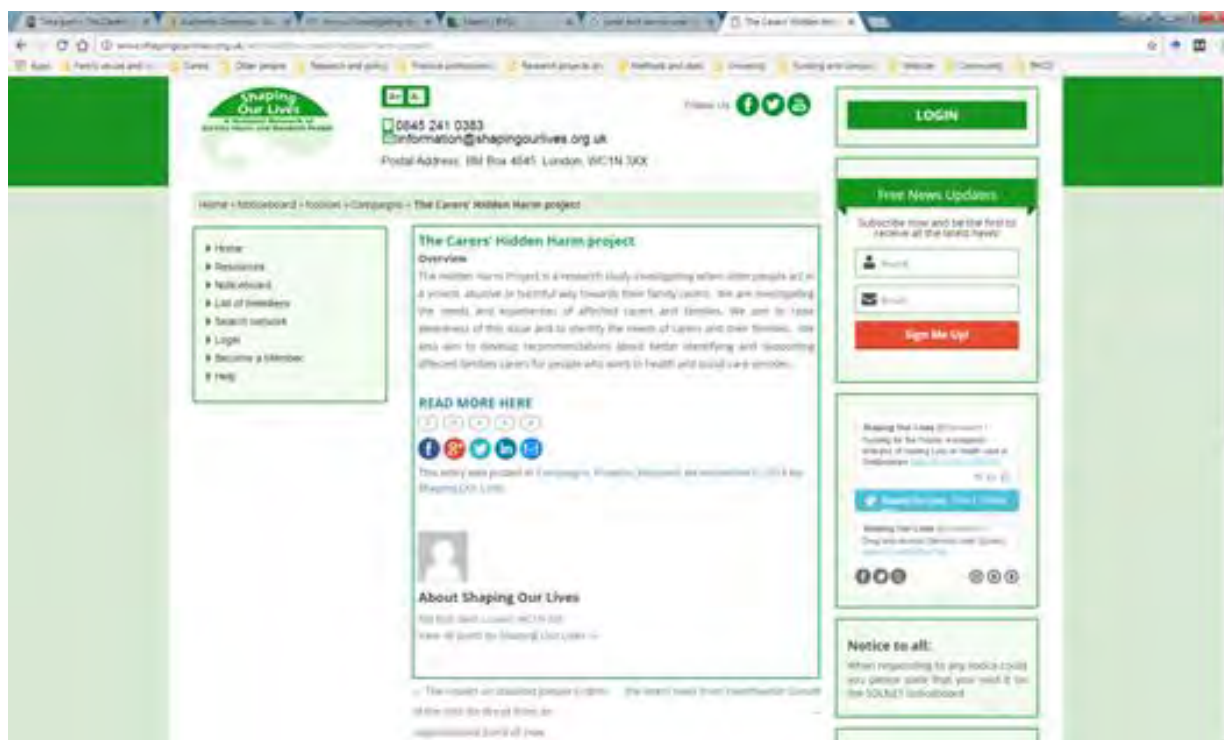


Image 3: Online recruitment (NIHR INVOLVE website)



Image 4: Online recruitment (Shaping our Lives website)





Interview participant consent form

The carers' hidden harm project: Investigating the needs and experiences of family carers affected by harmful behaviour by the older person for whom they care

Service user consent form

Please read the participant information sheet carefully and ask any questions that you have. If you are happy to participate, put your initials in the right hand box. Then print and sign your name below and enter today's date. This original form will be returned to you and the research team will retain a copy.

- | | Please initial
ALL boxes |
|---|---|
| 1. I confirm that I have read and understood the participant information sheet. | <div style="border: 1px solid black; height: 30px; width: 100%;"></div> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time. | <div style="border: 1px solid black; height: 30px; width: 100%;"></div> |
| 3. I understand that I can withdraw the information discussed in the interview for up to one month after it takes place. | <div style="border: 1px solid black; height: 30px; width: 100%;"></div> |
| 4. I consent to the collection and storage of the interview as an audio-recording which will then be transcribed. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publication. | <div style="border: 1px solid black; height: 30px; width: 100%;"></div> |
| 5. I am aware that this project has been reviewed by the West Midlands-Black Country Research Ethics Committee and the University of Birmingham Research Governance board. | <div style="border: 1px solid black; height: 30px; width: 100%;"></div> |
| 6. I agree to take part in this project. | <div style="border: 1px solid black; height: 30px; width: 100%;"></div> |

Person giving consent

Print

Sign

Date

Person taking consent

Print

Sign

Date



Interview participant information leaflet

The carers' hidden harm project: Investigating the needs and experiences of family carers affected by harmful behaviour by the older person for whom they care

Service user project information sheet

Invitation

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important for you to understand why the project is being carried out and what it will involve. Please take your time to read the following information carefully and please do discuss it with others should you wish. Please ask if there is anything that is not clear, or if you would like more information.

What is the purpose of the project?

The purpose of this project is to investigate the experiences and needs of family carers affected by harmful behaviour by the older person for whom they care/d. There is very limited research or practice guidance about this problem and its potentially serious and long-term effects. As a result, it can be considered a 'hidden' issue. This project aims to develop knowledge about it in order to raise awareness and to lead to better support for affected families.

What does harmful behaviour mean?

Harmful behaviour includes violent and abusive behaviour as well as behaviour that is controlling, difficult or challenging. We recognise that many (although not all) people who are unwell do not intend to act in a harmful way towards their carers. We are not seeking to blame or hold anyone to account for their behaviour. Rather, our aim is to explore carers and ex-carers views and experiences about harmful behaviour.

Why have I been given this leaflet?

We have sent this leaflet to you because a health professional has identified that you care/d for an older person. We are sending out information to a number of families who *may* be affected by harmful behaviour and *may* be interested in the project.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form to confirm that you understand what is involved when taking part in this project.

What will happen to me if I take part? What do I have to do?

If you decide to take part, you will be invited to take part in an interview with Louise, a member of the research team. Most interviews last for about an hour. We will arrange a time and place to meet that is convenient for you. This could be at your home, at the University or at in private meeting room in another building. Usually, Louise will come to meet you. However, if you prefer to meet away from home, we will reimburse any travel costs.

During the interview, you will be asked about your experiences as a carer and what harmful behaviour means for you. You will also be asked about how you coped with this behaviour and if/ how you were able to seek support. We would also like to know



about any other issues that you would like to raise and there will be time to do this during the interview session.

We will audio-record the interview. This is so we have an accurate record of what you said. Following the interviews, the project team will analyse and reflect on what you said – as well as other carers taking part in the project – to better identify carers' needs and experiences.

What are the possible disadvantages and risks of taking part?

As the focus of the interview is about your experiences of harmful behaviour, you may find the talking about it sensitive or difficult. Thinking and recalling events may make you feel upset or concerned. Should this happen, please let a member of the research team know. The interview can be stopped at any time, or you can take a short break from it. If this happens before the interview, you do not need to go ahead with it. All participants will be given information about available support groups and resources that may be useful. In addition, use of your valuable time is a disadvantage of taking part. To minimise inconvenience, the interview will be arranged at time and location that is most convenient for you.

What are the possible advantages of benefits of taking part?

Interviews provide a private, confidential space to talk with a researcher about topics that may be considered difficult or sensitive. Some people find it positive to have their views heard and to reflect on their experiences. In addition, some people share their knowledge and expertise in order to help develop thinking and knowledge about a topic, particularly if this new knowledge may help others.

What if there is a problem?

If you have a concern about any aspect of the project, you can speak to a member of the research team (contact details are at the end of this sheet).

Will my part in this study be kept confidential?

Yes. If you consent to take part then the information you provide will remain strictly confidential at all times under the provision of the 1998 Data Protection Act. Your personal details will not be passed to anyone outside of the project team. You will be allocated a study number, which will be used as a code to identify you. Your personal details, signed consent form and the transcript of your interview will either be held securely in a locked filing cabinet or held electronically on a password secure server at the University of Birmingham.

All personal information and copies of the audio recordings will be deleted no later than one month following the interview. The anonymised transcript of the interview will be retained for 5 years. This is so that the research team can carefully analyse the data and refer back to it should any questions arise after the findings are shared with a wider audience.

What will happen to the results of this study?

We will send a copy of our findings to you at the earliest opportunity and also send you the final lay summary of the wider project's work. We will share the project's findings with a range of services supporting and working with carers, families and older people. The projects' findings may be published in a scientific journal and shared at research-focused meetings and conferences.



The information that you share with us during the interview will be anonymised and no personal information about will be disclosed at any point when sharing the findings.

Who has reviewed the study?

The West Midlands - Black Country Research Ethics Committee and the University of Birmingham Research Governance board has reviewed the ethical suitability of the project and approved that it can take place.

Who should I contact for further information?

You are encouraged to ask any questions you wish, before or after the interview. If you have any unanswered questions after reading this leaflet, please contact a member of the research team.

I am interested, what do I need to do next?

If you are interested in taking part then please contact a member of the research team. We can discuss any questions that you have and, if you would like to proceed, arrange a time and place to meet for the interview.

Research team contact details

All members of the research team are based at the School of Nursing, University of Birmingham. Louise is a qualified social worker with practice experience. She is a doctoral researcher. Dr Caroline Bradbury-Jones and Dr Alistair Hewison are both qualified nurses and have significant experiences both in practice and as academics carrying out research on sensitive topics.



Louise Isham
Contact details:



Dr Caroline Bradbury-Jones
Contact: c.bradbury-jones@bham.ac.uk
0121 414 3951



Dr Alistair Hewison
Contact: a.hewison@bham.ac.uk
0121 414 3951

There is further information available about the project on our website, www.carershiddenharm.com.

Thank you for taking the time to read this information sheet and for considering taking part.



UNIVERSITY OF
BIRMINGHAM

Letter of invitation to interview participants

School of Nursing
College of Medical and Dental Sciences
University of Birmingham
Edgbaston
B15 2TT

The carers' hidden harm project: Investigating the needs and experiences of family carers affected by harmful behaviour by the older person for whom they care

Dear *** (insert name)

Thank you for your interest in our project and for making contact with our team. It was good to talk with you on *** (insert date).

Please find enclosed a copy of our recruitment leaflet and participant information sheet. There is additional information about the project along with some blogs that we have written available on our website (www.carershiddenharm.com). There are also details of support services and helplines available on the site and information about why some people are interested in taking part in the research. Taken together, we hope that you find this information helpful in making a decision about whether you would like to proceed to take part in an interview.

As agreed, we will contact you by email/ phone on *** (insert date) to confirm if you would like to arrange a time to meet. This can be at your home or at another, private location of your convenience. We would make any arrangements and cover expenses of travel and meeting.

In the meantime, please do contact us if you need any additional information or would like to discuss any aspect of the project or interview process further.

Kind regards,

Louise Isham
Doctoral researcher

Contact details:



Dr Caroline Bradbury-Jones
Reader in Nursing

Contact: c.bradbury-jones@bham.ac.uk
0121 414 3951

Dr Alistair Hewison
Senior lecturer and
Research Lead for
Nursing

Contact:
a.hewison@bham.ac.uk
0121 414 3951



Focus group participant information sheet

Investigating the needs and experiences of family carers affected by harmful behaviour by the older person for whom they care

Professionals' participant information leaflet

Invitation

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important for you to understand why the project is being carried out and what it will involve. Please take your time to read the following information carefully and please do discuss it with others should you wish. Please ask if there is anything that is not clear, or if you would like more information.

What is the purpose of the project?

The purpose of this project is to investigate the experiences and needs of family carers affected by violent, abusive, or, harmful behaviour by the older person for whom they care/d. This is a sensitive and in many ways 'hidden' issue and currently there is limited research or practice guidance about it. The aim of the project is to raise awareness of the problem and to develop knowledge about it to help inform policy and guidance for affected families and for practitioners with whom they work.

What is harmful behaviour?

Harmful behaviour includes violent and abusive behaviour as well as behaviour that is controlling, difficult, or challenging. We recognise that many (although not all) people who are unwell do not intend to act in a harmful way towards their carers. We are not seeking to blame or hold anyone to account for their behaviour. Rather, our aim is to explore carers and ex-carers views and experiences about harmful behaviour and the views and needs of professionals who work, or may work, with affected families. You are reading this leaflet because you are a professional who we would like to invite to take part in a group interview (also called a focus group).

What will happen to me if I take part? What do I have to do?

If you decide to take part, you will be invited to attend a group interview that will last for about an hour. We will arrange a time and place to meet that is convenient for you and other members of the group (i.e. at your workplace, as part of team meeting, etc.). We will reimburse any travel costs and provide refreshments as a small token of our appreciation for your participation.

The aim of the group interview is to hear your views and insights. In the group interview, we will share extracts from our interviews with carers and use these as prompts for discussion by the group. We are interested to hear your views and there is no 'right' or 'wrong' answers. In addition, it is at your discretion whether you would like to share experiences or observations from your own practice.

We will audio-record the group interview session and develop a transcript of the discussion. This is so that we have an accurate record of what was said. The transcript will be analysed by the research team.

**What are the possible disadvantages and risks of taking part?**

As the focus of the group interview is about carers' experiences of harmful behaviour, you may find talking about this issue sensitive or difficult. Thinking about and recalling events from your personal or professional life may make you feel upset or concerned. Should this happen, please let a member of the research team know. The group session can be stopped at any time, or you can take a short break from it. If this happens before the interview, you do not need to go ahead with it. In addition, use of your valuable time is a disadvantage of taking part.

What are the possible advantages of benefits of taking part?

Group interviews can provide a confidential space to talk with a researcher and professional peers about topics that may be considered difficult or sensitive. Some people find it positive to have their views heard and to reflect on their experiences. In addition, some people may find it a positive experience to take part in research, sharing their professional knowledge and expertise as a way of helping to raise awareness and to develop knowledge about an important issue.

What if there is a problem?

If you have a concern about any aspect of the project, you can speak to a member of the research team (contact details are at the end of this sheet).

Will my part in this study be kept confidential?

Yes. If you consent to take part then your personal information and the details of your contribution (i.e. what you say during the group interview) will remain strictly confidential under the provision of the 1998 Data Protection Act. Your personal details, signed consent form, and the transcript of your group interview will either be held securely in a locked filing cabinet or held electronically on a password secure server at the University of Birmingham.

All personal information and copies of the audio recordings will be deleted no later than one month following the interview. The anonymised transcript of the group interview will be retained for five years. This is so that the research team can carefully analyse the data and refer back to it should any questions arise after the findings are shared with a wider audience.

What will happen to the results of this study?

We will send a copy of our findings to you at the earliest opportunity and also send you the final lay summary of the wider project's work. We will share the project's findings with a range of services supporting and working with carers, families, and older people. The projects' findings may be published in a scientific journal and shared at research-focused meetings and conferences.

The information that you share with us during the group interview will be anonymised and no personal information will be disclosed at any point when sharing the project's findings.

Who has reviewed the study?

The University of Birmingham Research Ethics Committee has reviewed and approved the project.



Who should I contact for further information?

You are encouraged to ask any questions you wish, before or after the group interview. If you have any unanswered questions after reading this leaflet please contact a member of the research team.

I am interested, what do I need to do next?

If you are interested in taking part then please contact Louise in the first instance. The team can discuss any questions that you have and, if you would like to proceed, arrange a time and place to meet for the interview.

Research team contact details

All members of the research team are based at the School of Nursing, University of Birmingham. Louise is a doctoral researcher and a qualified social worker. Dr Caroline Bradbury-Jones and Dr Alistair Hewison are both qualified nurses and have significant experience both in practice and as academics carrying out research on sensitive topics.



Louise Isham
Contact details:



Dr Caroline Bradbury-Jones
Contact: c.bradbury-jones@bham.ac.uk
0121 414 3951



Dr Alistair Hewison
Contact: a.hewison@bham.ac.uk
0121 414 3620

There is further information available about the project on our website, www.carershiddenharm.com.

If you would like to make a complaint or to raise a query about the conduct of the research team, please contact:

Professor Julie Taylor, School of Nursing, University of Birmingham
Contact: 0121 414 8671 and j.taylor.1@bham.ac.uk

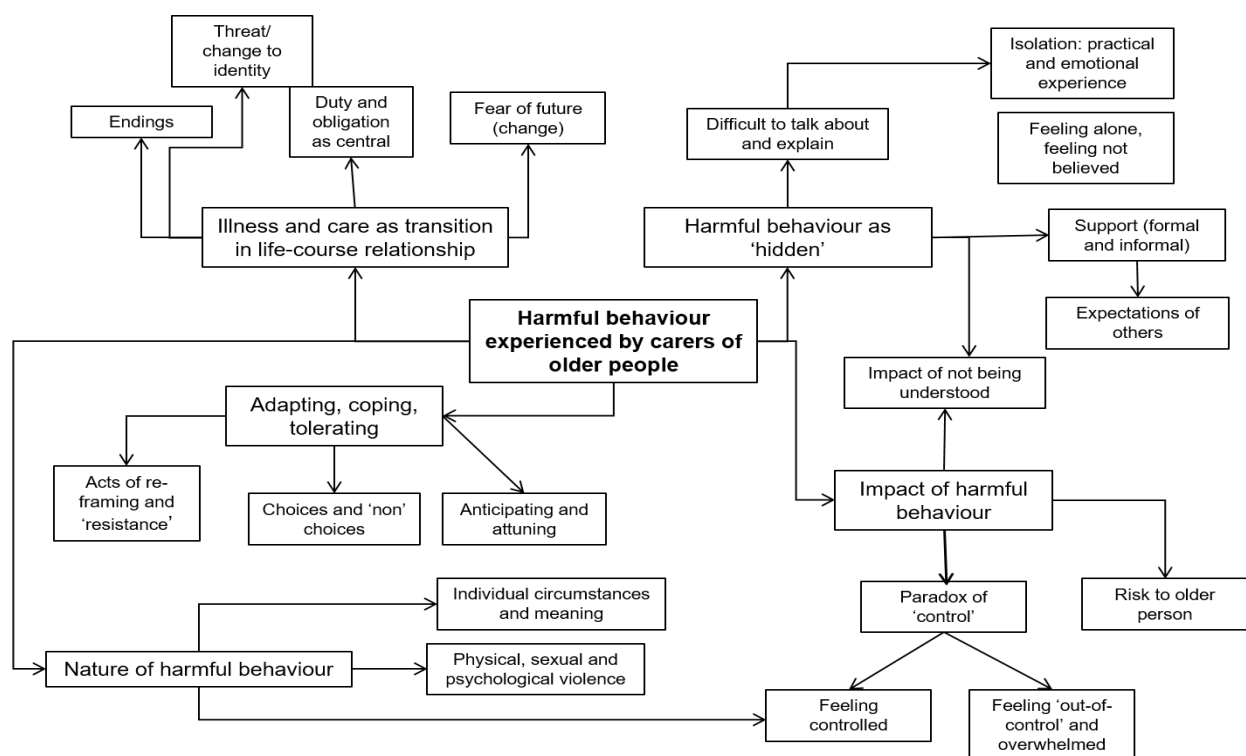
Thank you for taking the time to read this information sheet and for considering taking part.

Appendix 2: Analysing the interview transcripts: a reflective account

1. Familiarisation

As the primary researcher on the project, the process of familiarisation was bound up with my experiences developing and designing the study as well as recruiting and interviewing participants. I kept a reflective journal throughout and used this to note down questions, impressions, and my feelings after meeting and talking with each participant. The diary proved to be a valuable way of developing my initial ideas and drawing connections between some of the technical and interpretive aspects of the project. By taking time to re-consider certain events, contexts and processes, I also became more aware of new issues that were not apparent at first for example, the subtle and different ways that the women communicated their feelings of being 'hidden'. Critically, however, I regularly discussed all aspects of the project with my supervisors. Their advice and guidance was invaluable throughout. Moreover, supervision provided a space for questioning, and challenging aspects of my work that solitary reflection would be unlikely to engender. Figure 1 captures some of my initial, exploratory thinking about the interviews and my efforts to piece together some ideas, exploring connections between the emerging themes. These were initially descriptive and summarising in nature.

Figure 1: Initial themes and concept map

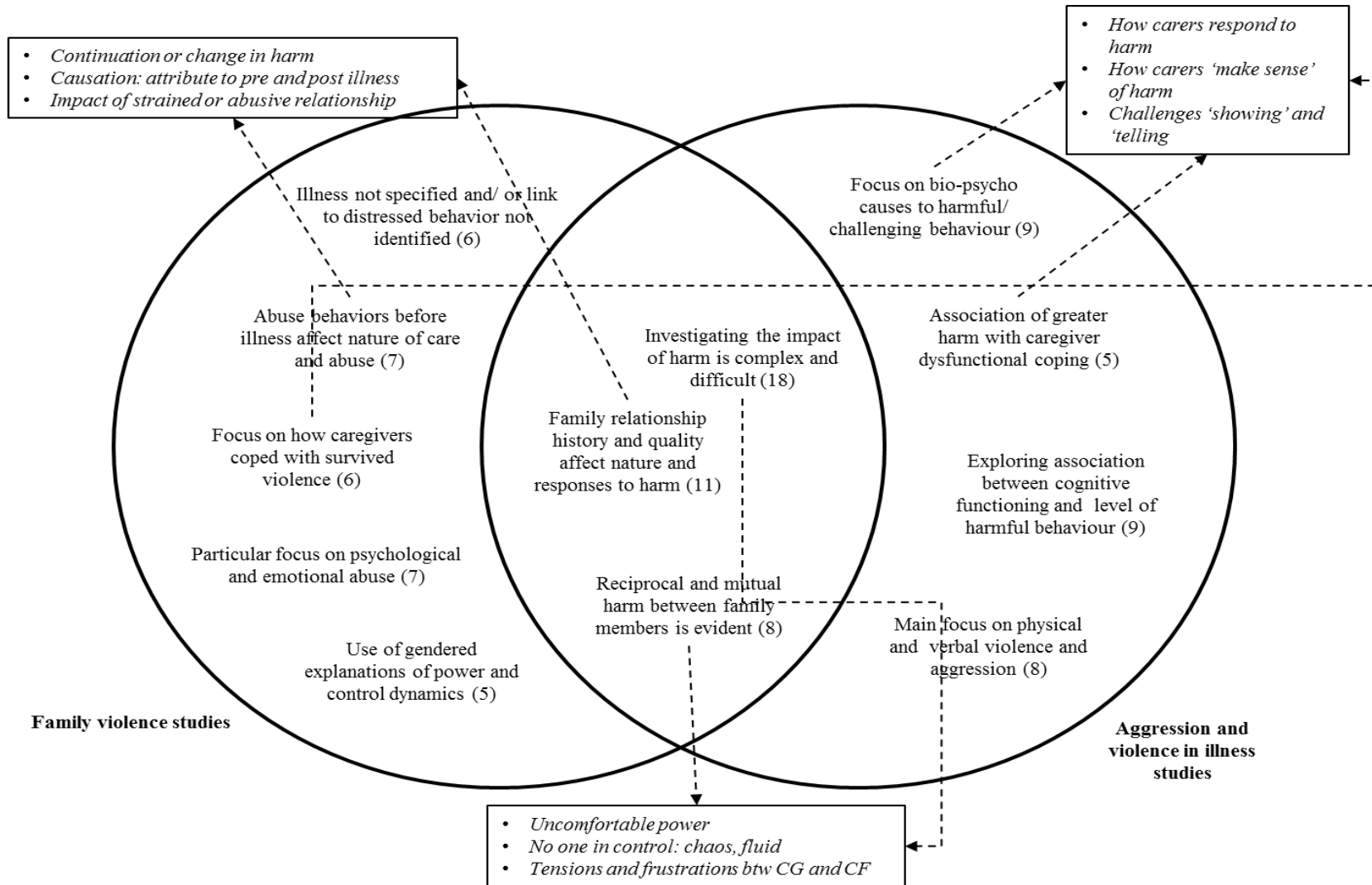


2. Generating initial codes

During this phase, I also decided to stop using a computer software package as the primary method for noting down my developing ideas and reflections. Instead, I reverted to coding paper copies of the transcripts by hand, annotating codes in the margins of the text and using a colour scheme to identify emerging 'broad' themes and categories. I then transposed these annotations to an electronic copy of the transcript so as to be able to record and share my analysis in a more systematic and easy-to-read format. I recognise that I would not have had this option if I was coding a larger dataset; moreover, there are many advantages to using analysis software, not least that it can quickly identify and retrieve data, as well as provide visual tools that can conceptualise relationships between themes and ideas. However, I found it more productive and creative to read and code the transcripts in this perhaps less sophisticated but immersive way (Basis, 2003). Given that each stage of the analytical process is cumulative as well as iterative (Braun & Clarke, 2006), taking the time to do this at an early stage seemed particularly important and strengthened my sense of 'familiarisation' with the data.

Perhaps, because I was working at the micro-level – exploring single words and sentence fragments – I felt that the initial codes that I was generating were primarily the result of inductive methods. In addition, I was not using a developed conceptual or theoretical framework and this, in turn, reinforced the feeling of building, albeit slowly, my own analytical scaffold. However, I came to recognise that many of my developing themes were shaped by my engagement with the literature. They also drew on my experiential knowledge of working with the advisory network and engaging with 'gatekeepers' and participants in the recruitment phases of the study. In this way, there was a blurring between the stages of inductive and deductive analysis rather than a linear progression between them. For example, I think that I was more alert to carers' descriptions or allusions to the nature and quality of their relationship with their FM, because I had identified this as a central and significant issue that was evident in many of the reviewed papers. I was also more alert to carers' explanations of the causes of behaviour and the language they used to express these views. In particular, I was interested in, and initially coded, whether carers used medical and health-related vocabulary and/ or whether their FM could and should be seen to be responsible for their behaviour. Figure 2 (below) maps the central concepts in the reviewed literature to their relationship with initial, thematic categories used to interpret the transcripts. As my analysis developed, I drew on evidence and theory relating to caring, familial and intimate partner violence, and, the broad field of medical/ health sociology, as is common practice in qualitative analysis (Fereday & Muir-Cochrane, 2006; Padgett, 2016).

Figure 2: Conceptual map of reviewed literature (see literature review chapter)



3. Searching for themes

Table 1 contains the initial themes that I developed and their associated codes. Almost all of these initial themes encompass a mixture of descriptive and more conceptual or abstract codes. Braun & Clarke (2006) highlight that not all codes are likely to ‘fit’ within the developing thematic schema and this may be because they are not as important or relevant as the researcher originally thought them to be. However, some codes are idiosyncratic because they are important but do not appear frequently in the data. This may be the case when a participant describes or reflects on an aspect of experience that is, amongst other participant accounts, implied or taken as a given assumption (Braun & Clarke, 2006). In fact, these codes can be powerful explanatory tools and linking points to an analyst. For me, the theme ‘dilemmas and decisions’ reflects some of these seemingly idiosyncratic codes: it is the ‘smallest’ theme in terms of the number of codes that it houses. It is also placed at the end of the coding framework, reflecting, perhaps that it felt like an unfinished and partial theme at this stage in the analysis, perhaps because I was struggling to articulate what was critical about the codes that it contained and, in particular, the emotional meaning and significance that they encompassed. In turn, I came to focus on and develop these, seemingly disparate codes.

Table 1: Initial themes and codes

Organising themes	Descriptive and analytical codes
Contexts	Intimate, long-term relationship Pattern or continuation of harm Cultural and spiritual context of commitment/ meaning of relationship Living together or apart Partners or adult child/parent
Illness as organising foci	Change through illness Being attentive, being attuned Living in a state of uncertainty/ flux Worry about the future Turning points in personal/family life Describing diagnosis and illness Caring as a way of life Becoming the parent Life on hold/ life changed
Harmful behaviour	Incidents/ examples Patterns of behaviour Memory of behaviour Explaining impact Tensions and frustrations Continuation of harm (from past) Physical violence (and threat of) Verbal abuse Sexual violence (and threat of) Feeling manipulated, controlled, without choice Living in a state of fear/ uncertainty Witnessing distressed and harmful behaviour (to self and others)

Coping/ responding	A way of life/ 'new normal' Seeking knowledge and education Minimising/ putting aside own needs Adapting, new ways of caring Difficult to be heard/ taken seriously Barriers and challenges of telling Not knowing where the 'line' is Advice and education Changing expectations Tolerating new/ unwanted changes Being attuned and attentive Anticipating needs and changes Causes of behaviour Explaining behaviour
Responsibility/ duty	Hierarchy of suffering Context of intimate relationship Vows, duties, expectations Reflections on meaning of caring Limited choice Not about me More important considerations Social, religious, generational, cultural norms and expectations and meanings No one else to care No one else to care in a close, intimate way
Support and responses by others	Feeling unsupported Feeling angry/ upset/ let down Peer support can be useful Reflections on need for change Motivated by wish for change Feeling hidden 'in plain sight' Expectations of others Reluctant to see or understand Nobody understands or knows
Dilemmas and decisions	Trying to protect family members Trying to protect others Safety and desirability of caring at home, caring in family Interventions – medication, hospital care, etc.

4. Reviewing themes

Reviewing themes involves the systematic cross-referencing and mapping of the empirical data with the analytical framework (see Table 2). At this stage I considered that the thematic framework was a useful way of thinking through each of the carers' individual accounts as well as synthesising and exploring them as a whole. The framework was sufficiently coherent for me to explore the inter-relationships between themes and sub-themes, as well a useful orientating point to explore more abstract and conceptual interpretations that I was beginning to develop. Nevertheless, I was aware that this schema was not exhaustive and that that whilst the themes were associated primarily with the empirical data, there were contextual and cultural issues that were not well-accounted for within the framework. I was also aware of several significant limitations of developing a single thematic framework to analyse the accounts of a heterogonous participant group. I was concerned, for example, about how appropriate it was to compare and integrate accounts of harmful behaviour that varied from intense feelings of stress and emotional (and often practical) isolation alongside accounts of sexual assault and extreme and repeated physical violence.

Braun & Clarke (2006) emphasise that although the process of reviewing themes requires a sustained and critical engagement with the empirical data – checking for the coherency and accuracy of the thematic schema – there is a point at which refinement is no longer helpful or required. They urge researchers to recognise when they have a “nuanced coding framework that already works”, they need to “stop” even if there are new avenues to explore (Braun & Clarke, 2006, pp. **). Because I was aware of the partial and limited nature of my data and thematic analysis, I later decided to enhance my interpretation of the data by adopting a theoretical approach too. This acted as a parallel and complementary analytical process (for more details, please see the methods chapter).

Table 2: Coding framework (used to code the transcripts)

Family member's illness as cause of change

<i>Code</i>	<i>Description (nodes)</i>
Diagnosis and initial changes	Initial worries; signs that things were 'not OK'; feeling confused about what was/is happening; seeking information, seeking clarity; process of being diagnosed; information and advice from professionals
Relationship between carer and older person	Taking on/ feeling responsible 'for' FM; loss of some/ many aspects of relationship; 'becoming the parent' to FM; a more intense, more intimate relationship; expectations of relationship have changed; reflecting on change in identity
Relationship with other friends and family members	New relationships and intimacies 'discovered' and made; changing expectations and roles within the wider family; family decision-making
Thoughts and feelings about the future	Concern about premature separation from FM; concern about longevity and/ or severity of situation; trajectory of illness/ end of life as significant; fear of serious harm or death; wanting to avoid feelings of regret
Feeling exhausted/ overwhelmed	Emotionally overwhelmed; physically tired/ exhausted; no time to think or reflect; not sure/ unable to tolerate any longer; disorientated
Significant past events/ patterns	How things were; who someone 'really' is; the nature of relationship in the past; important events remembered and/ or called on to explain current situation

Experiences of harmful behaviour

<i>Code</i>	<i>Description (nodes)</i>
Verbal harm	Name-calling; shouting; derogatory/ offensive language; aggressive and argumentative; threatening violence or harm
Physical harm	Hitting; kicking; biting; strangling; throwing objects near or at carer; threatening violence; restraining carer with force
Emotional/ psychological harm	Witnessing violent or distressed behaviour; threat of suicide; witnessed suicide; feeling manipulated by FM; feeling trapped; feeling scared for safety; living with memory of aggression, violence and harm in the past
Sexual harm	Inappropriate and unwanted touching or comments; forced physical contact; sexual intercourse without consent

'Difficult' behaviour	Emotion-driven and not 'logical' or proportionate behaviour; not understanding or recognising needs of carer; high (and unmanageable) expectations of carer; being 'provocative'/ seeking a reaction
Witnessing violence and distress	Seeing and being in the presence of distressed and/ or chaotic behaviour; witnessing FM being 'out of control'; witnessing violence or distress of FM to them themselves or to others
Risk and harm caused to FM	Physical pain or distress as a result of distress or violence; increased distress; self-harming behaviour; self-neglecting behaviour
Risk/ concern for others	Harmful or difficult behaviour affecting other people than FM or carer

Coping and responding

<i>Code</i>	<i>Description (nodes)</i>
Attuned and attentive	Recognising signs of distress or discomfort quickly; 'small' changes are important; empathic understanding of FM and their physical/ psychological distress; watching; waiting; taking proactive steps; distraction
Minimising harm	Taking action to prevent harm to self; hiding; avoiding; withstanding/ tolerating without reaction; not resisting or arguing back; avoiding potential conflict and stress; being careful about rushing to help or 'rescue'; 'part of normal life'
Escape and release	Making or guarding space and time for self; thinking about and/ or hoping for release or respite from situation; needing others to 'make things stop'
Knowledge and advice	Learning new things; finding out information and options; seeking out advice from friends, family, professionals; knowledge helping to inform
Medication and professional support (encounters)	Prescribed medication to address distressing or difficult behaviour; crisis interventions; sectioning under mental health act; following advice and strategies ; hospital admission; visits and meetings with professionals
Advocate and protector	Doing 'all that I can'; 'making the case' for FM with other people; asking 'difficult' questions of professionals; keeping FM safe (from others); making important decisions/ driving change; responsibility
Relationships and social support	Making decisions with others; shared understanding with other carers; practical support from family and friends; sharing caring

	responsibilities; time away from caring; connecting with 'old' way of life; feeling understood and/ or not needing to explain
Feeling alone	Carrying out all/ significant majority of caring; feeling without guidance and support; own needs not understood or recognised; not believed; emotional and existential dimension
Unpredictable, fluid situation	Chaotic; extreme changes in behaviour; not clear who is in charge in carer-FM relationship and interactions; change is regular – minutes, hours, days; situation at times feels unsafe (for FM and/ or carer); life is constantly changing
Turning point	Expectations of FM changed; expectations of relationship changed; turning point; new or different knowledge; new realisation or awareness

Explaining harm, explaining caring

<i>Code</i>	<i>Description (nodes)</i>
Not intentional / can be explained	Illness as cause of harmful behaviour; no one responsible, no one to blame; not able to control of change behaviour
Unclear cause	Feeling confused and uncertain; difficult behaviour before illness; seems that FM has some degree of agency or control over behaviour; question whether illness gives degree of power 'over' or 'against' others; unclear/ complex relationship between personality and illness
Explaining behaviour/ reflecting on behaviour	Reflecting/ making connections between personality/ past events/ feelings and behaviour (general and harmful)
Tension/ difference between FM and carer	Difference in opinion; arguments; frustration/ tension about a decision or interpretation of a situation; miscommunication or difficult communication between FM and carer
Recognition/ awareness by FM	FM does/ doesn't recall harmful behaviour; FM cannot (will not?) reflect on behaviour; points of recognition and awareness; atonement and apology (or its absence); dementia and mental ill health
Hierarchy of needs	Suffering and needs of FM 'come first'; recognises impact but this is less important than impact on FM of illness; 'wrong' to put own needs/ wants first
Responsibility and duty	Not a choice but a duty to care; pressure/ of expectations of others that will care; caring a part of being a spouse, child etc; religious or cultural meanings and value of care; 'doing the right thing'

Reflecting on caring behaviour/ responses	Identifying situations of misunderstanding and miscommunication; feeling ill-equipped to deal with situation; learning experiences
Ideas about support and help	Reflecting on experiences and needs of others; decisions about allocation of public resources; expectations of health and social care services; comparison and contrast with other carers; advocate for other carers
Good times, different times	Positive times with FM; things changing for the better; not always the same; feeling hopeful; finding new meaning; feeling relieved

Challenges and dilemmas

<i>Code</i>	<i>Description (nodes)</i>
Uncomfortable responsibility/ power	Making decisions on behalf of FM (e.g. medication, finances, care, etc.); protecting other people from harm; balance between protecting self and protecting FM
Barriers/ concerns sharing	Cautious to show or share information; worried about being judged; worried about consequences for FM; feelings of shame or embarrassment
No one has the 'full' picture (seeking understanding)	People who 'know' but do not ask questions; people not 'imagining' what lived experience of caring is like; feeling seen but not heard
Not knowing	Feeling that don't have necessary or sufficient information; unsure what the 'best' option is; disorientated; many options or explanations
Uncertainties about others' knowledge	Questioning if others have 'enough' or 'good' knowledge; differences of opinion/ conflict with others; hard to let go of role as main carer – person with the 'most' or 'best' understanding;
Without choice, constrained choice	Feeling trapped and/ or without options; considers there to be only 'one option'; closely linked with responsibility/ duty; feeling of powerlessness; feeling of helplessness; illness and care as organising foci of daily life
Difficulties explaining (making sense of)	Situation is confusing, disorientating; hard to put into words; hard to explain to others; not recognising patterns and implications at the time – only with reflection; not feeling believed or taken seriously

Excerpt of coding from Asrah's account

Transcript excerpt	Codes
So, I think that pretty much for about four, four or five years, we just cared in isolation. For, for dad. And I think that for that large chunk of time we pretty much did everything for him. When we got to the stage where it was affecting not only my working life but also, I would say, my own kinda physical and mental health, as well as me mum's physical and mental health anyway because she already had existing physical health issues anyhow....Uhh... dad had become so dependent on us, when it came to getting outside help or support, he became resistant in accessing that support. He didn't really see what was the need of accessing that support. And I think that the fact that we never really discussed how challenging he was, and how hard it is for us to look after him, he didn't really see the need as to why he would need outside help because we're supporting him as a family anyway. What was the need of bringing someone else from outside?	Without choice/ constrained choice Uncomfortable responsibility/ power Tension/ frustration between FM and carer Difficulties explaining Recognition/ awareness by FM

Excerpt from Mary's account

Transcript excerpt	Codes
He never felt that I was helping. Or, never admitted to me that anything I was doing was of any help to him at all. He never, I was never, no, I was never, no. That was what I was supposed to do. It just didn't happen. The trouble with stokes, with hypos, is that people don't know it's going on. The people that it's happening to, they just don't know it. And it's far worse for the people watching and I don't think that that's taken on board.	Recognition/ awareness of FM Responsibility/ duty Tension between FM and carer Difficulties explaining

5. Defining and naming the themes

The aim of this final stage in the analytic process is to synthesise and to develop a way of presenting and explaining the analysis. At this point, I found it refreshing to ‘step back’ from the more technical stages of analysis of the empirical data and to begin to draw links with the practical, ethical, and theoretical contexts that had informed and given rise to the study. Table 3 outlines the central themes that I used to synthesise and conceptualise the carers’ accounts.

Table 3: Over-arching themes

Caring in a long-term, intimate or family relationship	Carers are often highly attuned to the needs of their FM and many are providing high levels of care and/ or living with their FM. Caring is talked about as part of this relationship: a duty and responsibility that comes with being a wife, daughter or sister. In addition, Most carers are supporting their family member towards the end of their life; harmful behaviour is thus experienced within a process of ‘complicated’ grief and life transition.
A personal and private type of harm	A spectrum of behaviours that could be categorised as physical, psychological, and sexual in nature. The severity, duration, and intensity of behaviours described vary considerably between participants. How people talk about and explain harmful behaviour (and its impact) is often difficult to distinguish from how they understand, cope with, and feel about their role as a carer and their FM’s illness.
Caring in a context of paradoxical intimacy	Many carers appear to be both a protector and carer for someone is to a greater or lesser extent ‘vulnerable’ and in need of support or care. They are highly attuned to their needs, and empathic towards how illness has changed their FM. At the same time, adapting to living in a situation of ongoing and unpredictable change has left them feeling with control do day-to-day life. This is a confusing feeling, perhaps, when many carers also have significant responsibility for the welfare of their FM and are depended on in a real and immediate way. It is further complicated by the experience of grief and transition that many carers are experiencing, as the parent or partner is ‘lost’ and becomes ‘a different person’.
Challenges and dilemmas showing, telling and understanding	Many carers experience difficulties sharing their experiences of caring and/ or harmful behaviour. carers talk about feeling ignored, not taken seriously, and, sometimes, their experiences are ‘hidden in plain sight’: that people do not imagine and ‘think through’ what it is like to care and live in this way. Many carers worry about the implications of other people knowing the ‘full picture’ and there is a worry about ‘letting go’: allowing other people to influence the situation or important decisions, in part because they feel they know their FM the ‘best’ and are responsible for them.

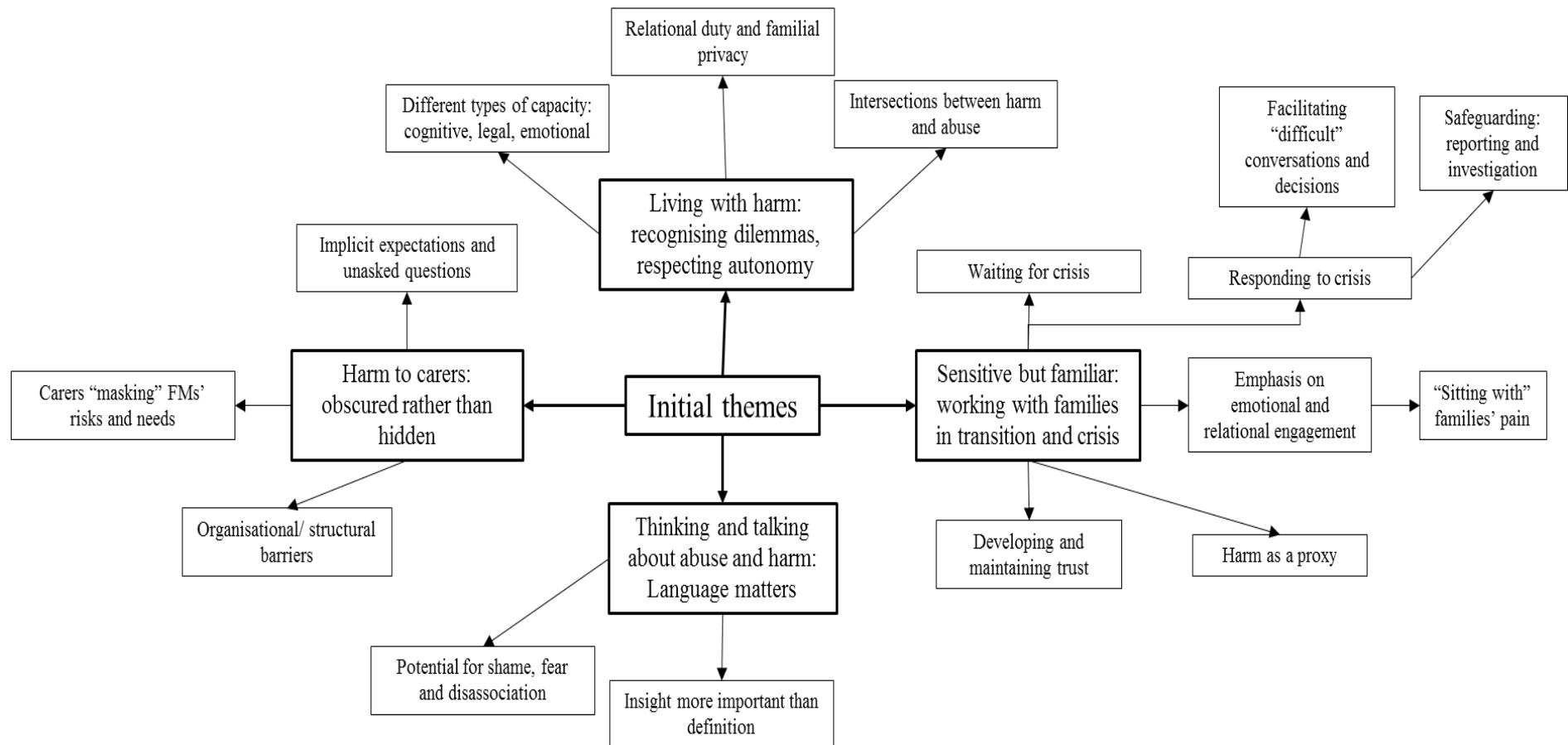
Appendix 3: Analysing the focus group transcripts: a reflective account

This appendix presents a selection of mind-maps, tables and reflective notes that I used in the process of developing a thematic analysis, using Braun and Clarke's (2006) approach, of the focus groups transcripts. These exercises and visual tools chart some of the central decisions I made identifying patterns, relationships and differences in the data. Presented in chronological order and with reference to the 'stages' of thematic analysis, they nevertheless highlight the iterative and gradual nature of the process. They also make visible some aspects of my role 'making meaning' and 'constructing' the analysis (Carter, 2007): an important dimension of research underpinned by social constructionist principles. This is particularly important given that as the primary researcher, I designed the structure of the focus group session, carried them out and transcribed the audio recordings. Moreover, I conducted the interviews from which the presented vignettes were developed. Thus, by this stage in the project, I had a significant influence on both the nature of the discussions and their analysis. By collating these excerpts, my aim is to open my work to critical scrutiny and to invite comments and feedback. This can in turn feed into and enrich interpretation of the practitioners' discussions and, more broadly, knowledge with and about carers affected by harmful behaviour. On a practical point, it may be helpful to read this appendix with reference to the 'methods' chapter of this thesis, as it provides a more detailed overview of both thematic analysis as an approach and my reasons for adopting it.

1. Familiarisation

Following transcription of the audio recordings and a review of my reflective notes, I created this mind-map. It highlights some of the key themes that would later come to structure the analysis. It also highlights common areas of conversation in and across the groups: for example, the importance of relationship-based practice and the need to be careful when talking about 'abuse' in the context of an older person's behaviour towards a family carer. The map also captures some ideas that seemed important or powerful but were not necessarily mentioned frequently: for example, discussions about 'sitting with' harm or abuse and 'waiting for crisis'. When I reviewed the transcripts, I was surprised that there was limited reference to the idea of 'sitting with' harm and yet, when facilitating the focus groups, I had been left with a strong impression that practitioners felt that this was both an important and inextricable part of their work. Excerpts from my reflective diary are provided overleaf.

Figure 1: Professionals' accounts: initial themes



Excerpts from reflective diary

Group 1: Admiral (dementia specialist) nurses

The group seemed engaged in the discussion. It seems that there are some aspects of the Admiral role that are quite distinctive (they used the word 'privileged') because of the time, space, and family-focus that their role and ethos afford. I wonder if other groups will have the same level of insight into families' lives. I also wonder what difference being a health practitioner - and having a strong focus on the needs of patients - might have in terms of how they attributed causes of harm as being rooted in disease/ diagnosis. It will be interesting to see how this discussion compares with other practitioner groups.

Group 2: Local authority social workers (adult care and safeguarding)

The practitioners talked about 'similar' scenarios to the ones described in the vignettes and about the potential conflict/ tensions working with families with competing needs. On several occasions, participants reflected on how policies/ legislation/ resources etc shaped (and constrained) their practice and/ or affected wider views and expectations about carers' roles and abilities. For example, there were several comments about practitioners feeling constrained to provide the level of support and follow-up that they felt carers needed, and, how carers who 'coped with' or 'masked' their needs were more likely to receive less support. In some ways, these comments dovetail with many of the carers' accounts, particularly those who felt 'hidden in plain sight'.

Group 3: Local authority social workers (adult care and safeguarding)

Again, no sense of surprise or resistance in terms of the topic matter. This was a small group who appeared to have worked together for some time and appeared relaxed talking together and challenging one another. In addition, there were no social work managers or senior social workers present and several times someone said, "I wouldn't say this if my manager was here".

From a methodological perspective, they seemed to respond positively to the vignette format. They asked detailed questions about the case, its context, what happened next, etc, as well as drawing comparisons with their own cases and, in one case, personal experience. One possible limitation is that there was a tendency to 'work' the case and to think about it from both a practitioner and operational perspective (what we do, as we work now), rather than in a more critical way.

There was a lot of discussion about the sexual harm vignette. Interestingly, it also evoked a direct comparison with the reports that SWs get from nursing homes regarding unwanted sexual contact and behaviour instigated by residents. This is not a comparison that the other groups have drawn, although it is an issue that is emerging in the research literature.

Group 4: Dementia advisors

An interesting and lively group discussion that was different in tone and content from the previous focus group sessions. It was initially difficult to start the meeting and to establish trust and rapport with the group as they had had limited information about the project and the session (although it had been sent out). For some people, I sensed wariness and this became more evident when it took a time it took to sign the consent forms. The group also seemed reluctant to engage with the vignettes. Perhaps this was because of the potentially 'school-like' nature of the exercises; perhaps because it felt more comfortable to reflect on cases and

talk with one another about shared experiences and sharing this knowledge with me, as they wished.

As a group, there was a clear and quick recognition of harmful behaviour as an issue affecting carers and people shared accounts of significant and complex types of harm from the outset of the session. There was seemingly no hint of surprise or discomfort talking about the issue although I recognise that because there appeared to be several more experienced (and in some cases more dominant) members of the group, this confidence may have masked the feelings and reaction of less vocal members.

Group 5: Local authority social workers (care coordination of nursing and residential home care)

Unfortunately, I didn't have the vignette cards with me (mistakenly packing them in the wrong bag) for this session. As a result, Alistair and I held a group discussion, exploring the practitioners' views and experiences working with carers affected by harmful behaviour. It was met with a different response from the other groups, with only a few people sharing experience and/ or making a connection with situations of long-term domestic violence. Several people talked about how care home staff didn't always have the time or training to understand 'challenging behaviour' and an issue that surfaced several times was the social workers' own limitations exploring 'difficult' issues with families due to their infrequent contact with them and the context of these meetings (in care and nursing homes). In addition, they talked about having limited services to offer 'ex' carers and often felt unable to do much for them (if needs were identified).

2. Generating initial codes

Table 1 outlines my initial attempt at deriving four broad, thematic areas into smaller codes or sub-themes. The codes in the first column are both analytical and descriptive. They were developed by reading the transcripts and noting down, line-by-line, summaries, and reflections about what the participants' shared. As a result, there is some overlap between the codes. The boundaries between them were refined and clarified at a subsequent stage of the analysis. Populating this table, I was struck by some of the tensions in the practitioners' accounts (e.g. the way they 'should' practice and the way that sometimes felt constrained to do so). I also noticed that there limited reference by any of the practitioners about the impact of working with families where abuse and neglect were central issues.

Table 1: Developing themes and codes

Organising themes	Descriptive and analytical codes	Reflections and observations
Harm to carers: obscured rather than hidden	<p><u>Positioning carers</u> Used and valued (to state, to society) "Masking" severity of FM's needs Not always a 'natural' choice or role Often isolating and difficult role Seeking control Fearing loss of control Coping and adapting Carers as resilient: "sticking with it" Protecting the vulnerable</p> <p><u>Impact of harm</u> Abnegation of carer needs Violence and injury Unpredictable/ chaotic situation Home is no longer safe Nowhere is safe Self-blame (not coping) "Chipping away": slow destruction Feeling confused/ disorientated People stay away/ distance themselves Feeling "between a rock and a hard place"</p> <p><u>Barriers to talking about harm</u> Shame cannot cope Loyalty (relational) Fear of consequences (e.g. separation) Loss of control, loss of choice Doesn't recognise as harm (or abuse) Incremental change so not recognised Needs to understand as a "symptom of illness"</p>	<p>Unsurprised responses</p> <p>Accepting of vignettes as 'real'</p> <p>Quick to talk about examples and comparison in practice</p> <p>Nevertheless, severe and sexual harm identified as "surprising" and "shocking" by some participants</p> <p>"Crisis" has different meaning and implications for different groups</p> <p>Striking how often all of the groups reflect on the unique and often fluid nature of every family circumstance.</p> <p>In general, the groups were careful to avoid generalisation and, if this did happen, group members would politely challenge or expand on each other's points.</p>

	<p><u>Barriers: inter-personal and organisational</u></p> <p>Taking time to build trust Meeting in crisis situations Limited resources Practitioner identity and power Nature of help-seeking Isolation (real and emotional) Cared-for doesn't recognise or admit Limited/ paucity of specialist services Medical focus on care needs and provision</p> <p><u>Lesser-asked or 'difficult' questions</u></p> <p>Meaning and experience of harm Experience during the night Sexual and physical intimacy Wanting to be a carer Wanting to no longer be a carer Degree of loss/ grief Beyond physical harm A lot that we don't know</p>	
<p>Living with harm: recognising dilemmas, respecting autonomy</p>	<p><u>"Working with" carers choices about:</u></p> <p>Tolerating harm Involving others Ways of coping Protecting FM Honouring the past (person or relationship) Reconciling past harm Ways of saying no "All about love" Understanding and assessing consent</p> <p><u>Considering capacity and choices</u></p> <p>Moral/ value issues Legal obligations Cognitive and intellectual Psychological/ emotional Changes in capacity</p> <p><u>Intersections between abuse and harm</u></p> <p>Situations dynamic Concern about harm to FM Concern about harm to others Harm as systemic in impact Subjective understandings Carer lacking knowledge Harm as an "element of control"</p>	<p>Indications that practitioner groups faced different constraints and opportunities to 'intervene' and working in the way they felt most appropriate</p> <p>Highly respectful and empathic language. Commitment to principle of autonomy. Likely to reflect legal and policy framework and culture in UK adult care.</p> <p>There was limited discussion/ reflection about how practitioners themselves felt about/ experienced working with families facing loss, crisis and transition. Discussion about this was almost always as a result of a direct question from me.</p> <p>This may reflect how familiar such work was and how well they coped/ were resilient. However, it may be that such</p>

	<p>Harm is often multi-causal</p> <p><u>Long-term domestic abuse</u></p> <p>Illness as excuse or cover</p> <p>Illness as complicating factor</p> <p>Carer seeking retribution/ recalibration</p> <p>Unclear cause</p> <p>Past experiences of help-seeking</p> <p>Limited services for older women</p> <p>“My abuse has already happened”</p> <p><u>Understanding as a symptom of illness</u></p> <p>Carers as empathic</p> <p>Carers placing FM needs first</p>	<p>issues were more difficult to talk about within this context, particularly given the level of peer scrutiny (and seeming consensus) in addition to the ‘formal’ nature of the discussion (being recorded, presence of ‘outsider’, etc).</p>
<p>Sensitive but familiar: working with families in transition and crisis</p>	<p><u>Relationship-orientated practice</u></p> <p>Time as resource</p> <p>Emotional engagement</p> <p>Building trust</p> <p>Trust facilitates engagement</p> <p>Every family is different</p> <p>Every family has a past</p> <p>Emphasis on instinct: “no rule book”</p> <p><u>What the role look like:</u></p> <p>Recognising strengths</p> <p>Encouraging reflection</p> <p>Facilitating ‘difficult’ decisions</p> <p>Stepping in: avoiding or minimising harm</p> <p>Talking: “digging deep”</p> <p>Talking: stimulation and company</p> <p>Recognising feelings (e.g. guilt, fear, loss)</p> <p>Challenging “less good” ways of coping</p> <p>Referring/ linking up with other services</p> <p>Recognising limitations to knowledge</p> <p><u>“Crisis” situations</u></p> <p>Anticipating and contingency planning</p> <p>Crisis necessary/ inevitable</p> <p>Role and responsibilities change</p> <p>Opportunities and challenges</p> <p>“Removing the risk”</p> <p>Curtails opportunity for rehabilitation</p> <p>Waiting for a “ticking time bomb”</p> <p>When nobody can say no</p> <p><u>Dilemmas/ challenges</u></p> <p>Safeguarding as punishment not</p>	<p>Although all groups made positive comments about their service and some of the strengths of how they worked with families, the three statutory SW teams were more reflective and critical (both analytically and making negative comments) about the limitations and constraints of their role. Literature suggests that this could reflect both real (and increasing) challenges facing adult SW, as well as a different cultural attitude amongst SWs (political focus, often position selves as ‘outside’ of the institutions they work for).</p> <p>Practitioners move between talking about harm and other, related, issues. Similar trend apparent in carers’ accounts. However, it might also implicitly ‘bury’ the issues and frame it as an ‘ethical’ one (e.g. autonomy, duty, etc.) and minimise consideration of lived experience (and safety) of the carer.</p> <p>Groups appear to have different objectives and prioritises about what are ‘good’ as well as what</p>

	<p>protection May not be any solutions/ 'good' outcomes Jeopardising the relationship Letting other practitioners 'in' Concerns about carers "slipping through the net" Other practitioners working in different (i.e. unhelpful/ inappropriate) ways "Forgetting that we are strangers" Becoming normalised/ not seeing from the 'outside'</p>	<p>are 'realistic' outcomes.</p> <p>Undertones of distancing/ positioning dynamics, particularly with DISC and Admiral nurses as being "relationship-focused" and having a "deeper understanding" of families. Some subtle comments about these workers finding it hard/ not wanting to let go of the way they worked (e.g. accepting that safeguarding was necessary but highly undesirable – because of how it came about as much as because of the outcome?)</p> <p>By positioning/ focusing on relational practice, many of the practitioners implicitly emphasise their relational skills and the unseen (and perhaps un-measurable) impact of their work.</p>
<p>Thinking and talking about abuse and harm: language matters</p>	<p><u>Cautious about abuse</u> Loaded/ emotive word Barrier to trust and relationship Subjective meaning important Not always necessary Not always appropriate Association with separation (removal) A practitioner word</p> <p><u>Dimensions to consider</u> Intentionality Impact (on carer and cared-for) Subjective meaning and experience Severity of behaviour Pattern (incl. frequency) Context</p> <p><u>Changing attitudes</u> Visibility and awareness make a difference Stigma of mental health and dementia illness Domestic abuse Attitudes to information and knowledge</p>	<p>Different attitudes amongst the practitioner group about this word and its associations.</p> <p>Sometimes contradictory/ confusing as abuse used in different contexts during the wider conversations (e.g. 'lay' and 'practitioner' associations/ contexts).</p> <p>Practitioners appeared to be comfortable (perhaps more familiar?) with concept and language of harm. All groups had concerns and seemingly stronger emotional reaction to the concept of abuse and the potential negative effects of using this term inappropriately. Careful, nuanced but unduly conservative? Harm as proxy but also, perhaps, unhelpfully vague?</p>

	<p>Decline in deference Different cultural contexts</p> <p><u>Harm as a proxy</u> For difficult decisions/ complex situations For emotional pain For significant change Not possible to separate</p>	<p>Discussion and/ or implicit reflections on the difference between ‘personal’ and ‘practitioner’ views about abuse and harm. Including several people talking about feeling ‘uncomfortable’ when terms used in the ‘wrong’ way. Appears to evoke more emotive as well as critical questions.</p>
Idiosyncratic codes	<p><u>Sexually harmful behaviour</u> Nursing home residents Male workers uncomfortable and/ or hesitant Unasked questions about night time More shocking/ surprising Complexities around consent Dynamics can change quickly</p> <p><u>Differences between practitioner and family carers</u> Different expectations Different levels of toleration Carers “holding” situations until crisis point</p> <p><u>Adult children as carers</u> Financial abuse/ exploitation Younger adults with complex needs Dilemmas around love and care</p> <p><u>Racial, ethnic and cultural minorities</u> Different types of shared knowledge Particular emphasis on trust Working both within and outside of the system Working in the shadow of societal racism Experiencing racial abuse</p> <p><u>Recommendations/ next steps</u> Continuing the conversation Asking and exploring Questioning (and mainly rejecting) formal guidance Organisational systems and priorities Doing what we do (i.e. continuing)</p>	<p>N.B. I raised issue of comparison between practitioner and family carers in the background/ intro of the sessions.</p> <p>DISC group of workers was predominately non-white, in contrast to each of the other groups. Race and ethnicity raised as an issue several times – re way they worked, dilemmas faced, and experiences of verbal abuse. Striking how absent these points of discussion were from the other groups. Not even seen/ heard?</p> <p>Different tone to conversations (if any) about ‘next steps’ and degree to which practitioner critically engaged with their own practice, in terms of both its strengths and its limitations.</p>

3. Searching for themes

Figure 2 outlines my second attempt to visually represent the emerging themes and clusters of codes. At this point in the analytic process, I was exploring new and different relationships between the codes and themes. I was developing new codes at the same time as refining others. It also introduces and refines new concepts that I had not identified at the time of creating the initial mind-map (Figure 1). This map was a useful guide when I began to put together the coding matrix (see Table 2).

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graph TD
    DT[Developing themes] --> HC[Choosing harm, living with harm]
    DT --> WT[Working with 'sensitive' but familiar issues]
    DT --> HCH[Engaging with harm]
    DT --> TH[Thinking and talking about abuse and harm]
    DT --> HCR[Reconciling relationship and crisis]
    DT --> HO[Obscured harm]

    HC --> C1[Attuned to carers' dilemmas]
    HC --> C2[Different types of capacity]
    HC --> C3[Possible intersections between abuse and harm]
    HC --> C4[Relationship-orientated practice]
    HC --> C5[My abuse has already happened: Histories of harm]

    WT --> W1[Crises as organising foci]
    WT --> W2[Opportunity: release, transition, change]
    WT --> W3[Spectre of safeguarding]
    WT --> W4[Pragmatism or powerlessness?]
    WT --> W5[Professional interfaces and interactions]
    WT --> W6[Not all about words: voices and silences]
    WT --> W7[Racial, ethnic, cultural minorities]
    WT --> W8[Communities of knowers]

    HCH --> HCH1[Engaging with harm]
    HCH --> HCH2[Evoking critical questions about role and practice]
    HCH --> HCH3[Reflections and recommendations]
    HCH --> HCH4[Sexually harmful behaviour: additional taboos]

    HO --> HO1[Challenges and barriers: personal/psychological]
    HO --> HO2[Challenges and barriers: interpersonal and organisational]
    HO --> HO3[Sexually harmful behaviour: additional taboos]

    TH --> TH1[Abuse as problematic/emotive]
    TH --> TH2[Considering role. Who are we protecting?]
    TH --> TH3[Urging caution]

    HCR --> HCR1[Reconciling relationship and crisis]
    HCR --> HCR2[Pragmatism or powerlessness?]
    HCR --> HCR3[Professional interfaces and interactions]
    HCR --> HCR4[Not all about words: voices and silences]
    HCR --> HCR5[Racial, ethnic, cultural minorities]
    HCR --> HCR6[Communities of knowers]

    C4 --> C4a[Emotionally-attuned]
    C4 --> C4b[Systemic understanding of illness within family]
    C4 --> C4c[Crises as organising foci]
    C4 --> C4d[Opportunity: release, transition, change]
    C4 --> C4e[Spectre of safeguarding]
    C4 --> C4f[Pragmatism or powerlessness?]
    C4 --> C4g[Professional interfaces and interactions]
    C4 --> C4h[Not all about words: voices and silences]
    C4 --> C4i[Racial, ethnic, cultural minorities]
    C4 --> C4j[Communities of knowers]

    C5 --> C5a[Crises as organising foci]
    C5 --> C5b[Opportunity: release, transition, change]
    C5 --> C5c[Spectre of safeguarding]
    C5 --> C5d[Pragmatism or powerlessness?]
    C5 --> C5e[Professional interfaces and interactions]
    C5 --> C5f[Not all about words: voices and silences]
    C5 --> C5g[Racial, ethnic, cultural minorities]
    C5 --> C5h[Communities of knowers]

    C3 --> C3a[Crises as organising foci]
    C3 --> C3b[Opportunity: release, transition, change]
    C3 --> C3c[Spectre of safeguarding]
    C3 --> C3d[Pragmatism or powerlessness?]
    C3 --> C3e[Professional interfaces and interactions]
    C3 --> C3f[Not all about words: voices and silences]
    C3 --> C3g[Racial, ethnic, cultural minorities]
    C3 --> C3h[Communities of knowers]

    C2 --> C2a[Crises as organising foci]
    C2 --> C2b[Opportunity: release, transition, change]
    C2 --> C2c[Spectre of safeguarding]
    C2 --> C2d[Pragmatism or powerlessness?]
    C2 --> C2e[Professional interfaces and interactions]
    C2 --> C2f[Not all about words: voices and silences]
    C2 --> C2g[Racial, ethnic, cultural minorities]
    C2 --> C2h[Communities of knowers]

    C1 --> C1a[Crises as organising foci]
    C1 --> C1b[Opportunity: release, transition, change]
    C1 --> C1c[Spectre of safeguarding]
    C1 --> C1d[Pragmatism or powerlessness?]
    C1 --> C1e[Professional interfaces and interactions]
    C1 --> C1f[Not all about words: voices and silences]
    C1 --> C1g[Racial, ethnic, cultural minorities]
    C1 --> C1h[Communities of knowers]

    C4a --> C4a1[Crises as organising foci]
    C4a --> C4a2[Opportunity: release, transition, change]
    C4a --> C4a3[Spectre of safeguarding]
    C4a --> C4a4[Pragmatism or powerlessness?]
    C4a --> C4a5[Professional interfaces and interactions]
    C4a --> C4a6[Not all about words: voices and silences]
    C4a --> C4a7[Racial, ethnic, cultural minorities]
    C4a --> C4a8[Communities of knowers]

    C4b --> C4b1[Crises as organising foci]
    C4b --> C4b2[Opportunity: release, transition, change]
    C4b --> C4b3[Spectre of safeguarding]
    C4b --> C4b4[Pragmatism or powerlessness?]
    C4b --> C4b5[Professional interfaces and interactions]
    C4b --> C4b6[Not all about words: voices and silences]
    C4b --> C4b7[Racial, ethnic, cultural minorities]
    C4b --> C4b8[Communities of knowers]

    C4c --> C4c1[Crises as organising foci]
    C4c --> C4c2[Opportunity: release, transition, change]
    C4c --> C4c3[Spectre of safeguarding]
    C4c --> C4c4[Pragmatism or powerlessness?]
    C4c --> C4c5[Professional interfaces and interactions]
    C4c --> C4c6[Not all about words: voices and silences]
    C4c --> C4c7[Racial, ethnic, cultural minorities]
    C4c --> C4c8[Communities of knowers]

    C4d --> C4d1[Crises as organising foci]
    C4d --> C4d2[Opportunity: release, transition, change]
    C4d --> C4d3[Spectre of safeguarding]
    C4d --> C4d4[Pragmatism or powerlessness?]
    C4d --> C4d5[Professional interfaces and interactions]
    C4d --> C4d6[Not all about words: voices and silences]
    C4d --> C4d7[Racial, ethnic, cultural minorities]
    C4d --> C4d8[Communities of knowers]

    C4e --> C4e1[Crises as organising foci]
    C4e --> C4e2[Opportunity: release, transition, change]
    C4e --> C4e3[Spectre of safeguarding]
    C4e --> C4e4[Pragmatism or powerlessness?]
    C4e --> C4e5[Professional interfaces and interactions]
    C4e --> C4e6[Not all about words: voices and silences]
    C4e --> C4e7[Racial, ethnic, cultural minorities]
    C4e --> C4e8[Communities of knowers]

    C4f --> C4f1[Crises as organising foci]
    C4f --> C4f2[Opportunity: release, transition, change]
    C4f --> C4f3[Spectre of safeguarding]
    C4f --> C4f4[Pragmatism or powerlessness?]
    C4f --> C4f5[Professional interfaces and interactions]
    C4f --> C4f6[Not all about words: voices and silences]
    C4f --> C4f7[Racial, ethnic, cultural minorities]
    C4f --> C4f8[Communities of knowers]

    C4g --> C4g1[Crises as organising foci]
    C4g --> C4g2[Opportunity: release, transition, change]
    C4g --> C4g3[Spectre of safeguarding]
    C4g --> C4g4[Pragmatism or powerlessness?]
    C4g --> C4g5[Professional interfaces and interactions]
    C4g --> C4g6[Not all about words: voices and silences]
    C4g --> C4g7[Racial, ethnic, cultural minorities]
    C4g --> C4g8[Communities of knowers]

    C4h --> C4h1[Crises as organising foci]
    C4h --> C4h2[Opportunity: release, transition, change]
    C4h --> C4h3[Spectre of safeguarding]
    C4h --> C4h4[Pragmatism or powerlessness?]
    C4h --> C4h5[Professional interfaces and interactions]
    C4h --> C4h6[Not all about words: voices and silences]
    C4h --> C4h7[Racial, ethnic, cultural minorities]
    C4h --> C4h8[Communities of knowers]

    C4i --> C4i1[Crises as organising foci]
    C4i --> C4i2[Opportunity: release, transition, change]
    C4i --> C4i3[Spectre of safeguarding]
    C4i --> C4i4[Pragmatism or powerlessness?]
    C4i --> C4i5[Professional interfaces and interactions]
    C4i --> C4i6[Not all about words: voices and silences]
    C4i --> C4i7[Racial, ethnic, cultural minorities]
    C4i --> C4i8[Communities of knowers]

    C4j --> C4j1[Crises as organising foci]
    C4j --> C4j2[Opportunity: release, transition, change]
    C4j --> C4j3[Spectre of safeguarding]
    C4j --> C4j4[Pragmatism or powerlessness?]
    C4j --> C4j5[Professional interfaces and interactions]
    C4j --> C4j6[Not all about words: voices and silences]
    C4j --> C4j7[Racial, ethnic, cultural minorities]
    C4j --> C4j8[Communities of knowers]

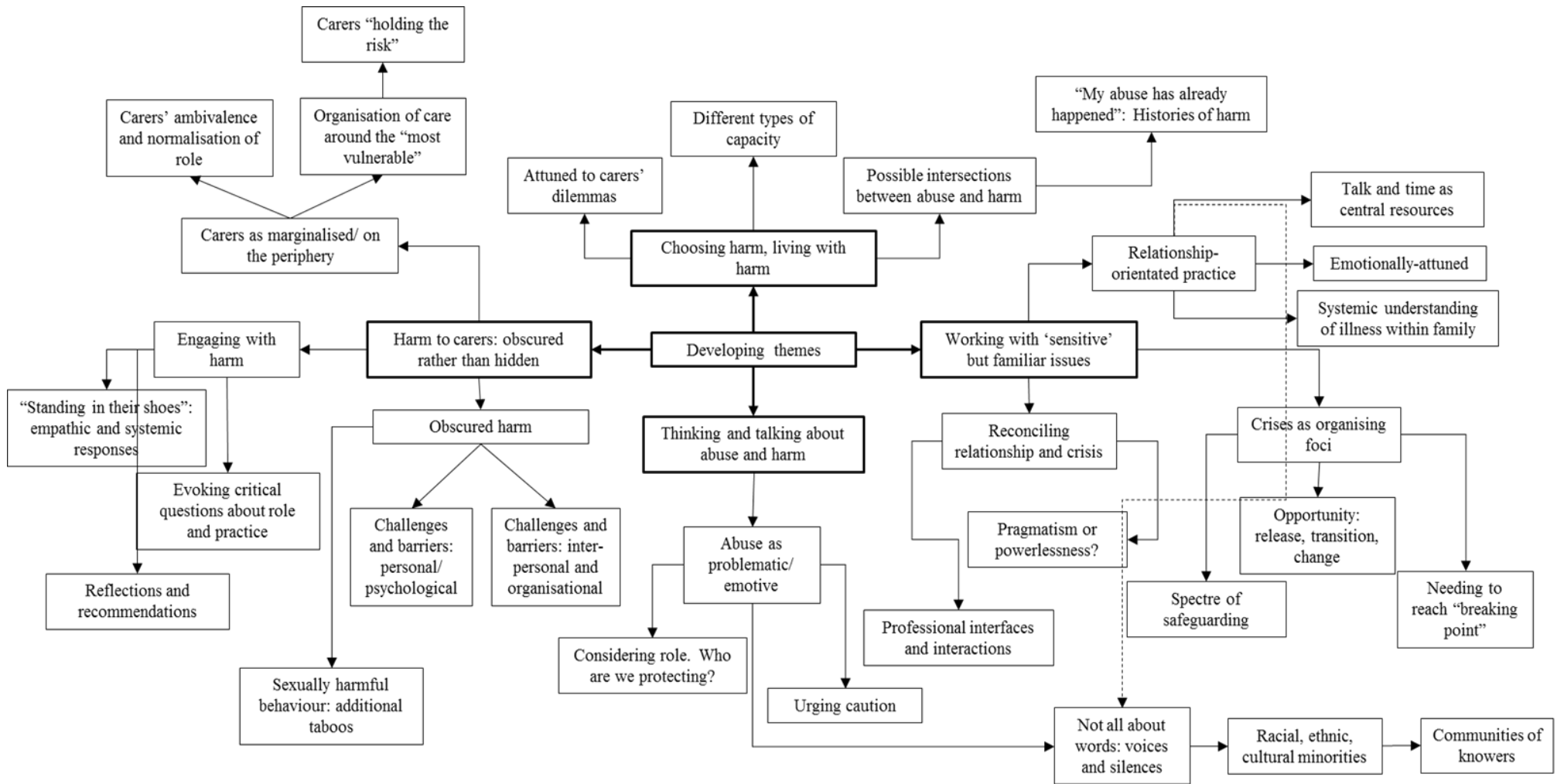
    C5a --> C5a1[Crises as organising foci]
    C5a --> C5a2[Opportunity: release, transition, change]
    C5a --> C5a3[Spectre of safeguarding]
    C5a --> C5a4[Pragmatism or powerlessness?]
    C5a --> C5a5[Professional interfaces and interactions]
    C5a --> C5a6[Not all about words: voices and silences]
    C5a --> C5a7[Racial, ethnic, cultural minorities]
    C5a --> C5a8[Communities of knowers]

    C5b --> C5b1[Crises as organising foci]
    C5b --> C5b2[Opportunity: release, transition, change]
    C5b --> C5b3[Spectre of safeguarding]
    C5b --> C5b4[Pragmatism or powerlessness?]
    C5b --> C5b5[Professional interfaces and interactions]
    C5b --> C5b6[Not all about words: voices and silences]
    C5b --> C5b7[Racial, ethnic, cultural minorities]
    C5b --> C5b8[Communities of knowers]

    C5c --> C5c1[Crises as organising foci]
    C5c --> C5c2[Opportunity: release, transition, change]
    C5c --> C5c3[Spectre of safeguarding]
    C5c --> C5c4[Pragmatism or powerlessness?]
    C5c --> C5c5[Professional interfaces and interactions]
    C5c --> C5c6[Not all about words: voices and silences]
    C5c --> C5c7[Racial, ethnic, cultural minorities]
    C5c --> C5c8[Communities of knowers]

    C5d --> C5d1[Crises as organising foci]
    C5d --> C5d2[Opportunity: release, transition, change]
    C5d --> C5d3[Spectre of safeguarding]
    C5d --> C5d4[Pragmatism or powerlessness?]
    C5d --> C5d5[Professional interfaces and interactions]
    C5d --> C5d6[Not all about words: voices and silences]
    C5d --> C5d7[Racial, ethnic, cultural minorities]
    C5d --> C5d8[Communities of knowers]

    C5e --> C5e1[Crises as organising foci]
    C5e --> C5e2[Opportunity: release, transition, change]
    C5e --> C5e3[Spectre of safeguarding]
    C5e --> C5e4[Pragmatism or powerlessness?]
    C5e --> C5e5[Professional interfaces and interactions]
    C5e --> C5e6[Not all about words: voices and sil
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4. Reviewing themes

This coding framework guided the next stage of thematic analysis: to re-code and review the themes identified in the original transcripts. Whilst some themes remained relatively unchanged, others expanded and developed in the process of returning to the original data. At this stage of analysis, the codes tended to be more abstract and thematic, rather than descriptive. When appropriate, some of the themes also draw on concepts and evidence in the wider research and practice literature: for example, those relating to working in ‘crisis’ situations and challenges identifying and responding to family carers. This situates the analysis in new contexts, drawing on debates and issues in contemporary UK health and social care. However, there are still many themes that are primarily inductive and that explore some of the issues that came up when talking about and working with carers affected by harm and abuse by the person for whom they care (see chapters on carers’ interviews and the advisory network).

Table 2: Coding framework

1. Harm to carers: obscured rather than hidden

Code	Description
Organisation of care/ services around the ‘most vulnerable’	Carers masking the severity/ complexity of needs of cared-for Service and resource focus Organising concepts of vulnerability, need and risk are health-focused Limited/ uneven support for carers as individuals Seeing and knowing some types of harm more than others
Carers’ paradox: at the centre and on the periphery	Recognise and aware of carers’ contribution/ debt to carers Carers placing needs of FM first Carers’ feelings of ambivalence and ambiguity about role Caring in relative isolation Carers as ‘strong’ and resilient
Challenges and barriers telling (personal and ethical)	Feelings of guilt and disloyalty Feelings of shame: breaking taboos and loss of control Strong sense of responsibility and duty to ‘carry on’ caring Pressure and expectations from other family members Cultural norms and complicating factors Not knowing/ not being sure about causes of harm
Challenges and barriers telling (inter-personal and organisational)	Intersections and complexities: gender, race and cultural issues Practitioner role and position: “We forget that we are strangers” The hidden risks that carers carry (practically and emotionally) The spectre of separation Social attitudes and expectations
Sexually harmful behaviour: more complex, more hidden	Reflecting on age-related expectations Consent and capacity in the context of sexual intimacy A sensitive issue for carers and practitioners

2. *Reflecting on and responding to harm to carers*

Code	Description
Engaging with the emotional experience	Fear and guilt as powerful and organising emotions Feelings of confusion and disorientation Harm in the context of loss and transition Individual experience and meaning is paramount ‘Deep’ feelings (e.g intimate relationship/ adult attachment) Abnegation of needs/ life and identity ‘consumed’ by caring role Division/ disjuncture between thoughts and behaviour Intensity of experience
Engaging with the ethical tensions and dilemmas	Decision-making rests with the carer Not wanting and/ or not feeling able to say ‘no’ Nothing is clear, everything is complex Capacity and intentionality matter The right to choose to live with harm? Disparity between practitioner and family carer gaze
Illness as an explanatory factor	The most appropriate way to understand harm Illness as cause and catalyst (complicating factor) Disruption
Histories of harm (DA, IPV, complex families)	A lifetime of coping and tolerating Cumulative and complex harm Complex family dynamics Retaliation: decisions about care and ‘pay-back’ abuse Separation is often not a solution
Alert to intersections between harm and abuse	When toleration becomes neglect Everybody is unsafe: recognising chaos Dynamic, rapidly changing situations Families as unique and different (e.g. diff norms, expectations, coping)
Patient or service user focus	Deciphering their needs The ‘most’ vulnerable Lack of knowledge/ skill on part of the carer Considering causes of harmful behaviour Forgotten/ misremembered harm
Difficulties and concerns ‘answering’	Not enough information: context and detail are key Key indicators: severity, frequency, duration, etc Not something that I have considered/ unfamiliar space

3.. *When everything is complex: trying to reconcile relationship and crisis orientated practice*

Code	Description
Building relationships	Trust: the linchpin of practitioner-service user relationships Taking time and making space ('difficult' conversations, to get to know families) Valuing difference and respecting autonomy Promoting affirmation/ recognition Responsiveness
Using and sharing practitioner knowledge	Supporting people to make informed decisions Developing contingency plans/ looking ahead Understanding and working the 'system' Promoting education and enhanced knowledge Building understanding with and about families Intuition and 'gut' instinct Humility/ awareness that do not know or see everything
Crisis or short-term focus	Families needing to reach 'breaking point' Recognising the signs Practitioners feeling concerned, feeling powerless Stepping in and taking decisions (for not with) Focus on 'risk' and safety (different kinds of crisis)
This is our way: differences in practitioner identities and roles	Concerns about 'letting go' of families "We're actually quite good at this": role and contribution Tensions and difference between practitioners and their approaches Critical questions about practitioner limitations and constraints Reconciling different viewpoints/ ways of seeing and thinking

4. An issue that has no name? Problematising abuse and preferring harm

Code	Description
Abuse as emotive and unhelpful	Likely to inhibit trust and disclosure Emotive and powerful Problematic implication of intention Feels rights: conveys severity, conveys impact Personal/ emotional responses: feeling uncomfortable Subjective dimensions
Harm as usefully vague	Can encompass different (intersecting) types of loss and pain Practitioner rather than emotive Feel right, feels real
Unresolved issues and future directions	Needing to carry on the conversation: no easy answers Raising awareness and visibility of the issue Inter-practitioner communication and systems "It's not something I had considered": reflections on the discussions

Coding excerpts

<p>David: I guess it is that thing, if we put ourselves in that situation, and if someone was to come to me and say ‘why did you hit your partner’? I would say ‘What? I didn’t! Why would I do that?’ And so the shock that they must feel. You can understand. You know, that doesn’t make it easier for Sarah necessarily but you can imagine the absolute horror that... because people will have their own personal standard about how to manage situations and for some... I mean, if I had some bobbies knocking on my door today and asking me why I had hit my wife... it would just be horrific... I mean, I didn’t so why would you ask that... I mean it is difficult to get into the mindset, because if someone said, well, how did she get that bruise you might start to think it was all a bit suspect... but then again it is hard to know. Because you need the memory and the cognition to figure out those kind of things.</p>	<p>Patient/ SU focus <i>Forgotten/misremembered harm</i></p> <p>Emotion <i>Confusion/ disorientation</i> <i>Harm in the context of loss and transition</i></p> <p>Talking about abuse <i>Personal/ emotional response or reflection</i></p>
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<p>Maggie: Sometimes it is a test of trust to you, as well. I know certainly that when you go into African-Caribbean communities – and I’m not saying all, but some – and they would say that they never get a service, they get this and they don’t get that. And then you walk in and sit down and there is this natural thing that you just get – which is “keep your mouth shut, I’m telling you” – and you’re trying to communicate with them to say that that is not as easy as you would like it to be. So, you have to almost guide them to say, “if you tell me this, then I’m going to have to do this”. But there is a great sense of risk that you pick up on as you go along. I know that thing, when you walk through the door... I knew this one lady that lived alone and when her referral came in, she was told that she didn’t have long to live. She would be popping her clogs and didn’t have long and all this sort of stuff. And she lived with her son. And the son was take, take, take, take... And there were</p>	<p>Building relationships <i>Trust</i> <i>Valuing difference respecting autonomy</i></p> <p>Developing knowledge <i>Sharing knowledge with and for families</i></p> <p>Challenges</p>
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<p>question marks about financial abuse and what was going on. And at first it was a little bit about well, yeah, she couldn't remember anything and she wasn't sure about anything. And when her son went then we had a conversation. And when I was talking to her, I was like, well, I felt that I had to talk with them using patois for them to really understand that this was acceptable or not acceptable. It is a picture that they are giving and it is not always the full picture. But then, straight away, what you have got is a bonded thing.</p>	<p><i>Inter-personal spaces</i> <i>Gender, generation and race/ ethnicity</i></p> <p>Ethical <i>Loyalty and guilt</i> <i>Choosing to live with harm</i></p>
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5. Defining and naming themes

This stage of thematic analysis focuses on synthesis and presentation. In the following two tables, I outline each of the three, central unifying themes. The first table summarises the central codes that are captured by each of the themes and there is a relationship between these ‘families’ of codes, each one building on or being connected to the other. The second table provides three short paragraphs that summarise the salient points of each theme. This exercise is intended, in part, to encourage researchers to check the clarity and ‘sense’ of their theme and to begin to turn their attention towards how to present and report their findings to a wider audience. As a result, this last table coheres closely with the structure of the analysis chapter and its orientating concept map.

Table 3: Central unifying themes and their associated codes

Unifying themes	Central themes
Harm as a proxy for dilemmas, difficulties and distress	<ul style="list-style-type: none">• The practical, emotional and ethical implications of harmful behaviour• Relationship ‘history’ and complexity• Challenges and barriers to seeing and intervening re harmful behaviour
Practitioners’ responses, role and working relationships	<ul style="list-style-type: none">• Alleviating the impact of harm: building choices and contingencies• Working in a system orientated toward crisis and health need• Inter-personal dimensions
Grey issues and future areas	<ul style="list-style-type: none">• Responding to (and differentiating between) abuse, autonomy and love• Carrying on the conversation: future directions and needs

Table 4: Description of central unifying themes

Central theme	Summary description
Harm as a proxy for dilemmas, difficulties and distress	Practitioners identified harmful behaviour towards carers as a ‘live’ issue that they encountered in varying degrees of frequency and severity in part depending on their role and position when working with families. Practitioners focused on the intense and complex emotional nature of the experience of being harmed (physically, emotionally, etc.); they also highlighted the ethical dilemmas and social expectations that carers were likely to navigate in responding to harm in the context of an intimate relationship. Taken together, these strands of discussion emphasised the personal and subjective nature of harm and the importance of considering social, familial and cultural factors.
Practitioners’ responses, role and working	Practitioners talked about responding to harmful behaviour, often, in the context of working with families at times of crisis, disruption and loss. There was an implication that these ‘crisis’ situations dislodged or even

relationships	<p>tore away the protective shields and distancing strategies that carers may have built up to cope and to contain experiences of harmful behaviour. This opened up wider discussions about the approaches, values and strengths that the different practitioners groups associated with their work. Often, these centred on developing relationships, informing decisions and supporting people to manage and minimise risks (often to physical safety). Developing knowledge with and for families was both a crucial and a hidden (under-valued, poorly understood, ‘difficult to measure’) aspect of each practitioner groups’ work. Nevertheless, practitioners highlighted some of the limitations and constraints on their role and some of the tensions and difficulties working with other practitioner groups who ‘did things differently’ and who had different values and priorities around issues such as risk, crisis and quality of life.</p>
<p>Recognising harm in the context of a system orientated to crisis and patient need</p>	<p>The practitioner groups urged caution and sensitivity labelling harmful behaviour as ‘abusive’ and highlighted, often implicitly, how non-intentional behaviour was qualitatively different from intentional behaviour. They stressed that the potentially emotive and visceral connotations of the word and identified this as a barrier to developing trust and honesty with families. There was reference made to inter-generational norms, the importance of distinguishing between domestic abuse and harm. Practitioners also questioned the appropriateness of understanding the phenomena as affecting only the carer and highlighted that the risks, needs and (unintentional) impact on their family member. Reflecting dominant legal and practice organising concepts, a high degree of emphasis was placed on autonomy and capacity, tacitly framing the issue as an ethical (and relational) one rather than about abuse and/ or trauma.</p>

Appendix 4: Oral and poster presentations

Oral presentations

- British Sociological Association (BSA) post-doctoral research conference on 'Research sensitive issues', York, November 2018
- BS) medical sociology annual conference, Glasgow, September 2018
- Centre for Violence Prevention annual conference, University of Worcester, June 2018
- University of Birmingham postgraduate research festival, Birmingham, April 2018
- Royal College of Nurses (RCN) West Midlands network meeting, Birmingham, Dec 2017
- Social Research Association (SRA) annual conference, London, December 2017, UK
- European Social Work Research Association (ESWRA) annual conference, Aalborg, Denmark, April 2017
- Suresearch: Mental Health User Research Network meeting, Birmingham, March 2017
- Universities 21 (U21) annual conference, Birmingham, September 2016
- School of Nursing seminar, University of Birmingham, May 2016

Poster presentations

- Collaborative Research and Practice, Birmingham City Council, November 2017
- Risk, Abuse and Violence conference launch, University of Birmingham, March 2017
- NIHR Older people's health and wellbeing event, Birmingham, October 2016



UNIVERSITY OF
BIRMINGHAM

FINANCE OFFICE

11th August 2017

To Whom It May Concern

Title: "When elderly people harm their carers: Investigating the experiences and needs of family carers (the EPAC study)"

Reference: Application for Ethical Review ERN_16-0534

Research student: Ms Louise Isham

Research supervisors: Dr Caroline Bradbury-Jones and Dr Alistair Hewison

I can confirm that the above project was granted full ethics approval by the University of Birmingham's Science, Technology, Engineering and Mathematics Ethics Committee on 25th August 2016.

Further information about the University of Birmingham's ethics review process can be accessed at <https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/University-Ethical-Review.aspx>.

If you have any queries regarding the above, please do not hesitate to contact me further.

Yours faithfully



Mrs Susan Cottam
Research Ethics Officer
Research Support Group
University of Birmingham

Dr Caroline Bradbury-Jones
School of Nursing,
University of Birmingham,
Edgbaston, Birmingham
B15 2TT

Email: hra.approval@nhs.net

13 June 2017

Dear Dr Bradbury-Jones

Letter of HRA Approval

Study title:	When older people harm their carers: investigating the experiences and needs of family carers
IRAS project ID:	224614
REC reference:	17/WM/0208
Sponsor	University of Birmingham UK

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **224614**. Please quote this on all correspondence.

Yours sincerely

Miss Helen Penistone
Assessor

Email: hra.approval@nhs.net

Copy to:

[Redacted]

[Redacted]

Mental Health NHS Foundation Trust

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [224614_Participant recruitment poster]	1.2	01 June 2017
Covering letter on headed paper [224614_Cover letter]	1	03 May 2017
Interview schedules or topic guides for participants [224614_Interview schedule]	1	03 May 2017
IRAS Application Form [IRAS_Form_18052017]		18 May 2017
Letter from funder [224614_Proof of funding]	1	03 May 2017
Letter from sponsor [224614_Sponsorship letter]	1	03 May 2017
Letters of invitation to participant [224614_Participant invitation letter]		01 June 2017
Other [224614_CI declaration]	1	03 May 2017
Other [224614_Sponsor insurance certificate]	1	03 May 2017
Other [Statement of Activities]	1	19 May 2017
Other [Schedule of Events]	1	19 May 2017
Other [224614_AH_CV_academic supervisor]	1	18 May 2017
Other [224614_Participant helpline services]	1.2	01 June 2017
Other [Cover Letter]	1	06 June 2017
Participant consent form	1.3	June 2017
Participant information sheet (PIS)	1.3	June 2017
Referee's report or other scientific critique report [224614_Funding review panel summary]	1	03 May 2017
Research protocol or project proposal [224614_Research protocol]	2	03 May 2017
Summary CV for Chief Investigator (CI) [224614_CI CV]	1	03 May 2017
Summary CV for student [224614_PhD student CV]	1	03 May 2017
Summary CV for supervisor (student research) [224614_Supervisor CV]	1	03 May 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [224614_Project process diagram]	1	03 May 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Louise Isham

Tel: [REDACTED]

Email: [REDACTED]

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	The IRAS ID was added to the Participant Information Sheet and Consent Form following REC favourable opinion.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Although formal confirmation of capacity and capability is not expected of all or some organisations participating in this study (see <i>Confirmation of Capacity and Capability</i> section for full details), and such organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and information within this Appendix B.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	There is funding to support the study from the University of Birmingham as part of a PhD studentship. There will be no funding available to site to support the study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no	Not Applicable	No comments

Section	HRA Assessment Criteria	Compliant with Standards	Comments
	objection received		
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There will be a single NHS site acting as a participant identification centre. Clinical practitioners at site will share information with affected families.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

The HRA has determined that participating NHS organisations in England **are not expected to formally confirm their capacity and capability to host this research**, because the study will involve minimal burden to staff at site and no research activities will be carried out at site.

- The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary.
- Following issue of the HRA Approval letter, and subject to the two conditions below, it is expected that these organisations will become participating NHS organisations 35 days after issue of this Letter of HRA Approval (no later than **18 July 2017**):
 - You may not include the NHS organisation if they provide justification to the sponsor and the HRA as to why the organisation cannot participate
 - You may not include the NHS organisation if they request additional time to confirm, until they notify you that the considerations have been satisfactorily completed..
- You may include NHS organisations in this study in advance of the deadline above where the

organisation confirms by email to the CI and sponsor that the research may proceed.

- The document “[Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected](#)” provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

It is not expected that there will be a principal investigator or local collaborator at site.

The sponsor will not be providing training and does not expect that local staff will have completed any particular training.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Local staff who have a contractual relationship with the organisation will undertake the expected activities. Therefore no honorary research contracts or letters of access are expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.



People Group

Policy Development Officer
Social Care & Support

Tel:
Email:

06/09/17

Dear Louise

The carers hidden harm project: Investigating the experiences and needs of family carers affected by violent, abusive or harmful behaviour by the older person for whom they care

I am writing on behalf of [REDACTED] Research Governance Board with feedback from the Board on your research proposal.

We have seen and considered the following documents:

- Confirmation of university ethical approval
- Insurance certificate
- Confirmation of Insurance
- Professionals_consent form_version 1
- Professionals_focus group vignettes and questions_version 1
- Professionals_letter of invitation_version 1
- Professionals_participant_information_version 1
- Project timetable_version 1
- Research protocol
- [REDACTED] social care research governance application_Louise Isham

The overall view of the Board is that this application should be supported. However, Board members have some comments which you may wish to consider.

We agreed this is an extremely well prepared application and a potentially a very useful study of an under-researched area. Consent forms and information sheets are well written and clear and the vignettes are ones that will, we think, lead to some interesting and productive debates within the proposed focus groups. The design and methods reflect a good understanding of the operational pressures facing Adult Social Care Departments these days and set out to consciously minimise the impact of the study on busy working lives. The study is achievable within available timescales and resources.

Please proceed with your research. There is no need to contact me about the points below.

Professionals' Participant Information

- Heading: 'What is behaviour?' Should this read 'harmful behaviour?'
- Who has reviewed the study? – You can now add [REDACTED] People Group Research Governance Board'
- 'If you would like to make a complaint or to raise a query about the conduct of the research team, please contact ***' Don't forget to add the relevant name.

Professionals Consent Form

- 'If you agree to participate, please put your initials in the right-hand box.' Might be re-worded - *If you agree with the statements below, please put your initials in the box to the right of the statement.*
- Point 4) should read: 'I am aware that this project has been reviewed by the [redacted] Council Research Governance Board and the University of Birmingham Research Ethics Panel' (not [redacted] Council Research Ethics Panel and the University of Birmingham Research Governance board).

We hope the feedback is helpful and wish you well with your research. Please remember to send us a copy of the final report or summary when the research is complete.

Yours sincerely

[redacted]

[redacted]

Research Governance Lead

cc. Dr Caroline Bradbury-Jones
Dr Alistair Hewison

[redacted], Interim Head of Social Care & Support, People Group, [redacted]
[redacted] Council
[redacted], Head of Social Care & Support, People Group, [redacted] Council

