

# Female family carers' experiences of violent, abusive or harmful behaviour by the older person for whom they care

Isham, Louise; Bradbury-Jones, Caroline; Hewison, Alistair

DOI:

[10.1111/1467-9566.12986](https://doi.org/10.1111/1467-9566.12986)

License:

Other (please specify with Rights Statement)

*Document Version*

Peer reviewed version

*Citation for published version (Harvard):*

Isham, L, Bradbury-Jones, C & Hewison, A 2020, 'Female family carers' experiences of violent, abusive or harmful behaviour by the older person for whom they care: a case of epistemic injustice?', *Sociology of Health and Illness*, vol. 42, no. 1, pp. 80-94. <https://doi.org/10.1111/1467-9566.12986>

[Link to publication on Research at Birmingham portal](#)

## **Publisher Rights Statement:**

This is the peer reviewed version of the following article: Isham, L., Bradbury-Jones, C. and Hewison, A. (2019), Female family carers' experiences of violent, abusive or harmful behaviour by the older person for whom they care: a case of epistemic injustice?. *Sociol Health Illn*. doi:10.1111/1467-9566.12986 which has been published in final form at <https://doi.org/10.1111/1467-9566.12986>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.

## **General rights**

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

## **Take down policy**

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.



**Female family carers' experiences of violent, abusive or harmful behaviour by the older person for whom they care: a case of epistemic injustice?**

Journal:	<i>Sociology of Health and Illness</i>
Manuscript ID	SHI-00125-2019.R1
Manuscript Type:	Original Article
Subject Area:	Care work < RESEARCH AREAS, Family/kinship < RESEARCH AREAS, Experience of illness < RESEARCH AREAS, Inequalities/social inequalities in health status < RESEARCH AREAS
Abstract:	<p>Family carers affected by violent, abusive or harmful behaviour by the older person for whom they care face social and epistemic challenges in developing and sharing knowledge about their experiences. These difficulties have contributed to a situation in which there is a paucity of evidence and public discourse about how we understand violence and harm instigated by people who have care needs or are 'vulnerable'. This paper reports the findings of a qualitative study that involved twelve in-depth interviews with female carers affected by violence, abuse or harm. The study was informed theoretically by Miranda Fricker's concept of epistemic injustice which was used as a framework for analysis. There were two principal findings: 1) Carers were sensitive to anticipatory stigma and loss of moral autonomy. As a result, they self-censored what they shared and, at times, were met with subtle but powerful processes of silencing. 2) Carers had limited linguistic and conceptual resources to explain the emotional and social aspects of the harm they experienced, exacerbated by implicit social norms about the 'private' and gendered nature of familial care. To conclude, we discuss the implications of these findings for sociological research and health and social care practice.</p>

1  
2  
3  
4 **Female family carers' experiences of violent, abusive or harmful behaviour by the older**  
5  
6 **person for whom they care: a case of epistemic injustice?**  
7  
8  
9

10 **Abstract**  
11

12 Family carers affected by violent, abusive or harmful behaviour by the older person for  
13 whom they care face social and epistemic challenges in developing and sharing knowledge  
14 about their experiences. These difficulties have contributed to a situation in which there is a  
15 paucity of evidence and public discourse about how we understand violence and harm  
16 instigated by people who have care needs or are 'vulnerable'. This paper reports the findings  
17 of a qualitative study that involved twelve in-depth interviews with female carers affected by  
18 violence, abuse or harm. The study was informed theoretically by Miranda Fricker's concept  
19 of epistemic injustice which was used as a framework for analysis. There were two principal  
20 findings: 1) Carers were sensitive to anticipatory stigma and loss of moral autonomy. As a  
21 result, they self-censored what they shared and, at times, were met with subtle but powerful  
22 processes of silencing. 2) Carers had limited linguistic and conceptual resources to explain  
23 the emotional and social aspects of the harm they experienced, exacerbated by implicit social  
24 norms about the 'private' and gendered nature of familial care. To conclude, we discuss the  
25 implications of these findings for sociological research and health and social care practice.  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Introduction

In the last fifty years, the average age of mortality has risen steadily across the globe and the proportion of older people relative to younger adults and children continues to rise year-on-year (World Health Organization, 2015). Furthermore, ill health in later life is increasingly characterised by the experience of long-term, co-morbid and complex illness (Pin and Spini, 2016). It is in this context that the number of families undertaking caring responsibilities continues to rise such that family or 'informal' carers make up the largest single group of caregivers for older adults, who are generally but not uniformly, defined as **adults aged 60 and over** (Pinquart and Sörensen, 2011). It has been found 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 (Carmichael and Ercolani, 2016). However, it is also important to recognise that the experience of caring is both an intimate and personal one, unique to the relational, spiritual and cultural context in which family members navigate responsibility and accountability for one another's needs (Kittay, 2011). Appreciation of caring should therefore take into account the complex, lived experience of looking after (and being looked after) whilst recognising that many carers experience the role as primarily relational, imbued with biographical and social meaning (Larkin et al, 2018).

This paper reports a study that explored a hidden aspect of the caring experience: that of family carers affected by violent, abusive or harmful behaviour instigated by the older person for whom they care. We set out some of the factors that can give rise to such behaviour in the following section of the paper. However, we were not principally concerned with whether the behaviour could helpfully be described as a 'symptom of illness' or an 'act of abuse', reflecting two implicit but powerful characterisations in the research literature (Isham et al, 2017). Rather, we sought to explore how carers talked about and understood the experience

1  
2  
3 of caring for, and, frequently living with, a family member who was violent, abusive or  
4  
5 harmful towards them. We carried out twelve in-depth interviews with affected carers and  
6  
7 analysed the data using the analytic lens of Miranda Fricker's theory of epistemic injustice.  
8  
9 The contribution of this study is that it uncovers a previously 'hidden' element of the carer  
10  
11 experience and to identify some of the social and epistemic challenges carers in this situation  
12  
13 face. The paper is likely to be of interest to researchers and theoreticians working across the  
14  
15 health and social sciences. It is also of relevance to health and social care practitioners  
16  
17 working with older adults and their families.  
18  
19  
20  
21  
22  
23

### 24 **A hidden problem**

25  
26 There is a paucity of research and practice knowledge about the causes, contexts, and  
27  
28 implications of what happens when older people act in a violent, abusive or harmful way  
29  
30 towards the family member who cares for them. The research that does exist spans the field  
31  
32 of elder abuse (Pillemer and Suitor, 1992; Pillemer et al, 2016), intimate partner abuse in  
33  
34 older age (Koenig et al, 2006; Band-Winterstein, 2014) and studies about the lived  
35  
36 experience of cognitive and serious mental ill health (Cahill and Shapiro, 1993; Herron and  
37  
38 Rosenberg, 2017). Consistently characterised as a 'sensitive' issue, there are a number of  
39  
40 ethical and methodological challenges involved in identifying and carrying out research with  
41  
42 this 'hidden' population: for example, the taboo nature of the topic and a concern to not  
43  
44 stigmatise individuals with mental and physical health problems who act in a violent or  
45  
46 unpredictable way. There are also methodological difficulties measuring and defining what  
47  
48 constitutes harmful or abusive behaviour in the caring context (Spencer et al, 2018).  
49  
50  
51  
52  
53  
54

55  
56 Difficulties defining and conceptualising this form of harm also reflect social norms and  
57  
58 expectations about older people who are ill or have a disability. Because there is a link  
59  
60

1  
2  
3  
4 between the concepts of illness and patient-hood there is also a subtle but pervasive  
5  
6 assumption that people who are ill or vulnerable in some way cannot instigate violence or  
7  
8 abuse intentionally (Dixon et al, 2013). With this comes a release from responsibility for  
9  
10 individual action in most legal and moral understandings of these terms. In the context of  
11  
12 caring relationships, this implicit assumption makes it difficult to recognise the complex and  
13  
14 fluid nature of power between adults. Rather it closely positions those with (any) care needs  
15  
16 as having less power than those they rely on for care (McDonald and Thomas, 2013). This  
17  
18 association is compounded further if a person has characteristics that are consistent with  
19  
20 prevailing social norms of passivity, oppression or perceived weakness: for example, older  
21  
22 age, disability or impairment. Such associations may obscure the relational and temporal  
23  
24 nature of co-dependency and intimacy in adult relationships over the life-course (Daniel and  
25  
26 Bowes, 2010; Dunn et al, 2008). Narrow and static understandings of 'vulnerability' also tend  
27  
28 to overlook the unique ways that people cope and adapt to situations of distress and difficulty  
29  
30 later in life (McKay, 2017). It is thus possible to trace inconsistencies in how violent, abusive  
31  
32 or harmful behaviour towards and by some groups is defined and understood. It is against this  
33  
34 backdrop that we discuss the theoretical framework that underpinned our analysis: Miranda  
35  
36 Fricker's concept of epistemic injustice.  
37  
38  
39  
40  
41  
42  
43  
44

### 45 **Theoretical orientation: epistemic injustice**

46  
47 Epistemic injustice relates to the unfair dismissal or suppression of a person's knowledge or  
48  
49 way of communicating. Initially adopted by political and feminist scholars – exploring  
50  
51 epistemic injustice in the context of gender and racial inequalities (Medina, 2012; Dotson,  
52  
53 2011) – over the past decade, the concept has since been developed in the fields of applied  
54  
55 social science and bioethics (Freeman, 2014; Kidd and Carel, 2017). Although several  
56  
57 scholars have contributed to the critical development of the concept, Miranda Fricker's work  
58  
59  
60

1  
2  
3 on the subject has perhaps made the most noteworthy and unique contribution (Riggs, 2012;  
4 Origgi, 2012). Fricker argues that there are two kinds of epistemic injustice - testimonial and  
5  
6 hermeneutic - that cause harm to individuals or groups whose knowledge is disregarded.  
7  
8 Fricker identifies a close and inherent connection between the operation of social power in  
9  
10 epistemic interactions which gives them an ethical dimension (Fricker, 2007, pp.2). This  
11  
12 means that social injustices, that often have a material, political and cultural dimension, will  
13  
14 find expression in and are compounded by epistemic injustices, which tend to be social, inter-  
15  
16 personal and psychological in nature.  
17  
18  
19  
20  
21  
22  
23

24 Testimonial injustice is when a knower (someone who is communicating) is not heard  
25  
26 (meaningfully listened to). Examples of testimonial injustice include having one's opinion  
27  
28 disregarded or ignored, not being allowed to explain an aspect of one's experience to  
29  
30 someone or being shamed, ignored or undermined when communicating. Testimonial  
31  
32 injustice is an attack on an individual's status as a rational and equal member of a social  
33  
34 community. The failure to hear them reflects the epistemic and social prejudices of the  
35  
36 listener that what and how the knower communicates are of limited or no value (Fricker,  
37  
38 2007). This is harmful because being valued as a knower is a basic condition for human  
39  
40 flourishing as well as a tenet of reciprocity and social association between individuals  
41  
42 (Fricker, 2015). Testimonial injustice can also have secondary effects, including the  
43  
44 experience of psychological distress, loss of social status, and feelings of confusion and  
45  
46 uncertainty (Fricker, 2007). Testimonial injustice can happen on an incidental and systematic  
47  
48 basis. It can also occur as the result of deliberate and unchecked prejudicial attitudes as well  
49  
50 as non-intentional silencing practices by people who have different epistemic experiences and  
51  
52 ways of communicating.  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4 The second type of epistemic injustice identified by Fricker is hermeneutic injustice. This  
5  
6 takes place when significant parts of a person's social experience are obscured from  
7  
8 understanding owing to prejudicial flaws in shared resources for social interpretation  
9  
10 (Fricker, 2007). These flaws are principally created by the social and historical conditions  
11  
12 that knowers and listeners inhabit. That is, they reflect how dominant social norms,  
13  
14 behaviours and expectations create epistemic ecologies that privilege some forms and ways  
15  
16 of knowing over others. This can result in certain types of knowledge and experience being  
17  
18 'hidden' because they cannot be meaningfully seen or heard. Fricker describes such a  
19  
20 situation as an epistemic 'lacuna': where neither knower nor hearer can understand the other  
21  
22 and the knower becomes unable to meaningfully define and describe an important aspect of  
23  
24 their lived experience to themselves or others (Fricker 2006). An example of hermeneutic  
25  
26 injustice is the suppression and marginalisation of women's experience (and knowledge of)  
27  
28 sexual assault in social environments that privilege patriarchal power and unequal gender  
29  
30 relations (Dotson, 2011). Another example is the failure of people from a dominant racial  
31  
32 group to recognise the social, political and economic privileges afforded to them as a result of  
33  
34 historic practices of oppression and subordination. This can result in hermeneutic injustices  
35  
36 when people fail to recognise that how they communicate (and what they know) both  
37  
38 overlays and prevents the expression of people with different types of knowledge: an  
39  
40 archetypal case is that of unchecked 'white privilege' (Polihaus, 2012).  
41  
42  
43  
44  
45  
46  
47  
48

49 Fricker argues that the harm caused by hermeneutic injustice is multi-faceted. It affects  
50  
51 communities and social groups because it compounds feelings of mistrust and anxiety, often  
52  
53 rooted in existing prejudices and unequal power relations. At an individual level, for those  
54  
55 knowers who cannot explain important parts of their own experience to themselves, the harm  
56  
57 is likely to be particularly pernicious and psychological. It may result in a form of  
58  
59  
60



1  
2  
3  
4 psychological dissonance, as they seek to minimise, ignore or find alternative explanations  
5  
6 for their experiences and feelings without sufficient internal or external epistemic resources  
7  
8 (Fricker, 2007). It is set within this conceptual context that we configured the  
9  
10 epistemological, methodological and method-focused decisions of this study.  
11  
12  
13  
14

### 15 **Epistemological, methodological and methods decisions**

#### 16 *Social constructionism*

17  
18  
19 This paper reports a study that was orientated within a social constructionist epistemological  
20  
21 framework. Social constructionists argue that knowledge develops as part of a dynamic  
22  
23 interaction between subject and object (Burr, 1998). This means that individuals play an  
24  
25 important role in shaping how and what they know because they have interpretive agency and  
26  
27 are constantly engaged in processes of reflection, communication and social association  
28  
29 (Berger and Luckmann, 1967). From a social constructionist perspective, human interpretive  
30  
31 activity finds expression through the conventions of language, culture and different forms of  
32  
33 socialisation and interaction. These processes are foregrounded in the norms, expectations  
34  
35 and material realities of individuals' social and historical circumstances (Puig et al, 2008).  
36  
37 Reflexivity is a critical aspect of social constructionist research because it involves  
38  
39 researchers thinking critically about their role shaping, or co-constructing, knowledge at any  
40  
41 (or indeed every) stage of the research process. In-keeping with this perspective, this paper  
42  
43 contains several reflexive notes about the research process and study context.  
44  
45  
46  
47  
48  
49  
50  
51

#### 52 *Semi-structured interviews*

53  
54 We elected to carry out semi-structured interviews as the primary research method to explore  
55  
56 family carers' experiences of violent, abusive and harmful behaviour. Often characterised as  
57  
58 an exchange or a process, research interviews provide a forum to develop (and test) relational  
59  
60

1  
2  
3 dynamics between researcher and researched. Attending to social cues and non-verbal  
4  
5 communication is pivotal in building a sense of trust and rapport between people that may in  
6  
7 turn facilitate conversations about complex or emotionally-charged topics, as was the case in  
8  
9 this study (Dickson-Swift et al, 2007). The interview method was thus congruent with the  
10  
11 social constructionist orientation of this project and its emphasis on social interaction and  
12  
13 language as central mechanisms by which subjective and social meaning is developed (Puig  
14  
15 et al, 2008). In order to ensure the views of people with experience of care and/or harmful  
16  
17 behaviour were the central focus of the study, we also worked in partnership with a network  
18  
19 of advisors to design the study, including the development of the interview schedule and  
20  
21 approach to recruitment (Isham et al, 2019).  
22  
23  
24  
25  
26  
27  
28

29 We recruited carers over a twelve-month period primarily by sharing information about the  
30  
31 project with carers' organisations and health and social care services working with older  
32  
33 people and their families. Organisations distributed a link to our project website and shared  
34  
35 electronic and paper copies of information leaflets. Interested carers contacted the study team  
36  
37 for an initial discussion about what participation would involve. The study team worked  
38  
39 closely with potential participants, through a process of careful engagement work, to inform  
40  
41 and facilitate decision-making about if and how they took part. Following each interview, a  
42  
43 'de-brief' session was carried out and participants were given information about potentially  
44  
45 relevant services and helplines. Participants were able to contact the research team (and  
46  
47 academics who were not part of the team) throughout the course of the study if necessary.  
48  
49  
50 This study was conducted in the United Kingdom (UK).  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

### *Theoretically-informed analysis*

The interviews were audio-recorded, transcribed verbatim and then read carefully by the study team. The transcripts were initially analysed using a thematic approach (Braun and Clarke 2006). Thematic analysis is a systematic and rigorous analytic process commonly used to organise and interpret qualitative data. Braun and Clarke (2006) developed a six stage process of: familiarisation with the data; generating initial, descriptive codes; searching for thematic patterns and latent meanings; reviewing and refining the themes by returning to the data and relevant critical literature; defining and characterising the themes; and, finally, presenting and reporting on the findings. LI carried out the first stage of the analytical process, identifying initial codes, categories and themes. These emerging findings were then iteratively refined, developed and organised by the research team. Following this phase, a second 'layer' of analytic work was carried out, drawing on the principal concepts of Fricker's theory of epistemic justice. This conceptual framework orientated the analysis such that it took explicit account of social factors and processes that might affect how carers 'constructed' our discussions. This was particularly helpful given the limited social and linguistic vocabulary pertaining to this issue (Ayres and Wooditi, 2001).

### *Participant characteristics*

We carried out twelve in-depth, semi-structured interviews with female carers who identified themselves as having experienced harmful behaviour. We did not set out to interview only female carers and thus it is a finding as well as a potential limitation of this study that no men decided to take part. The interviews were conducted face-to-face and lasted approximately two hours. Eight women agreed to be interviewed in their home and four women in a private room at a public location. Of these, three were held at a university and one in a local library. In the process of transcribing and collating the accounts, each woman was assigned a

1  
2  
3  
4 pseudonym and these names are used consistently in this paper. The chosen names seek to  
5  
6 preserve some sensitivity to the individual's gender, age and ethnic background, whilst  
7  
8 maintaining their anonymity. The interview participants had a range of relationships with the  
9  
10 person for whom they cared: six were spouses, four were adult daughters, one participant was  
11  
12 a sister and one a niece. Table 1 outlines some demographic details about each participants  
13  
14 and their caring situation at the time of interview.  
15  
16  
17  
18  
19

20 *Insert Table 1: Interview participant characteristics*  
21  
22

23  
24 Finally, participants identified that they cared for older people who had physical, cognitive  
25  
26 and non-diagnosed illnesses and disabilities. For many participants, it was difficult, and  
27  
28 sometimes distressing, to identify what caused their family member's harmful behaviour: for  
29  
30 example, as a symptom of illness, an expression of a personality trait or part of a longer-term  
31  
32 pattern of violent or strained relationships. We explore the contested issue of attribution – and  
33  
34 the way participants responded to it – in greater detail in the following sections of this paper.  
35  
36  
37  
38  
39

## 40 Findings

41  
42 Participants shared experiences of harmful behaviour that varied in their severity, duration  
43  
44 and impact. The behaviour they described encompassed acts, and patterns, of physical,  
45  
46 verbal, psychological and sexual harm. One recurring theme was of carers feeling  
47  
48 overwhelmed and having no meaningful agency when responding to their family member's  
49  
50 illness and behaviour. Whilst carers attributed this feeling to the chaotic and sometimes  
51  
52 highly unpredictable nature of the caring task, they also talked about family member's  
53  
54 attempts to control, manipulate and dominate situations, whether intentionally or  
55  
56 unintentionally. Carers talked about the isolating and complex processes required to manage,  
57  
58  
59  
60

1  
2  
3 cope with and tolerate harmful behaviour. This was done, for example, through strategies of  
4 emotional containment and by minimising the frequency of interaction with their family  
5 member. Carers also talked about the ethical and relational value of protecting and  
6 advocating for their family member. Nevertheless, pervading the participants' accounts were  
7 descriptions of feeling 'hidden' in terms of being misunderstood, overlooked and ignored.  
8 This gave rise to considerations about the epistemic and social harms that the women  
9 encountered, and it is this issue that is the focus of the following discussion.  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21

### 22 Testimonial dimensions

23  
24 Participants talked frequently about self-censuring who they spoke to and what they spoke  
25 about in relation to their experiences of harmful behaviour. Carer harm is a sensitive and  
26 taboo issue that can engender feelings of shame and guilt, particularly for individuals who  
27 emphasise the sanctity of the home and private life (Band-Winterstein, 2014). Similarly,  
28 feelings of embarrassment arose from the seemingly atypical and distressing behaviour of an  
29 older person: for example, when they engaged in serious acts of physical or sexual violence.  
30 Carers also talked about fears that disclosure would lead to the family member being taken  
31 into statutory care and 'removed' from their family environment (Cahill and Shaprio, 1993).  
32 Such a transition was understood to be highly undesirable because it ran counter to the belief  
33 that being cared for within a familial or intimate relationship was qualitatively better than  
34 being cared for by a professional or within an institutional space (Lynch, 2007).  
35 Relinquishing care could also represent a loss of autonomy on the part of the carer and was  
36 bound up with fears about a family member becoming progressively ill or entering the final  
37 phases of their life. Taken together, feelings of anticipatory shame and loss of moral  
38 autonomy exacerbated the women's difficulties exploring and explaining their experiences of  
39 harmful behaviour, as is evident in Rose and Sarah's accounts:  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5 *I used to feel shame and embarrassment about going out after there had been lots of*  
6 *shouting and violence. I was worried about what the neighbours would think. I stayed*  
7 *inside; I wanted to stay hidden. You take on the shame of your loved one's behaviour*  
8 *because you know that people don't understand why they are acting in a difficult or*  
9 *upsetting way. You also worry that people blame you and hold you responsible. There*  
10 *are so many layers to how this affects your life. Rose, caring for her husband*  
11

12  
13 *I feel disloyal talking about this... That's the feeling that you have to understand*  
14 *(crying). That's the feeling that inhibits you know, it inhibits you, because you feel*  
15 *guilty. Sarah, caring for her husband*  
16  
17

18  
19 In other circumstances, participants talked about their 'testimony' not being believed and  
20 in some cases ignored. Participants described a range of subtle, often unintentional,  
21 silencing practices used by family and friends. These included: stopping coming to see  
22 their family member in their home environment or only seeing them for short periods of  
23 time; refusing to talk about 'serious' topics such as nursing home or end-of-life care; and  
24 talking about the family member in a relentlessly positive and sometimes infantilising  
25 way. These practices made it difficult for carers to initiate conversations about harmful  
26 behaviour because they drew on and reinforced social norms about the moral value and  
27 unconditional nature of familial care. These silencing practices also had the effect of  
28 distancing listeners from occupying positions where they could meaningfully understand  
29 what it looked and felt like to care for, live with, and protect someone who acted in a  
30 violent, abusive or harmful way. Put another way, listeners engaged in communication  
31 practices that made it difficult for them to 'hear' or understand caring experiences that  
32 were atypical and that contravened their expectations.  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50

51  
52  
53 In the following excerpts, Megan talks about her distant and tense relationship with her  
54 extended family at a time when her husband was becoming increasingly unwell and  
55 violent towards her. This culminated in several strangulation attempts, and her husband  
56 being sectioned under the Mental Health Act. Asrah meanwhile describes her sense of  
57  
58  
59  
60

1  
2  
3  
4 isolation caring for her father which she attributed in part to the lack of curiosity and  
5  
6 empathy that was extended by visiting family members.  
7  
8

9  
10 *I told them (family) all the way through. I would say, "well, this has happened today"*  
11 *.... So I kept them informed all of the time. And then because they didn't respond to*  
12 *anything when he (husband) dipped, when this happened, I didn't tell them. I thought*  
13 *why should I? Because you haven't been here at all. Why tell you now? What can you*  
14 *do now? Megan, previously caring for her husband*  
15

16  
17 *It was always a case of people coming from the outside and saying "you're doing a*  
18 *really, really fantastic job, you're all kind muddling together and looking after him:*  
19 *fantastic, great work that you're doing". And that was it. They would just leave. And no*  
20 *one actually asked the question, "are you coping?" And that just made things so much*  
21 *more difficult... Asrah, previously caring for her father*  
22

23  
24 Participants also talked about times when they had felt they were not believed or mistrusted  
25  
26 when they shared their experiences of harmful behaviour. Such a dynamic could lead to  
27  
28 adversarial communication with people who, carers identified, were invested with power and  
29  
30 capability to bring about change in their situation; invariably, health and social care  
31  
32 professionals. Indeed, several carers talked about needing to 'fight' and 'battle' to gain access  
33  
34 to resources and to advocate on behalf of their family member. This placed them in the  
35  
36 somewhat paradoxical, uncomfortable position of both protecting their family member and  
37  
38 feeling manipulated or frightened by them. In these circumstances, carers talked about  
39  
40 feelings of frustration at not being taken seriously and being left to cope in dangerous  
41  
42 situations often with limited support. In contrast, other participants characterised their  
43  
44 interactions with professionals as being fleeting and fragile, describing instances when they  
45  
46 felt on the periphery of conversations and decision-making about their family members' care.  
47  
48 This sense of having contingent and limited credibility is described by Jane and Dorris in the  
49  
50 following excerpts:  
51  
52  
53  
54  
55  
56

57  
58 *I'm floundering to establish relationships with all these transient personalities and*  
59 *their effects and all the energies that they bring in... To respect them as professionals*  
60 *but know that I know my parents better than they do; not make waves but explain*

1  
2  
3  
4 *reality as it is in our house – not theirs’; and ending up, just so jangled up. I just don’t*  
5 *know which emotion to feel for the best! Jane, caring for her parents*  
6

7 *He (dad) started to walk around with a knife in his pocket. And I’m telling them, the*  
8 *social workers, ‘no, this is not going to work! It’s not going to work for someone to be*  
9 *living here with him, it’s not safe!’ And then they (social workers) decided to come and*  
10 *they said about putting him in the respite for two weeks and I had to say, ‘no, no, no,*  
11 *that is not enough, two weeks is not enough!’ Dorris, previously caring for her father*  
12  
13  
14

15 Fricker argues that when a person’s knowledge is mistrusted or overlooked without good  
16 reason they are likely to suffer a credibility ‘deficit’ and this deficit often stems from social or  
17 ‘identity’ prejudices about the knower (Fricker, 2007). It may also reflect subtle but powerful  
18 inequalities in the ‘credibility economy’ in which knowers and listeners interact. In the UK,  
19 health and social care professionals work within a policy and legislative framework that  
20 emphasises individuals’ rights to self-determination and the need to protect and prioritise the  
21 needs of adults requiring care (Butler and Manthorpe, 2016). Whilst there may be a clear  
22 ethical and legal basis for this position it is nevertheless possible to see how, in some  
23 situations, this perspective can lead to carers’ needs being unintentionally rendered less  
24 visible, particularly if carers’ views seemingly contradict or undermine the needs and wishes  
25 of the person for whom they care. Thus, aside from feeling that their opinion is of lesser  
26 value, carers’ lack of credibility could have serious consequences in situations where older  
27 people held different views about the extent and severity of their care needs from that of their  
28 carer: for example, when older people did not agree to receive support, treatment or being  
29 cared for outside of the family home. In the following section we explore the hermeneutic  
30 conditions that may contribute to and exacerbate these testimonial tensions and harms.  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50

#### 51 52 53 54 Hermeneutic dimensions

55 The women’s accounts were characterised by descriptions of a pervasive feeling of having  
56 limited or contested knowledge about the cause of their family member’s harmful behaviour.  
57  
58  
59  
60



1  
2  
3  
4 It was also apparent that many women found it difficult to disentangle the effects of harmful  
5  
6 behaviour from other challenges and concerns relating to their intimate or familial  
7  
8 relationship. It is in this context that participants consistently talked about caring as a  
9  
10 'natural' or inevitable role and one they sought to fulfil to the best of their ability.  
11  
12 Irrespective of the nature and severity of harmful behaviour, caring was discussed in terms of  
13  
14 an expression of love and, frequently, duty: a realisation of a moral commitment as well as an  
15  
16 inevitable, albeit challenging, stage of an intimate or familial relationship. Caring was thus  
17  
18 both a practice and a way of living, inseparable from identities, commitments and feelings  
19  
20 forged across the life-course (Fine and Glendenning, 2005; Forbat, 2005).  
21  
22  
23  
24  
25

26  
27 The following excerpts from Anna and Sally's accounts illustrate how the 'private' and  
28  
29 'personal' nature of caring reinforced participants' views that it was necessary to keep their  
30  
31 experiences to themselves, irrespective of the difficulties and challenges they faced. Both  
32  
33 women discussed how their approach had developed and, in many respects helped them, to  
34  
35 care for their family member over several decades.  
36  
37  
38

39  
40 *I became aware very young of the fact that nobody was in charge. So, it felt like my*  
41 *duty to listen, to support, to help in whatever way I could and certainly not to put any*  
42 *pressure on them (brother and mother). I had an abortion when I was young because I*  
43 *was raped when I was young but nobody knows about that and in fact that is the first*  
44 *time that I have said that to anyone... It's just a good example to show that, you know,*  
45 *nobody is going to be there for you. You keep everything for yourself... You know, you*  
46 *keep everything for yourself.* Anna, previously caring for her brother  
47

48  
49 *I made the choice. I know that it's really stupid of me, to make my bed and lie in it. But*  
50 *to me, it shows strength: stupid strength. That I can get through it, that I can survive it*  
51 *and I chose it. That he's the father of my kids. You know? And actually there is just a*  
52 *lot of me that is scared. The actual practicalities of leaving him, you know, like, what*  
53 *would he do? You know? I would be fine. I would be fine.* Sally, caring for her husband  
54  
55

56  
57 Anna and Sally's comments also touch on a common thread that ran through the carers'  
58  
59 accounts: that there was a hierarchy of needs and, irrespective of the violence, abuse or loss  
60

1  
2  
3 of agency that they experienced, their needs were of a qualitatively different nature (and  
4 thereby less important) than those of the person for whom they cared. A further expression of  
5 this view was carers' evident difficulties 'making sense' of their circumstances. As discussed,  
6 this was in part attributable to the perceived social taboos and unfamiliarity of their family  
7 member's behaviour. However, participants' ability to develop understanding may also have  
8 been complicated by the sometimes chaotic, overwhelming nature of their caring experiences.  
9  
10 Lacking time, space and opportunities for reflection and shared dialogue with their family  
11 member (and other people) served to deplete further carers' ability to explain and to make  
12 decisions about the difficult situations engendered by their experiences of carer harm. This  
13 could be compounded if their family member was not able or, in some cases, unwilling to  
14 discuss or to change their behaviour. The following excerpts, taken from Mary, Anna and  
15 Christine's accounts, illustrate the emotionally-charged nature of their caring experiences.  
16  
17 They also underline the troubling experience of accommodating or 'coping' with their family  
18 member's behaviour when it was difficult to understand or predict.  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36

37 *It was, I guess, it was more or less continual. Actually, that's the point, it's when it*  
38 *becomes the norm. This continual walking on hot coals: you don't know what's going*  
39 *to happen from moment to moment... I think I used to live, well, I used to call it the*  
40 *Sword of Damocles, I lived under the Sword. You never knew, from moment to moment,*  
41 *what was going to happen!* Mary, previously caring for her husband  
42

43  
44 *There were just loads and loads of details that I could never work out that made it*  
45 *impossible to live a normal life...I don't know any more. I've lost the sense, I've*  
46 *completely lost the capacity to see my brother and to see how much is illness and how*  
47 *much is part of his character. I guess I still choose to think that it's completely the*  
48 *illness but I'm not sure.* Anna, previously caring for her brother  
49

50  
51 *I mean I have never really gotten over the fact that he would rather kill himself than be*  
52 *with me... And no matter how logical and sensible I try and be, it's still there, it really*  
53 *is. I can't make sense of it, I can't talk about it.* Christine, caring for her husband  
54

55  
56 On a related point, because most family members were considered not to be culpable either  
57 fully or consistently for their behaviour, participants were sensitive to the seemingly emotive  
58  
59  
60

1  
2  
3 and loaded connotations of the word 'abuse' and often rejected comparisons of their situation  
4  
5 with that of domestic or intimate partner violence. It is important to note, however, that some  
6  
7 participants did consider their family member capable of controlling and changing their  
8  
9 behaviour and described it in reference to a continuation of personality or behavioural  
10  
11 patterns that were evident in the past. Nevertheless, almost all participants questioned the  
12  
13 appropriateness of the term 'abuse'. The following excerpts, taken from Rose, Mary and  
14  
15 Sarah's accounts, demonstrate how participants were often highly attuned to the difficulties  
16  
17 associated with naming and explaining carer harm. This meant it was difficult for the carers  
18  
19 to know what, if any, type of help or support was appropriate for them to access 'outside' of  
20  
21 their family. It also reinforced their feelings of isolation when coping with carer harm in,  
22  
23 what Fricker describes as a social, psychological and epistemic sense.  
24  
25  
26  
27  
28  
29

30  
31 *In the past they have sent me to things for people suffering domestic abuse. They have*  
32 *even offered me a place in a refuge before. In some ways this is domestic abuse. But it*  
33 *is also very different. My husband can't help how he is. He has no control over his*  
34 *behaviour and how he feels. So I didn't feel like this was the right place to be. I needed*  
35 *to be able to help my husband and to stay with him.* Rose, caring for her husband  
36

37  
38 *You can't, you can't... can you be critical of someone who is ill? It's not the illness but*  
39 *it is the effect that it has on you and I think that we need a word to describe the effect*  
40 *on the person, on the care-giver, rather than then the service user being an 'abuser'.*  
41 *That's what I would like to try and find.* Mary, previously caring for her husband  
42

43  
44 *I think that what people have to understand is that risk from dementia, for the carer, it*  
45 *comes in many forms. It isn't just physical. It is also mental... The one particular*  
46 *occasion that sticks in my mind, is when he literally dragged me out of the bed by my*  
47 *legs and dragged me across the floor and I slipped a disk in my back. And, umm, on*  
48 *that particular night it was because I said no.... So, in that respect it is mental sexual*  
49 *violence. Do you know what I mean?* Sarah, caring for her husband  
50

51  
52 Fricker's concept of hermeneutic injustice is relevant here because it helps to illustrate the  
53  
54 social and cultural factors that contributed to the carers' difficulties understanding and  
55  
56 explaining the harm they experienced, to themselves and to others. It also surfaces the subtle  
57  
58 and cumulative nature of different types of epistemic harm and the powerful effect these had  
59  
60

1  
2  
3 on affected individuals. Reflecting on the strong themes of loyalty, love and duty that ran  
4 through the participants' accounts, we suggest that the gendered inequalities that underpin  
5 expectations that women adopt formal and informal caring roles (Barnes, 2012; Lynch, 2007)  
6 - and perform these role in a certain way, particularly in later life - create additional  
7 'prejudicial flaws' that limit listeners' capacity to recognise and respond to carer harm. In  
8 short, they are likely to overlay expectations that carers tolerate and cope with harmful  
9 behaviour. They also inhibit expression of the subtle but important differences between  
10 feelings of stress and anxiety, for example, and that of caring for someone at the same time as  
11 being afraid of them.  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25

26 Furthermore, participants' discomfort in explaining their experiences as 'abusive' may speak  
27 to prevailing contemporary social norms about who can be regarded as a 'victim' or  
28 'perpetrator' of harm. The binary, legally-orientated nature of these concepts makes them  
29 uncomfortable spaces in which to explore and explain experiences of mutual powerlessness  
30 and loss of relational and, at times, physical autonomy. This is particularly the case if it is  
31 unclear to what extent the incidents or patterns of behaviour are unintentional. These  
32 ambiguities raise uncomfortable questions that require exploration and critical engagement:  
33 practices that are difficult to carry out, for listeners and speakers, in the current epistemic  
34 climate. The concept of hermeneutic injustice thus has value in helping to contextualise the  
35 spaces and silences that surround this seemingly hidden issue. By identifying them, it is  
36 possible to explain some of the reasons that contribute to carers normalising and tolerating  
37 harmful behaviour. It can also help to make sense of the context in which carers struggle to  
38 describe their needs and experiences until the behaviour places themselves or their family  
39 member in serious physical and psychological danger and it can no longer be kept 'hidden'.  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Limitations

We recognise there are limitations in using Fricker's theory to inform our analysis. By exploring the social and epistemic aspects of the carers' accounts her work may not, for example, elicit or help to explain several, important issues: such as the spatial and environmental factors affecting carers' coping strategies (Herron and Wrathall, 2018), the processes by which some violent behaviours are pathologised and constructed as 'challenging' (Dupuis et al, 2012) and the inter-relationship between carer harm and intimate partner violence in older age (Wydall and Zerk, 2017). We recognise these limitations and identify avenues for future work in the discussion section. Furthermore, because Fricker's work focuses primarily on the experiences of individuals, she may not fully account for the epistemic context of intimate and familial relationships and their attendant ethical norms and behaviour systems (Origgi, 2012). This last point is not so much a limitation of the current study as a suggestion for future development and innovation of the theory.

## Discussion

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. For some research participants, having their expertise and views valued can be a positive and sometimes cathartic experience and this may be more significant if participants have experienced feelings of disenfranchisement and marginalisation in the past (Buchanan and Wendt, 2017). We consider that for participants in this study, sharing their experiences was not necessarily about taking part in research but about raising awareness of an often sensitive and sometimes deeply painful issue. This is an important finding and one that begs questions about how and when carers can be better supported to

1  
2  
3 disclose and explore their needs. Facilitating these opportunities and responding to them  
4  
5 appropriately when they do occur may make a critical difference to alleviating carers' acute  
6  
7 sense of responsibility and isolation when coping with and tolerating harmful behaviour.  
8  
9

10  
11  
12 It is also important to emphasise that the aim of this study was not to corroborate, challenge  
13  
14 or evidence carers' explanations of their family member's behaviour. We were not  
15  
16 investigating whether it was or was not abusive. Rather, we sought to explore carers' lived  
17  
18 experiences of harm and the way they shared and developed meaning about their experiences.  
19  
20 By suggesting that carers suffered hermeneutic and testimonial injustices, we are not  
21  
22 therefore arguing that their explanations were partial or incorrect. Indeed, illness-orientated  
23  
24 explanations may have helped carers to psychologically disengage from abuse and harm that  
25  
26 was deliberate because they helped to de-personalise the experience of violent or  
27  
28 manipulative behaviour (Jackson, 2003). Similarly, by positioning themselves as advocates  
29  
30 and protectors, carrying out a moral and personal duty, carers may have been less prone to  
31  
32 feelings of powerlessness (Band-Winterstien, 2014). Such understandings are also congruent  
33  
34 with role expectations of women to care and love in an unconditional manner (Ayres and  
35  
36 Wooditi, 2001). These are important factors to consider, not least because they speak to the  
37  
38 plural and dynamic ways that people construct understanding of their psychic and social  
39  
40 worlds. They also illustrate the powerful and different ways that caring roles and experiences  
41  
42 coalesce with ideas about people's identity, relationship and values (Barnes, 2012; Forbat,  
43  
44 2005).  
45  
46  
47  
48  
49  
50  
51

52  
53  
54 Echoing the findings of recent work which explains carers' experience of violence, abuse or  
55  
56 harm, there is a clear and as yet unmet need for further critical, in-depth sociological  
57  
58 informed research about this hitherto hidden aspect of the caring experience (Herron and  
59  
60

1  
2  
3 Rosenberg, 2017; Spencer et al, 2018). This study makes one of the first contributions to an  
4 emerging field and, by using qualitative techniques and a sociological, theoretically informed  
5 analysis, it contributes new insights. However, there is a need for further innovation and  
6 development, exploring different carer groups such as male carers and carers in same-sex  
7 relationships. There is also value in exploring the experience of families from a wider range  
8 of social and cultural backgrounds. Given the critical role of social norms and social contexts  
9 affecting the disclosure and help-seeking processes of carers in this study, it is important to  
10 consider critically what factors affect these potentially more 'hidden' and marginalised carer  
11 groups.  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25

26 Analysing the women's accounts with reference to the theory of epistemic injustice thus  
27 surfaces critical questions about how to recalibrate some of the epistemic inequalities and  
28 identity prejudices that shape what we understand to constitute violence, abuse and harm in  
29 familial and domestic spaces. One potential way of improving identification and responses to  
30 carer harm is to consider how safe and supportive spaces can be opened up for affected carers  
31 to disclose, explore and make decisions about their situation. The ability to relate to and talk  
32 about one's experiences – particularly when they are negative, atypical and marginalised by  
33 dominant political and social discourse – can be valuable in alleviating individuals' sense of  
34 isolation and stress (Fricker, 2006; 2007; 2015). From an epistemic perspective, such  
35 opportunities can also help to shift the balance of epistemic resources and thus enable some  
36 individuals to find a collective voice however, mediated this may be by other forms of social  
37 and political disadvantage (Pollihaus, 2012). Over the past 30 to 40 years, there has been a  
38 discernible shift in how abuse and harm are defined and conceptualised in 'public' and  
39 'private' space. This has in turn contributed to changes in what is considered a legitimate  
40 sphere of state intervention in the 'private' life of children and families and, to some extent,  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 intimate partner relationships between adults. We are not advocating that carer harm requires  
4  
5 'discovering', or that is fundamentally similar to other types of abuse and violence (Olafson  
6  
7 et al, 1993). Nevertheless, consideration of the factors that have facilitated greater awareness  
8  
9 of these 'types' of harmful behaviour may provide a useful starting point in thinking about  
10  
11 how to raise awareness and improve responses to carer harm.  
12  
13  
14  
15  
16

17  
18 Lastly, it is evident that the framing of carer harm as a private, moral issue may implicitly  
19  
20 reinforces the view that if adults have the cognitive capacity to make decisions, then they are  
21  
22 free to do so. This has important implications for health and social care practice with older  
23  
24 adults and their families. Understanding capacity as a primarily cognitive state elevates the  
25  
26 status of logic and privileges the idea of individual autonomy in a way that is congruent with  
27  
28 contemporary legal constructions of domestic and familial violence but may not attend to the  
29  
30 emotional, relational and ethical heuristics that carers deploy to talk about caring *and* harmful  
31  
32 behaviour within caring relationships (Kittay, 2011). It also highlights how, by strengthening  
33  
34 the rights and needs of one group of people – often because they have historically  
35  
36 experienced disadvantage and discrimination – an implicit hierarchy may be created. To fully  
37  
38 understand the complex inter-dependencies of caring relationships a more critical approach  
39  
40 is required focussing in particular on the unintended implications of how 'vulnerability' is  
41  
42 understood and how the 'rights' and responsibilities it engenders benefits some groups and  
43  
44 not others (Barnes, 2012; McKay, 2017). Thus, improving responses to carers' needs  
45  
46 requires an unravelling of some of the central concepts in contemporary law and policy  
47  
48 relating to 'vulnerable' adults and the determination of capacity and choice in the context of  
49  
50 harm and abuse, irrespective of its cause.  
51  
52  
53  
54  
55  
56  
57  
58

## 59 **Conclusion**

60



1  
2  
3  
4 The globally ageing population raises pressing questions about how a growing number of  
5  
6 families will cope and care for older partners and relatives. For some carers, later life brings  
7  
8 about changes, or exacerbates existing tendencies, that result in them experiencing abusive,  
9  
10 violent or harmful behaviour by the person for whom they care. The findings of this study  
11  
12 indicate there are important practical, ethical and conceptual factors that make it difficult to  
13  
14 talk and think about harmful or abusive behaviour towards family carers: both from a  
15  
16 ‘testimonial’ and ‘hermeneutic’ perspective. This can exacerbate families’ difficulties in  
17  
18 seeking help and understanding their situation at a challenging and often traumatic period of  
19  
20 life. Set against the backdrop of a sparse research landscape, replete with conceptual  
21  
22 ambiguities and ethical questions, this study makes an important contribution to the limited  
23  
24 knowledge base about carer harm. It also goes some way in challenging the assumption that  
25  
26 carer harm is too sensitive or complex an issue to be explored – in research or practice  
27  
28 contexts - in a meaningful way. Perhaps most importantly, the participants’ decision to share  
29  
30 their testimonies questions the latent assumption that carers cannot or do not want to talk  
31  
32 about carer harm or to affect other affected families.  
33  
34  
35  
36  
37  
38  
39  
40

### 41 **Acknowledgements**

42 We would like to warmly thank the study’s participants and advisors for their valuable  
43  
44 contributions and the generous nature with which they gave advice and shared their insights.  
45  
46 We are deeply grateful to them for taking the time – and for several people, the emotional  
47  
48 risk - to share their views and experiences about the ‘sensitive’ issue of carer harm.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## References

- Ayres, M.M. and Woodtli, A., 2001. Concept analysis: abuse of ageing caregivers by elderly care recipients. *Journal of advanced nursing*, 35(3), pp.326-334.. doi: 10. 1046/j. 1365-2648. 2001. 01849
- Baldassar, L., Baldock, C.V. and Wilding, R., 2006. *Families caring across borders: Migration, ageing and transnational caregiving*. Springer.
- Band-Winterstein, T., 2014. The impact of lifelong exposure to IPV on adult children and their aging parents. *Journal of family issues*, 35(4), pp.439-461, doi. org/10. 1177/0192513X12472657
- Barnes, M. (2012). *Care in everyday life: An ethic of care in practice*. Policy Press.
- Beaulaurier, R.L., Seff, L.R., Newman, F.L. and Dunlop, B., 2006. Internal barriers to help seeking for middle-aged and older women who experience intimate partner violence. *Journal of Elder Abuse and Neglect*, 17(3), pp.53-74. doi:10. 1300/J084v17n03\_04
- Berger, P. L. and Luckmann, T. (1967). *The social construction of reality*. New York: Anchor
- Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), pp.77-101, doi: 10.1191/1478088706qp063oa
- Buchanan, F. and Wendt, S., 2018. Opening doors: Women's participation in feminist studies about domestic violence. *Qualitative social work*, 17(6), pp.762-777, doi.org/10.1177/1473325017694081
- Burr, V., 1998. Overview: Realism, relativism, social constructionism and discourse. *Social constructionism, discourse and realism*, pp.13-26.
- Butler, L. and 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), pp.204-213, doi.org/10.1108/JAP-03-2016-0003
- Cahill, S. and Shapiro, M., 1993. 'I think he might have hit me once': Aggression towards caregivers in dementia care. *Australian Journal on Ageing*, 12(4), pp.10-15. Retrieved from: [https://www. researchgate. net/](https://www.researchgate.net/)
- Carmichael, F. and Ercolani, M.G., 2016. Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes. *Social Science and Medicine*, 156, pp.1-11, doi.org/10.1016/j.socscimed.2016.03.020
- Daniel, B. and Bowes, A., 2010. Re-thinking harm and abuse: Insights from a lifespan perspective. *British Journal of Social Work*, 41(5), pp.820-836, doi: 10. 1093/bjsw/bcq116
- Dixon, J., Biggs, S., Stevens, M., Manthorpe, J. and Tinker, A., 2013. Defining the "perpetrator": abuse, neglect and dignity in care. *The Journal of Adult Protection*, 15(1), pp.5-14, doi:10. 1108/14668201311299872

1  
2  
3  
4 Dotson, K., 2011. Tracking epistemic violence, tracking practices of silencing. *Hypatia*,  
5 26(2), pp.236-257, doi:10.1111/j.1527-2001.2011.01177.x

6  
7 Dupuis, S.L., Wiersma, E. and Loiselle, L., 2012. Pathologizing behavior: Meanings of  
8 behaviors in dementia care. *Journal of Aging Studies*, 26(2), pp.162-173, doi,  
9 10.1016/j.jaging.2011.12.001

10  
11 Dunn, M.C., Clare, I.C. and Holland, A.J., 2008. To empower or to protect? Constructing the  
12 'vulnerable adult' in English law and public policy. *Legal Studies*, 28(2), pp.234-253

13  
14 Fine, M. and Glendinning, C., 2005. Dependence, independence or inter-dependence?  
15 Revisiting the concepts of 'care' and 'dependency'. *Ageing and society*, 25(4), pp.601-621,  
16 doi. org/10. 1017/S0144686X05003600

17  
18 Forbat, L., 2005. *Talking about care: Two sides to the story*. Policy Press

19  
20  
21 Freeman, L., 2014, December. Confronting diminished epistemic privilege and epistemic  
22 injustice in pregnancy by challenging a "panoptics of the womb". In *The Journal of Medicine*  
23 *and Philosophy: A Forum for Bioethics and Philosophy of Medicine* (Vol. 40, No. 1, pp. 44-  
24 68). Journal of Medicine and Philosophy Inc, doi:10. 1093/jmp/jhu046

25  
26 Fricker, M., 2006, Powerlessness and social interpretation. *Episteme*, 3(1-2), 96-108. doi.  
27 org/10. 3366/epi. 2006. 3. 1-2. 96

28  
29 Fricker, M., 2007. *Epistemic injustice: Power and the ethics of knowing*. Oxford University  
30 Press.

31  
32 Fricker, M., 2015. Epistemic contribution as a central human capability. *The Equal Society*,  
33 pp.73-91.

34  
35 Herron, R.V. and Rosenberg, M.W., 2017. Responding to aggression and reactive behaviours  
36 in the home. *Dementia*, doi. org/10. 1177/1471301217699676

37  
38 Herron, R.V. and Wrathall, M.A., 2018. Putting responsive behaviours in place: Examining  
39 how formal and informal carers understand the actions of people with dementia. *Social*  
40 *Science and Medicine*, 204, pp.9-15, doi: 10.1016/j.socscimed.2018.03.017

41  
42 Isham, L., Bradbury-Jones, C. and Hewison, A., 2018. Reflections on engaging with an  
43 advisory network in the context of a 'sensitive' research study. *International Journal of Social*  
44 *Research Methodology*, 22(1), pp.67-79, doi.org/10.1080/13645579.2018.1494971

45  
46 Isham, L., Hewison, A. and Bradbury-Jones, C., 2017. When older people are violent or  
47 abusive toward their family caregiver: A review of mixed-methods research. *Trauma,*  
48 *Violence, & Abuse*, doi: 10.1177/1524838017726425

49  
50 Jackson, D., 2003. Broadening constructions of family violence: mothers' perspectives of  
51 aggression from their children. *Child and Family Social Work*, 8(4), pp.321-329,  
52 doi:10.1046/j.1365-2206.2003.00298.x

1  
2  
3  
4 Kidd, I.J. and Carel, H., 2017. Epistemic injustice and illness. *Journal of applied philosophy*,  
5 34(2), pp.172-190, doi:10.1111/japp.12172

6  
7 Kittay, E.F., 2011. The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), pp.49-  
8 58, doi.org/10.1111/j.1467-9337.2010.00473.x

9  
10 Koenig, T.L., Rinfrette, E.S. and Lutz, W.A., 2006, Female carers' reflections on ethical-  
11 decision making: the intersection of domestic violence and elder care, *Clinical Social Work*  
12 *Journal*, 34(3), pp. 361-372, doi: 10. 1007/s10615-005-0023-3

13  
14 Larkin, M., Henwood, M. and Milne, A., 2019. Carer-related research and knowledge:  
15 Findings from a scoping review. *Health and social care in the community*, 27(1), pp.55-67,  
16 doi.org/10.1111/hsc.12586

17  
18 Lynch, K., 2007. Love labour as a distinct and non-commodifiable form of care labour. *The*  
19 *Sociological Review*, 55(3), pp.550-570, doi. org/10. 1111/j. 1467-954X. 2007. 00714

20  
21 Mackay, K., 2017. Choosing to live with harm? A presentation of two case studies to explore  
22 the perspective of those who experienced adult safeguarding interventions. *Ethics and Social*  
23 *Welfare*, 11(1), pp.33-46, doi. org/10. 1080/17496535. 2017. 1280069

24  
25 McDonald, L. and Thomas, C., 2013. Elder abuse through a life course lens. *International*  
26 *psychogeriatrics*, 25(8), pp.1235-1243, doi: 10. 1017/S104161021300015X

27  
28 Medina, J., 2013. *The epistemology of resistance: Gender and racial oppression, epistemic*  
29 *injustice, and the social imagination*. Oxford University Press.

30  
31 Newton, V.L., 2017, March. 'It's good to be able to talk': An exploration of the complexities  
32 of participant and researcher relationships when conducting sensitive research. In *Women's*  
33 *Studies International Forum* (Vol. 61, pp. 93-99). Pergamon, doi:org/10. 1016/j. wsif. 2016.  
34 11. 011

35  
36 Olafson, E., Corwin, D.L. and Summit, R.C., 1993. Modern history of child sexual abuse  
37 awareness: Cycles of discovery and suppression. *Child abuse & neglect*, 17(1), pp.7-24,  
38

39  
40 Origgi, G., 2012. Epistemic injustice and epistemic trust. *Social Epistemology*, 26(2), pp.221-  
41 235, doi. org/10. 1080/02691728. 2011. 652213

42  
43 Pillemer, K. and Suito, J.J., 1992. Violence and violent feelings: what causes them among  
44 family caregivers?. *Journal of Gerontology*, 47(4), pp.S165-S172, doi:  
45 10.1093/geronj/47.4.S165

46  
47 Pin, S. and Spini, D., 2016. Meeting the needs of the growing very old population: policy  
48 implications for a global challenge. *Journal of aging and social policy*, 28(3), pp.218-231,  
49 doi: 10.1080/08959420.2016.1181972

50  
51 Pinquart, M. and Sörensen, S., 2011. Spouses, adult children, and children-in-law as  
52 caregivers of older adults: a meta-analytic comparison. *Psychology and aging*, 26(1), p.1,  
53 doi:10.1037/a0021863

1  
2  
3  
4  
5 Pohlhaus Jr, G., 2012. Relational knowing and epistemic injustice: Toward a theory of willful  
6 hermeneutical ignorance. *Hypatia*, 27(4), pp.715-735, doi.org/10.1111/j.1527-  
7 2001.2011.01222.x

8  
9 Puig, A., Koro-Ljungberg, M. and Echevarria-Doan, S., 2008. Social constructionist family  
10 systems research: Conceptual considerations. *The Family Journal*, 16(2), pp.139-146, doi.  
11 org/10. 1177/1066480707313785

12  
13 Riggs, W., 2012. Culpability for Epistemic Injustice: Deontic or Aretetic?. *Social*  
14 *Epistemology*, 26(2), pp.149-16, doi. org/10. 1080/02691728. 2011. 652210

15  
16 Rosen, T., Lachs, M.S. and Pillemer, K., 2010. Sexual aggression between residents in  
17 nursing homes: literature synthesis of an underrecognized problem. *Journal of the American*  
18 *Geriatrics Society*, 58(10), pp.1970-197, doi:10.1111/j.1532-5415.2010.03064.x.

19  
20 Spencer, D., Funk, L.M., Herron, R.V., Gerbrandt, E. and Dansereau, L., 2019. Fear,  
21 defensive strategies and caring for cognitively impaired family members. *Journal of*  
22 *gerontological social work*, 62(1), pp.67-85, doi. org/10. 1080/01634372. 2018. 1505796

23  
24 Wydall, S. and Zerk, R., 2017. Domestic abuse and older people: factors influencing help-  
25 seeking. *The Journal of Adult Protection*, 19(5), pp.247-260, doi.org/10.1108/JAP-03-2017-  
26 0010

Inset Table 1: Interview participant characteristics

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

*\*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.*