

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

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

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

Abstract

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.

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

of caring for, and, frequently living with, a family member who was violent, abusive or harmful towards them. We carried out twelve in-depth interviews with affected carers and analysed the data using the analytic lens of Miranda Fricker's theory of epistemic injustice. The contribution of this study is that it uncovers a previously 'hidden' element of the carer experience and to identify some of the social and epistemic challenges carers in this situation face. The paper is likely to be of interest to researchers and theoreticians working across the health and social sciences. It is also of relevance to health and social care practitioners working with older adults and their families.

A hidden problem

There is a paucity of research and practice knowledge about the causes, contexts, and implications of what happens when older people act in a violent, abusive or harmful way towards the family member who cares for them. The research that does exist spans the field of elder abuse (Pillemer and Suitor, 1992; Pillemer et al, 2016), intimate partner abuse in older age (Koenig et al, 2006; Band-Winterstein, 2014) and studies about the lived experience of cognitive and serious mental ill health (Cahill and Shapiro, 1993; Herron and Rosenberg, 2017). Consistently characterised as a 'sensitive' issue, there are a number of ethical and methodological challenges involved in identifying and carrying out research with this 'hidden' population: for example, the taboo nature of the topic and a concern to not stigmatise individuals with mental and physical health problems who act in a violent or unpredictable way. There are also methodological difficulties measuring and defining what constitutes harmful or abusive behaviour in the caring context (Spencer et al, 2018).

Difficulties defining and conceptualising this form of harm also reflect social norms and expectations about older people who are ill or have a disability. 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 and 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 they rely on for care (McDonald and Thomas, 2013). This association is compounded further if a person has characteristics that are consistent with prevailing social norms of passivity, oppression or perceived weakness: for example, older age, disability or impairment. Such associations may obscure the relational and temporal nature of co-dependency and intimacy in adult relationships over the life-course (Daniel and Bowes, 2010; Dunn et al, 2008). Narrow and static understandings of 'vulnerability' also tend to overlook the unique ways that people cope and adapt to situations of distress and difficulty later in life (McKay, 2017). It is thus possible to trace inconsistencies in how violent, abusive or harmful behaviour towards and by some groups is defined and understood. It is against this backdrop that we discuss the theoretical framework that underpinned our analysis: Miranda Fricker's concept of epistemic injustice.

Theoretical orientation: epistemic injustice

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

on the subject has perhaps made the most noteworthy and unique contribution (Riggs, 2012; Origgi, 2012). Fricker argues that there are two kinds of epistemic injustice - testimonial and hermeneutic - that cause harm to individuals or groups whose knowledge is disregarded. Fricker identifies a close and inherent connection between the operation of social power in epistemic interactions which 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.

Testimonial injustice is when a knower (someone who is communicating) is not heard (meaningfully listened to). Examples of testimonial injustice include having one's opinion disregarded or ignored, not being allowed to explain an aspect of one's experience to someone or being shamed, ignored or undermined when communicating. Testimonial injustice is an attack on an individual's status as a rational and equal member of a social community. The failure to hear them reflects the epistemic and social prejudices of the listener that what and how the knower communicates are of limited or no value (Fricker, 2007). This is harmful because being valued as a knower is a basic condition for human flourishing as well as a tenet of reciprocity and social association between individuals (Fricker, 2015). Testimonial injustice can also have secondary effects, including the experience of psychological distress, loss of social status, and feelings of confusion and uncertainty (Fricker, 2007). Testimonial injustice can happen on an incidental and systematic basis. It can also occur as the result of deliberate and unchecked prejudicial attitudes as well as non-intentional silencing practices by people who have different epistemic experiences and ways of communicating.

The second type of epistemic injustice identified by Fricker is hermeneutic injustice. 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). These flaws are principally created by the social and historical conditions that knowers and listeners inhabit. That is, they reflect how dominant social norms, behaviours and expectations create epistemic ecologies that privilege some forms and ways of knowing over others. This can result in certain types of knowledge and experience being 'hidden' because they cannot be meaningfully seen or heard. Fricker describes such a situation as an epistemic 'lacuna': where neither knower nor hearer can understand the other and the knower becomes unable to meaningfully define and describe an important aspect of their lived experience to themselves or others (Fricker 2006). An example of hermeneutic injustice is the suppression and marginalisation of women's experience (and knowledge of) sexual assault in social environments that privilege patriarchal power and unequal gender relations (Dotson, 2011). Another example is the failure of people from a dominant racial group to recognise the social, political and economic privileges afforded to them as a result of historic practices of oppression and subordination. This can result in hermeneutic injustices when people fail to recognise that how they communicate (and what they know) both overlays and prevents the expression of people with different types of knowledge: an archetypal case is that of unchecked 'white privilege' (Polihaus, 2012).

Fricker argues that the harm caused by hermeneutic injustice is multi-faceted. It affects communities and social groups because it compounds feelings of mistrust and anxiety, often rooted in existing prejudices and unequal power relations. At an individual level, for those knowers who cannot explain 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

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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). It is set within this conceptual context that we configured the epistemological, methodological and method-focused decisions of this study.

Epistemological, methodological and methods decisions

Social constructionism

This paper reports a study that was orientated within a social constructionist epistemological framework. Social constructionists argue that knowledge develops as part of a dynamic interaction between subject and object (Burr, 1998). This means that individuals play an important role in 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). From a social constructionist perspective, human interpretive activity finds expression through the conventions of language, culture and different forms of socialisation and interaction. These processes are foregrounded in the norms, expectations and material realities of individuals’ social and historical circumstances (Puig et al, 2008). Reflexivity is a critical aspect of social constructionist research because it involves researchers thinking critically about their role shaping, or co-constructing, knowledge at any (or indeed every) stage of the research process. In-keeping with this perspective, this paper contains several reflexive notes about the research process and study context.

Semi-structured interviews

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

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4 dynamics between researcher and researched. Attending to social cues and non-verbal
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6 communication is pivotal in building a sense of trust and rapport between people that may in
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8 turn facilitate conversations about complex or emotionally-charged topics, as was the case in
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10 this study (Dickson-Swift et al, 2007). The interview method was thus congruent with the
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12 social constructionist orientation of this project and its emphasis on social interaction and
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14 language as central mechanisms by which subjective and social meaning is developed (Puig
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16 et al, 2008). In order to ensure the views of people with experience of care and/or harmful
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18 behaviour were the central focus of the study, we also worked in partnership with a network
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20 of advisors to design the study, including the development of the interview schedule and
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22 approach to recruitment (Isham et al, 2019).
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28 We recruited carers over a twelve-month period primarily by sharing information about the
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30 project with carers' organisations and health and social care services working with older
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32 people and their families. Organisations distributed a link to our project website and shared
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34 electronic and paper copies of information leaflets. Interested carers contacted the study team
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36 for an initial discussion about what participation would involve. The study team worked
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38 closely with potential participants, through a process of careful engagement work, to inform
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40 and facilitate decision-making about if and how they took part. Following each interview, a
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42 'de-brief' session was carried out and participants were given information about potentially
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44 relevant services and helplines. Participants were able to contact the research team (and
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46 academics who were not part of the team) throughout the course of the study if necessary.
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49 This study was conducted in the United Kingdom (UK).
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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

pseudonym and these names are used consistently in this paper. The chosen names seek to preserve some sensitivity to the individual's gender, age and ethnic background, whilst maintaining their anonymity. The interview participants had a range of relationships with the person for whom they cared: six were spouses, four were adult daughters, one participant was a sister and one a niece. Table 1 outlines some demographic details about each participants and their caring situation at the time of interview.

Insert Table 1: Interview participant characteristics

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

Findings

Participants shared experiences of harmful behaviour that varied in their severity, duration and impact. The behaviour they described encompassed acts, and patterns, of physical, verbal, psychological and sexual harm. One recurring theme was of carers feeling overwhelmed and having no meaningful agency when responding to their family member's illness and behaviour. Whilst carers attributed this feeling to the chaotic and sometimes highly unpredictable nature of the caring task, they also talked about family member's attempts to control, manipulate and dominate situations, whether intentionally or unintentionally. Carers talked about the isolating and complex processes required to manage,

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

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, caring for her husband

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, caring for her husband

In other circumstances, participants talked about their 'testimony' not being believed and in some cases ignored. Participants described a range of subtle, often unintentional, silencing practices used by family and friends. These included: stopping coming to see their family member in their home environment or only seeing them for short periods of time; refusing to talk about 'serious' topics such as nursing home or end-of-life care; and talking about the family member in a relentlessly positive and sometimes infantilising way. These practices made it difficult for carers to initiate conversations about harmful behaviour because they drew on and reinforced social norms about the moral value and unconditional nature of familial care. These silencing practices also had the effect of distancing listeners from occupying positions where they could meaningfully understand what it looked and felt like to care for, live with, and protect someone who acted in a violent, abusive or harmful way. Put another way, listeners engaged in communication practices that made it difficult for them to 'hear' or understand caring experiences that were atypical and that contravened their expectations.

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

isolation caring for her father which she attributed in part to the lack of curiosity and empathy that was extended by visiting family members.

I told them (family) 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, 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? Megan, previously caring for her husband

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 more difficult... Asrah, previously caring for her father

Participants also talked about times when they had felt they were not believed or mistrusted when they shared their experiences of harmful behaviour. Such a dynamic could lead to adversarial communication with people who, carers identified, were invested with power and capability to bring about change in their situation; invariably, health and social care professionals. Indeed, several carers talked about needing to 'fight' and 'battle' to gain access to resources and to advocate on behalf of their family member. This placed them in the somewhat paradoxical, uncomfortable position of both protecting their family member and feeling manipulated or frightened by them. In these circumstances, carers talked about feelings of frustration at not being taken seriously and being left to cope in dangerous situations often with limited support. In contrast, other participants characterised their interactions with professionals as being fleeting and fragile, describing instances when they felt on the periphery of conversations and decision-making about their family members' care. This sense of having contingent and limited credibility is described by Jane and Dorris in the following excerpts:

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

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

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56 The women’s accounts were characterised by descriptions of a pervasive feeling of having
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58 limited or contested knowledge about the cause of their family member’s harmful behaviour.
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It was also apparent that many women found it difficult to disentangle the effects of harmful behaviour from other challenges and concerns relating to their intimate or familial relationship. It is in this context that participants consistently talked about caring as a 'natural' or inevitable role and one they sought to fulfil to the best of their ability. Irrespective of the nature and severity of harmful behaviour, caring was discussed in terms of an expression of love and, frequently, duty: a realisation of a moral commitment as well as an inevitable, albeit challenging, stage of an intimate or familial relationship. Caring was thus both a practice and a way of living, inseparable from identities, commitments and feelings forged across the life-course (Fine and Glendenning, 2005; Forbat, 2005).

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

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, previously caring for her brother

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, caring for her husband

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

of agency that they experienced, their needs were of a qualitatively different nature (and thereby less important) than those of the person for whom they cared. A further expression of this view was carers' evident difficulties 'making sense' of their circumstances. As discussed, this was in part attributable to the perceived social taboos and unfamiliarity of their family member's behaviour. However, participants' ability to develop understanding may also have been complicated by the sometimes chaotic, overwhelming nature of their caring experiences. Lacking time, space and opportunities for reflection and shared dialogue with their family member (and other people) served to deplete further carers' ability to explain and to make decisions about the difficult situations engendered by their experiences of carer harm. This could be compounded if their family member was not able or, in some cases, unwilling to discuss or to change their behaviour. The following excerpts, taken from Mary, Anna and Christine's accounts, illustrate the emotionally-charged nature of their caring experiences. They also underline the troubling experience of accommodating or 'coping' with their family member's behaviour when it was difficult to understand or predict.

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... 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! Mary, previously caring for her husband

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, previously caring for her brother

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, caring for her husband

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

and loaded connotations of the word 'abuse' and often rejected comparisons of their situation with that of domestic or intimate partner violence. It is important to note, however, that some participants did consider their family member capable of controlling and changing their behaviour and described it in reference to a continuation of personality or behavioural patterns that were evident in the past. Nevertheless, almost all participants questioned the appropriateness of the term 'abuse'. The following excerpts, taken from Rose, Mary and Sarah's accounts, demonstrate how participants were often highly attuned to the difficulties associated with naming and explaining carer harm. This meant it was difficult for the carers to know what, if any, type of help or support was appropriate for them to access 'outside' of their family. It also reinforced their feelings of isolation when coping with carer harm in, what Fricker describes as a social, psychological and epistemic sense.

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, caring for her husband

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, previously caring for her husband

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... 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, umm, on that particular night it was because I said no.... So, in that respect it is mental sexual violence. Do you know what I mean? Sarah, caring for her husband

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

on affected individuals. Reflecting on the strong themes of loyalty, love and duty that ran through the participants' accounts, we suggest that the gendered inequalities that underpin expectations that women adopt formal and informal caring roles (Barnes, 2012; Lynch, 2007) - and perform these role in a certain way, particularly in later life - create additional 'prejudicial flaws' that limit listeners' capacity to recognise and respond to carer harm. In short, they are likely to overlay expectations that carers tolerate and cope with harmful behaviour. They also inhibit expression of the subtle but important differences between feelings of stress and anxiety, for example, and that of caring for someone at the same time as being afraid of them.

Furthermore, participants' discomfort in explaining their experiences as 'abusive' may speak to prevailing contemporary social norms about who can be regarded as a 'victim' or 'perpetrator' of harm. The binary, legally-orientated nature of these concepts makes them uncomfortable spaces in which to explore and explain experiences of mutual powerlessness and loss of relational and, at times, physical autonomy. This is particularly the case if it is unclear to what extent the incidents or patterns of behaviour are unintentional. These ambiguities raise uncomfortable questions that require exploration and critical engagement: practices that are difficult to carry out, for listeners and speakers, in the current epistemic climate. The concept of hermeneutic injustice thus has value in helping to contextualise the spaces and silences that surround this seemingly hidden issue. By identifying them, it is possible to explain some of the reasons that contribute to carers normalising and tolerating harmful behaviour. It can also help to make sense of the context in which carers struggle to describe their needs and experiences until the behaviour places themselves or their family member in serious physical and psychological danger and it can no longer be kept 'hidden'.

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

disclose and explore their needs. Facilitating these opportunities and responding to them appropriately when they do occur may make a critical difference to alleviating carers' acute sense of responsibility and isolation when coping with and tolerating harmful behaviour.

It is also important to emphasise that the aim of this study was not to corroborate, challenge or evidence carers' explanations of their family member's behaviour. We were not investigating whether it was or was not abusive. Rather, we sought to explore carers' lived experiences of harm and the way they shared and developed meaning about their experiences. By suggesting that carers suffered hermeneutic and testimonial injustices, we are not therefore arguing that their explanations were partial or incorrect. Indeed, illness-orientated explanations may have helped carers to psychologically disengage from abuse and harm that was deliberate because they helped to de-personalise the experience of violent or manipulative 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 (Band-Winterstien, 2014). Such understandings are also congruent with role expectations of women to care and love in an unconditional manner (Ayres and Wooditi, 2001). These are important factors to consider, not least because they speak to the plural and dynamic ways that people construct understanding of their psychic and social worlds. They also illustrate the powerful and different ways that caring roles and experiences coalesce with ideas about people's identity, relationship and values (Barnes, 2012; Forbat, 2005).

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

Rosenberg, 2017; Spencer et al, 2018). This study makes one of the first contributions to an emerging field and, by using qualitative techniques and a sociological, theoretically informed analysis, it contributes new insights. However, there is a need for further innovation and development, exploring different carer groups such as male carers and carers in same-sex relationships. There is also value in exploring the experience of families from a wider range of social and cultural backgrounds. Given the critical role of social norms and social contexts affecting the disclosure and help-seeking processes of carers in this study, it is important to consider critically what factors affect these potentially more 'hidden' and marginalised carer groups.

Analysing the women's accounts with reference to the theory of epistemic injustice thus surfaces critical questions about how to recalibrate some of the epistemic inequalities and identity prejudices that shape what we understand to constitute violence, abuse and harm in familial and domestic spaces. One potential way of improving identification and responses to carer harm is to consider how safe and supportive spaces can be opened up for affected carers to disclose, explore and make decisions about their situation. 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; 2015). From an epistemic perspective, such opportunities can also help to shift the balance of epistemic resources and thus enable some individuals to find a collective voice however, mediated this may be by other forms of social and political disadvantage (Pollihaus, 2012). Over the past 30 to 40 years, there has been a discernible shift in how abuse and harm are defined and conceptualised in 'public' and 'private' space. This has in turn contributed to changes in what is considered a legitimate sphere of state intervention in the 'private' life of children and families and, to some extent,

intimate partner relationships between adults. We are not advocating that carer harm requires 'discovering', or that is fundamentally similar to other types of abuse and violence (Olafson et al, 1993). Nevertheless, consideration of the factors that have facilitated greater awareness of these 'types' of harmful behaviour may provide a useful starting point in thinking about how to raise awareness and improve responses to carer harm.

Lastly, it is evident that the framing of carer harm as a private, moral issue may implicitly reinforces the view that if adults have the cognitive capacity to make decisions, then they are free to do so. This has important implications for health and social care practice with older adults and their families. Understanding capacity as a primarily cognitive state 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 deploy to talk about caring *and* harmful behaviour within caring relationships (Kittay, 2011). It also highlights how, by strengthening the rights and needs of one group of people – often because they have historically experienced disadvantage and discrimination – an implicit hierarchy may be created. To fully understand the complex inter-dependencies of caring relationships a more critical approach is required focussing in particular on the unintended implications of how 'vulnerability' is understood and how the 'rights' and responsibilities it engenders benefits some groups and not others (Barnes, 2012; McKay, 2017). 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.

Conclusion

The globally ageing population raises pressing questions about how a growing number of families will cope and care for older partners and relatives. For some carers, later life brings about changes, or exacerbates existing tendencies, that result in them experiencing abusive, violent or harmful behaviour by the person for whom they care. The findings of this study indicate there are important practical, ethical and conceptual factors that make it difficult to talk and think about harmful or abusive behaviour towards family carers: both from a ‘testimonial’ and ‘hermeneutic’ perspective. This can exacerbate families’ difficulties in seeking help and understanding their situation at a challenging and often traumatic period of life. 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 base about carer harm. It also goes some way in challenging the assumption that carer harm is too sensitive or complex an issue to be explored – in research or practice contexts - in a meaningful way. Perhaps most importantly, the participants’ decision to share their testimonies questions the latent assumption that carers cannot or do not want to talk about carer harm or to affect other affected families.

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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.*