

“This is still all about love”

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“This is still all about love”: Practitioners’ perspectives of working with family carers affected by the harmful behaviour of the older person for whom they care

Abstract

This article explores a hidden and under-acknowledged dimension of caring in family life: when older people with care needs act in a harmful, abusive or violent way towards the family member(s) who cares for them. Thirty-eight health and social care professionals, working in the UK, took part in five focus groups to explore their experience of working with families in this situation. The group discussions were stimulated by vignettes developed from interviews with carers affected by harmful behaviour and the data generated using this method were analysed using a thematic approach. There were two principal findings: 1. ‘Carer harm’ is a serious and under-acknowledged problem which practitioners have extensive experiential knowledge of. 2. Practitioners face considerable practical and ethical challenges working with affected families. Drawing on Miranda Fricker’s concept of epistemic injustice, we discuss how contemporary social, legal and policy systems can make it difficult for health and social care practitioners to identify and meet the needs of affected families. There is a need for clarity at a policy level to support social workers engage with the practice challenges of recognising and responding to affected carers and families.

Introduction

Over the past three decades, there has been an increase in the global awareness of, and knowledge about, the prevalence, nature and deleterious effects of elder abuse amongst health and social care practice communities and the wider public (Yon et al, 2017). Research, policy and campaigning have all combined to challenge social norms about the acceptability of older people being subject to poor care and experiencing powerlessness and inequality within familial, institutional and social spaces (Doyle, 2014). This in turn has raised questions about the extent to which intimate partner violence in older age should be considered a ‘type’ of elder abuse and whether typologies of abuse based on developmental stage (e. g. child, adult and older adult) should be re-considered in light of evidence about the cumulative effects of trauma over the life course, which may be precipitated by abuse or violence in earlier life (Erns and Maschi, 2018).

For some families, the intersecting challenges of illness and caregiving are particularly intense and complex and a link between so-called ‘caregiver burden’ and neglectful, potentially abusive, care is often cited in research and practice literature (Momtaz et al, 2013). However, such associations can perpetuate binary characterisations of those who ‘need’ and those who ‘give’ care that do not reflect the complex inter-dependencies, and subjective understandings, of families and intimate relationships over the life-course (Barnes et al, 2015; Daniel & Bowes, 2010). The framing and response to these questions have important implications for how health and social work practitioners work with those who ‘perpetrate’ and those who are ‘victims’ of harmful and abusive behaviours, particularly within the family context. This article explores the experiences and responses of practitioners to ‘carer harm’: that is, when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological and/or sexual harm.

Research about violence towards people who take on familial caring roles has to date focused for the most part on families of (younger) adults with serious mental health needs (Solomon et al, 2005) and parent-carers of children with ‘challenging’ behaviour (Holt, 2016). In the context of older adults,

harm to carers has been examined in the study of elder abuse (Pillemer and Sutor, 1992), intimate partner abuse in older age (Band-Winterstein and Avieli, 2019), and studies about the lived experience of cognitive and serious mental ill health (Cahill and Shapiro, 1993; Herron et al, 2019). That these studies conceptualise and name dimensions of harm and violence in such different ways, highlights the complexities of the subject and the potential difficulties of finding shared understandings. They also emphasise the increasing wider relevance of the topic. For example a growing number of families across the world are caring for older members (Pinquart & Sörensen, 2011), and it is possible that a hidden minority will be caring in complex circumstances, which may include responding to harm and violence. Indeed, a recent international review of English language literature identified 18 studies which reported evidence of caregivers' experience of violent, abusive, or harmful behaviour from the older person for whom they care in North America, Europe, Australia and South Asia (authors' own).

Rather than seeking to uncover whether this is/not a 'type' of abuse or a facet of so-called 'caregiver burden', a potentially more useful starting point is to privilege families' experiences and develop understanding, for example, about how people make meaning, seek help and make decisions about how to navigate, resist or accept violence as a part of caring (Herron and Rosenberg, 2018; Spencer et al, 2018). It is also important to explore how those who are in a position to identify, support and work alongside these families talk about and make sense of violence and harm in caring contexts. For these reasons, we carried out a focus group study that explored the views and experiences of social work practitioners working with families who are, or could be, affected by 'carer harm'. To our knowledge, it is the first study to focus on practitioners' views and experiences of the issue. It is likely to be of interest to social work and health care professionals working with older adults and policy-makers working in the fields of older age care, mental health and domestic violence in the UK and internationally.

Background

Identifying and responding to violence, abuse and harm

Social workers are well-positioned, perhaps uniquely so, to identify and support older people and their families, particularly those who are isolated and socially marginalised. They work within domestic spaces and engage with the intimate and ‘private’ sphere on a routine basis as part of their practice, providing opportunities for people to disclose and seek help with issues considered to be ‘sensitive’ or taboo (Strümpel and Hackl, 2011). Often working alongside colleagues in health and social care, older adult social workers support older adults in taking decisions at times of crisis, loss and transition: for example, making decisions about ‘leaving’ an abusive relationship or ‘placing’ a family member in a care home. When working on behalf of state or welfare bodies, practitioners are also directly and indirectly invested with power and responsibility to interpret law, policy and organisational guidance about how families are (or are not) engaged with and supported (Johnson, 2012; Ash, 2014).

There is a small but growing number of studies that explore how practitioners interpret and operationalise concepts such as abuse, care and risk in their work with older adults (Johnson, 2012; Nuahgton et al, 2013). These studies highlight how professionals’ identification of and responses to abuse and harm are shaped by a range of factors: including but not limited to organisational culture, environmental pressures and personal and professional values (e.g. Band-Winterstein et al, 2014; Ash, 2014). This underlines the importance of examining the social and cultural factors that shape the way professionals understand, think about and communicate ideas relating to risk and vulnerability, particularly when there is limited formal guidance available to orientate their practice. For example, professionals’ understanding of what makes older people ‘vulnerable’ has been found to generally focus on the importance of physical – rather than psychological or spiritual – welfare (Crockett et al, 2018). This may be at odds with people’s views of what makes them feel unsafe and what, more importantly, they are willing to tolerate and adapt to in order to ensure personal wishes, such as staying in their home environment are respected (Abley et al, 2012; Naughton et al, 2013).

Whilst the latter examples may reflect a paternalistic or risk-averse approach to older people’s safety and welfare, there is also evidence that some types of harm caused to and by older people can be underestimated and overlooked. For example practitioners have been found to be reluctant to ask

questions about sexual violence of older people (carried out by adults of all ages), assuming that older people would find it uncomfortable or embarrassing to talk about such experiences whether carried out by a stranger, intimate partner or other known adult (for example in a nursing or residential home context) (Jeary, 2004; Bows, 2018). When violence is carried out by an older person, practitioners seek to explain and to contextualise then behaviour in a way that is dissimilar from approaches to working with younger adults (Crockett et al, 2018). Whilst this may be a valuable perspective, it is equally important that the impact of violence on others is not ‘explained away’, particularly when it affects another older person (Bows, 2018). Similarly, domestic violence ‘grown old’ - understood as a continuation and development of abusive behaviours that stem from adulthood, manifest in later life – is not consistently recognised or understood by practitioners working in community contexts (Brossoie and Roberto, 2015) and the paucity of developmentally-sensitive domestic and sexual violence services for older people is likely to make it more difficult for people to seek help and talk about their experiences (Crockett et al, 2018).

The carers’ hidden harm project

This article reports an exploratory study that investigated the experiences and needs of family carers who identified as being affected by violent, abusive or harmful behaviour by the older person for whom they cared. The first empirical stage, involved twelve in-depth interviews with affected family carers and analysis of the data, drawing on Miranda Fricker’s theory of epistemic injustice (Fricker, 2007). This article reports the second empirical stage which was a vignette-based focus group study of social work and healthcare professionals’ perspectives and experiences of working with affected carers. In the following sections of the article, we outline the methodological, ethical and methods-orientated aspects of the study.

Methodological and methods-focused decisions

Vignette-based focus groups

Focus groups are commonly characterised as a discussion between individuals that is ‘focused’ on a topic and facilitated by the convening researcher (Robinson, 1999). Focus groups produce rich, often

complex, data about points of comparison, contrast, and consensus among members of a group (Kitzinger, 1994). The group environment can help people talk about ‘difficult’ topics because it facilitates exploration of latent, shared social meanings that can otherwise be difficult to name or describe (Bradbury-Jones et al, 2014). To stimulate discussion amongst group members, we used vignettes, based on extracts of the interview data, alongside a short semi-structured topic guide (see Text boxes 1, 2 and 3).

Insert Text boxes 1, 2 and 3 here

Methods and participant characteristics

We conducted five focus groups with social work and health care practitioners working in the UK (see Table 1). Thirty-eight practitioners took part in the discussions, which lasted between 60 and 90 minutes. Initially, the research team contacted team managers to discuss the study and the potential benefits and disadvantages of taking part. Information about the study (including an outline of the topic guide, background to the project and consent forms) were shared via email and post, and distributed to potential participants by team managers. Participation in the research was entirely voluntary and the research team were not aware of who (or how many) people would be attending the discussion sessions in advance.

All participants worked with older people and their families. The members of four of the groups worked with families in their homes and community settings. Two groups specialised in work with older adults affected by dementia illnesses: the Admiral Nurses and the Dementia advisors. The three groups of local authority (statutory) social workers worked primarily, but not exclusively, with older adults. The vignettes were not used with Group 5. Because these practitioners had less direct contact with families we considered it more appropriate to facilitate a discussion session, exploring their knowledge and views about the topic of carer harm, rather than using the vignette method to reflect on practice cases. Pseudonyms are used to provide an indication of the range of contributions from the members of the focus groups whilst protecting their identity.

Insert Table 1 here

Ethical considerations

When assurances of confidentiality and anonymity are strictly upheld, vignette-based focus groups confer the advantages of enabling participants to talk about issues from a hypothetical or third-party perspective if they do not wish to share examples from their own practice (Bradbury-Jones et al, 2014). We considered these to be strengths of the vignette method given the potential sensitivities of professionals talking about carer harm – and their own responses to it – amongst colleagues. We also recognised that despite their professional expertise in talking about sensitive issues, participants may be affected by the issues of care and violence in their personal lives. We raised this issue with participants and encouraged them to consider the impact of taking part in a group discussion, where people may hold different views that could feel challenging or insensitive. On completing the vignette-based discussion, we ensured there was time to de-brief and provided participants with contact details of the research team should they wish to raise any questions or concerns following our meeting. The study protocol was peer reviewed and received approval from (anonymised) Research Ethics committee (ERN_16-0534) and relevant ethical permissions from the participating local authorities.

Process of analysis

The focus group sessions were audio-recorded and transcribed verbatim. The transcripts were initially analysed using Braun and Clarke's (2006) approach to thematic analysis. This is a systematic and rigorous analytic process used to organise and interpret qualitative data. It involves six stages: 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 (Braun and Clarke, 2006). We also drew on the theory of epistemic injustice in the final phases of the analytic process, as discussed in the following section.

Theoretically informed analysis and synthesis of the findings

The debate about a ‘theory practice gap’ has been a feature of the academic discourse of a number of professions, including social work, as a result of the perceived disconnect between what is taught and what happens in practice (Clapton et al 2006). This has engendered some hostility towards theory because of its perceived lack of utility (Sharland, 2012). However, it has been argued that being guided by theory can enhance practitioners’ ability to communicate and understand their practice (Fargion 2007) and that social work theory can draw on plural forms of knowledge generation, including those rooted in the use of tacit knowledge (Fook, 2002).

The way theory was used in this study demonstrates how it can inform practice directly. We drew on Miranda Fricker’s theory of epistemic injustice to orientate our analysis towards an exploration of the social and epistemic factors that may affect how families and practitioners construct and respond to carer harm. Fricker argues that there are two different types of epistemic injustice - testimonial and hermeneutic – that can cause ‘harm’ to individuals or groups whose knowledge is disregarded. Testimonial injustice is characterised as when a ‘speaker’ (someone who is communicating) is not heard (meaningfully listened to) because how and what they are saying are not given sufficient credibility and respect. It can occur on an incidental as well as a systematic basis and the degree of harm caused is likely to reflect the frequency and severity with which this form of epistemic injustice takes place. Hermeneutic injustice is the second type of epistemic injustice explored by Fricker. This occurs when significant parts of a person’s social experience are obscured from understanding. This results in a ‘lacuna’ where neither knower nor hearer can understand the other and, in some cases, the knower is unable to meaningfully define and describe important aspects of their own experience to themselves (Fricker, 2007). Fricker argues the close and inherent connection between the “operation of social power in epistemic interactions” (Fricker, 2007, pp.2) gives them an ethical dimension. This means that social injustices – that often have a material, political and cultural dimension – find expression in and are compounded by, epistemic injustices, which tend to be social, inter-personal and psychological in nature. In the following sections of the article, we present the findings of our synthesised thematic analysis and discuss its implications by drawing on some of the central concepts of epistemic injustice.

Findings

1. Hidden in plain sight: a serious and under-acknowledged problem

There was broad agreement across the groups that carer harm was a complex and difficult issue that affected the families they worked with. Participants identified multiple, often intersecting reasons why violent, abusive or harmful behaviour of this nature occurred. One of the principal causes was that disinhibited, or ‘challenging’ behaviour developed as a result of cognitive impairment or serious mental ill health, both of which were common problems amongst families. Practitioners also talked about how illness was sometimes deployed as an ‘excuse’ or explanation for violent or manipulative behaviour that had begun before the onset of illness, as illustrated by Katrina and Cathy’s observations:

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

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

Participants also reported how some people took on a caring role in ambivalent and constrained circumstances and that social, economic and relational issues were contributory factors to ‘breakdowns’ in the care relationship. This often led to the development of unpredictable and more expressive behaviour on the part of carers and the family members with care needs. This was, participants suggested, exacerbated in cases where there was a history of domestic or relational violence. In the following extracts, Kate and Suresh share their experiences of working with women who cared for partners who had, throughout their relationship, acted in a harmful and abusive way towards them.

She (carer) had gone through this historical abuse and then her husband was diagnosed with dementia but the abuse continued. It only came out because of his dementia. Once he went into residential care, his behaviour was excused because of his dementia. And then she was sat with all of this. Kate (Student social worker, Group 5)

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

In different ways, then, the participants highlighted how perceptions of what was permissible and tolerable behaviour varied between families and that people could, and did, habituate themselves to a range of difficult and abusive circumstances. Participants also explained how carers developed a range of concealment strategies that had the effect of under-playing the impact of the harm they experienced and the nature of their family member's illness or disability. For example, some carers were described as being reluctant to allow professionals – particularly 'formal' carers – in their home, to avoid what felt like scrutiny of and disruption to intimate care practices that had developed between family members. The participants believed these strategies helped families to retain a degree of control and autonomy over who was involved in their lives and how the older person they were caring for was regarded, within and outside of their home environment. This was a particularly important factor for families who were concerned about the possibility of family members being placed in nursing homes or secure hospitals, against their wishes. In the context of these discussions, the practitioners made frequent references to the "dilemmas" and "difficult choices" that carers faced. This reinforced, they emphasised, how important it was, to understand carers' experiences in relation to their feelings of love, loyalty and responsibility towards their family member.

I think that often people do see the situation is getting worse but what they tend not to do is acknowledge that their ability to manage the situation is getting less and... So, they see it happening,

but they just carry on because that is what they have always done. Emily (Social care coordinator, Group 2)

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

This framing of carer harm as a moral, private issue was coupled with a reluctance expressed by many practitioners to name such behaviour as ‘abusive’. The word was widely considered to be “emotive” and “loaded” and to imply an older person was fully or partially culpable for their behaviour. Instead, participants emphasised the importance of exploring carers’ perspectives and finding terminology that was more socially and culturally sensitive. This approach was reported to be enable practitioners to maintain trusting relationships with families and to prevent them “pushing people away”. However, several professionals explained how they sometimes felt uncomfortable raising the topic of abuse, particularly when it was sexual in nature:

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

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

Across the focus groups, there was acknowledgement that carers did experience violent, abusive or harmful behaviour and the causes of this behaviour were unique to families' relational and social circumstances. These circumstances also shaped the different ways carers coped with and, sometimes concealed, what they experienced which in turn affected how and when practitioners engaged with families- a point we explore in greater detail in the following section.

2. Identifying and responding to affected families

A consistent thread woven through the participants' accounts was a focus on 'relationship-based' care and support. This was characterised as exploring families' unique history and circumstances and working with members in a respectful, empathic way. Building trusting relationships with families was considered to be critical, both in terms of gaining 'access' to them and having meaningful communication about decisions relating to people's care, safety and welfare. Practitioners also talked about the positive role they could play in sharing knowledge and giving advice, to support families in making complex and difficult decisions, for example, in making plans to manage and/or prevent violent or 'challenging' behaviour on the part of the older person being cared for.

I think that the work that we can do is preparatory sometimes. In terms of strategies but also in terms of contingency plans and practical issues about how somebody can keep themselves safe in a risky situation... Rita (Admiral Nurse, Group 1)

Although I could see that he (service user acting in a harmful way) was getting worse and that it was just going to get worse, it took her (wife and carer) a while to get there, to see it. I tried to help reflect back to her that this is the situation as I see it. Angie (Adult social worker, Group 3)

Nevertheless, a consistent strand in all the discussions was the difficulty practitioners experienced working in what many of them described as a crisis-orientated system. Participants voiced concerns that carer harm was one of several issues that could be, if not prevented, then better managed if they

had more time and resources to work with families. Participants talked about their limited capacity for preventative and rehabilitative work and it was not uncommon for them to work with families in challenging situations where there were few realistic options left. Consequently, carers were often left “sitting with” or “sitting in” – phrases used by several participants – situations that were violent, traumatic or distressing.

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

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

Reflecting on their own experience, practitioners talked about the challenges that carers faced when trying to make their views and needs known to health and social care professionals. Social worker participants in particular reported they had limited scope to carry out in-depth work with carers. If issues of harm and/or violence were raised, it was generally in the context of protecting older people with care needs. Participants also talked about the lack of formal guidance for their work with families where the needs of individuals were complex and inter-dependent, such that carers could also be considered ‘vulnerable’. They explained that these problems were compounded by the limited (and dwindling) number of dedicated services for carers and the difficulties involved in meeting their needs if they were not congruent with the wishes and needs of the older person for whom they cared.

I think that the perception is that when we have removed that person (causing harm) then everything is fine now... We just remove the risk, essentially, but we don't actually follow it up. I mean that is

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

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

These comments highlight the difficulties practitioners faced when trying to work in a person-centred and relational manner with couples and families who had significantly different and changing needs. They also reflect the tensions involved in balancing carers' and families' rights with their choice to care and support one another when harm and violence took place. This was a particularly difficult issue when both family members had care and support needs and/ or when the older person's insight and capacity to make decisions fluctuated. In the context of these discussions, several practitioners suggested that a carer's choice to 'tolerate' harm could in fact reflect a lack of understanding of the severity of their family member's needs. As Rita explains in the following extract, this could result in the unintentional neglect of an older person:

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

Echoing comments made by participants in the other groups, Rita's observation indicates how carer harm could be a proxy for stressful and chaotic circumstances in which the delineation between carer and cared-for and, by implication, the balance of perceived capacity and decision-making power, was blurred and fluid. It is a stark example of the complex inter-dependencies of some caring relationships

and the potential for mutual harm and abuse instigated and experienced by older people. In the following section these data are subject to further second-order analysis in order to examine the practice context in greater depth.

Discussion

In light of the growing number of families caring for older people with multiple chronic, often complex health conditions, it is perhaps unsurprising that social work practitioners are involved in the challenging situations that some families confront when care and violence intersect (Spencer et al, 2018). We found that whilst carer harm is both serious and not uncommon, it remains a somewhat hidden aspect of the care experience. Drawing on Fricker's concept of epistemic injustice (Fricker, 2007), we discuss how this may be in part a consequence of inequalities in the epistemic environment in which carers and professionals communicate with one another.

Testimonial dimensions

To recap, testimonial injustice is characterised as when a 'speaker' (someone who is communicating) is not heard (meaningfully listened to) because how and what they are saying are not given sufficient credibility and respect. The participants in this study identified the testimonial challenges of working with affected families, many of which were attributed to carers' perceived reluctance to disclose sensitive information that could be interpreted as shameful or embarrassing, or as contravening norms about family life and domestic space (Crockett et al, 2018). There was also evidence that practitioners were not consistently able to initiate or 'listen' to (i.e. meaningfully hear) families' testimony about harm in the context of care and illness. For example, many participants were reluctant to name the situations in the vignettes as 'abusive', even when it was made clear there was a known history of domestic violence. They also shared the feelings of the discomfort they felt when asking carers about abuse and harm and several participants acknowledged they had not previously considered the possibility of older people instigating or being subject to sexual violence. These examples raise questions about the unintentional silencing practices that practitioners may deploy. For example, not asking direct or routine questions about the nature and frequency of harm that carers experience or

accepting, perhaps at face value, carers' explanations for 'staying with' and 'tolerating' harm. Uncritical assumptions about the passivity and asexuality of older people (Bows, 2018; Jeary, 2004) may also affect practitioners' ability to recognise and respond to sexual violence instigated by, or affecting, older adults. Analysis of the data also points to the stressful and distressing epistemic (and social) context in which affected carers may encounter health and social care professionals – i.e. at a point of crisis and/ or when there are limited options available - and the likelihood that this will impair meaningful communication and shared decision-making. These conditions place undue responsibility on families to recognise and articulate their needs, in an epistemic environment in which their credibility and legitimacy are not consistently considered to be equal to that of professionals.

Social workers can play a crucial role in attending to these epistemic issues by sensitively and proactively exploring what harm might look and feel like to carers and older family members, drawing on their skills of working with people at times of loss, crisis and transition. Raising this taboo issue may also help to help to create an environment in which talking about it is acceptable and this supports families to seek help and make decisions before they reach 'crisis' moments where options feel (and often are) limited (Parkinson, et al, 2018; Butler et al, 2016). Such work would necessarily include identifying the support and care needs of the older person instigating harmful behaviour as well as those of their family carer (Herron & Wrathall, 2018). Given social workers' expertise working with family and social groups – and the contemporary appetite to renew this expertise in adult social work – they are particularly well-positioned to carry out this work (Parkinson, et al, 2018).

Hermeneutic dimensions

Fricker's concept of hermeneutic injustice – that is, situations in which both listeners and speakers having insufficient epistemic resources to communicate and understand one another as a result of their shared social and cultural context (Fricker, 2007) – helps to situate the way practitioners understood and responded to the vignettes. Drawing on this concept, we suggest that the policies, laws and cultural practices that inform contemporary understandings of who is 'vulnerable' and what it means to have

‘capacity’ make it particularly difficult to identify and respond to affected carers because they rest on an implicit assumption that those with fewer or no care needs can (and should) be able to look after themselves. Critically, the coupling of vulnerability and health and care needs obfuscates consideration of how people can be both vulnerable and have capacity – intentionally or unintentionally - to instigate violence and to cause harm to another person. This creates the conditions in which hermeneutic injustices may develop, namely that carers who experience harm cannot explain their experience to themselves or be understood by others. Carers’ difficulties are also likely to be exacerbated by economic and resource injustice. Within a health and social care system that is increasingly crisis orientated (BMA, 2018; Thorlby et al, 2018) and only able to offer consistent support to individuals who have been assessed to have critical and complex needs, as a result of their physical and mental health condition (Higgs and Hafford-Letchfield, 2018), it is likely that the needs of carers with less obvious or immediate needs will be of priority and be given less attention. As the practitioners in this study reported, there was a limit to what they could offer carers in terms of signposting and practical and therapeutic support when they ‘knew’ that harm was taking place, leaving them in the uncomfortable position, as Cathy explained, of trying “to explore how much they are willing to put up with”. There was then a hermeneutic lacuna, we suggest, in which some types of harm and need could not be rendered collectively visible or mutually understood by practitioners and carers.

It is critical that stakeholders, including commissioners, policymakers and people in senior leadership roles, support social workers to work more proactively with families where care and violence intersect. This is necessary because, regardless of the acceptability of entrusting practitioners to have ‘difficult conversations’ and to work in a reflective way, there needs to be a commitment to develop systems that promote practitioner well-being and foster a culture of reflection and peer support (Hewison & Sawbridge, 2016). It would also be beneficial to provide greater conceptual clarity at a policy level about how social workers can recognise and respond to carer harm. This will require a more critical engagement by policy-makers with how concepts of mental capacity and personal choice shape but do not encompass all aspects of the physical, psychological and ethical inter-dependencies

between adults in care relationships (Barnes et al, 2015; Storey et al, 2018). By shifting the focus to the experience of caring within social and relational contexts – rather than individuals who give or receive care - it may also be possible to better recognise the intersections between older adult domestic abuse, mental health and adult safeguarding and in turn to strengthen partnership work between these historically distinct sectors.

Limitations

Given some of the ethical and practical challenges inherent in working with affected families and surfacing a seemingly ‘hidden’ practice issue, this study provides some important empirical insights about carer harm. There is nevertheless ample scope to build on this exploratory study. As with all qualitative research, the insights it generates are sensitive to and grounded in their social and, for this study, organisational contexts. It would be beneficial if future work explored the views and experience of a greater number of professionals, from a range of disciplinary and organisational backgrounds, as well as professionals working across different geographical and cultural contexts. Such work could help to trace the shared and divergent experiences of families and social workers from an international perspective. Use of alternative and additional research methods could also provide critical and different knowledge about how health and social care professionals identify and respond to carer harm: for example, through case study analysis or in-depth interviews with practitioners and managers working in adult care and safeguarding roles.

Conclusion

Currently practitioners have limited option but to draw on their experiential knowledge when identifying and engaging with families affected by ‘carer harm’. Although there are benefits that can accrue from such an approach, there is a risk that it places undue expectation on individual practitioners, particularly those with less experience, to ‘know’ when and how to explore, challenge and support family members make decisions about how best to care for and support one another at a difficult and potentially traumatic period in their lives. Furthermore, drawing only on experiential knowledge runs the risk that practitioners are not supported to think critically and collectively about

how to identify and respond to carers and families in different and perhaps more effective ways.

Challenging social norms of what is tolerated, expected and said is particularly important given the epistemic, social and resource injustices faced by some carers and families. It is hoped that naming this form of harm and drawing on the concept of epistemic injustice to explore its 'hidden' dimensions will prompt greater recognition of it as an issue and the development of systems and procedures to address it. Social workers can play a lead role in surfacing the issue and challenging some of the service-level and structural inequalities that inhibit families from seeking support.

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Group	Practitioner group	Focus/ specialism of work	No. of participants	Gender ration (F:M)
1	Admiral Nurses	Specialist dementia nursing	10	9:1
2	Adult social workers	Safeguarding and care coordination	5	4:1
3	Adult social workers	Safeguarding and care coordination	6	5:1
4	Dementia advisors (N)	Community dementia support/ advice	10	9:1
5	Adult social workers (N)	Care coordination (nursing/ residential care)	7	6:1

Table 1: Focus group characteristics

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

Text box 1: Rose's vignette

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

Text box 2: Sarah's vignette

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

Text box 3: Megan's vignette