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Abstract

Purpose

Most abuse affecting older adults in the UK, as across Europe, takes place within caring relationships, where one person is disabled and needs care/support. This article critically appraises two of the key theoretical explanations. First, feminist theories of "intimate partner abuse" tell us that it is mostly men who perpetrate abuse against women. Second, "carer strain": the stress caused by caring responsibilities, often with inadequate help from services. Neither fully reflects the complex dynamics of "dangerous care" leading to a lack of voice and choice in safeguarding responses.

This article articulates the need for an overarching theoretical framework, informed by a deeper understanding of the intersectional risk factors that create and compound the diverse experiences of harm by disabled people and family carers over the lifecourse.

Design/methodology/approach

The critical synthesis of the theoretical approaches informing UK policy and practice presented here arises from a structured literature review and discussions held with three relevant third sector agencies during the development of a research proposal.

Findings

No single theory fully explains dangerous care and there are significant gaps in policy, resources and practice across service sectors, highlighting the need for joint training, intersectional working and research across service sectors.

Originality

Drawing both on existing literature and on discussions across contrasting policy and practice sectors, this article raises awareness of some less well-acknowledged complexities of abuse and responses to abuse in later life.

Introduction

This paper concerns "dangerous care", which is our working term for the abuse or harm that can develop between disabled people and carers in family or intimate relationships. Either person or both might be the "perpetrator". The term dangerous care not only refers to harm that might occur between individuals, but to how welfare policy and service delivery can create and aggravate the stresses within such relationships and responses to that harm. For present purposes, we are especially interested in ageing in the context of dangerous care and we are focusing on older people who have lifelong disabilities or a pre-existing long-term health condition. In this regard we are not focusing exclusively on the literature around "older people" or "disabled people" but using aspects of both to highlight the origins and complexities of dangerous care. This means at times we talk about "disabled people", following the relevant literature, and at other times we talk about "older people".

We argue that there are two key theoretical frameworks within which dangerous care might be understood, but which do not fully reflect its complexities. There are also gaps in policies, services and knowledge for safeguarding practice with specific challenges for making affected people's experiences visible and having their voices heard. Our arguments are informed by exploratory discussions we have had with the Coalition of Carers in Scotland, Inclusion Scotland and Scottish Women's Aid about recognising and then responding to dangerous care, and how we might best research this. Our arguments are also informed by a structured literature review that took a 'State-of- the-Art' approach (Grant and Booth 2009, p 101). This approach does not seek to systematically review all possibly relevant literature. Instead, it focuses on a current issue and seeks to identify gaps in knowledge that might then be addressed through new ways of theorising and future research. This approach was enhanced by taking the key words and phrases used by our partner agencies as search variables.

The paper first reviews what we know about caring relationships in the context of ageing and abuse. It then considers two conceptual lenses that underpin key policy areas across the UK that dangerous care could fall under; a) domestic abuse policies where abuse is seen as the exercise of power, especially gendered power and b) adult safeguarding where dangerous care is often viewed, though not exclusively, as carer strain. There is a particular focus within each section as to whether people experiencing dangerous care are likely to recognise themselves and their predicaments in either of these theorisations. Through this, we identify how each model can help to explain dangerous care, but that more development is needed. We conclude the paper by articulating a plan for knowledge, policy and service development that would centre older people's voices in a fuller way.

Ageing in caring relationships

Disabled people commonly rely on family members to meet some of their care and support needs (Norman and Purdam, 2012). Indeed, this is an increasingly common feature of contemporary ageing in the global north, given increased life expectancies, geographical dispersal of extended families and the shrinking welfare state (Zigante *et al.*, 2021). Care and support are themselves complex phenomena, extending well beyond assistance with day-to-day, practical tasks to keeping up with friends and wider family and being involved in community. We take as our premise that care includes emotional, relational and practical elements and that it is rarely one-way (Rummery and Fine, 2012; Ward and Barnes, 2016). We return to some implications of this framing later in the paper.

Sometimes harm and abuse can happen in caring relationships. Qualitative explorations of adult safeguarding concerns demonstrate the diversity and complexity of this type of abuse. For instance, abuse can happen between an older parent and an adult child who does not live with them as well as between co-resident spouses or partners (Schiamberg and Gans, 2000). One cannot assume that the disabled and/or older person is the "victim", and the carer is the "perpetrator", nor that the "victim" is always female (Mackay, 2017; Mackay *et al.*, 2011). In addition to gender, disability and age, there are also risks associated with ethnicity, sexuality, poverty, poor health, substance abuse and homelessness that can increase the complexity of tackling abuse and harm, including dangerous care (Band-Winterstein and Eisikovits, 2009; Fahmy and Williamson, 2018; Mackay *et al.*, 2011; Shepard, 2005; Thiara *et al.*, 2011; Walsh *et al.*, 2007).

Appreciating how relationships have developed over time is important to understanding dangerous care. For instance, we know that some situations, which fit the definitions of both dangerous care

and elder abuse, are in fact continuations of abuse that began in earlier years (Band-Winterstein and Eisikovits, 2009). We can also predict that the incidence and severity of dangerous care are likely to increase as people age. In part, this is because of the cumulative impacts of advantage/disadvantage over the lifecourse: for instance, health inequalities widen for age cohorts over time (Dannefer, 2003) and increasing care needs are associated with the risk of abuse (Pillemer *et al.*, 2016; Thiara *et al.*, 2011). Previous abuse itself appears to be associated with a higher incidence of subsequent abuse (Hightower *et al.*, 2006; Schiamberg & Gans, 2000; Walsh *et al.*, 2007). In addition, we know that inadequate service responses can play their part in the perpetuation and deterioration of harmful and abusive situations (Carr *et al.*, 2019; Rogers *et al.*, 2012). The COVID-19 pandemic has aggravated the situation by cutting support overnight and reducing access to support for carers (Sriram *et al.*, 2021) and disabled people (Pearson *et al.*, 2022).

Notwithstanding the above, there are significant gaps in the research knowledge about disabled older people's experiences of dangerous care over time. This is particularly the case given that related and more widely researched concepts such as "domestic abuse" and "elder abuse" are; a) defined in different ways in different studies, and in different legislative, policy and practice contexts b) trigger different responses depending which policy is chosen for intervention and c) don't map neatly, in any of their operationalisations, onto the concept we are developing here. Especially lacking for present purposes are relational understandings of care over time, as we discuss further below.

We contend that inadequate service responses can arise because of the poor fit between a harmful situation and the existing theorisations from which policy and service responses have been developed. In our discussions with our delivery partners we have recognised that theoretical explanations for abuse coalesce, across various academic disciplines, around two distinct themes, gendered power and strain in care. These have led to the creation of separate policy streams, and distinct service delivery and practice models. We address each of these themes below.

Abuse as the exercise of gendered power

There is a large body of literature worldwide, with a developed policy and practice sector in the UK and elsewhere, that addresses domestic abuse. Definitions vary however between countries meaning some people who experience dangerous care will be excluded. For example, Scotland frames domestic abuse as within intimate partner relationships whereas England and Wales extend it to other types of relationships, though the majority of cases that come to light do take the form of controlling partners (usually male) exercising mental and/or physical coercion over partners (usually women) (Damonti and Leache, 2020; McPhail et al., 2007). An understanding of gender as the primary index of the power differential in intimate relationships has long informed practice in this sector, although other intersectional factors have been more recently considered in terms of age, poverty, sexuality, culture and race (Callaghan et al., 2021; Damonti and Leache, 2020; Fahmy and Williamson, 2018; Mirza, 2016; Subirana-Malaret et al., 2019). Additionally, the concept of coercive control, rather than one-off abuse or a series of isolated abusive acts, has increasingly influenced legislative, policy and practice responses to domestic abuse in the UK (Wydall et al., 2018). Research has identified that disabled women are more likely to experience domestic abuse than other women and that disabled women can be coerced and harmed in specific additional ways, for instance by withholding medication or walking aids (Thiara et al., 2011; Van Deinse et al., 2019). Research and policy have also increasingly recognised older women's experiences of domestic abuse (Hightower et al., 2006; Wydall et al., 2018).

Services across the UK for domestic abuse are largely located in the voluntary and criminal justice sectors. They foreground support to access civil rights, including rights to justice, and they offer resources to access safety on women's own terms, for instance by developing safety plans in the home, or by entering new accommodation, including refuge accommodation. Domestic abuse services are generally informed by an appreciation that not all women wish to leave their abusive partner, and many women do not wish to leave their homes. Where they choose to do so, leaving can be a process that involves several attempts which can in some cases increase the risk of further abuse: there is on average a 75% increase in violence upon separation (Ahmadabadi *et al.*, 2018). Women's Aid is the key voluntary service providing domestic abuse services across the UK, and it is dependent upon state funding. There is currently limited specialist support for people in domestically abusive same sex relationships (Miltz et al. 2021) and within trans and non-binary relationships (Rogers 2021). Similarly, whilst national policies might recognise the need for diversity of responses, these have yet to develop where the person is also of an older age (Wydall 2021) and to address the care needs and caring responsibilities in disabled people's lives (Straka & Montminy, 2006; Thiara et al., 2011; Zink et al., 2003).

One of the complexities in addressing dangerous care is that some manifestations might be seen to sit fully within the sphere of domestic abuse policy and services or others within the carers' and adult safeguarding policy sphere. We argue that people can easily fall between these policy silos and service responses. Our aim is not to suggest that domestic abuse policy and services have to widen their remit, but rather that dangerous care often has added dimensions that demand recognition of and responses to it. Firstly, people experiencing dangerous care may not recognise their own predicament in definitions of domestic abuse if they associate that with physical violence and not with other types of abuse such as coercive control, financial or emotional harm (Stark and Hester, 2019). Secondly, older women who care for their disabled spouses may experience particular pressure to remain in these relationships (Thiara et al., 2011). This pressure might come from the disabled spouse but also from societal expectations under which older people grew up, from family expectations, and/or from a sense of self, duty and purpose on the part of the person providing care (Zink et al., 2003). Thirdly, there appear to be more situations within adult safeguarding where both parties are 'harmer' and 'harmed' and/or where the 'harmed' person is male. These will all require different types of safety planning, not least because moving home may be less suitable for older disabled people whose homes have been specially adapted, and/or where people wish to retain contact with each other.

Services like Women's Aid have a high profile in UK society and there have been national campaigns for zero tolerance of domestic abuse but it still requires older disabled people or their carers to seek help. As we have seen they might not associate their experiences with domestic abuse or might be fearful of the consequences of self-reporting. This means there is greater reliance on others to recognise any abuse taking place. Adult safeguarding literature discusses some reasons why social care workers might not recognise domestic abuse. Ash (2014) argues that limited social care resources mean abuse can be viewed as carer stress or not seen at all. There can be an overfocus on the independent, autonomous citizen and a presumption they are making the choice to live with harm (Braye *et al.*, 2017). This is despite evidence that the effects of abuse itself, as well as the effects of being disbelieved and/or left unsupported, may diminish people's own sense of self-efficacy and hope over time (Carr *et al.*, 2019; Mackay 2017). There are parallel concerns within social care more widely that construction of the individual as an autonomous agent overlooks a range of structural factors that enable some people to defend their interests more effectively than others (Ferguson, 2007; Roulstone and Morgan, 2009). Crucially, in the context of increasingly resource-starved health and care services, we can assume that some people experiencing dangerous

care within family relationships will fall through the gaps. Situations of dangerous care may only get referred when abuse later becomes more obvious, and often at a crisis point, to adult care or safeguarding services. The primary explanation of abuse in these settings encompasses ideas about carer strain and the "vulnerability" of the person subject to abuse, which we discuss below.

Abuse as carer strain

In contrast to domestic abuse, policy, practice and theorising within adult safeguarding tend to envisage power in abusive relationships as related in crucial ways to care needs and/or care provision, disability, poor health and associated "vulnerability", albeit that these are contested concepts and associations (Keywood, 2017; Lonbay, 2018; Sherwood-Johnson, 2013). The common assumption of these associations also applies to policy, practice and theorising about elder abuse that are more in evidence in countries such as the Republic of Ireland where elder abuse has received more stand-alone attention (Phelan 2020). In contrast, across UK policy and practice elder abuse is subsumed within adult safeguarding. However, a common recent development across these policy contexts is to try to move theorising away from individual vulnerabilities to a more systematic approach to analysing vulnerability, highlighting cultural and structural factors that cause or aggravate harm (Phelan and O'Donnell 2020)

The strain associated with caring for a "vulnerable" individual has long been proposed as an explanation for the abuse of adults. There is mixed evidence about the causal relationships between abuse and carer strain (Hightower *et al.*, 2006; Hunt, 2003), and definitional issues weaken the body of research on this topic, as on related subjects. There are also strong arguments that linking violence and abuse in a causal way to a disabled person's care and/or support needs is a type of victim-blaming, which is discriminatory and unhelpful (Hollomotz, 2009; Wishart, 2003; Wydall *et al.*, 2018). Nevertheless, where carer strain is understood to arise from a lack of appropriate informal social networks and formal services, then some associations with abuse and harm fit the existing evidence well (Hollomotz, 2013; Hunt, 2003; Rogers *et al.*, 2012).

An additional explanatory concept that is drawn on in the adult safeguarding literature is "vulnerability", often applied to the person assessed as needing care. The language of theory, policy and practice has increasingly moved towards an agreement that vulnerability is best conceptualised as residing in situations rather than in individuals (Hollomotz, 2013; Rogers et al., 2012). Hence an older person is not vulnerable because she has limited mobility, but because she has limited mobility in the context of inaccessible physical environments and because her support needs are not prioritised in a society that discriminates against her on a number of grounds (including age, sex, ethnicity and socioeconomic position) and perhaps also because her partner feels motivated and able to withhold her walking aid (Thiara et al., 2011). Nevertheless, whilst adult safeguarding practice strives towards ecological understandings, gatekeeping processes determining who safeguarding is for still bear vestiges of vulnerability understood as inherent to the individual. Hence safeguarding services do not usually provide help in cases of domestic abuse, unless one or both parties are considered "vulnerable" or in need of care (Mackay, 2017; Sherwood-Johnson, 2013; Wydall et al., 2018; Strydom, 2014). Additionally, and in contrast to many domestic abuse services, some safeguarding approaches have been critiqued for their assumptions of limited agency of the person deemed "vulnerable", and for overlooking structural and cultural barriers that deliver diminished citizenship rights (Lonbay, 2018; Mackay, 2019).

There are problems with conceptualising dangerous care through the lens of carer strain. Firstly, this theory doesn't prove a good fit for all manifestations of dangerous care. For instance, the older disabled person may be the abuser. The abuse may be two-way, as noted, and the care itself is very often also two-way. Beginning instead with current difficulties in meeting the needs of just one party, the theory of carer strain doesn't necessarily account for the lifecourse of disabled people and co-resident carers having led to difficult relationships, both inter and intra-generationally (Myhill and Hohl, 2016; Shepard, 2005). It is also important to appreciate that the dynamics of coercive control, as discussed above, may provide a more appropriate explanation of some (though not all) dangerous care scenarios. In these types of situations, attributions of violence or communications of distress to problems of care and caregiving, and/or to age-related conditions like dementia and strokes, have significant potential to compound oppressive situations (Ash, 2014; Band-Winterstein and Avieli, 2019; Cooper et al., 2010; Wydall et al., 2018).

A second, related problem with carer strain theory as an explanation for dangerous care is similar to a problem identified with domestic abuse theory above; many people involved in dangerous care scenarios would not recognise their own struggles as relating to this theory. This may be because the dynamics of caring within the relationship are much more complex than a one-way provision of practical assistance in the context of disability. It may also be because being labelled "vulnerable", and the "welfarist" responses that might be expected to follow, are very commonly resisted by disabled and older people (Sherwood-Johnson *et al.*, 2021; Spiers, 2000; Wydall *et al.*, 2018). Writing in the context of UK policy responses to the COVID-19 pandemic, Crowther (2020) demonstrates the "othering" effect of the concept of vulnerability, at least where it is understood that some people are vulnerable, and some people are not. For people in relationships involving dangerous care, similar issues apply with respect to safeguarding services. Specifically, people may not come forward for support, or they may resist support when offered, because they do not class themselves as vulnerable (Spiers, 2000). They might also be concerned that safeguarding services will disempower them and take away their choices (Lonbay, 2018; Sherwood-Johnson *et al.*, 2013).

This part of the paper has demonstrated that some people experiencing dangerous care may not recognise themselves in theories of vulnerability and carer strain and may not feel well-matched with safeguarding services. Some of these people will feel their situations better captured by theories of gendered power, and they might feel better served by domestic abuse services. Others, significantly, will not.

Discussion: towards an expanded understanding

We have established that abuse takes place in intimate and family caring relationships, that people are increasingly likely to experience this as they age, and we have termed the phenomenon "dangerous care". Theoretical explanations of domestic abuse underline the role of power in abusive relationships, and whilst most of the literature focuses on abuse of women by male partners, we have noted the more recent acknowledgement of abuse within non-heterosexual relationships. Similarly, dangerous care covers a greater diversity of relationships and types of harm and this will add greater complexity to the power dynamics. However, service responses typically fail to meet this need for greater recognition and diversity of support. We then highlighted how carer strain theory and theories of vulnerability associated with disability, frailty and ill health do not address the complexity of dangerous care. We concluded that policies and services based either on domestic abuse theories or on theories of carer strain and vulnerability risk failing people experiencing dangerous care relationships; they may not access help because they do not recognise themselves as the target group of the services available. Alternatively, those people may try to seek help but find

services to be inaccessible or inappropriate, in particular because of their support needs, their caring responsibilities and the importance of these to their sense of themselves and their emotional and relational wellbeing. In these situations, choice is only a meaningful concept if people have options to choose from, and inappropriate services can leave people with no choices at all.

Our discussion has overlapped at some points with an existing body of literature that compares domestic abuse theories and services with elder abuse theories and services, generally taking the experiences of older women abused by their partners as its focal point (Straka and Montminy, 2006; Wydall *et al.*, 2018; Zink *et al.*, 2003). There is also literature exploring the relationship between "hate crime" and other types of abuse of disabled people (McCarthy, 2017; Roulstone *et al.*, 2011). We note some conclusions similar to our own in respect of the need for more integrated and inclusive theories, policies and services. However, in taking as our focal point the experiences of disabled people in caring familial relationships over time, we have identified some less commonly foregrounded gaps in existing understandings and approaches.

One key implication of our exploration here is that we do not yet know enough about older disabled people's experiences of dangerous care. To develop more appropriate and integrated policy and practice responses there is a need to know more about how these experiences develop, including how aspects of social difference (e.g. gender, sexuality, ethnicity, socio-economic position) are perceived, intersecting with family histories, events and opportunities over time to produce (and sometimes subsequently to mitigate) situations of dangerous care. There is also a need for more experiential insights; by working with specialist domestic abuse, carer, disability and safeguarding services to evaluate how current policy and practice responds to dangerous care, and what learning and developments can be shared across services to improve responses.

However, expanding knowledge based on the perspective of those who have experienced dangerous care is not without challenges. Together with our agency collaborators we have identified ethical considerations for research in seeking to access people's accounts of abuse they have experienced or perpetrated. Furthermore, given dangerous care is often characterised both by its complexity and by its longevity, people with experience and knowledge to share may still be experiencing or perpetrating harm. It is vital first and foremost not to compromise people's safety, including by not re-traumatising them. These challenges are one reason why people's own experiences of abuse and harm are under-represented in research (Sherwood-Johnson and Mackay, 2021). In the specific case of dangerous care there are also challenges with finding the words and the questions to approach this topic at all. Words themselves can harm self-concept (Brookes et al., 2012). They can also mean people opt out from sharing their experiences because they do not construct those experiences in terms of "abuse" or "vulnerability" or indeed of "dangerous care". Approaches to eliciting people's accounts must necessarily be exploratory and broad, in the absence of shared concepts. One way to achieve this is to bring together staff from domestic abuse services with those from disabled people, carers and older people services to establish language and approaches to safely explore difficult caring relationships and embedded instances of dangerous care.

We contend that a broad programme of knowledge development for policy and practice is required. This will involve iterative discussions with disabled and older people and their representative groups and practitioners, with their agencies, in the domestic abuse, adult safeguarding and social care sectors. Co-produced, inductive research is needed, spending considerable time staking out the areas for discussion and the means to approach them, in respect of working theories, useful and respectful language to use, and ways to uphold people's welfare and their safety in the broadest sense.

Related to this is the theoretical basis for an expanded understanding of dangerous care. We suggest that individualist constructions of concepts including care, risk, autonomy and vulnerability have long proved barriers to re-imagining theory, policy and practice in this field. We propose instead that this work should foreground theories constructing care and vulnerability as relational experiences, and as core components of the human condition, so that nobody is "othered" (Barnes, 2011; Crowther, 2020; Dodds, 2007; Fineman, 2008). We further suggest that time and the development of relationships over time should form a significant component of new theorising, drawing on promising developments in this field to date (Schiamberg and Gans, 2000; Hutton and Hirst, 2000).

Conclusion

This article has used the term "dangerous care" to identify a diverse group of older disabled people and their family carers experiencing harmful or abusive relationships, the reasons for which might be related to earlier life events of those individuals or collectively as a family. It is a term that also acknowledges the impact of wider social and structural factors on people's ability to give and receive care. Finally, it also acknowledges that policy and service delivery within distinct "service user groups" do not yet respond to the relational nature of dangerous care. What is needed is a diversity of responses to support the "older disabled person" and often the "carer" as well. To achieve this, we first need to fill the knowledge gaps identified in co-production with staff across the specialist services. Then we must engage with those who use their services if we are to hear the voice of older disabled people and carers and ultimately give them greater control in avoiding or reducing dangerous care in their lives.

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