Carer harm: a challenge for practitioners, services and research

Sarah Donnelly, Louise Isham, Kathryn Mackay, Alisoun Milne, Lorna Montgomery, Fiona Sherwood-Johnson and Sarah Wydall

Abstract

Purpose - The purpose of this study is to consider how carer harm is understood, surfaced and responded to in contemporary policy, practice and research.

Design/methodology/approach - This paper offers a reflective commentary on the current "state of play" relating to carer harm drawing on existing research and related literature. This study focuses on how we define carer harm and what we know about its impact; lessons from, and for, practice and service provision; and (some) considerations for policy development and future research.

Findings - The authors highlight the importance of engaging with the gendered dimensions (and inequalities) that lie at the intersection of experience of care and violence and the need to move beyond binary conceptions of power (lessness) in family and intimate relationships over the life course. They suggest that changing how we think and talk about carer harm may support practitioners to better recognise the impact of direct and indirect forms of carer harm on carers without stigmatising or blaming people with care needs. The findings of this study also consider how carer harm is "hidden in plain sight" on two accounts. The issue falls through the gaps between, broadly, domestic abuse and adult and child safeguarding services; similarly, the nature and impact of harm is often kept private by carers who are fearful of the moral and practical consequences of sharing their experiences.

Originality/value - This study sets out recommendations to this effect and invites an ongoing conversation about how change for carers and families can be realised.

Keywords Carer harm, Domestic abuse, Social work, Family carers, Harm, Policy and practice Paper type Viewpoint

Introduction

There is an increasing demand for care from family members. This is driven by several intersecting factors: longer life expectancy alongside a policy emphasis on "ageing in place"; growing numbers of working-age adults with long-term health conditions; and the impact of reduced access to welfare services including long-term (residential) care (Milne and Larkin, 2023). In Europe, 80% of long-term care is provided by unpaid carers, that is, people who provide care to a friend or family member who, because of illness, disability, a mental health problem or an addiction, cannot cope without their support (https://carers. org/about-caring/about-caring). In the UK, 6.5 million people, or 10.4% of the total population, have some kind of caring role (European Institute for Gender Equality (EIGE),

Since the 1980s, responsibility for providing care has shifted almost completely away from formal services onto families (Fraser, 2016). The profile of "who cares", and what carers do, has also changed significantly. Carers are generally older, providing support to (primarily) relatives who may be frail and living with - often complex - long-term conditions such as dementia. Carers are also undertaking more challenging care tasks such as changing dressings or monitoring medication and are caring for more hours per week and over a

(Information about the authors can be found at the end of this article.)

Received 15 September 2024 Revised 1 November 2024 2 December 2024 31 December 2024 Accepted 2 January 2025

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longer timeframe (Family Carers Ireland, College of Psychiatrists and University College Dublin, 2019).

While there is an emerging interest in the phenomena of family carers who experience harm or abuse by the person they are caring for, to date, carer harm has received limited academic, policy or practice attention (Donnelly and O'Brien, 2023; Holt and Brennan, 2022; Isham *et al.*, 2020, 2021; Obst *et al.*, 2022). This paper offers a reflective commentary on the current "state of play" relating to carer harm, drawing on existing research and related literature. The authors focus on: how we define carer harm and what we know about its impact; lessons from, and for, practice and service provision; and (some) considerations for policy development and future research.

What is carer harm?

Although there is no universally agreed definition of carer harm, a seminal contribution has been made by Isham *et al.* (2021). Carer harm occurs when "carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological or sexual harm" from the person they support (Isham *et al.*, 2021, p. 2; Anka and Penhale, 2024). Definitions of abuse are also relevant. Abusive behaviour towards another person(s) is defined as "domestic abuse if both people are aged 16 or over and are personally connected to each other, and the behaviour is abusive" (Domestic Abuse Act, 2021). In safeguarding policy, abuse is defined as "a single or repeated act, or omission (including within a relationship where there is an expectation of trust) which violates a person's civil or human rights and/or causes harm or distress to that person" (Department of Health, 2024, p. 3). MacKay and Notman (2017) note that the use of "harm" in legislation provides a lower threshold for intervention in Scotland compared to England and Wales, where the term "abuse" is used.

Carers who are at risk of harm are usually embedded in an interdependent, intimate or familial relationship or in a complex and demanding care context. Relationships are most often (spousal) partnerships, parent carers of children or adults with a disability or filial carers of a parent (Milne and Larkin, 2023). Risk of harm may increase at times of transition; for example, with autistic children, this may include puberty, changing schools or moving from school to a support service or day centre. For people living with dementia, harm may begin or intensify when family carers are required to provide more complex or personal care (Donnelly and O'Brien, 2023). Carers, and the person they are caring for, are often isolated, have few resources and limited contact with services (Donnelly and O'Brien, 2023).

Carer harm has a number of conceptual dimensions; the role played by "intentionality" is the subject of contention, with some evidence suggesting that intent to harm may change over time (Clarke et al., 2016). The nature and longevity of carer harm is also the focus of debate (Donnelly et al., 2025). We know, for example, that patterns of harmful behaviour may predate the need for care. This is the case in long-term intimate partner contexts where domestic abuse is a feature. Abusive behaviours may also begin or worsen when one partner or other close relative becomes disabled, and there is a new or additional need for care and support (Milne, 2023). There is evidence, for example, that the development of more severe dementia can lead to an increase in levels of domestic abuse (Milne, 2023; Williams et al., 2013). Harm and abuse may be bi-directional too. Simplistic and often bifurcatory constructions of an "abuser" and "victim" simply do not fit the more complex, nuanced, relational context of many care dyads, particularly over the longer term (Mackay et al., 2011). Using varied definitions of "carer" and "harm" or "abuse" in research is a key barrier to drawing evidence together and developing shared understandings of key concepts, including that of "carer harm" itself (Isham et al., 2021).

A fundamental facet of carer harm is its gendered nature. For a woman, the risk of harm appears to be a consequence of three intersecting factors. Firstly, caring is culturally seen

as "women's work": two-thirds of carers in the European Union are women (aged 18 years or over) (Eurocarers, 2024). Secondly, women disproportionately provide the type of intimate and personal care that the cared for adult is reluctant to receive, such as bathing and toileting which is associated with higher risks of harm, and third, this type of care is intensive, increasing the time spent in close proximity to the person receiving care (Family Carers Ireland, 2023). Parental care of a son or daughter with complex needs highlights the gendered issues. In Donnelly and O'Brien's (2023) Irish study of parent carers of autistic sons or daughters, it was mothers, as opposed to fathers, who identified themselves as "the main target" of harmful behaviour. Additionally, studies on intimate partner contexts (Milne, 2023; Warburton-Wynn, 2023; Wydall, 2021) draw attention to the specific needs of older women victim-survivors who have taken on the role of "carer" for an abusive partner or spouse.

Interestingly, in relation to how we conceptualise harm to carers, there has been more research on the "impact of caring", that is, *indirect harm as a consequence of caring* rather than *direct harm by* the cared for person. For example, intensive caring is associated with an increased risk of impaired physical and mental health, social isolation and poverty (Carmichael and Ercolani, 2016). Furthermore, the longer a carer provides care, the more profound the impacts of indirect harm tend to be. Carers also experience significant challenges in accessing support from health and social care services for either their relative *or* themselves. Both the negative impact(s) of caring and reduced access to services were amplified during the pandemic (Donnelly and O'Brien, 2023). The number of carers who "report neglecting themselves due to pressures of caring" is also an issue. In England, for example, this figure rose from 18% of carers in 2018/2019 to 19.5% in 2021/2022 (Survey of Adult Carers in England, NHS Digital, 2022).

In terms of research on *direct harm and abuse*, there is some recognition that cared for relatives may be the subject, or "victim", of abuse: carers may "lash out" and cause harm to the person they are supporting. This is widely – often erroneously – attributed to "carer stress" or strain rather than to any other, more complex relationally embedded "causes", such as long-standing domestic abuse (Clarke *et al.*, 2016; Wydall *et al.*, 2018). Currently, there is far less acknowledgement that the carer may be at risk of direct harm and abuse *by* the cared for person (Momtaz *et al.*, 2013). It is important to highlight the challenging, multifactorial nature of carer harm and/or abuse in terms of causation; there is no evidence, for example, of linear causation between carer stress and harm or abuse.

One of the drivers of the lack of recognition is a strong policy emphasis on "keeping carers caring" (Dowling, 2022). This underscores the dependency that the care system has on carers' input. Carers are routinely treated as a free resource, or even unpaid care workers, by professionals and the state (Milne and Larkin, 2023). The economic value of family care in the UK has been estimated to be £162bn; this is significantly more than the total budget of the NHS (Petrillo and Bennett, 2023; Zhang et al., 2023).

What we know about the impact of (direct) carer harm

There is currently no data available in the British Isles on the number of carers who are exposed to harm by the cared for person. However, in one recent survey of carers (n=1102) in Ireland, over two-fifths (44%) reported that they "regularly experienced" either physical aggression or verbal/emotional abuse from their relative (Family Carers Ireland, College of Psychiatrists and University College Dublin, 2019). There is a widespread lack of awareness about abusive behaviour towards carers, and "carer harm" is not a commonly used term by carers, professionals, service providers or policymakers (Donnelly and O'Brien, 2023). In fact, amongst carers, there is a high level of discomfort about using the term, particularly when it is assumed to have a link with active "intent". A crisis situation, such as the involvement of emergency medical care or the police, is one of the few

situations where carer harm is identified; the crisis may act as a trigger to recognition (Donnelly and O'Brien, 2023).

Structural issues such as a chronic lack of support from services and working practices focused exclusively on the individual receiving care are factors that amplify the risk of carer harm. As noted by Condry and Miles (2023), "the case of a son, with mental health issues and with little other ability to look after and finance themselves, are (expected to be) put up by their mothers [...]. in the face of a lack of appropriate access to care and support" (Femicide Census, 2020, cited by Condry and Miles, 2023, p. 49). Another group of parent carers who are expected to "get on with it" are parents of children or adults with autism (Donnelly *et al.*, 2025). One of the key dimensions of this context is that the risks posed by the cared for person not only affect the parent(s) but also other members of the family such as siblings (Thorley and Coates, 2018; Donnelly and O'Brien, 2023).

Some – limited – work has been done on the impact of carer harm. Unsurprisingly harmful treatment, especially over the longer term, is associated with high levels of stress, depression, anxiety, poor mental health, isolation, shame and suicidal ideation (Isham *et al.*, 2020, 2021). Parents of children or adults with autism have described living with the daily threat of harm; never knowing when a situation would deteriorate and they would experience physical assault or other types of harm, for example, psychological or emotional abuse and no sleep. They also spoke about the need to put in place safety measures to protect themselves and other family members (Donnelly *et al.*, 2025; Donnelly and O'Brien, 2023).

Evidence about carer harm: Hidden in plain sight

Data on carer harm is opaque: it is likely to be hidden in "other data" such as national statistics on crime(s) and routine data collected by agencies such as local authorities. It is known that 8% of homicide victims in England between Oct 2019 and Sept 2020 were carers (Home Office, 2023). Interactions between long-term caring, "vulnerabilities" of the cared for person and serious harm and abuse are beginning to be recognised in both domestic homicide reviews (Benbow et al., 2019; Bracewell et al., 2022) and mental health homicide reviews (Condry and Miles, 2023). Although not explicitly categorised or quantified, it seems likely that carer harm is a feature of crimes or police enquiries relating to assault, domestic incidents and rape. It is almost certainly a feature of Safeguarding Adult Reviews, Serious Case Reviews, safeguarding alerts and domestic abuse referrals. In addition, carer harm may also be a "presenting", but under-recognised issue, in health services consultations such as in Primary Care and Accident and Emergency Departments; harm to carers may well be recorded as an "accident" or an "unexplained injury" (Milne, 2023). This lack of recognition of actual or potential harm to carers leads the practitioner away from enquiring about it and undermines efforts to incorporate questions about domestic abuse into routine screening or developing any systems of "safety planning" for carers in these health-care encounters. The authors' view is that unless data is collected with carer harm in mind, or considered to be a "type of abuse", it will continue to remain hidden.

Data management systems in safeguarding contexts have been labelled "not fit for purpose" when recording the multiple forms and patterns of domestic abuse in later life; perhaps, this is also the case for carer harm? (Wydall *et al.*, 2015). The publication of a briefing paper on "Carers and safeguarding" – written by the English Local Government Association and Association of Directors of Adult Services (2022) – makes a welcome contribution to highlighting the issue of carer harm in the safeguarding arena. It outlines potential situations where abuse of carers is more likely and strongly advises that timely and careful assessments of *both* the carer and the cared for person are critical for safeguarding all family members.

Why do we know so little about carer harm?

There are numerous individual, structural and socio-cultural barriers to disclosure. Traditional norms about the family "sorting out its own problems", the need to protect "privacy" and the perceived "failure" amongst carers to manage care-related challenges are powerful inhibitors (Donnelly *et al.*, 2025). report/report situations may occur for a number of reasons. Two key barriers are concern on the part of the carer about what might happen to the cared for person (e.g. unwelcome service interventions or criminal responses) (Donnelly and O'Brien, 2023) and/or "shame" about the situation which is often constructed as a "personal failure" on the part of the carer by themselves or by others, including professionals and wider society.

In contexts where domestic abuse is present, fear of repercussions from the perpetrator inhibits disclosure (Clarke *et al.*, 2016). There may also be concerns about disrupting domestic patterns. Professionals described some carers as being reluctant to allow support from services – particularly "formal" paid carers – into their home, to avoid what felt like scrutiny of long-standing intimate care practices as well as carers desire to "protect" the identification of the person causing harm (Isham *et al.*, 2021). Carer harm also profoundly challenges the persistent framing of family caring as "normative, positive and virtuous" and carers as "heroic" (Manthorpe and Iliffe, 2016).

Carers report feeling guilty, embarrassed, ashamed or "disloyal to the cared for person" if they disclose being subjected to harm. Many feel sympathy for their relative's condition and may frame harmful behaviours as "symptoms" (Isham et al., 2019; Donnelly and O'Brien, 2023). There can also be a commitment by carers not to stigmatise (further) relatives with cognitive impairments or mental health problems. Carers are often reluctant to describe their relative as abusive, especially if they view the harm as unintentional, that is, arising from a health condition such as dementia. However, just because harm is, or is seen as, "unintentional," this does not mean it has not occurred or that it is not harmful; what it does mean is that perhaps it is less likely to be responded to or dealt with. Intentionality is an important and underexplored dimension of carer harm (and of other contexts of harm and abuse).

Many carers normalise or minimise the extent of their relative's harmful behaviours, and some carers feel responsible for the harm or the perceived "failure" to deal with it effectively (Donnelly and O'Brien, 2023; Isham *et al.*, 2020). Stigma and the "vulnerability discourse" may also act as barriers. There is a subtle but pervasive assumption that people with care and support needs lack agency and the ability to exercise power or be the perpetrator of abuse. This view intersects with the "victim/abuser" dichotomy referred to earlier (Dixon *et al.*, 2013; Isham *et al.*, 2020).

Fear of the consequences of disclosure is also a challenge. Services tend to adopt a "rule of optimism" approach routinely overlooking or minimising the harm the carer is exposed to and the risks they face (Wydall *et al.*, 2018). Parent carers fear being "blamed" by professionals (Coogan, 2012). There may also be concerns about what will happen to the cared for person, for example, the person living with dementia being admitted to a care home (Donnelly and O'Brien, 2023). Parent carers appear only willing to seek help when their other children are placed at risk of significant harm (Donnelly and O'Brien, 2023).

Additionally, professionals often do not have the time to explore issues of harm with the carer and may be reluctant to do so because they are unsure what to offer by way of support; they are also aware that the state relies on carers to provide care. It is a challenge for state actors such as social workers to meaningfully respond to the situation because of, at least in part, a lack of systemic appreciation of carer harm and limited access to resources for the carer and the person with care and support needs. In terms of assessing risk, it may be difficult to disentangle carer harm from (inter) dependency and the embedded relational nature of care (Milne, 2023). In situations of domestic abuse, carer

harm is, most often, not considered to be a feature of the "problem": it neither is a part of the practice purview nor are responses designed to address the intersecting complexities of "care" and "domestic abuse" (Milne, 2023; Wydall *et al.*, 2018). Similarly, there is evidence that carers' advice and support services, where they exist, may not be considering the possibility of carer harm when they have contact with carers (Sherwood-Johnson *et al.*, 2023).

Key considerations

A profound lack of awareness about carer harm means that the health and care system does not know "what to do" about it (Donnelly et al., 2025). Carer harm does not fit with the societal narrative about caring and what happens within caring relationships – and dealing with it – or maybe even recognising it – means that "something needs to be done" about it; the wholly positive carer narrative would also need to change. This would have significant policy, service and practice implications. In addition, carer harm does not align with either the "public story" of domestic abuse (Donovan and Hester, 2015) or the safeguarding paradigm (Isham et al., 2021; Milne, 2023). There is more than one person at risk in the context of carer harm: those involved in caring and the adult (or child) with care and support needs. Practice frameworks relating to abuse struggle to work effectively across a terrain where levels of intentionality, or at least responsibility-taking, add an additional dimension (Johnson, 2012; Warburton-Wynn, 2023). Tensions exist with balancing the needs, rights, safety and protection of all family members: the carer, the person with care needs and (often) other family members (Donnelly et al., 2025; Isham et al., 2021). Barriers to recognition include service poverty, a reluctance to engage with the issues, lack of professional curiosity, excessive workloads and challenges inherent in multiagency working and information sharing (Doyle et al., 2023).

There are also a number of important policy issues to consider. Currently, safeguarding responses prioritise the "adult with care and support needs", not the carer. In England, evidence exists of the increasing marginalisation of carer rights to assessment and support despite parity of esteem being offered by the Care Act, 2014 (Robson, 2023). In the context of austerity and welfare state retrenchment, there is an even greater drive to treat carers as unpaid members of the care workforce. There is also a lack of a "safety net" for carers as (often) delayed and time poor superficial interactions with social workers result in limited opportunities to look below the surface or engage with the challenges of caring including harmful behaviour(s). This may be because of time and workload pressures as well as resource constraints within the context of neoliberalism and an overriding expectation that intersections with carers and people with care and support needs are of limited duration and intensity. As noted earlier, the state relies heavily on family carers to "do caring". It is, thus, reluctant, or even unwilling, to "see" harm even if it is serious and persistent. If carers are harmed, then the welfare state may need to engage in developing ways to protect carers and provide more support for the cared for person too. The message of "more support" is an unwelcome one in the current context (Humphries, 2022).

There is also a lack of awareness amongst carers in relation to their rights to assessment and support. The review of adult social care in Scotland identified that only 16% of carers knew what the Carers (Scotland) Act 2016 was and the rights it accords them; 33% had heard of the Act but did not know what its aims were; and 51% had never heard of it (Feeley, 2021). Much more needs to be done to publicise carers' rights to an assessment of need and (more) pressure needs to be brought to bear on governments and policymakers to fund services for carers and those they support. More support is very likely to prevent, or at least, ameliorate, carer harm. Furthermore, assessments of carers should engage with relational aspects of caring. A dyadic approach (Rand et al., 2022) that focuses on the care relationship – not just the instrumental aspects of care – offers an opportunity to consider the relational dimensions of caring and to hear about the lived experiences of carers,

including their concerns about abuse and harm. This is a time-rich nuanced process that demands skills and expertise as well as awareness of issues of carer harm (Tanner *et al.*, 2024; Tanner *et al.*, 2023).

The following important issues for practitioners have been identified from emerging work on carer harm:

- 1. There needs to be much higher levels of awareness of the extent and nature of carer harm amongst professionals and service providers.
- 2. It is critical to use language that "fits" with the carers' own language: the term carer harm is unlikely to resonate with the carer.
- 3. Allow carers to "tell their own stories" about the challenges they are facing and how they would like to be supported (Holt and Brennan, 2022).
- 4. Partnership working with carers, agencies and health and social care colleagues is vital:
 - Effective responses include multi-agency interventions that incorporate support for the cared for person as well as the carer.
 - Offering a non-criminalising route of support to families of children or adults who display violent behaviour (Thorley and Coates, 2018).
- 5. There is a strong case for ensuring that carer assessments are not just about "keeping carers caring" but that they also, sensitively, address issues of harm and risk; it is critical that practitioners are open to hearing and responding to honest carer testimony and are given the time required to develop a trust relationship with the carer (Isham et al., 2021; Fricker, 2007).
- 6. Allocating a named social worker role to a care dyad or family where harm is an issue, to ensure a holistic approach is adopted to planning and providing help and support.
- 7. Recognising and ensuring that family carers, siblings and other family members have a right to live in a safe environment, free from harm.
- 8. Awareness raising amongst carers, and establishing peer support groups, in local communities provides a space to share concerns about and/or experiences of carer harm (Donnelly and O'Brien, 2023).

Conclusion

Carer harm is situated on the nexus of family care, abuse, risk and need for care and support. At present, there is no limit on what carers are expected to tolerate: paid carers are protected from abuse by law, but family carers are not. There is a strong case for affording carers the right to be protected from harm and to live without fear of abuse from their relative (Anka and Penhale, 2024). One of the most significant challenges is the competing rights of the carer and the cared for person: how are these to be meaningfully operationalised and by whom? We need to consider "carer harm" as of equivalent importance to other "types" of harm such as domestic abuse (Condry and Miles, 2023). This would elevate carer harm as a policy and a human rights issue – outside of the lens of safeguarding – and demand a higher level of recognition and response from a range of health and social care services, policymakers and the law.

The demand for family caring, and intensive caring in particular, is growing. Carer harm is also likely to increase: "[...] abuse of unpaid family carers can flourish where the demand for care is great and where there are complexities in relation to the needs of the cared for person" (Anka and Penhale, 2024, p. 8). It may be exacerbated in contexts where the cared

for person lacks understanding of the harm caused by the abuse and where services are limited or tightly rationed.

We have a long way to go in terms of understanding the shape, nature and profile of carer harm and incorporating any new knowledge and understanding into our welfare and justice systems and health and social care policies, services and practice responses. Current safeguarding and domestic abuse systems have not yet widened their lens of analysis to adequately accommodate the complex and multi-faceted nature of the issue(s). Carer harm is poorly conceptualised, hidden and taboo; it also receives very limited or inconsistent responses from professionals and services and is significantly under-researched. There is a pressing need for more empirical work with carers and for investment in creative ways that carer harm can be prevented or risks of harm reduced. We hope that our paper will contribute to developments to address carer harm and help protect carers across policy, services, research and practice domains.

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Author affiliations

Sarah Donnelly is based at School of Social Policy, Social Work and Social Justice, University College Dublin, Dublin, Ireland.

Lorna Montgomery is based at School of Social Sciences, Education and Social Work, Queen's University Belfast, Belfast, UK.

Kathryn Mackay is based at Faculty of Social Science, University of Stirling, Stirling, UK.

Fiona Sherwood-Johnson is based at Faculty of Social Sciences, University of Stirling, Stirling, UK.

Alisoun Milne is based at the Department of School of Social Policy, Sociology and Social Work, University of Kent, Kent, UK.

Louise Isham is based at the Department of Social Work and Social Care, University of Birmingham, Birmingham, UK.

Sarah Wydall is based at School of Social Sciences, Swansea University, Swansea, UK.

Corresponding author

Sarah Donnelly can be contacted at:sarah.donnelly@ucd.ie