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Exploring unintentional ‘carer harm’—Insights from family carers and professionals: An Irish case study

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Abstract

This article explores the poorly understood and under-researched topic of carer harm, where family carers experience harm from the person they are caring for. Nine narrative interviews were conducted with family carers of people living with dementia and autism, and two with professionals. Three focus groups were convened with professionals, including social workers, nurses, and advocacy organizations, with four to five participants in each ($n = 14$). Four key themes emerged: ‘Understanding Carer Harm’, ‘Stigma and Guilt’, ‘Types of Harm Experienced’, and ‘Expectations, Responses and Systems that Harm’. Conflicts existed for many professionals when balancing the needs, safety, and protection of all family members. We conclude that a range of intersecting enforceable legal rights would help to ensure that carers are better protected. These rights would include the right to an assessment of need for both the carer and the child or adult with care and support needs, as well as a statutory

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entitlement to services that the assessment identifies for both parties. Proactive support from a social worker could go some way to addressing the challenges, putting in place a range of supports that prevent harm, reduce risk, and meet the needs of all family members.

Keywords: autism; adult safeguarding; carer harm; dementia; family carers and social work

Accepted: December 2024

Introduction

This article reports on a study carried out in 2022 conducted by the authors in partnership with Family Carers Ireland (FCI), a charity that supports family carers (carers) in Ireland. The study was funded by the Irish Research Council's New Foundations Award. It explores the concept of 'carer harm' from the perspective of carers of people living with dementia (PLWD), parents of autistic children/adults, FCI support workers, and other professionals including social workers, nurses, educators, and advocacy organizations.

We offer a background to the study drawing primarily on Irish and UK literature before outlining our methodology, key findings, and implications for social work policy and practice.

Background context

'A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support' (Carers Trust 2024). In Europe, 80 percent of all long-term care is provided by carers (Eurocarers 2024). There is a growing demand for carers too. Key drivers include the ageing profile of the population(s), alongside growing numbers of adults of working age with long-term health conditions; the impact of reduced access to welfare services, including residential care, is also a factor (Milne and Larkin 2023). Furthermore, most people with care and support needs wish to remain in their own homes and in the community, for as long as possible (Donnelly *et al.* 2019).

Responsibility for providing care has shifted almost completely away from formal services to families (Fraser 2016). In the UK, 6.5 million people—10.4 percent of the adult population—have some kind of caring responsibility (Milne and Larkin 2023). In Ireland, 85.9 percent of *all care* is provided by family carers (Care Alliance Ireland 2018). There has been a 53 percent increase in the number of family carers in Ireland

from 195,263 people in 2016 to 299,128 in 2022; as is consistent with other jurisdictions, a larger proportion of carers are female ([Census 2022](#)). It has been estimated that family carers save the Irish state €22 billion per annum ([Family Carers Ireland 2023](#)).

The profile of who cares, and what carers do, has changed significantly over the last twenty years. Carers are now providing support to relatives with more challenging comorbid long-term conditions, such as frailty, dementia, and autism. Carers are also doing more complex care tasks, for example, managing continence issues, and are caring for more hours per week too (Family Carers Ireland, College of Psychiatrists of Ireland and University College Dublin 2019). In Ireland, the proportion of carers providing care for forty-three hours or more per week increased from 21 percent in 2016 to 29 percent in 2022. While people aged between fifty and fifty-nine years were the group most likely to be providing 'regular unpaid care', there are also significant numbers of young carers (aged under eighteen years) and older carers (sixty-five plus years) ([Census 2022](#)). Caring tends to be regarded as 'women's work'; two-thirds of carers in the European Union are women (aged eighteen years or over) ([Eurocarers 2024](#)). Women disproportionately provide intimate and personal care, such as bathing and toileting, which are associated with higher risks of harm (see below, [Family Carers Ireland 2023](#)).

Caring for someone with complex needs is associated with an increased risk of impaired physical and mental health, becoming socially isolated, as well as insecure employment and poverty ([Carmichael and Ercolani 2016](#)). Carers often have limited access to support from services for either their relatives or themselves ([Family Carers Ireland 2023](#)). For some families, the challenges of caring are particularly intense and may result in cumulative and prolonged stress, commonly referred to as 'caregiver burden' ([Isham et al. 2019](#)). Caregiver burden is associated with an increased risk of harm to the care recipient, that is, a fall or missed medication ([Momtaz et al. 2013](#)).

Service provision in Ireland for those with care needs and their carers is discretionary and has been described as a 'postcode lottery' ([Donnelly et al. 2019](#)). While Ireland has a *National Carers Strategy 2012*, it is not underpinned by ring-fenced resources. In addition, while children and adults with disabilities, including people with dementia, are entitled to an 'assessment of need' under the *Disability Act 2005*, the Irish State is currently not legally required to honour the recommendations of that assessment, including the provision of services such as home-care or day care. In Ireland, people with care and support needs have a legislative entitlement to long-term residential care under the *Nursing Home Support Scheme Act, 2009* but they currently have no statutory entitlement to community-based services.

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, p2; 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 in Ireland, 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: 3).

Carer harm is routinely overlooked, or misunderstood, by social workers, other professionals, and policymakers (Warburton-Wynn 2023; Anka and Penhale 2024). Considering the growing number of families caring for people with multiple, chronic health conditions—some of which are associated with challenging behaviours—social workers will be, perhaps inevitably, increasingly exposed to situations where family care intersects with violence and/or harm to carers (Spencer et al. 2019). The issue of carer harm has, to date, been (almost) wholly unacknowledged by statutory organizations, carer support agencies, and professionals. This study aims to shed light on this poorly understood and under-researched issue.

Exploring harm in the context of caring: a case study

FCI is an Irish not-for-profit organization that supports carers. They provide free counselling, specialized training and education for carers, peer support groups, and advocacy services. In 2019, FCI set out to explore the ‘impact of caring’ on Irish carers’ physical and mental health, surveying 1,102 carers, 90 percent of whom were female. Almost half (44 percent) reported that they ‘regularly experienced’ either physical aggression or verbal/emotional abuse from a cared-for relative (Family Carers Ireland, College of Psychiatrists of Ireland and University College Dublin 2019). The survey findings indicated specific challenges for carers of PLWD and parents of autistic children/adults. Our study provides an in-depth exploration of the experience of carer harm highlighted in the 2019 survey, focusing on these two groups of carers.

Research design and methodology

This study’s key research question is:

How do carers perceive and experience carer harm and what are the perceptions of professionals who support those experiencing carer harm?

A qualitative approach was employed in order to carry out an in-depth exploration of the lived experiences and views of carers and professionals; the majority were female. The research consisted of three work packages (see Fig. 1). In this article, we report on the findings of WP2: the narrative interview and the focus group data. The overall findings of the study are reported in the 'Understanding Carer Harm' report, an online resource (Donnelly and O'Brien 2023).

The study received ethical approval from University College Dublin's Human Research Ethics Committee (HS-22-33-Donnelly). Due to the sensitivity of the issues, the team followed strict ethical guidelines concerning data anonymity and confidentiality. A comprehensive 'distress protocol' was also developed (see Supplementary data). These included researchers being acutely alert to any potential indications of distress amongst participants during fieldwork and, where needed, making appropriate referrals to FCI support services.

Narrative interviews were conducted with nine carer participants between September 2022 and January 2023 (see Table 1). Participants were given the option of an online or face-to-face interview; the majority chose to participate online. In addition, one face-to-face interview was conducted with two teachers working with autistic children and one online interview with an FCI senior manager. Interviews lasted between twenty-one and seventy-five minutes. Pseudonyms have been used for all carer participants.

A purposeful sampling approach was employed. Inclusion criteria were: (1) self-identified as a carer who has experienced carer harm, (2) being a carer of a PLWD or an autistic child/adult, and (3) having the cognitive capacity to engage in a narrative interview. For carers who met the inclusion criteria, an FCI support worker who was familiar with the carer and their circumstances informed them about the study and provided them with the Participant Information Leaflet. Carers contacted the research team if they wished to participate in the study.

The parent carers cared for either a child or an adult with autism. Some of the cared-for individuals had autism with mental health difficulties, others had autism with profound intellectual disabilities. Two of the children were non-verbal with one was partially sighted. Another had a rare genetic disorder. All the cared-for individuals had complex needs. The PLWD had a variety of types of dementia, including Alzheimer's disease and Frontal Temporal Dementia. One cared-for person also had a chronic alcohol misuse problem, one had also suffered a stroke, and another had type 1 diabetes. In the fourth case, the PLWD had long-standing functional mental health issues.

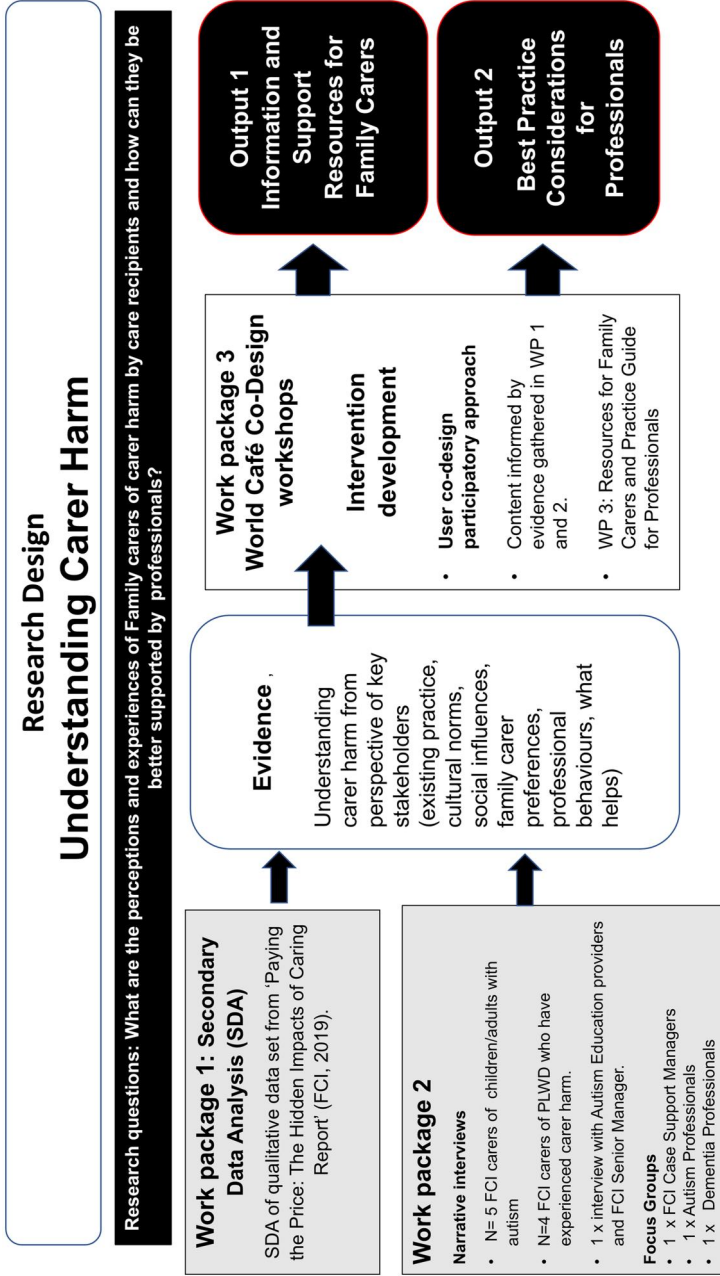


Figure 1. shows a diagram of the research design for this study. It outlines the key research question as well as the research approaches used in Work Package 1: Secondary data analysis; Work Package 2: Narrative interviews with nine family carers and three focus groups with professionals; and Work Package 3 involved two World Café's to co-design outputs. The outputs generated were Information Leaflets on Carer Harm and Best Practice Considerations for Professionals.

Table 1. Carer interview participants

Carer	Relationship to care recipient
Katrina	Mother to two autistic sons (18 years and 20 years)
Paula and Sean	Mother and Father to 12-year-old autistic son
Valerie	Mother to 12-year-old autistic son
Noleen	Mother to a 12-year-old autistic daughter
Lana	Mother to 17-year-old autistic son
Patrice	Wife of husband with dementia
Mairead	Daughter to father with dementia
Jennifer	Daughter to mother with dementia
Oonagh	Daughter to mother with dementia

Focus groups

Three focus groups were convened, with four to five participants in each ($n = 14$). The first was with five FCI support managers (four females and one male), the second was with four senior social workers (all female) who work with people with autism, and the third was with five professionals (four female and one male) who work with PLWD (two nurses, one occupational therapist, social worker, and dementia advisor). They were conducted between November and December 2022 and lasted between 100 and 120 min. All interviews and focus groups were audio-recorded. Verbal and written consent were given by participants before the recording started. Recordings were transcribed verbatim. The management of research data met with the requirements set out under GDPR and Irish data protection legislation.

Data analysis

Thematic analysis was used for the interview and focus group data. It is a widely employed and trusted method for examining the perspectives of a range of different participants, highlighting similarities and differences, generating new insights, and providing a rich and detailed account of lived experiences (Braun and Clarke 2006). A two-step process was used in the data analysis process and coding: (1) initial open *in vivo* coding and (2) aggregation of *in vivo* codes and abstraction into higher-order themes with supportive quotations identified. All transcripts were coded into the lower order codes independently by the two study researchers (M.O'B. and S.D.). Higher-order themes were then extracted and shared with the co-researchers (A.M., D.OD. and N.D.). Discrepancies were discussed and resolved at weekly meetings.

Findings

Four key themes emerged from the analysis of the interview and focus group data.

Understanding carer harm

Participants, particularly professionals, explored the difficulty of defining and understanding what is meant by the term ‘carer harm’. They reflected that the term ‘carer harm’ is not widely recognized or used in the everyday language of carers, services, or professionals:

You know when we think of carer harm, ... I struggle with the language ... what other language could you use? I don’t know. (Dementia FG)

Another commented

‘Some people (carers) ... would never describe it as carer harm, they would never use the word ...’ (FCI FG)

Autism professionals expressed concerns about intentionality and finding the ‘right language’ to express the distinction between intentional and unintentional harm:

But in relation to carer harm, I don’t like that term ... harm because it does suggest intent ... I don’t know what else you would put in it. (Educator interview)

Another reflected,

This is not willful abuse like it’s abuse but it’s within the context of that person’s autism and responsive behaviours. (Autism FG)

Professionals also reported that carer harm only tended to be recognized in a ‘crisis’ situation,

It’s only when that crisis happens and somebody ends up in hospital. (Autism FG)

The issue of increased levels of harm in a context where the carer is becoming older was also highlighted,

I suppose our carers are now beginning to age ... we are seeing an increase ... physical violence towards the carer essentially, pushing, shoving, hitting and biting would be some of the things we are being told about. (Autism FG)

Interestingly, family carer narratives tended to focus much more on their experiences of carer harm rather than how it is defined. One dementia carer did however reflect on their discomfort with the use of the word ‘harm’. They suggested that *‘behaviours that challenge’* or *‘behavioural and emotional expression of need’* could be more

‘acceptable’ ways to describe behaviours that are not intentionally harmful.

Stigma and guilt

Carers spoke emotionally about the stigma and guilt they experienced when disclosing their experiences. For some carers, the study interview was the first time they had spoken about the harm they had been exposed to. They reported conflicting emotions,

‘Carers don’t talk about it. I think there’s a huge stigma around ... There’s a huge silence. I mean, I haven’t told most people what I’ve told you this morning and even when I’m talking to other carers, we don’t talk about it, you know. It’s taboo’. (Katrina, Autism Carer)

Professionals also highlighted a lack of awareness amongst carers as to what is and is not ‘acceptable behaviour’ and how difficult it is for carers to speak about the harm they experienced.

I find that when I do have carers wanting to talk to me and share their experience, they are very apologetic you know, please don’t judge me ... it’s guilt, so much guilt you know I should not be disloyal to my loved one by discussing this. (Dementia FG)

One professional commented on the length of time it took for carers to open up about their experiences and that a group setting helped with this,

I think definitely, yeah (stigma). I think in our carers group I know it takes many weeks for people to finally open up ... sometimes it takes six weeks and then it comes out. They realise what harm is and what’s not acceptable behaviour because I think some people don’t know. (Dementia FG)

Fear of the consequences of disclosure was also a barrier. For many, their fears related to other children or family members being seen to be ‘at risk’ and that unwelcome interventions would be imposed, for example, admission to residential care,

Fear, you know, ... I mean the first thing that was said to me was residential care (Katrina, Autism Carer)

An FCI worker reflected on the guilt and significant emotional impact of the disclosure process,

That sense of guilt ... of failure, I think the emotional toll is probably the more difficult than the physical toll ... when we come to carer harm. That physiological or psychological fear to go out of the home, fear of shame. (FCI FG)

Another professional expressed concern about formal responses, particularly around ‘training’ for parents,

... there's a lot of burden ... on carers ... it's really important that this is recognised. Sometimes what I'm hearing from services is 'train the parents' ... this burden of responsibility is put on the parent's shoulders. (FCI FG)

The enormous guilt family carers often experience about their inability to protect other family members, for example, younger siblings or other family members was a recurring narrative for both carers and professionals,

Not only can they not protect themselves, but they can't protect the younger siblings, then there's also this overwhelming feeling of guilt. (Autism FG)

Types of harm experienced and the impact of harm

Carers spoke at length about the range of 'types of harm' they experienced including shouting, screaming, damage and destruction of personal possessions or the family home, significant levels of physical violence, and emotional and psychological distress. They also reflected on the impact on their own health and well-being as well as the impact on siblings (autism carers) and other family members (dementia carers).

Many of the parents of children with autism described living with the daily threat of harm, never knowing when they would be exposed to physical assault, psychological abuse, and no sleep,

She would beat down the door, she has broken the door about three or four times. And when she can't get at me, she will break everything ... broken televisions, computers, laptops, and she'd break things belonging to herself. She has broken her Nintendo three or four times. Cups, plates, stand on it then with no shoes so I'd end up having to bring her to A&E. (Noleen, Autism Carer)

The mothers in our sample identified themselves as the main target of harmful behaviour. Interestingly, it was often only when their other children were placed at risk of significant violence did they feel that they had to act to protect them.

Lana spoke of the psychological trauma she experienced after one harmful incident where her 11-year-old son, had to physically restrain his autistic brother to protect her,

D came back from school and had a tremendous meltdown, he pulled my hair with such force that I hit my head on the ground ... I was there for a few seconds. And then my eldest child came from school ... can you imagine what it's like for an 11-year-old child to restrain his brother on the sofa to give me the chance to get up. I (will) remember this day to the day I die ... my eldest was crying, he was saying 'Mammy I don't know how long I can restrain him'. (Lana, Autism Carer)

Lana went on to reflect that despite the unintentional nature of her son's harmful behaviour, it was still a form of domestic violence,

And I don't think that part is understood, we are talking about domestic violence here, you know, something should be done about it. (Lana, Autism Carer)

Autism carers spoke about the need to put in place 'safety plans' to protect themselves and other family members. For some, the harm they were experiencing was life-threatening in nature,

C knocked me to the ground, had a knife in her hand and put it up to P's [younger sibling] throat ... C was choking [sibling] at the same time ... P's eyes were closing, I had to make a decision I had to go for her [C] just to save my younger child. (Noleen, Autism Carer)

Harm experienced by dementia carers was more likely to take the form of verbal outbursts, aggression, and lack of sleep,

Some nights she's screaming outside my door, she's confused, and she gets agitated so some nights I could be up all night trying to settle her and get her back to bed. And when she comes up screaming that wakes the (grand)kids up, so some nights are awful. (Jennifer, Dementia Carer)

One dementia carer described the risk of direct harm to them and, potentially, to members of the public,

Things spiraled out of control ... I think it was a kind of psychotic episode where she started threatening us with knives and she was taking the knives with her in the car when she was going out ...'. (Oonagh, Dementia Carer)

Carers of PLWD reported struggling to know how to manage harmful behaviours and for some, professional advice was not always seen as helpful,

The Community Mental Health Team immediately put her on anti-psychotics ... we didn't get any tips on how we could deal with her behaviour. (Oonagh, Dementia Carer)

The professionals described a range of behaviours as carer harm. In relation to people with autism, this included physical aggression/assault, emotional stress, destroying property and the house, a constant sense of threat, and negative effects on the carers' mental health. Autism professionals also spoke about the significant impact on other family members including neglect of other children or breakdown of the family unit. Dementia professionals described the following as harmful: psychological, emotional, and physical behaviours such as shouting, physical assault and, in some cases, unwelcome sexual advances.

Expectations, responses, and systems that harm

Carers and professionals reported that both carers and the person they are supporting may be exposed to additional, or exacerbated, harm by the 'system'. System-related harms include unrealistic expectations by services and practitioners; being put under undue pressure to 'carry on'; lack of services and support; and being made to feel 'undeserving' or inadequate by some healthcare professionals.

Participants spoke frequently about the system and societal expectations that carers 'should be able to manage' regardless of the level or impact of abuse they are exposed to. When carers do not manage to meet these expectations, they feel an enormous sense of guilt, that they have 'failed' to be a 'good' parent or carer,

This is the harm of the system ... And I think the State really takes advantage of that. And by doing that people like me get run into the ground over years and years of it. (Katrina, Autism Carer)

Professionals reported that this expectation extends to the whole family including other children being expected to act as young carers,

There are so many siblings out there taking full responsibility (for care), I was only talking to a lady last week who has a child with quite complex needs and siblings who are very close in age. She is a single mother. Those siblings are taking the responsibility to the point that they are missing days of college because they have to be with their brother. And that is just, just wrong on so many levels to have children looking after children. (Autism FG)

Katrina discussed how she was expected to care of two adults with multiple disabilities alone, without any help from any formal services,

He has moderate autism and moderate intellectual disability but he's a big chap, not quite as big as his brother J but he's still growing, he's six foot two. A is incontinent so would need, you know, I suppose very intimate care needs around incontinence ... would also need full support around washing, shaving, dressing, you know ...

It is noteworthy that the expectations placed on family carers do not extend to paid carers. Whilst Mairead and her 80-year-old mother were expected to continue to care for her elderly father with dementia and challenging behaviours, service providers walked away because the paid carers were deemed to be 'too much at risk',

It was just the two carers in the room at the time. She (the carer) got injured ... the next day, I got a phone call from the Manager of Older Person Services, advising me that care had been withdrawn with immediate effect. She advised that there was a physical assault within the home, that my Dad needed a psychiatric assessment, it wasn't safe

for her employees to be coming into the home and we could expect a call from the Gardaí (police)! (Mairead, Dementia Carer)

Mairead commented on the lack of understanding and compassion by the service provider and the difficult knock-on impact on the family including the criminalization of her father's behaviour.

In situations where there was an immediate danger of harm to the carer and/or other children, the parents' only course of action was to call the Gardaí (the police). In this situation, the Gardaí can seek a 'Section 12' Order and then take the child to the Accident and Emergency Department of the local hospital. Noleen explains the process:

The poor Guards (police), they know C inside out, and they even have said to me that it's so unfair that you have no other choice but to ring us ... And as they say, they are not professionals to be able to do anything for C, they can only calm down the situation ... I ended up in A&E with bruises and four broken ribs and C was taken in by the guards on a Section 12. This is how C ended up in voluntary care. (Noleen, Autism Carer)

Noleen also reflected on her interactions with the social workers from the Child and Family Agency when they visited her in the hospital. She spoke of her fear and shock when the proposed response was to take Noleen's younger child into foster care and leave Noleen to care for her daughter who was exhibiting harmful behaviours in the family home.

Some family carers reported that they were 'forced to' abandon their autistic child/adult in order to gain access to any support for them, but also to keep themselves and their other children safe,

We didn't want this [to put 12-year-old child into residential care] and if we had more respite, we might have been able to (carry on) ... I still don't want this but it's the safest situation at the moment. (Paula and Sean, Autism Carer)

Several carers described having to resort to engaging with politicians or the media to advocate for essential support and services to keep all members of their families safe and free from harm.

Discussion

This article offers new evidence, insights, and reflections on an issue that is, largely, hidden behind closed doors in the private domain of the family home. It explores the experiences of carers who have been exposed to harm by their relatives and opens up a discourse about the shape and nature of carer harm from the perspectives of carers, service providers, and professionals in Ireland. The findings suggest that we are at the beginning of a longer journey towards understanding carer harm and taking account of it in our welfare systems, health and social care policies,

services, and practice responses. It is important to acknowledge that this study primarily illuminates issues relating to *unintentional* carer harm. There are several key issues to highlight.

First, there is the terminological challenge: how to describe carer harm. Findings indicate a general lack of awareness about what is, and is not, harmful behaviour or actions. ‘Carer harm’ was not a commonly recognized term; carers were very uncomfortable about using it, particularly in relation to the unintentionality of the harm experienced. Carers were sensitive to the stigma they felt relating to sharing their experiences of harm but also reported feelings of guilt and shame (Isham et al. 2021). These may be exacerbated by social norms including the need to protect the (already noted) ‘private’ nature of familial care (Milne and Larkin 2023) and the perceived ‘failure’ amongst carers to manage. The policy shift towards neoliberalism, responsabilization, and individualization (Raibee 2013) amplifies these issues too; the greater expectations placed on families to provide care unaided is a prominent example. Participants’ discomfort in describing their experiences as ‘abusive’ also speaks to prevailing narratives about who can legitimately be regarded as a ‘victim’ or a ‘perpetrator’ of abuse; current discourse is overwhelmingly binary (Isham et al. 2020). The discourse also intersects with the language of criminality. Findings suggest a need to revisit Isham et al.’s (2021) definition of ‘carer harm’ which assumes intent and a coercive or controlling element to harmful behaviour. This was not the picture of harm reported in our study.

A second, significant issue, is professional helplessness and a reluctance on the part of services to engage with carer harm. It is a complex and messy terrain; it also effectively, demands that services ‘do more’ by way of responding. This study highlights a failure to acknowledge and/or address carers—and other family members’—rights to be protected from harm. Current responses are clearly inadequate (Anka and Penhale 2024). Mandatory reporting concerning the ‘safeguarding of children’ and referrals to Safeguarding and Protection Teams concerning ‘vulnerable adults’, resulted in limited meaningful action to provide vital services which could help reduce harm. Services such as respite, behavioural support, or home care. Little support was offered to carers either. Services that were offered tended to reinforce the carer’s role as ‘carer’ not as a victim of abuse or a person in need of protection or—even—care and support.

The sociocultural nature of carer harm is a third issue. A fundamental facet of carer harm is its gendered nature. Caring is widely regarded as ‘women’s work’. In our study, mothers disproportionately provided intimate and personal care such as bathing and toileting; this type of care is evidenced as being associated with higher risks of harm (Family Carers Ireland, College of Psychiatrists and University College Dublin, 2019). The—linked—relational nature of care is also profoundly relevant.

Carers, particularly those who provide intimate care, are most often embedded in an interdependent familial relationship; they are simultaneously embedded in a complex and demanding care context (Donnelly et al. 2025, in press). These intertwine in distinctive and self-reinforcing ways. ‘Intent’ is a fourth issue. Just because a person with care and support needs has no, or little, intent to harm does not change the fact that the act is harmful. Unintentional harm challenges the lenses through which we view abuse; it does not align with either ‘traditional patterns’ of domestic abuse or with the profile of safeguarding referrals (Isham et al. 2021; Milne 2023).

Another—fifth—feature of carer harm is the fact that there are at least two people at risk: the carer *and* the adult/child with care and support needs as well as other family members such as siblings. Existing frameworks relating to abuse struggle to accommodate this overlapping terrain. Current responses tend to be informed by the ‘victim vs perpetrator’ paradigm (noted above) and also (some level of) intentionality (Warburton-Wynn 2023). This lens does not ‘fit’ with the profile of abuse identified in this study.

There is also the related matter of competing rights. Both the carer and the person with care and support needs have a right to be protected from harm but if one of the parties causes harm to the other in the context of a care relationship how are these rights to be meaningfully operationalized and by whom? Legal tensions and ethical dilemmas exist at least theoretically, in relation to balancing the needs, safety, and protection of the carer *and* the person with care and support needs as well as (often) other family members (Isham et al. 2021). This is a very challenging issue to address, let alone resolve.

That family caring is framed as positive, ‘virtuous, and a moral obligation’ is a sixth issue (Manthorpe and Iliffe 2016). As noted at the beginning of this paper, the welfare state relies heavily on family carers to ‘do caring’. This underscores the dependency that the care system has on carers’ input. Carers are routinely treated as a free resource by professionals and the state (Milne and Larkin 2023). The economic value of family care in the UK has been estimated to be £162 billion; this is significantly more than the total budget of the NHS (Petrillo and Bennett 2023). The state 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 an era of austerity (Humphries 2022).

That many carers do not identify as carers is a seventh issue. The term “carer” is antithetical to the way that many spouses/partners and parents view their role (Carers Trust 2018). They tend not to report, or even discuss, the harm they are experiencing because they feel it is ‘part and parcel’ of their caring responsibilities. Barriers to seeking help include

carers' perceived reluctance to disclose sensitive 'private' information, that may contravene family or cultural norms and disrupt domestic patterns (Crockett *et al.* 2018; Isham *et al.* 2021). Failure to 'cope' and embarrassment about somehow having 'caused' the harm were also facets of the carers' stories in our study. Many parents who were harmed by their children deny or minimize it or blame themselves (Holt and Brennan 2022). The role played by stigma, shame, and guilt is a primary barrier to disclosure.

Concerns about reporting the harm were a related issue. Although carers were often anxious about the safety of other family members such as siblings, they feared that disclosure might lead to unwanted interventions such as the removal of children to a place of safety and/or the break-up of the family unit. It is to the practice implications of this study that we now turn.

Implications for social work and the care system

Carer harm is situated at the intersection of abuse, risk, the need for care and support, the right to be protected from harm, and justice for both carers and the cared-for person (Anka and Penhale 2024; World Health Organisation 2024). Although this is squarely social work terrain, the roles of social workers in accommodating these issues are only beginning to be considered. As social work is located inside the wider care system, we suggest changes to both are needed.

Assessments of carers should engage with relational aspects of caring (Donnelly and O'Brien 2023; Donnelly *et al.* 2025, in press). A range of intersecting enforceable legal rights would help to ensure that carers are better protected. These rights would include a right to an assessment of need for *both* the carer and the child or adult with care and support needs, as well as a statutory entitlement to the services that the assessment identifies for both parties. A new legal duty should also be placed on local authorities—and other agencies—to 'provide assistance' where a carer is identified, either by themselves or others, to be at risk of harm (Donnelly and O'Brien 2023; Donnelly *et al.* 2025, in press). There is a strong case for ensuring that carer assessments—sensitively and empathically—cover issues of harm, risk, and protection (Milne and Larkin 2023). Carers need to be able to provide care safely and to be safe too; this is a human right. It is noteworthy that paid care staff are protected by employment law from abuse by the people they support. It may be instructive to explore how to 'translate' these rights into rights for family carers (Sherwood-Johnson *et al.* 2023).

Proactive support from a social worker could go some way to raising awareness of carer harm, addressing the challenges, putting in place a range of supports that prevent harm, reducing risk, and meeting the

needs of all family members. The current model, which ‘waits’ for a family situation to reach a crisis point is not only damaging, but effectively, knowingly places carers at increased risk. Social workers need to be willing to engage in a discourse that permits carers to reduce the levels of care they provide or even to walk away from caring altogether. Social workers can play a crucial role in attending to epistemic issues by sensitively and proactively exploring what harm might ‘look and feel like’ to carers, attune to the language used by them to describe the harm, and listen to what they say they want by way of support both for themselves and the cared for person (Isham et al. 2020).

Social workers can positively impact carers’ quality of life and well-being; the skills of advocacy, empathy, and engagement, as well as the values of upholding legal and human rights, social justice, and promotion of agency are especially valued. Evidence is particularly robust in situations where families and carers are overwhelmed, scared, or unsure ‘where to turn’, and in contexts where a dyadic or wider family approach is adopted (Tanner et al. 2023).

Carers’ organizations have a key role to play too. For example, raising awareness about carer harm and extending the role of carer and peer support groups to provide a space for carers to share concerns and/or experiences of carer harm (Donnelly and O’Brien 2023).

We have noted that the current system responses do not ‘fit’ the profile of unintentional carer harm. We need to extend conceptual thinking and challenge existing narrow service and practice responses, particularly those relating to safeguarding. The range of practitioners who encountered carers at risk of harm and/or the child/adult with care needs in this study, suggests that there is room to explore what shape ‘good practice’ could take across professional disciplines and service and policy domains. There may even be a case for an ‘inquiry’ approach to considering system-wide—and social work—responses to carer harm. Emerging work on domestic abuse of older people may be instructive to draw on as it has engaged with a range of disciplines, models of support, service settings, conceptual frameworks, and legal systems (Milne 2023). It also overtly intersects with caring and carers (Warburton-Wynn 2023).

Study limitations

This study is a small-scale exploratory study in Ireland that used a purposeful sampling approach. The sample was made up exclusively of carers of people living with more advanced dementia and parents of children and adults with autism (and other conditions). Participants were primarily female too. We acknowledge an unevenness in terms of the balance and quantity of evidence relating to our key themes; more

evidence was available relating to autism carers than dementia carers. These limitations are typical of studies of this type.

Conclusions

Carer harm is an uncomfortable issue. Whilst it is acknowledged that caring can have an indirect negative impact on carers' health and well-being, it is far less recognized that carers may be exposed directly to harm from the person they are supporting. Carer harm is likely to grow in prevalence and seriousness. There are increasing numbers of people with complex needs being supported by family carers in Ireland and many other countries. There are also shrinking welfare resources with fewer carers and people with care and support needs gaining access to services. It is a perfect storm: one of the consequences of the storm is higher levels of carer harm.

It is clear that much more work is needed in this emerging field. Effective protection for carers at risk of harm, particularly unintentional harm, needs to be shaped by the views and experiences of carers themselves. There are conceptual challenges too. Taking account of existing work on the ethic of care, interdependence and notions of 'risk' and 'vulnerability' could inform future work and enrich existing thinking about carer harm (Tronto 1993). Work on social risk is also relevant (Morgan 2018). A primary cause of carer harm is limitless societal and state expectations of carers; a model where responsibility for, *and* risks related to, care were shared with the community and wider society would offer greater levels of protection. Definitional issues also need attention; engaging with a lack of intent to harm is a primary challenge (Isham *et al.* 2021).

Regarding services and social work, we call for a jigsaw of interrelated issues to be addressed. There is a primary need to develop and commit to policies to better protect and support carers including enforceable rights and accessible and dependable services for carers and their relative(s) (Family Carers Ireland, College of Psychiatrists and University College Dublin 2019). Although social workers have much to offer carers at risk of harm, there is currently limited room to develop preventive or protective practices (Donnelly and O'Brien 2022). Research is needed on how social workers, and the wider care system, 'manage' issues relating to carer harm, what form 'good social work practice' that reduces risks would take, and how this could be achieved (Isham *et al.* 2020, 2021; Anka and Penhale 2024). We hope that our paper can contribute to greater understanding and engagement with the complex issue of carer harm, and to the development of a system that can offer much greater levels of protection to carers and can proactively act to address, and reduce, risks.

Acknowledgements

This project was carried out in partnership with FCI. We would particularly like to thank Dr Nikki Dunne for her ongoing help, guidance, and support, as well as all the FCI staff who assisted with recruitment and participated in the study. We would like to thank our Steering Group Members for their invaluable support and expertise. We also extend our thanks to Professor Jim Campbell, University College Dublin for peer reviewing the draft online resource.

Conflicts of interest

None declared.

Funding

This study was funded by the Irish Research Council's New Foundations Award, R22740.

Supplementary data

[Supplementary data](#) is available at *British Journal of Social Work* online.

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British Journal of Social Work, 2025, 00, 1–21

<https://doi.org/10.1093/bjsw/bcaf004>

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