



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn



Family
Carers
Ireland

no one should have to care alone

HIDDEN HARM SAFEGUARDING FAMILY CARERS FROM CARER HARM

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What is Carer Harm?

- 'Carer harm' is when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological and/or sexual harm (Isham et al.2020, p.2).
- While the risk of deterioration in carers' health and wellbeing as a result of caring has been well documented, there is also clear evidence of the significant, long-term negative impact on the health of those who experience abuse (FCI,2019).
- Little is known however about the harm experienced by carers at the hands of the person for whom they provide care to.
- Challenges are often faced by social workers and other professionals when care and violence intersect, and a service user/child is the alleged perpetrator of abuse against their family carer.
- Practitioners struggle to engage with families' testimonies about harm in the context of care and illness and there have been calls for all stakeholders to work more proactively with families where care and violence intersect (Isham et al.2020).



Context to Current Study

Key findings from the current report, *Paying the Price: The Hidden Impacts of Caring*.

44%

of carers surveyed regularly deal with abusive behaviour

70%

of carers experiencing abuse as part of their caring role said their loved one did not have access to suitable respite

76%

of care recipients did not receive any home support hours

74%

of care recipients requiring 100+ hours of care per week had no access to home support hours

49%

of carers said that no supports and services were available

79%

of carers supporting children with care needs found it difficult to make ends meet

25%

of carers could not access supports and services due to distance and/or transport issues

PAYING THE PRICE THE HIDDEN IMPACTS OF CARING

- Almost half (44%) of carers reported that they regularly experienced either physical aggression or verbal/emotional abuse as part of their caring role.
- 35% of carers regularly dealt with verbal and emotional abuse.
- 32% of carers regularly dealt with physical aggression and violence.
- 57% of those experiencing physical and verbal abuse were diagnosed with anxiety and/or depression.
- 72% of carers dealing with physically abusive behaviour reported a physical ill health diagnosis.

Recommendations from 2019 Report

The impact of physical and verbal abuse on family carers remains hidden and underresearched.

Further research and public discussion on this hitherto hidden aspect of the caring experience is key to recognising carers as victims of abuse and developing effective interventions to allow them to care safely.

Project Design



The research design is mapped out over **four work packages (WP)** combining a multimethod approach that uses secondary data analysis, qualitative exploration and co-design.

Research Design will include:

- In-depth thematic analysis of secondary qualitative data set

8-10 Narrative Interview with carers who have experienced carer harm

- Focus Group x 1 with FCI Carer Support Managers and Focus Groups x 2 with professionals and service providers in order to explore local practice and generate evidence synthesis

- World Café Co-Design Workshop with Family Carers, FCI Carer Support Workers, professionals, and service providers. Content will be informed by evidence gathered in WP 1, 2 and 3.

- Development of information resources and Practice Guide



Research Questions

What are the perceptions and experiences of family carers of carer harm by the person they are caring for?

How can professionals and service providers better support family carers experiencing carer harm?



WP1 Secondary Qualitative Data Analysis

Is there anything else you feel is important to carer health and wellbeing that is not covered in the questionnaire?

(328 responses)

- Entitlements and financial assistance and advice
- Respite
- Isolation and need for more support
- Need for more psychological support and counselling
- ***Family relationships and conflict and how they impact on caring relationships***
- Self-care

Family relationships and conflict and how these impact on health and wellbeing

"The relationship of carer to person being cared for needs to be analysed. We carers know we need to care for ourselves but cannot when we are being manipulated. How do we become free of manipulation without being less caring."



General Training Needs Identified (734 responses)

- *I need training on how to protect myself from getting hurt during my child's violent behaviour and how to prevent the person you are caring for hurting themselves during a violent outburst.*
- *Dealing with aggressive behaviour +++*
- *Managing time or dealing with family dynamics when the person being cared for takes up a lot of the focus*
- *How best to deal with violence and mood swings*
- *Managing verbal abuse of someone with limited control or preventing aggressive impulsive outbursts in ADHD*



Training Needs Dementia Carers

(166 responses)

- Health & well-being for the carer

"How to talk to others about what it's like to be a carer. Learning to accept life not turning out the way you thought it would-the disappointment on having to become a carer rather than a wife or mother."

- More challenging behaviour training

"Help for when he is aggressive - some sort of self-protection training".

- Manual handling +++

"To be better informed regarding issues surrounding my mother's health/condition and to be trained in handling her mobility issues better".

- Training in effective ways of stimulating the patient and how to deal with mood changes.

"I'm not a nurse but I really feel I require some qualifications to help in caring for my husband during the day".

Dementia specific training

"How do I recognise UTI, serious chest infection, other ailments? How do I calm agitation? How do I think on my feet, deal with my own stress levels in the moment".

Training Needs Autism Carers

- Caring for a child with disability

"How to care properly for my child. How to deal with emotions coming up to teenage years".

- Communicating with people who are non-verbal; Communication training like speech therapy

"How best to respond to my sons needs. He is non verbal. Would love someone to come into my home and show me how to best care for him to meet his needs."

- Behavioural training

"Dealing with autism meltdowns. Teaching other members of the family how to deal with it"

- Autism and Sensory processing workshops.



Preliminary Findings: Narrative Interviews

- The findings while not generalisable, indicate high levels of unmet need and psychological distress with family carers of people with dementia and adults/children with autism reported regularly experiencing verbal and physical aggression.
- Those experiencing carer harm reported 'falling through the cracks' of support services and often feeling abandoned by professionals.
- Key themes included **fear, shame, stigma, helplessness, despair, conflicting emotions, resilience and self/family advocacy.**





Outputs

Research report including a lay summary of findings, a formal launch and an awareness raising webinar on carer harm

1x peer-review journal articles (journals will be targeted who have open access policy with UCD)

Development of information and support resources for family carers and a practice guide for professionals

Co-teaching between FCI staff and applicant to social work students

Policy submission to the Department of Health Adult Safeguarding National Policy Working Group

Presentations at annual European Conference for Social Work Research and Eurocarers Conference (Applicant and FCI will self-fund attendance)

