STUDY PROTOCOL

Stage 1 Registered Report: A scoping review protocol to map the evidence on family carers who combine work with care
[version 1; peer review: 2 approved]

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Abstract

Background: Family carers are considered the backbone of care provision in the community for those who are dependent due to frailty, disability or chronic illness. As the proportion of older people increases worldwide, it is anticipated that there will be a corresponding increase in reliance on family carers. Furthermore, due to the increasing participation of women in the workforce and delayed retirement, the proportion of carers who combine paid employment with caregiving responsibilities is likely to increase. Consequently, support for family carers who balance work with care is becoming a growing health, business, economic and social issue. However, research in this field is somewhat fragmented.

Aim: This paper presents a protocol for a scoping review which aims to systematically and comprehensively map out the available published and unpublished literature on family carers who combine work with caring responsibilities.

Methods: The scoping review will be undertaken in six steps: (1) identify the research question; (2) identify relevant studies; (3) select studies; (4) chart the data; (5) collate, summarise and report the results and (6) consult with relevant stakeholders. The review will be guided by the PRISMA-ScR framework guidelines to ensure methodological and reporting quality. A minimum of two reviewers will independently review articles for inclusion within the review. The review process will be iterative and the research question(s) and search strategy will be refined as the review progresses.

Conclusion: This review will provide a mapped synthesis of the extent and nature of the available published and unpublished literature on family carers who juggle the competing demands of caregiving and paid work. Findings will be used to determine whether there is merit in carrying out a full systematic literature review and will provide direction for the next steps of a larger research project, which aims to support family carers in the workplace.
Keywords
Family carers, employment, employer, support, scoping review, protocol

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Author roles: Lafferty A: Conceptualization, Funding Acquisition, Investigation, Methodology, Project Administration, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; Phillips D: Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing; Paul G: Conceptualization, Funding Acquisition, Writing – Review & Editing; Fealy G: Conceptualization, Funding Acquisition, Writing – Review & Editing; Fahy M: Conceptualization, Funding Acquisition, Writing – Review & Editing; Duffy C: Conceptualization, Funding Acquisition, Writing – Review & Editing; Dowling-Hetherington L: Conceptualization, Funding Acquisition, Writing – Review & Editing; Moloney B: Writing – Review & Editing; Kroll T: Conceptualization, Funding Acquisition, Supervision, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: Health Research Board Ireland [EIA-2017-039; Emerging Investigator Awards (EIA) 2017 to AL].

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Introduction

As the population ages globally, the reliance on family carers to provide care in the community is expected to increase. A family carer can be defined as a person who ‘provides regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability, regardless of whether or not they are in receipt of a Carer’s Allowance or Benefit’ (CSO, 2016; p.24). The 2016 Census revealed that 4.1% of the Irish population are family carers and provide more than 343 million hours per annum of unpaid care to a dependent person. Two thirds of carers are female and over half (52.7%) are in the 40 to 59 age group. The census data also reported that 57.4% of carers aged 15 years and older were in paid employment (CSO, 2016a).

The number of family carers reported tends to be underestimated as family carers do not always recognise the care that they provide and can therefore sometimes struggle to self-identify as a ‘carer’ (Care Alliance Ireland, 2015; Care Alliance Ireland, 2017; Family Carers Ireland, 2017). The Irish Health Survey found a substantially higher percentage of people who reported that they provided care to a family relative. Based on a sample of 10,323 people aged 15 years and older, one in ten reported that they provided care to a person with a chronic condition or an infirmity due to old age (CSO, 2016b). This suggests that there are approximately 370,000 family carers in Ireland. This figure is consistent with statistics in other countries, most notably the UK (Office for National Statistics, 2011).

Caregiving can be a rewarding experience, but it is widely acknowledged that the demands associated with caregiving can negatively impact carers’ mental and physical health (Albert et al., 2010; NHS GP Patient Survey Oversight Group, 2019; Whittaker & Gallagher, 2019). It is also widely recognised that carers frequently experience relationship issues (Angermeyer et al., 2006) and social isolation (Greenwood et al., 2018).

Family carers who are in paid employment can face the additional challenge of trying to balance both the role of carer with that of an employee, and as a consequence may end up reducing their hours at work, taking a job with less responsibility or leaving their job entirely to provide care. This can result in financial loss (Carers UK, 2014) and impede careers (Carers UK, 2013). Women are more likely to reduce their hours due to caregiving obligations than men (Evandrou & Glaser, 2003; King & Pickard, 2013).

Recent research carried out by Carers UK (2019) showed that the number of people leaving the workforce to provide care for a relative or friend due to ageing, a disability or serious illness in the UK has increased from 2.3 million to 2.6 million between 2013 and 2018. Data from the English Longitudinal Study on Ageing (ELSA) indicated that providing just ten or more hours of care a week significantly increases the chances of a person aged between 50 and 65 leaving work within two years (King & Pickard, 2013). It was recently reported in the US that as many as 32% of all employees voluntarily left a job during the course of their career due to caregiving obligations (Fuller & Manjari, 2019).

The WHO recognises the importance of introducing ‘measures aimed at reconciling the conflicting pressures of paid work and care for carers, enabling them to engage with or retain paid employment’ (Tarricone & Tsoulos, 2008, p.26). In Ireland, the Health Service Executive (HSE) (2019) has committed to implementing the National Carer’s Strategy (2012) and its objectives to enable family carers to remain in employment and achieve a work-life balance. The Strategy states that carers should be enabled ‘to remain in touch with the labour market to the greatest extent possible’ and recognises the need to ‘encourage work-life balance provisions [which] are needed to ensure that working arrangements are carer friendly’ (Department of Health, 2012, p.25).

Recent figures released by Carers UK, estimate that as many as one in seven carers balance work with caregiving responsibilities for someone who is older, disabled or seriously ill (Carers UK, 2019). This statistic shows that the number of carers in paid employment has increased, when compared to available data from previous years (Carers UK, 2019; Office for National Statistics, 2011). Research suggests that enabling carers to maintain a working identity increases carers’ levels of happiness, financial security, and social inclusion (Eurofound, 2015; Stiell et al., 2006). Providing a supportive work environment for carers can bring many benefits for employers also, aiding the retention of their most talented and experienced staff, reducing absenteeism and presenteeism, and increasing productivity (Carers UK, 2013).

There is no single theoretical framework or model to explain the relationship between caregiving and employment. In a recent review of eldercare and work, Clancy et al. (2019) used four theories to construct their integrated model of eldercare and employment. These four theories comprised of role theory, social role theory, job demands/resources model, and biocological systems theory. A scoping review would help to ascertain the theoretical frameworks currently used to understand caregiving and employment across all types of caregiving.

With an ageing population, a shift in dependency ratio, delayed retirement, more women participating in the labour market and smaller family sizes, an increasing number of people are going to find themselves juggling both caregiving responsibilities and employment. Reconciling work with family caregiving responsibilities is becoming a growing health, economic and social issue, along with a business issue in the context of the talent management challenges being faced by many organisations. According to Employers for Carers (2019), employers must act to avoid a workplace ‘crisis’ among carers. Governments across Europe are mandating for carer-friendly workplace policies to enforce a work-life balance for all parents and carers (EC, Employment, Social Affairs and Inclusion July, 2018).

The current body of literature relating to family carers tends to be fragmented (Larkin et al., 2019). There is a dearth of evidence on family carers who combine work with care. A systematic approach to examining the extant literature on ‘working family carers’ has not yet been conducted. The authors will
undertake a scoping review to collate and synthesise the available literature to map the available evidence.

Study aim and objectives
The overall aim of this scoping review is to systematically and comprehensively scope the extent, range and nature of available evidence on ‘family carers who are in paid employment’.

The objectives of the review are to:
- Describe the type and nature of previous and ongoing research that examines family carers who combine paid employment with caregiving.
- Identify workplace interventions that enable a supportive work environment for carers.
- Identify the gaps in the literature relating to family carers who balance work with caregiving responsibilities.
- Identify the theoretical frameworks that are applied to understanding the ‘working carer’ role.

The review will map out and summarise the available body of evidence, which will help to identify research gaps in the literature and in doing so, will help to ascertain whether there is merit in pursuing a full systematic review (Arksey & O’Malley, 2005). The scope of the review has been kept deliberately broad. This review is the first step in a multi-phased research project which aims to develop an evidence-informed initiative to promote health and wellness among family carers in the workplace.

Protocol design
The scoping review will be guided by Arksey & O’Malley’s (2005) and Levac et al.’s (2010) scoping review methodology. According to this framework, there are six different stages in undertaking a scoping review: (1) identify the research question; (2) identify relevant studies; (3) select studies; (4) chart the data; (5) collate, summarise and report the results and (6) consult with relevant stakeholders.

(1) Identify the research question
The research question that will guide the scope of the review is: what evidence is available about family carers who balance work with caregiving? The research question for this scoping review is purposively broad in order to comprehensively map out what is known about family carers who are in paid employment. A ‘family carer’ is defined as anyone who provides help to a person who is in need of care and assistance due to frailty, a long-term illness or disability, with whom they have a kinship relationship (e.g. a relative, neighbour or close friend). In Ireland, the Central Statistics Office reports national data for carers aged 15 years and older who are in the labour force. In addition, carers who are in receipt of a carer’s allowance are permitted to work and/or study outside of the home for up to 15 hours a week. This research precludes carers in receipt of the state-funded carer’s allowance. Therefore, for the purposes of this review, a ‘working family carer’ is defined as a family carer who is aged 15 years and older and is in paid employment (including full-time, part-time, temporary) for more than 15 hours a week. As recommended by Arksey & O’Malley (2005), the approach will be iterative and the research question(s) will be refined as the reviewers become increasingly familiar with the literature.

(2) Identify relevant studies
A comprehensive search strategy will be developed to identify relevant studies. The systematic review will be guided by the PRISMA-ScR framework guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) (Tricco et al., 2018), to enhance methodological and reporting quality. In order to ensure that the breadth of the search is far-reaching, several electronic databases will be searched to identify relevant studies in the published literature. These will include: Cumulative Index of Nursing and Allied Health Literature (CINAHL) (EBSCO), Applied Social Sciences Index and Abstracts (ASSIA) (ProQuest), Business Source Complete (EBSCO), Sociological Abstracts (ProQuest), PsycINFO (ProQuest), MEDLINE (Ovid), PubMed Central, Excerpta Medica Database (EMBASE), Social Science Citation Index (ProQuest), International Bibliography of the Social Sciences (ProQuest), ABIInform (ProQuest), SCOPUS, and Academic Search Complete (EBSCO). Reference lists will also be hand searched to identify any additional relevant studies that may not have been identified through the scholarly databases.

Unpublished and grey literature will be searched for in the following sources: Open Grey; Grey Literature Reports; Carer Research and Knowledge Exchange Network (CAREN); Family Carers Ireland; SCIE Social Care Online; Google Scholar; Lenus; The Irish Health Repository; Care Alliance Ireland; International Alliance of Carer Organisations (IACO); Organisation for Economic Cooperation and Development (OECD); and the World Health Organisation (WHO). Additional grey literature will be sourced through the expertise and links of team members and collaborators. The School’s research librarian was consulted in the design and refining stage of the protocol development.

Search terms have been determined by team members, and in consultation with the research librarian. Searches will combine terms such as ‘family carer’ (e.g. caregiver, non-professional carer, informal carer, etc.), ‘workplace’ (e.g. employment, work, paid, labour, etc.), and ‘flexible working’ and ‘work-life balance’. Terms will be searched for in titles and abstracts and under subject headings (e.g. MeSH), where available. Searches will be limited to English language due to the costs involved in interpretation, and the search period will be confined to 1999–2019 in order to capture prominent developments in the past 20 years and recently published articles. Relevant key journals will also be hand searched. The search results will be imported into Endnote, a bibliographic manager, and any duplicates will be removed.
(3) Study selection
The literature searching will adopt an iterative approach and refinement of the search strategy will be ongoing as screening is undertaken. Team members and the librarian have reviewed the inclusion and exclusion criteria (see Table 1) and a minimum of two reviewers will independently review articles for inclusion in the review. Screening will be conducted initially with titles and abstracts of the retrieved citations, and those deemed eligible according to the inclusion and exclusion criteria will then be subjected to independent full text review screening. Reviewers will meet at the start, during and at the end of the full-text review process and any disagreements on article inclusion will be presented to a third reviewer until full consensus is achieved. Studies will be included if they concern family carers who are (or were) in paid employment. All study designs (e.g. randomised control trials, case studies, prospective or retrospective cohort studies, quasi-experimental designs or qualitative studies, etc.) will be included. Studies involving larger groups, either in the workforce or the general public, will be included in the review, as long as findings relating to the group of family carers balancing care with work can be independently extracted from the overall findings. Studies which focus on formal or professional/paid carers will only be included if the group also have caregiving responsibilities outside of their place of work.

(4) Data collection
The research team will collectively develop an Excel data chart and will identify the characteristics that are relevant to the research question. This will be an iterative process and may include: authors, publication year, country, research design, objectives, sample, work setting, instrument/measures, theoretical framework, intervention type, and key findings. In order to ensure that the relevant data is being appropriately mapped, the chart will be pre-tested: two reviewers will independently chart the first five to ten studies and then meet to determine whether consistency and accuracy is being achieved. If consistency is not being achieved, then the two reviewers will discuss the charting process and will independently chart a further five to ten studies to ensure consistency.

(5) Synthesise, summarise and report the results
The data will be analysed, aggregated and presented using descriptive numerical summary analysis and qualitative thematic analysis. The results will summarise the main theories, key sources, types of evidence, and will provide an overview of the scope of research that has been undertaken on this topic. The purpose of a scoping review is not to assess the quality of the studies, but rather to map out the extent to which the topic has been studied, the research designs, and the concepts that have been examined. The review will also highlight areas which have been under-researched. The inclusion and exclusion of publications will be presented in a flow chart using the PRISMA-ScR guidelines (Tricco et al., 2018).

The results from this scoping review will inform the research team as to whether a full systematic review is warranted. As the research team also plan to design and develop a programme to support family carers in the workplace, the scoping review will provide an overview of such programmes that have been published in the literature, including information on the study design, participants, theoretical frameworks, main outcomes, etc.

(6) Consultation with relevant stakeholders
Preliminary findings from the scoping review will be presented to the research team, collaborators, and to working family carers by way of carer consultation groups. The purpose of these presentations will be to get feedback, identify any omissions and establish the next steps for the research, such as undertaking a full systematic review. Should the feedback involve new published or unpublished grey literature, this will be integrated into the scoping review chart, analysed with the preliminary findings and the date, source and contribution will be recorded.

Table 1. Inclusion and exclusion criteria.

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<th>Inclusion criteria</th>
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<tr>
<td>• Articles confined to the English language</td>
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<tr>
<td>• Articles published between 2009 and 2019</td>
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<tr>
<td>• Articles relating to family carers, defined as ‘a person(s) who provides help to a person who is in need of care and assistance due to frailty, a long-term illness or disability, with whom they have a kinship relationship (e.g. a relative, neighbour or close friend)’.</td>
</tr>
<tr>
<td>• Articles relating to (former) family carers who are aged 15 years and older and who are in (or have been in) paid employment (including full-time, part-time, temporary) for more than 15 hours a week.</td>
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<th>Exclusion criteria</th>
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<tr>
<td>• Articles in a language other than English</td>
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<td>• Articles published outside of 2009 – 2019</td>
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<td>• Articles relating to younger carers i.e. aged under 15 years</td>
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<tr>
<td>• Articles relating to (former) family carers who are (or were) in paid employment for less than 15 hours a week.</td>
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Study status
At the time of publication of this protocol, informal preliminary searches of the literature had been undertaken primarily to help to identity key search terms.

Discussion
The number of carers in paid employment is rising. Employers need to implement specific measures to support carers among their workforce to ensure they remain in the organisation and are not forced to exit the workforce due to a lack of support. While some research on family carers who combine work with care has been carried out internationally, the literature is somewhat fragmented, and seminal documents are often found in the grey literature and can therefore be difficult to locate. This scoping review will approach the available evidence systematically and will provide a mapped synthesis of the size and scope of the literature found through published and unpublished sources, as well as grey literature sources. This review will assist in determining whether a systematic literature review is warranted.

It will also inform the next steps of a larger multi-phased research project which aims to support family carers and their wellness in the workplace.

Self-certification
The authors confirm that although preliminary searches have been conducted, no formal screening or data extraction has been performed.

Data availability
No data are associated with this article.

Grant information
Health Research Board Ireland [EIA-2017-039; Emerging Investigator Awards (EIA) 2017 to AL].

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

References


Stoil B, Shipton L, Yeandle S: Caring for Sick or Disabled Children: Parents’...

Reference Source

Reference Source

Open Peer Review

Current Peer Review Status: ✔ ✔

Version 1

Reviewer Report 13 May 2019

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Mary Larkin
Faculty of Wellbeing, Education and Language Studies (WELS), The Open University, Milton Keynes, UK

I think this is a much-needed scoping review which follows on well and logically from existing work in this area. My comments in relation to the questions below are:

- There is a bit of confusion as to whether the study relates to carers in Ireland or carers generally (e.g. stats are given for caring in Ireland).
- Objective 3 is very narrow – it only focuses on support in the workplace. What about other interventions that might help carers stay in employment?
- Carers who had to give up work because of their caring responsibilities will also provide invaluable insights and should be included in the consultation workshop invitations.
- Identify interventions that enable a supportive work environment for carers outside of the workplace.

Points to address:

- Make it clearer whether this study relates to carers generally.
- Revisit objective 3 (see above).
- Give a rationale for choosing the databases listed for the searches.
- Consider having carers who had to give up work because of their caring responsibilities at the workshop.

Have the authors pre-specified sufficient outcome-neutral tests for ensuring that the results obtained can test the stated hypotheses, including positive controls and quality checks?

Yes

Is the rationale for, and objectives of, the study clearly described?

Partly

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?
Partly

Are the datasets clearly presented in a useable and accessible format?
Not applicable

Competing Interests: No competing interests were disclosed.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 28 May 2019

Attracta Lafferty, University College Dublin, Dublin, Ireland

The authors would like to thank you for your comments to our scoping review protocol and for your suggestions. We have responded to your points below:

- While much of the information provided is based within an Irish context, the scoping review will indeed relate to a review of the literature on family carers internationally.
- We have reviewed objective 3, and given that the overall aim of the larger study, which this scoping review is part of, is to develop a ‘workplace-based’ programme for carers, we have decided to keep the focus on the workplace as it provides context for the review and is the ‘central hub’ of the research.
- The databases were chosen based on preliminary searches of the literature and in consultation with the School’s librarian, to ensure that the scope of the review is far-reaching.
- As part of the larger research project, case studies are being undertaken with carers who have had to give up work because of their caring responsibilities and therefore their insights are being represented elsewhere in the programme of research.

We appreciate your comments, and we will ensure that information relating to the above points, are made clear throughout the scoping review. Thank you once again.

Competing Interests: None

Reviewer Report 13 May 2019

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Mika Nonoyama
Faculty of Health Sciences, University of Ontario Institute of Technology, Oshawa, Canada

This protocol describes a scoping review on family caregivers who are also in paid employment (not related to care-giving). It will be completed to provide an understanding of these caregivers, any supportive interventions, gaps in evidence and theoretical frameworks that may exist. It will serve as a basis for future research, and to determine if a full systematic review is needed.
This protocol was well written, clear and detailed. It will address a gap and be highly relevant given the changing landscape in healthcare (from institutional to community/home). Indeed I have very few criticisms. The only suggestion I have is to expand on what specific numerical summary analysis and qualitative thematic analysis they are planning to use.

I look forward to seeing the results of this research.

**Have the authors pre-specified sufficient outcome-neutral tests for ensuring that the results obtained can test the stated hypotheses, including positive controls and quality checks?**
Yes

**Is the rationale for, and objectives of, the study clearly described?**
Yes

**Is the study design appropriate for the research question?**
Yes

**Are sufficient details of the methods provided to allow replication by others?**
Yes

**Are the datasets clearly presented in a useable and accessible format?**
Not applicable

*Competing Interests*: No competing interests were disclosed.

*Reviewer Expertise*: Chronic respiratory disease management, home mechanical ventilation (that includes caregiver support), pediatric respiratory therapy.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 28 May 2019

**Attracta Lafferty**, University College Dublin, Dublin, Ireland

The authors would like to thank you for taking the time to read our scoping review protocol and for your positive feedback. We would like to clarify that this scoping review will include family carers who are in employment, including those in employment related to caregiving. In other words, the review will include literature that relates to carers who are in paid work, in caregiving and non-caregiving occupations. We intend to use numerical summary analysis and qualitative thematic analysis, by merely counting the number of studies that are grouped under each category and summarising these in a table format. This will be an iterative process and the team will identify the characteristics relevant to the research questions. We will ensure that we document each step and that this information is presented clearly in the review. Many thanks again.

*Competing Interests*: None