

Utilising carer related research and knowledge: a scoping review and information resource

There are gaps in evidence on, for example: 'hard to reach' carers generally, and BAME carers and LGBT groups more specifically; caring across the life course; older carers; sandwich carers; the satisfactions and intrinsic benefits of caring

Considerable evidence exists on carers' characteristics, negative consequences of caring and mental health issues

There are a number of areas where future policy, practice and research might most fruitfully be directed, for example: carers' breaks, building resilience, delivering tailored support





BACKGROUND

Carers are crucial to the care system. There is now a wealth of national and international material and research about carers. However, it is fragmented, disparate, lacks accessibility and utility which in turn

- makes finding information about carer research problematic
- impedes its capacity to inform future research, policy and practice aimed at improving outcomes for carers.
- support the implementation of the Care Act 2014.

UNPAID CARERS People who look after, or give help or support to family members, friends, neighbours or others because of either long-term physical or mental ill-health/disability, or problems related to old age

This project makes a significant contribution to addressing these deficits in that – for the first time – it brings together all of this knowledge and underpins a fully accessible digital resource to help with supporting carers, in line with the Care Act 2014.

The primary focus of this timely project was a comprehensive scoping review of carer-related knowledge. The review had two complementary purposes:

- to provide a unique, academically robust and detailed mapping of carer-related evidence and knowledge that can also contribute to the identification of future research priorities relating to carers and inform social care practice
- to underpin an accessible digital resource, developed in partnership with, and hosted, the Social Care Institute for Excellence (SCIE) as part of their resources to support the implementation of the Care Act 2014. This sustainable resource will be for use by commissioners, care workers, social workers, carer organisations, carers' support workers, carers and people who use services.



METHODS

The scoping review showed that national and international knowledge and evidence about carers is extensive, varied and has many sources. Searches were undertaken between June and December 2016. A total of 3,434 references were captured from 10 electronic bibliographic databases, the JiscMail carer research email discussion list, and miscellaneous other searches through following reference lists. The three most productive databases were Social Care Online, HMIC and Web of Science); together these accounted for more than 60 per cent of all references captured.

Classification of the materials led to the identification of 17 'types' of knowledge resources. The leading category (accounting for almost 70% of citations) was that of 'Journal Articles'. These were mainly peer-reviewed articles in academic journals, but also included scholarly reflections and discussions of issues. The second highest category was 'Magazine articles' comprising those identified in the professional and 'trade' press, which either report on events or developments, or which offer opinions on carer issues. 'Government Documents,' represented the third highest category.

Analysis of the resources adopted a thematic approach and facilitated a mapping of the parameters and content of the existing research and other knowledge resources; 62 themes were identified which in turn were classified into four categories:

Impact of care: the consequences and sequela of caring (39%)

Carer variables: the characteristics and features of different types of carer and caring situations (27%)

Type of care: the nature of needs of the cared for person, and the features of the care situation (18%)

Support and carers: The provision and impact of general and specific help and support (16%).

While these categories were not absolute (e.g. some of the themes under 'Impact of care' also blend into 'Support and carers'), in general the four categories discriminated well and cumulatively described the full landscape of the knowledge and literature.

Charting the frequencies of themes across the categories provided an overview of areas that have attracted considerable focus and those that are relatively under-explored.

FINDINGS

A summary of the key messages from the scoping review is set out below:

- caring is extremely diverse and involves all sections and age groups of the population
- people are increasingly likely to experience one or more periods of caregiving during a lifetime
- there are similarities in the experiences of carers but at the same time all caring is unique
- all care takes place in a relationship, and every relationship is different, with distinctive strengths and weaknesses, positive and negative dimensions, and typically resulting in complex and ambivalent emotions associated with caring. Attention to both parties in a dyadic relationship is vital in understanding where interests coincide and where they diverge
- knowledge about groups of 'hard-to-reach' carers remains relatively poor and there are deficits in relation to BAME carers and LGBT groups
- while the profile of and research about 'young carers' has grown considerably in recent years they remain a small proportion of total carers
- most care is provided for older people, and typically by adult children or by a spouse/partner. Co-resident carers are the most likely to be spouses or partners and are the most heavily involved in care, while also being more likely to have their own health needs
- older carers continue to be relatively invisible in policy, practice and research. They are less likely to identify themselves as carers as their caring relationship is characterised by long-term reciprocity, mutuality and interdependence
- More issues are emerging about the 'sandwich care' generation (those providing care for an older relative and younger one): carers providing most intensive support (at least 20 hours a week) are aged under 65 and typically juggling the demands of caring and paid employment. Evidence indicates that a third of women aged 55-69 are providing care to both younger and older generations
- mental health (including dementia) – both in supporting people with mental health needs, and the mental health of carers – attracts considerable attention, and the tensions and contradictions in the caring role are particular considerations here
- every aspect of life can be impacted by caring. Much research and associated narrative has adopted a 'burden of care' discourse focusing on the negative consequences of caring. However, this view needs to be

considered alongside the co-existing satisfactions and intrinsic benefits of caring

- how carers cope – and how they can be taught appropriate coping strategies – is attracting more attention. Although results are promising in terms of improved wellbeing for carers, the impact on people being supported may be less evident
- increasing attention is being directed to balancing the demands of work, life and caring, and supporting working carers is a recurrent policy theme. However, this a complex territory e.g. flexibility may not be offered to carers in low paid, or low skilled work compared with those in more professional and managerial roles
- evidence about the effectiveness of services and support for carers is equivocal and sometimes contradictory (e.g. evidence on respite care). Psychosocial interventions appear to have the best evidence of making a difference for some carers (notably for carers of people with dementia, with cancer, and those who have had a stroke)
- support has to be tailored, and sometimes it is the process of support and interventions that may be valued even if the end outcomes do not indicate positive effects.



IMPLICATIONS & CONCLUSIONS

IMPLICATIONS

The implications of these findings for policy, practice and research are:

- breaks from care are generally valued by carers
- building carers' resilience and enabling them to develop strategies to manage the stress and pressure they experience appear to be important areas to develop further
- knowledge about carers lived experience should be maintained and extended, but is not the present research priority
- deficits in knowledge need to be addressed, expanding the evidence base through using appropriate methodologies and models. A model entitled 'Understanding and Applying' is suggested which seeks to integrate previously separate research paradigms within carer research, acknowledges and incorporates the complexity of knowledge about care and care giving, and seeks to understand the interdependencies inherent in caring relationships
- it has long been recognised that there is a need to examine the impact and experience of caring over time, and over the life course; the capacity to do so would be enhanced by the availability of more robust longitudinal data.

CONCLUSIONS

This project provides a unique and robust synthesis of carer-related research and knowledge.

Although the evidence that emerged is complicated and nuanced, and almost all the conclusions need to be understood in relation to specific contexts of caring, the scoping review provides an overview of the extent and nature of current research and knowledge. In so doing, it highlights the way that whilst much progress has

been made in terms of extending knowledge, there are significant deficits which need to be addressed. The review also shows that priority needs to be given to expanding the evidence base in certain areas.

In addressing the weaknesses and gaps identified through the scoping review, carer-related research and knowledge will be better placed to support improvements in, and the evidence based nature of social care practice and those they support. This accords with the Care Act 2014 emphasis on improving social care in relation to carers.

By bringing together the wide ranging and disparate body of knowledge for the first time, this project has made a significant contribution to ensuring

that carer-related research and knowledge can more effectively inform adult social care practice with carers and those cared for in England.

In addition to its dissemination to stakeholders (such as Local Authority and NHS commissioners, carers organisations, carers, those who use services, and practitioners) the scoping review represents a foundation for the development of sustainable, accessible resources that can support the information requirements of, for example commissioners, care workers, social workers, carer organisations, carers' support workers, carers, and people who use services. Such resources are particularly relevant to the implementation of the Care Act 2014.

RESOURCES

Full scoping review

Seeing the Wood for the Trees: Carer-related Research and Knowledge

[www.sscr.nihr.ac.uk/PDF/Findings/RF91\(SR\).pdf](http://www.sscr.nihr.ac.uk/PDF/Findings/RF91(SR).pdf)

Carer Research and Knowledge Exchange Network (CAREN)

CAREN developed from the scoping review of carer-related research and is a freely accessible knowledge exchange resource. The resources within this network are organised into 62 themes.

<http://wels.open.ac.uk/research-project/caren>

SCIE: Understanding Carers' Hub

The scoping review underpins, together with associated Social Care Institute for Excellence (SCIE) material and work on carers, in SCIE's freely available 'Understanding carers' hub.

Over time new material will be added and existing resources updated.

www.scie.org.uk/carers/knowledge-review

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
WC2A 2AE

Tel: 020 7955 6238

Email: sscr@lse.ac.uk

sscr.nihr.ac.uk



The research team comprised:

Dr Mary Larkin (Principal Investigator), The Open University

Professor Alisoun Milne (Co-Investigator), University of Kent

Dr Melanie Henwood (Research Associate), Henwood Associates

For further information, please contact Mary Larkin
mary.larkin@open.ac.uk

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