Carer related research and knowledge: findings from a scoping review

Abstract

The review discussed in this paper provides a unique synthesis of evidence and knowledge about carers. The authors adopted a scoping review methodology drawing on a wide range of material from many different sources published between 2000-16. It offers key insights into *what* we know and *how* we know it; reinforces and expands evidence about carers' profile; shows knowledge is uneven e.g. much is known about working carers, young carers, and carers of people with dementia but far less i about older carers or caring for someone with multiple needs. A striking feature of much research is a focus on caring as a set of tasks, rather than a dimension of an, often dyadic, relationship. Whilst there is substantive evidence about the negative impact of caring, the review suggests that links between caring and carer outcomes are neither linear nor inevitable and vary in depth and nature. A reliance on cross-sectional studies using standardised measures is a major weakness of existing research: this approach fails to capture the multi-dimensionality of the caring role, and the lived experience of the carer. Although research relating to formal support suggests that specific interventions for particular groups of carers may be effective, overall the evidence base is weak. There is a tension between cost effectiveness and what is valued by carers. Developing robust evaluative models that accommodate this tension and take account of the dyadic context of caring is a critical challenge. A fundamental deficit of carer related research is its location in one of two, largely separate, paradigmatic frameworks: the 'Gatherers and Evaluators' and the 'Conceptualisers and Theorisers'. The authors suggest that developing an integrated paradigm, that draws on the

strengths and methods of existing paradigms, has considerable potential to generate new knowledge and new evidence and extend understanding of care and caring.

Key words: carers; carer-related evidence; carer-related knowledge; carers research

What is known

- There is an extensive but fragmented body of knowledge and evidence about carers and caring.
- Increasing numbers of carers, and the complexity of their role, has led to growing interest in carer research.
- Two largely separate research paradigms dominate the field.

What this paper adds

- Existing work reveals significant deficits in relationship to the: profile of carers, impact of caring, and interventions and support.
- The design and methods of most research are relatively narrow; there is a need to accommodate the dyadic and relational context of caring.
- Developing an integrated research paradigm, that draws on existing paradigms, has potential to generate new knowledge and new evidence.

Introduction

There is a worldwide increase in the number of family carers and there are well documented concerns about how the care related challenges arising from the world's ageing population can be met by families and communities (OECD 2011, Pickard 2015). The national and international research, knowledge and evidence base around the role and contribution of carers has grown significantly in size and shape since the

1980s. This has: helped raise carers' profile in public discourse; ensure the foregrounding of caring as an important issue within social policy nationally and internationally; driven forward carer research; and informed improvements in support services and practice (Stalker 2003, Larkin and Milne 2015). In England for example, there have been a number of recent policy commitments to carers, most notably in the Care Act 2014 (Department of Health 2014, NHS England, 2014).

However, this now extensive body of knowledge is considerably fragmented and is located in numerous different spheres and places. It also takes many forms; there is a wide range of research articles, projects, reports, data sets, official statistics, conference proceedings and digital resources. These are produced by diverse bodies and sectors, including carers charities and other third sector organisations, universities, research institutes/centres and government departments. There is also a plethora of policy, practice and guidance documents, web-based advice/information sources, consultations and discussion forums (e.g. blogs) hosted by a range of different organisations (e.g. charities, government departments and independent networks) (Mason *et al*. 2007, Larkin and Milne 2014, Greenwood & Smith 2016).

To date, carer-related evidence and knowledge has not been synthesised into a single report, nor has it been comprehensively reviewed in a coherent or robust way. Consequently, there is no overall understanding of the nature and range of this prodigious and disparate body of work. This constrains knowledge generation and appreciation of its breadth and totality. Facilitating a full understanding of *what is known* about carers is important because it can:

- Inform policy and practice developments relevant to carers including understanding more about the implications of evidence for arranging effective support and services (Barnes 2006, Department of Health 2012, Milne and Larkin 2015).
- Inform thinking about how carers - and caring - are conceptualised and understood and the type(s) of evidence and knowledge that is privileged, or conversely, marginalised.
- Help the research community identify areas where evidence is limited or lacking, target research investment more appropriately and reduce duplication.

In 2016, a comprehensive scoping review was undertaken to specifically address these objectives and - for the first time - drew together national and international carer-related knowledge and evidence (Henwood *et al.* 2017). It was funded by the National Institute for Health Research School for Social Care Research (NIHR SSCR). As a core objective of this review was to be as inclusive as possible, it adopted a broad definition of knowledge. It drew on a wide spectrum of sources to simultaneously provide a unique overview of the type, range and nature of evidence *and* offer a comprehensive and informed synthesis of knowledge about carers.

The review can be seen in the wider context of a growing national interest in carer-related research and knowledge. This is reflected, for example, in: a Special Edition of the academic journal *Health and Social Care in the Community* (Volume 23 Issue 1, Jan 2015) based on papers drawn from an Economic and Social Research Council funded seminar series on carer research; in the recently established *International Journal of Care and Caring*; and through a range of carer-related research and

information resources, such as the international Carers Research collaborative (using JISCmail).

This paper outlines the methodology used for the review and the consequent mapping of knowledge about carers and caring. Reflections on the key findings in relation to current and future understanding and knowledge generation are also offered.

Design and Methodology

A scoping review methodology was adopted as this approach offers the most effective means of coherently capturing an evidence and knowledge base that is of considerable breadth and depth. It also enables the identification of *'key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking and research'* (Daudt *et al*. 2012, p. 8). Further, this methodology facilitates detailed and wide-ranging mapping, as well as active analysis and interpretation of findings, from an extensive multi-source landscape (Arksey and O'Malley 2005, Daudt *et al*. 2012, Pham, e*t al*. 2014). Scoping reviews are especially relevant in fields where there is emerging evidence rather than in those where evidence is well established, and where knowledge beyond the confines of traditional 'research' literature is sought (Arksey & O'Malley 2005, Levac *et al.* 2010). Other possible methodological approaches, such as systematic reviews, typically address specific and more narrowly defined research questions and assess the quality of a (usually) smaller number of academic research studies.

Arksey and O'Malley's (2005) framework for scoping studies was used to guide the iterative, reflexive and developmental approach to the review. This framework comprises the following stages:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting the results
6. Consultation exercise.

Although the sixth stage is optional, consultation activities were integral to this project.

The inclusion criteria for the study were: material (including grey literature) on carers of adults, published between January 2000 and December 2016 and available in the English language. 'Grey literature' in this context refers to resources beyond academic and peer-reviewed or scholarly articles. In addition to articles and reports in the professional trade press, this 'literature' was widely defined to include resources in multiple formats including digital, and audio visual. This reflects not only the increasing diversity of material which is available, but also the disparate audiences for whom it is intended, rather than being concerned largely or exclusively with academic and policy discourse. Material published prior to 2000 was excluded because of the review's need to capture contemporary evidence; the fact that new material often builds on, or further develops, existing evidence is also relevant. It became apparent early in the project that there was a law of diminishing returns on searching through multiple databases (i.e. there was considerable duplication of material and limited value in adding other data sources once this point had been reached). The following 10

electronic bibliographic databases were searched: Academic Search Complete, AMED, ASSIA, BNI, CINAHL, HMIC, MEDLINE, SCOPUS, Social Care Online, and Web of Science. Searches based on the Carers Research collaborative network (JiscMail) and through reference lists in items that had already been selected were also undertaken.

The searches took place between March and December 2016 and focused on material meeting the inclusion criteria and where the title or abstract included 'carer' or 'caregiver' (a commonly used term outside of the UK). All materials were saved using EndNote data management software. After the removal of duplicates and erroneously identified materials, the database total was 3,434 references.

The review was led by a research team and conducted by Melanie Henwood Associates. The research team benefitted from the ongoing input of a Project Advisory Group (PAG) comprising key stakeholders including: carers; people who use services; social work practitioners; a GP; Third Sector carers agencies and Department of Health representatives. The expertise of this group (individually and collectively) was used strategically and flexibly. A consultation workshop hosted by SCIE was held towards the end of the project period with participation from the PAG and other invited interested parties including NHS England; the Chief Social Worker for Adults for England; care workers; carers' support workers; and carers' service commissioners. The aim of the workshop was to discuss the draft scoping review findings, capture ways the review will be useful to social care practice and identify future research priorities. The James Lind Alliance guidance (http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/) on the production of jointly agreed priorities was used to guide

the workshop (Cowan & Oliver 2013). Outcomes and reflections from the workshop informed the final version of the review.

Mapping the territory

The review identified the major dimensions of knowledge about carers and caring in relation to its sources, parameters and content.

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 resources (respectively: 31%; 20% and 11%) of all references captured. Coding of reference categories led to the identification of 17 'types' of material and resources. These are set out in Figure 1 (*N=3,434)*; no attempt was made to establish a hierarchy or to imply that any given type is 'better' or 'superior' to any other. 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 caring issues in non-academic journals or trade and professional press in the care sector. 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 carers' issues. 'Government Material,' represented the third highest category, and this included documents which mentioned or addressed carers issues either exclusively or as part of wider public policy. It was clear that the range of relevant resources was considerable and included, for example, training materials. This underlined the value of adopting a scoping review approach to the work, and to drawing on a wide range of

resources; these materials would have been excluded in a conventional systematic review.

Insert Figure 1 here

The review found that, increasingly, many resources and 'documents' exist only in electronic and digital form rather than in print. There are also a growing number of audio-visual and digital materials including computer programmes; toolkits and e-training; web-based resources; and films and broadcasts.

In terms of the nature of review material much of the academic literature contributes to three domains: the development of theoretical or sociological discourse on carers; promoting debate of policy and practice issues; reporting on particular initiatives, interventions or evaluations. Most non-academic resources - including reports, briefings, standards, toolkits and training materials - are focused on the improvement of services and support, development of innovation and delivering best practice.

Analysis of the resources captured adopted a thematic approach, and using EndNote's capacity to generate dynamic 'smart groups' led to the identification of 62 major themes[1] derived from keyword analysis. These themes were in turn, methodically 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

[1] Definitions of each of the themes can be found in Table 1 in the online version of this paper

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%)

Whilst these four categories were not exclusive, in general they discriminated well between items and offered a lens to analyse the topography of the landscape. Figure 2 (*N=13, 373*) presents the frequencies of the themes. As references could appear under multiple themes, the total number of smart group entries was far larger than the number of discrete references (13,373 smart group allocations of 3,434 items).

Insert Figure 2 here

Charting the frequencies of themes across the categories provided an overview of dimensions of caring that have attracted considerable attention and those that are relatively under-explored. The 12 most, and least, frequently identified themes are summarised in Table 2.

Insert Table 2 here

Key findings and reflections

Analysis of the wide range and types of literature, through the prism of the four categories, provides a comprehensive overview about 'what is known' about carers and caring. This is presented and discussed in the full review report (Henwood *et al.* 2017) The following reflections on the key findings for both current and future understanding and knowledge generation include examples of relevant references from the review and references directly linked to the commentary.

Profile of Carers and Caring

There are now around 6.5 million carers in the UK. This is a shifting population; each year more than 2.1 million people become carers and a similar number end their caring responsibilities. A growing number of people are now experiencing more than one period of caregiving in their lifetime e.g. caring for a parent and subsequently a spouse (Hirst 2014, Carers UK 2015).

Existing evidence that caring involves all sections of society and is characterised by a lack of homogeneity was amplified in the review. Carers differ in terms of their age and gender, who they support and for how many hours per week they provide care. Although 4 million carers are caring for less than 20 hours each week, 1.4 million people are providing at least 50 hours a week. People in mid-life (55-64) are most likely to be carers; this is the case for almost one in five of this age group (18%) (Health and Social Care Information Centre 2010). More than 40% of carers are aged 45-65 and a quarter (1.3 million people) are aged 65 years or over. Evidence also suggests that most carers support a close family member such as a parent (33% of all carers), or spouse/partner (26%). However, this differs by age; older carers are much more

likely to be caring for a spouse or partner (58% of older carers), whilst middle aged carers are more likely to care for a parent or parent in-law (50% of this age group). A higher proportion of carers are female (58%) than male (42%) overall but among the oldest age groups (over 85), almost 60% of carers are men (Hirst 2014).

Literature in the review also categorises carers in relation to the 'reasons' they provide care. Evidence suggests that the most frequently identified reasons - in descending order of likelihood - are:

- Old age
- Dementia
- Mental illness
- End of Life
- Cancer
- Long term condition(s) (including neurological conditions)

There are fewer references in the literature associated with caring for people with multiple and complex needs; stroke survivors; learning disabilities, and AIDS/HIV. Quite a lot of literature focuses on one group of carers and tends to define them either via the 'condition' of the cared for person e.g. carers of people with dementia, or via a key characteristic of the carer e.g. young carers, spouse carers, carers from black and minority ethnic groups, or less frequently, a dominant feature of the carer's living situation e.g. rural carers. The fact that few of these groups of carers are mutually exclusive and that there is considerable intersectionality (i.e. between old age and dementia), highlights the limitations of descriptive 'categories'. The adoption of this rather narrow lens in much carer research means that neither a full picture of the carer

population nor of the complexity of caring or cared for groups is captured. It also contributes to the fragmentation of knowledge referred to above.

The review highlights the importance of a number of sociodemographic trends that do, and will in the future, have an impact on carers and patterns of caring. The first is improved longevity. This trend, in combination with increasing policy emphasis (in the UK at least) on community-based care, self-management of long-term conditions and funding cuts to welfare services, has a number of specific implications for carers. There are an ever-growing number of older people with complex co-morbid conditions living in their own homes relying on family carers to support them. Carers are increasingly expected to perform intensive - often quasi medical - care tasks and to provide care for many hours per week with less and less support from formal services (Stewart & MacIntyre 2013, Vassilev *et al.* 2013). Smaller and more disparate family models are also significant, including the relative decline of adult daughters or sons to support an elderly parent due to ageing without children (Richards *et al*. 2014).

The second trend is linked to the first and relates to older carers; an ageing population means not only that are there more older people who need care, but also that older people, are increasingly involved in *providing care*. A third of all carers - usually a spouse/partner or son or daughter - are now aged 65 years and over and their numbers are increasing, particularly as dementia rates rise (Pickard *et al.* 2000, Carers Trust 2014). While sons and daughters may be in their 60s or early 70s caring for a very elderly parent, spouse carers are usually a similar age to their partner i.e. late 70's, 80's or 90's. Spouse carers are invariably co-resident, tend to be very heavily involved in care, and have health needs of their own (Pickard *et al*. 2000, McGarry &

Arthur 2001, Milne and Hatzidimitriadou 2003). There is also an increasing number of older parent carers supporting a son or daughter with (usually) a learning disability. Their profile is distinctive; they have had very long-term responsibility for care and often have concerns about the future care of their son or daughter after their death or incapacity (Perkins & Haley, 2013).

Despite their number, and the significance of their role(s), the review found that older carers are underexplored in research. This invisibility not only limits our understanding about a growing group of carers, but opportunities to explore two key dimensions of long term caring are being missed: spousal care and male carers as over half of older spouse carers are men (Milne and Hatzidimitriadou 2003, Dahlberg *et al*. 2007). Given their particular profile and needs (i.e. many have their own health problems), the case for developing effective support for older carers is compelling and it is clearly an area that requires further exploration.

A third trend relates to the extension of economic dependency of young adults on their parents. As Gans *et al.* (2013) point out, in the past the life course periods of 'childcare' and 'elder care' were separated by some years but now they are increasingly overlapping. Research suggests that in Britain one third of women aged 55-69 are supporting both younger (typically young adult children) and older generations - the so called 'sandwich generation carers' (Grundy & Henretta 2006). Whilst these midlife women (mainly) may only be 'carers' for an older relative with health care needs, juggling the demands of caring with parental responsibilities for children is a new phenomenon which takes a considerable toll on their health, finances, relationships and employment. Evidence suggests that over half of people in this situation worry

about the ‘effects of caring’ on their children whilst four in 10 fear they ‘are letting down their elderly parents’. As a consequence, the majority of sandwich carers feel obliged to give up work (Carers UK & Employers for Carers 2012, Leime *et al*. 2017).

Older carers are not the only group of carers whose needs and profile remain under-explored. We still know relatively little about Black and Minority Ethnicity (BAME) carers and carers who are Lesbian, Gay, Bisexual, or Transgender (LGBT). In contrast, young carers[2] have attracted a great deal of research interest despite them representing only 3% the total carer population (Office for National Statistics 2011). The reasons for this disproportionate focus appear to be two-fold. Because caring at a young age can have life course implications for psychological and physical health, friendships and education it could be argued that young carers warrant particular attention; they also attract policy concern and there is public unease about the extent to which children *should be* involved in caring (Aldridge 2008, Hounsell 2013). Whilst these are not unreasonable drivers it is nonetheless noteworthy that research and funders prioritise some groups of carers over others and that this tendency produces an uneven - perhaps unbalanced - evidence and knowledge base.

A key feature of the review is explicit recognition that all caregiving is embedded within a relationship - typically a dyadic one. This is an obvious point, but it is often invisible or overlooked in much carer literature. The nature of the dyad (i.e. whether spousal, parent/child, siblings, friends or ‘other’) significantly influences the experience of being

[2] Young carers are officially defined as children aged under 18 who help to look after a relative (typically a parent or sibling) with a condition, disability, illness, mental health condition or a drug or alcohol problem.

a carer and of caring (Sebern & Whitlatch 2007). For example, older spouse carers are less likely to self-identify as carers as they tend to view their caring role as a normative extension of their existing role of wife or husband. In addition, they often wish to protect the dignity of the cared for person; identifying as a carer not only undermines this desire but challenges their status as a 'couple'. This reflects the particular context of the marital dyad which is often characterised by life course related reciprocity, mutuality and interdependence (Milne and Hatzidimitriadou 2003, McGovern 2011).

The review explored some of the reasons for the absence of focus on the caring dyad. Contributing factors include: a policy driven emphasis on 'interventions' for 'carers' *or* 'patients with long term conditions'; a research frame of reference that focuses on an individual and not a couple; and the methodological challenge of trying to capture the impact of a treatment or intervention on a dyad as opposed to individuals. In much health-related research carers tend to be marginalised; they are either excluded altogether or are used as 'proxies' for the patient who may lack capacity e.g. they may have advanced dementia (Larkin *et al.* 2018).

With some exceptions, an overarching feature of carer related research is its tendency to focus on caring as an activity outwith the care relationship. This approach risks eclipsing the dyad and of failing to take account of the pre-existing *and* current relationship in influencing caring. As caring is a product of the relationship this runs counter to the lived experiences of carers and to the life course of the dyad. Whilst appreciating the distinctive and separate needs of the carer *and* the cared for person is important, a focus on the dyadic context and relationship is pivotal to extending our

understanding of caring and to developing policies and services that go with the grain of caring, not against it.

In terms of the different types of caring relationships, less is known about caregiving by siblings, extended kin, and friends as opposed to parent carers, spouse carers and young carers and we know little about how care is provided to the increasing numbers of people ageing without children. A longstanding criticism of carer research is the limited quantity of longitudinal data available and any evidence that captures how care relationships change through time (Cohen *et al*. 2002); this is particularly relevant to carers who have been caring for most of their life course and/or are long-term carers such as older spouses.

Impact of caring

As noted above, the impact of care represented almost 40 per cent of the themes identified in the review and was the largest of the four categories. This is likely to reflect the fact that caring is recognised as having a profound and myriad effect on carers' lives (Cohen *et al*. 2002, Lyonette & Yardley 2003, Lecovich 2011). Impact is multi-dimensional, complex and varied and is a product of a number of intersecting factors including, as noted above, a shared life course.

There is extensive evidence about the ways in which caring impacts negatively on carers' health, social life, employment and finances. Specifically, long term caring is associated with poorer physical health e.g. back pain, high blood pressure and impaired psychological health e.g. anxiety, stress and depression, and with poverty. It is also linked with higher mortality rates for carers and increased likelihood of

permanent admission of the cared-for person into a care home (Cohen *et al.* 2002, Larkin and Milne 2014, Purkis & Ceci 2015, Carers UK 2016).

The impact of caring on paid employment is particularly well-documented. Around half of all carers are in paid employment and caring responsibilities are a key reason for reduction in hours or premature withdrawal from the labour market (especially for women) (King & Pickard 2013, Age UK & Carers UK 2016). The review showed that this has a number of overlapping implications; not only do carers suffer financially but can experience the loss of work-related skills, identity and social contacts. A dimension that is often overlooked is the way that these adverse consequences extend beyond carers' working lives into retirement; time out of the workforce reduces pension contributions, compromising post retirement income (Cronin *et al.* 2015, Carmichael & Ercolan 2016). This has an impact on the quality of life of both the carer and cared for person.

Analysis of this evidence suggests that links between caring and carer outcomes are neither linear nor inevitable and that they vary significantly in both depth and nature. Negative outcomes can be mediated, or amplified, by a wide range of factors. For example, carers who identify more positive feelings have been found to be less likely to report some of the negative outcomes of caring such as depression or poor physical health (Cohen *et al*. 2002). However, unravelling the interaction between positive and negative aspects of caring and the direction and strength of effect(s) is inherently problematic. The possibility of two-way effects (e.g. whether a poor relationship with the cared-for person creates carer stress or carer stress is the cause of the poor relationship) also makes distilling cause from consequence highly problematic

(Lyonette & Yardley 2003). Other influential factors include the competing demands carers face (e.g. the simultaneous demands of paid employment, caring and other family responsibilities); individuals' coping skills and resources; and the support they receive more widely (e.g. from other family members and services) (Glaser *et al.* 2008).

One of the key reasons that caring related research tends to paint a mainly negative picture can be attributed to the way evidence about the 'impact of caring' is gathered (Charlesworth *et al*. 2007). Assessment tools are routinely used in research to evaluate carer wellbeing and/or assess the 'impact' of an intervention. These have been found to lack sensitivity to the complexity of the caring role and/or to take account of the subjective perspective of the carer (Campbell *et al*. 2008, Sequeira 2013). We know how important subjective assessment, versus objective assessment, of key indicators is in terms of influencing health and wellbeing - for example in relationship to older people's quality of life (Bowling 2014). Hence omission of carers' subjective views is a significant weakness and contributes to incomplete understandings of the impact of caring.

There are also methodological issues; different research methods produce different findings. For example, Vlachantoni *et al.* (2013) distinguished between cross-sectional and longitudinal analysis of the impact of caring on carer health. Cross-sectional analysis of data shows 'mixed associations between informal care provision and poor health outcomes for the carer' whereas longitudinal analysis shows more definitively that 'informal care provision is not *per se* associated with adverse health and mortality outcomes' (p.114) but that the picture is more complex. Longitudinal analysis may

provide a more accurate picture because it both captures the impact of caring on health over a longer timeframe *and* the interaction between caring and other factors e.g. employment, support from family members and life course events. There is evidence for example, that 'satisfaction from caring' can reduce negative outcomes for carers, and similarly undertaking other roles and identities in addition to caring can be protective (De La Cuesta-Benjumea 2011, Sequeira 2013). These findings suggest that valuable additional insights about the dynamic nature of caring could be gained from greater investment in longitudinal research including extending knowledge about the long-term impact of caring on health - both negative and positive, and between care 'inputs' e.g. services for both carer and cared for person and care 'outcomes' e.g. mental health. One of the fundamental weaknesses of cross-sectional studies is the 'snapshot effect'; they only offer a picture of caring at that moment and struggle to capture causal links, or to understand fully the pathway of the carer journey over a lifecycle.

A recent focus of research has been exploring carer resilience and coping strategies in relation to reducing the risk of negative outcomes. Variables that have been identified as influencing both of these issues are: age of carer; the type of health conditions(s) the cared-for person has; the unpredictability of a condition (e.g. dementia where the caring journey evolves and changes); individual and community support (e.g. support provided by friends); use of health and social care services; and information and training to help with the practical elements of caring Greenwood *et al.* 2009, Lockeridge & Simpson 2013, Quinn *et al*. 2014, Donnellan *et al*. 2015). As these factors intersect and influence one another, the picture is complicated. Although the

establishment of definitive links is a challenge, research in this field is growing and/ likely to inform future carer support development.

This area of knowledge overlaps with the issue of carer support and intervention and it is to this evidence that we now turn.

Interventions and support

There is considerable policy interest in how best to support carers, especially those who care long term. Despite a substantive and sustained research focus on establishing evidence about what constitutes 'effective' interventions and support for carers the work is beset with methodological weaknesses and is equivocal, contradictory and often inconclusive (Arksey *et al*. 2002, Arksey *et al*. 2004, Mason *et al.* 2007, Lopez-Hartmann *et al*. 2012, Thomas *et al.* 2016).

Evidence is strongest in relationship to how interventions for particular groups of carers make a difference to their lives. This includes dementia carers and carers of a relative with cancer or who has had a stroke. Specific interventions that have been evidenced as effective include: caregiver support groups; telephone counselling; educational programmes; art therapy; meditation-based interventions; computer-mediated interventions; cognitive reframing; couple-based interventions; and psychosocial interventions Examples of positive effects of such interventions are reduced depression, anxiety and stress levels and improved relationship and family functioning (McKechnie *et al*. 2014, Thomas *et al.* 2016).

Beyond this relatively narrow area evidence is far less definitive. Arksey *et al*.'s (2004) review of respite services and short-term breaks for dementia carers illustrates this well. Whilst there was limited evidence of the effectiveness and cost-effectiveness of either respite care or short-term breaks there was considerable qualitative evidence from carers (and some from care recipients) of the *perceived* benefits of the use of respite services. This reinforces the point above about the importance of 'the subjective' when assessing the impact of caring. Indeed, the review highlighted that many carers value *the process* of setting up support - particularly developing a relationship with an assessor - and how interventions are delivered even if the outcomes do not suggest positive effect. More specifically, they see the recognition and validation of their role and experiences and the opportunity to talk about their needs with a professional as a form of support in itself.

Current research into interventions and support is characterised by a number of shortcomings. The most significant is that it fails to consider the differential effects of interventions on carer-care recipient relationships and distil the 'impact' of a service in a dyadic context (see above). For example, whilst services may be provided to support a person needing care (such as home care) this support may also, or even *only*, benefit the carer. Some interventions may even have detrimental unintended consequences for the carer, as in the case of some respite care for dementia carers. Whilst it is relatively common to offer 'respite' to a dementia carer by admitting the cared for person into a care home for a short break, if they return home distressed and upset as a consequence of the change in routines, this may actually increase stress for the carer rather than the intended reduction (McKechnie *et al.* 2014).

One of the oft noted weaknesses of 'carer intervention research' is also its lack of compatibility with traditional models of evaluation such as Random Control Trials (RCTs). To elaborate, some 'interventions' (e.g. respite care) are not discrete models but encompass a range of services (respite care can take a number of different forms such as day respite at home, a care home stay etc). When evaluating the impact of respite care, it is unlikely that a comparison of like with like is being made, even in the same geographical area let alone across two or three very different areas. Furthermore, given the diversity of the carer population, identifying two large sample groups that share carer and cared for characteristics, one of whom receives a specific service and the other does not is almost impossible (and potentially unethical). How far a medically driven model of research such as the RCT is appropriate for assessing the impact of a social intervention is a related question.

Adopting an evaluative approach which takes account of the dyadic context is a key way to strengthen the evidence base and enhance understanding of impact. Recent developments in evaluation are beginning to do this. One such evaluation is of the START intervention (STrAtegies for RelaTives) (Knapp *et al*. 2013, Livingston *et al*. 2014). This is an intervention which uses a manual-based therapy to teach dementia carers coping strategies. Evidence suggests that START is cost-effective in terms of outcomes for *both* the carer and the cared for person. Follow-up evaluation found, for example that carers' mental health and quality of life were improved in the short, medium and long term (after 2 years). Residential care costs rose for both the intervention group of people with dementia and for the control group of people receiving 'Treatment as Usual' (TAU), but at a faster rate in the TAU group. The difference was not – at the time – statistically significant, but longer term follow up over

five years is expected to show greater differentiation. Whilst most outcomes are linked to *either* the carer *or* the cared for person it is important to acknowledge the significance of evaluative models that gather evidence about both members of a dyadic relationship and not just one. This has important implications for future developments in research and for our understanding of impact. It may, in time, also inform policy, service development and practice.

Working carers need for support is a recent policy priority (Age UK & Carers UK 2016, King & Pickard 2013, Pickard *et al*. 2017a). There is general consensus about the business case for employers to support carers. Flexible employment and carer-friendly workplace policies that have been introduced appear to help in recruitment and retention, and in supporting employee commitment and productivity. Furthermore, a recent study about ways of supporting carers to work *and* care found a positive association between carers' employment and receipt of paid services by the cared-for person (Pickard *et al*. 2017b). However, as in other areas of carer support, the assumption that there are generalisable 'solutions' is unsound; one size does not fit all. For instance, flexible employment opportunities (such as working part-time hours) may not be offered equally to carers in low paid, or low skilled jobs compared with those in professional and managerial roles. 'Informal flexibility' has been found to be more useful, including being contactable at work by the cared for person or support workers; this gives carers peace of mind and enables them to focus more effectively on their jobs. Such informal arrangements however, are predicated on trust between carers and their employers which is neither always available nor can be mandated by policy makers (Vickerstaff *et al.* 2009; Leime *et al*.2017).

Conclusions and ways forward

The scoping review discussed in this paper offers a unique synthesis of evidence and knowledge about carers, drawing on a wide range of material from many different sources.

It provides a number of important insights into both *what* we know and *how* we know it. Although it reinforces existing evidence about the profile of carers in the UK, the authors highlight its uneven nature. Most notably, whilst there is considerable knowledge about working carers, young carers, midlife sons and daughters caring for an older parent, and dementia carers, far less is known about older carers, carers from Black and Minority Ethnicity groups, and caring for a relative with multiple needs. One of the most striking features of the literature on carers' profiles is the focus of research on caring as an activity or set of tasks, rather than a dimension of, and embedded in, an often dyadic relationship.

With reference to the effects of caring the review underscores the fact that although there is an extensive body of evidence about the ways caring impacts negatively on carers' lives and wellbeing, the picture is often more complex. It suggests that links between caring and carer outcomes are neither linear nor inevitable, they vary significantly in depth and nature, and may be mediated by a number of context specific factors. A key issue relates to the way evidence is gathered, primarily via cross-sectional studies using standardised research measures. This methodology not only paints a picture of a single time point but tend to assess the 'impact of an intervention', failing to capture the multi-dimensionality of the caring role, nor the subjective perspective of the carer. Evidence relating to the effectiveness of interventions and

support is strongest in relationship to specific interventions for particular groups of carers. At times there is a tension between outcomes relating to cost effectiveness and the perspectives of carers about what is 'valued'. This, and the absence of evidence about the 'impact' of a service on a dyad as opposed to an individual, suggest that current studies are frequently limited in terms of both design and method. Developing evaluative models that are both robust and accommodate the dyadic context of caring is a primary challenge.

In addition to the findings themselves, the review raises more fundamental questions about the nature of evidence and knowledge generation in the carers field. Most existing evidence is focused on: describing and quantifying the carer population's profile; documenting the impact and sequela of care-giving; and evaluating support for carers, usually within relatively narrow cost-effectiveness parameters of 'what works' in enabling carers to continue caring. This evidence is located in, and reflects, a paradigmatic approach defined by Milne and Larkin (2015) as the 'Gatherers and Evaluators'. The authors suggest that this paradigm is 'closely aligned to the dominant policy discourse about caring in the UK' (p5) and is associated with 'traditional research'. This research tends to be (relatively) well-funded, quantitative and is 'trusted' by policy makers, research groups and service commissioners. It is widely regarded as 'objective' and scientifically robust; research studies are often larger in size and employ research instruments and tools. A second paradigm, referred to by Milne and Larkin (2015) as 'Conceptualising and Theorising' focuses on 'the conceptual and experiential nature of care; it aims to extend thinking and theory about caring as a multidimensional activity and as an integral part of human relationships' (p 6/7). This paradigm engages with research that is non-traditional, qualitative and

smaller in scale and scope. Its focus and findings tend to resonate with carers' experiences; it often captures subjectivity and relational and emotional issues. However, it is often viewed as less robust or 'objective', struggles to find purchase inside the policy tent, finds limited application in practice and tends not to influence budgetary decisions or service investment. These two paradigms tend to be quite separate and 'belong' in different conceptual and theoretical spheres.

Milne and Larkin (2015) argue that drawing on the strengths of both paradigms and encouraging cross fertilisation has *'*considerable potential to meet the needs of citizens, families and carers, generate new knowledge*',* and evidence and meaningfully address one of the most challenging and complex issues of the 21st century (P.10). A model that brings together the key features of the two existing paradigms is suggested in the final section of the review (Henwood *et al.* 2017). The proposed paradigm 'Understanding and Applying' - would facilitate the integration of knowledge from a range of quantitative and qualitative sources, encourage the use of mixed methodologies, and aim to extend understanding of the practical, emotional, experiential and relational nature of care and care giving. Whilst at an early stage of development, this paradigm has considerable potential to address deficits in existing knowledge and take the carer research agenda forward in innovative directions.

This review has showcased the benefits of bringing together analysis and perspectives from a number of different traditional and non-traditional sources, thereby adding depth and richness to carer-related discourse. The review also underscores a need to look beyond the narrow confines of existing paradigmatic frameworks and 'traditional' sources of evidence and extend the lens of the research 'imagination'. A fusion of

approaches, thinking, conceptual analysis and methods not only has the capacity to generate new knowledge and understanding but to produce new evidence and insights upon which to base sustainable and coherent policy, services and practice developments. Given the increasing importance of carers in families and communities, and their growing prominence as a research and policy priority, this review and the questions it raises, are particularly timely both in the UK and internationally.

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