

SEEING THE WOOD FOR THE TREES

CARER-RELATED RESEARCH AND KNOWLEDGE



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The School for Social Care Research

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This scoping review on which this summary report is based was funded by NIHR School for Social Care Research (NIHR SSCR). The views expressed in the report are those of the authors, and not necessarily those of the Advisory Group members, nor of the Department of Health and Social Care, the NIHR nor the NIHR SSCR.

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Executive summary

An NIHR SSCR-funded scoping review on carer-related evidence and knowledge was undertaken between April 2016 and January 2017. While research and evidence about carers is now extensive, it is generally fragmented, located in a variety of places and often difficult to access. For the first time, this scoping review pulls together all published carer-related knowledge and provides a unique, comprehensive and detailed mapping of what is known about carers and caring. This is a summary report of the scoping review; an extended report including a full bibliography of resources is also available¹.

The report contextualises the review in relation to research and policy since the mid-1980s.

Arksey and O'Malley's (2005) framework for scoping studies was used to guide the iterative, reflexive and developmental approach to the review. The inclusion criteria for the study were: material on carers of adults, published since 2000 and available in the English language. Searches of 10 key electronic bibliographic databases were undertaken. These were supplemented by additional web searches to capture other resources, published knowledge and grey literature. All resources were organised using EndNote, and a library of 3,434 items was generated with materials classified under four categories and sixty-two themes.

Using a four-fold categorisation of key themes – Carer variables, Type of care, Impact of care, Support and carers – the nature of carer- related knowledge was examined. This analysis highlighted some of the major issues and questions. These are:

- carers are diverse and involve all sections and age groups of the population; people are likely to experience one or more periods of caregiving over the course of a lifetime;
- there are both similarities and differences in the experiences of carers, but all caring takes place within a relationship, and each relationship is unique. Attention to both parties in a dyad is essential in understanding where interests are shared and where they diverge
- knowledge about 'hard to reach' groups – notably Black and Minority Ethnic (BAME) and Lesbian Gay Bisexual and Transgender (LGBT) carers – remains relatively sparse. The profile of young carers has grown considerably in recent years, but they remain a small proportion of carers overall. Older carers (i.e. aged over 65) are of increasing importance in society, particularly in providing care for an elderly spouse or partner; such carers are the most heavily involved in caregiving but remain relatively invisible both in policy and research terms;
- the impact of caring is multi-faceted and much of this is referred to within a 'burden of care' discourse that can be seen as pejorative, and which fails to take account of the simultaneous reported satisfactions of caring, or of the complexities and interdependencies within a caring relationship. How carers cope, and what strategies are effective in enabling them to do so are attracting increasing attention;
- many carers face multiple and at times competing demands, not least those trying to balance caring responsibilities with other family demands and paid employment. The business case for increasing flexibility to accommodate working carers is increasingly recognised, but context specific strategies are required to do this;
- much of the knowledge about carers and their circumstances relates to their characteristics, their lived experience and the nature and duration of their caregiving; relatively less is known about the effectiveness of interventions to support carers. Some of the findings – such as on respite care – are contradictory. The evidence in support of some psychosocial interventions seems to be the strongest, but it would appear there is no 'quick fix'. Indeed, even where

¹ www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000RCtCnAAL

interventions do not appear successful against specified outcome criteria, carers may report positive subjective benefit from the process and experience of interventions;

- carer-related knowledge and evidence is complicated and nuanced and almost all the conclusions need to be seen within specific contexts and with caveats.

The key messages for practice, policy and research from this review are:

- the factors that may make the most difference to carers, and those they care for, may not be the standard service 'offer';
- it is important to build carers' resilience and enable them to develop strategies to manage the stress and pressure they experience;
- the adoption of an integrated approach to research which acknowledges and incorporates the complexity of knowledge about care and care giving, and that seeks to understand the interdependencies inherent in caring relationships;
- address the identified deficits in existing knowledge with priority given to expanding the evidence base through using appropriate methodologies and models;
- greater generation and use of longitudinal data in order to examine the impact and experience of caring over time, and the nature of caring through the life cycle.

Introduction

While their contested nature is acknowledged, the terms 'carer' and 'caregiver' are used throughout this report to refer to people who provide care and support on an unpaid basis to adults because of needs arising from their being, for example, sick, disabled, frail or elderly,

The number of carers is increasing rapidly; the 2011 population census indicated that 6.5 million people in the UK were carers, an increase of 11% since the previous census of 2001 (Carers UK 2015). There is also considerable 'churn' in the carer population; each year more than 2.1 million people become carers and a similar number end their caring responsibilities (Hirst 2014). It is now estimated that three in five people will be carers at some point in their lives.

Around four million carers are caring for fewer than 20 hours a week, while 1.4 million people are providing 50 or more hours a week. Those aged 55–64 are the most likely to be carers, and this is true of almost one in five of the age group (18%) (Health and Social Care Information Centre 2010). More than 40% of carers are aged 45–65, but a quarter (1.3 million people) are aged at least 65. Those most likely to be cared for are a close family member such as a parent (33%), or a spouse or partner (26%). However, this differs by age and older carers are the most likely to be caring for a spouse or partner (58%), while those of middle age are more likely to care for a parent or in-law (50%). Women are more likely to be carers than men (58% of carers are female and 42% male), but among the oldest age groups (aged over 85), almost 60% of carers are men.

There has been a growing interest in carers and caregiving in UK and international research, and in the wider public discourse. The now extensive body of research and knowledge that has developed since the 1980s is diverse; although academic papers feature strongly, it also includes: non-peer reviewed project reports; lobbying and campaigning materials from interest groups; conference papers and proceedings; national and local policy and practice documents, guidance and strategies; data sets and statistical publications; digital resources and interactive media. These materials are generated by a range of individuals, organisations, research centres and departments; third sector bodies and government departments and quangos. Whilst this richness and diversity is to be celebrated, because of the disparate and wide-ranging nature of this knowledge it is difficult to get an overall sense of what we know about carers and how best to support them.

The rise of carers as a focus of research and analysis paralleled the growing recognition of carers within policy and practice, both nationally and locally. Policy development in the UK can be tracked from the mid-1980s. Prior to this time political and policy references to the role of families and communities were highly general in nature and largely expressed in terms that emphasised the duty of families rather than acknowledging the needs of carers. The rights of carers were first given legislative effect in the 1995 Carers (Recognition and Services) Act and in the subsequent development since 1999 of the National Carers Strategy supported by successive governments and providing the vision for recognising, valuing and supporting carers.

There has also been a series of national health and social care policies which have focussed explicitly on carers' rights to have their needs assessed, their health and wellbeing protected, access to support, training and employment, and to 'live a life outside caring' (Department of Health 1999, 2008, 2010a, Moran *et al.* 2012). At the time of writing (March 2017) the latest iteration of a new National Carers Strategy was expected from government.

The Care Act 2014 is the most recent piece of legislation. This substantially replaced and consolidated previous legislation for carers and those they support. It introduces parity of esteem between carers and service users, strengthens carers' rights to an assessment of need and places a new duty on local authorities to fund support for carers' 'eligible needs'. Furthermore, the Care Act legally entitles carers to information and advice (HM Government 2014, Larkin and Mitchell 2016).

The expectations and aspirations of carer-related policy and legislation also need to be seen in the wider context of social care reform and the introduction of the personalisation agenda, with themes of choice, control and empowerment frequently referenced (Larkin and Milne 2013, Needham 2011, 2014, Larkin and Mitchell 2016).

Despite such greater 'carer awareness' there is much evidence that many carers – such as the growing number of older carers – are still routinely overlooked and unsupported (Glasby *et al.* 2010, Ridley *et al.* 2010, Buckner and Yeandle 2011, Pickard *et al.* 2016). There is also evidence that carers' willingness and ability to care is often assumed by social care workers conducting assessments of need, with the result that separate carers' assessments are rarely offered (Department of Health 2010b).

To date, the extensive body of carer-related research and knowledge has not been mapped, delineated and analysed. Consequently, accessing helpful evidence is often challenging for key groups, including:

- carers and social care practitioners seeking information to support decision-making about a particular situation and needs: this is increasingly important in the light of the implementation of the Care Act 2014;
- those closely involved in carer practice and policy: these stakeholders need to be able to make use of information and knowledge quickly to make evidence-informed decisions to improve practice with carers (Barnes 2006, Milne and Larkin 2015);
- the research community: it is imperative that these stakeholders can readily identify areas where evidence is thin or lacking and for future research to be targeted accordingly; and to avoid duplication of research investment.

This review represents the first attempt to comprehensively scope out carer-related knowledge and evidence to assist such audiences. It is also being used to underpin two other resources that can be further developed to reflect this dynamic and evolving territory and support these audiences:

- in partnership with, and hosted by Social Care Institute for Excellence (SCIE), a fully accessible, sustainable digital resource to help meet the information requirements of the Care Act 2014 and inform decision making relating to social care practice with carers. This is entitled 'Understanding carers' and is for use by a range of stakeholders: including commissioners, care workers, social workers, carer organisations, carers' support workers, carers, people who use services and personal assistants²;
- a freely accessible knowledge exchange digital resource for all national and international stakeholders who require any form of carer-related knowledge. This is known as the Carer Research and Knowledge Exchange Network (CAREN)³.

In the next section of this report the methodological approach used for the scoping review is set out. This is followed by discussions of the findings from the mapping and the analysis of carer-related knowledge. Throughout these discussions, examples of sources identified in the review are used to illustrate key points. Some of the major issues and questions are also highlighted

² www.scie.org.uk/carers/knowledge-review

³ wels.open.ac.uk/research-project/caren

Methodology

A scoping review methodology was adopted as this offers the most effective means in this context of synthesising a range of evidence and knowledge that is of considerable breadth and depth and allows the identification of 'key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking and research' (Daudt *et al.* 2013). This method also facilitates detailed and wide-ranging mapping as well as active analysis and interpretation of findings across an extensive landscape (Arksey and O'Malley 2005, Daudt *et al.* 2013, Pham *et al.* 2014). Other methods, such as systematic reviews, typically address more narrowly defined research questions and, as such, were not suitable for this review. Additionally, scoping reviews are especially relevant in fields where there is emerging evidence, rather than in those where evidence is more definitive, and in topics where knowledge beyond the confines of research literature is sought (Arksey and O'Malley 2005, Levac *et al.* 2010).

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 on carers of adults, published since 2000 and available in the English language. 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. The following bibliographic databases were searched between June and December 2016: 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 the reference lists in items that had already been selected were also undertaken. 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 beyond a certain point).

The searches were for material meeting the inclusion criteria and where the title or abstract included 'carer' or 'caregiver' (a commonly used term outside of the UK). Prior to undertaking the searches, a number of key themes had been identified as important. These included 'young carers'; 'older carers'; 'carers and health'; 'carers and employment'; and 'carers in end of life care'. Further searches were made around these themes but it was concluded that the generic search criteria were successfully identifying a wide range of references and citations including these categories. All materials were saved using EndNote data management software. After the removal of duplicates and materials out of scope (for example, references to paid carers and caring for children) a total of 3,434 references were captured.

Analysis of the references captured adopted a thematic approach, and using EndNote's capacity to generate dynamic 'smart groups' led to the identification of 62 major themes derived from keyword analysis. These themes were, in turn, methodically classified into four categories:

- **Carer variables:** the characteristics and features of different types of carer and caring situations
- **Type of care:** the nature of needs of the cared for person, and the features of the care situation

- **Impact of care:** the consequences and sequela of caring
- **Support and carers:** The provision and impact of general and specific help and support

Throughout the study the research team benefitted from the 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. A Consultation workshop hosted by SCIE was held towards the end of the project period with participation from the PAG and other 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 guidance⁴ on the production of jointly agreed priorities was used to guide the workshop (Cowan and Oliver 2013). Outcomes and reflections from the workshop informed the final version of this report.

⁴ www.jla.nihr.ac.uk/about-the-james-lind-alliance

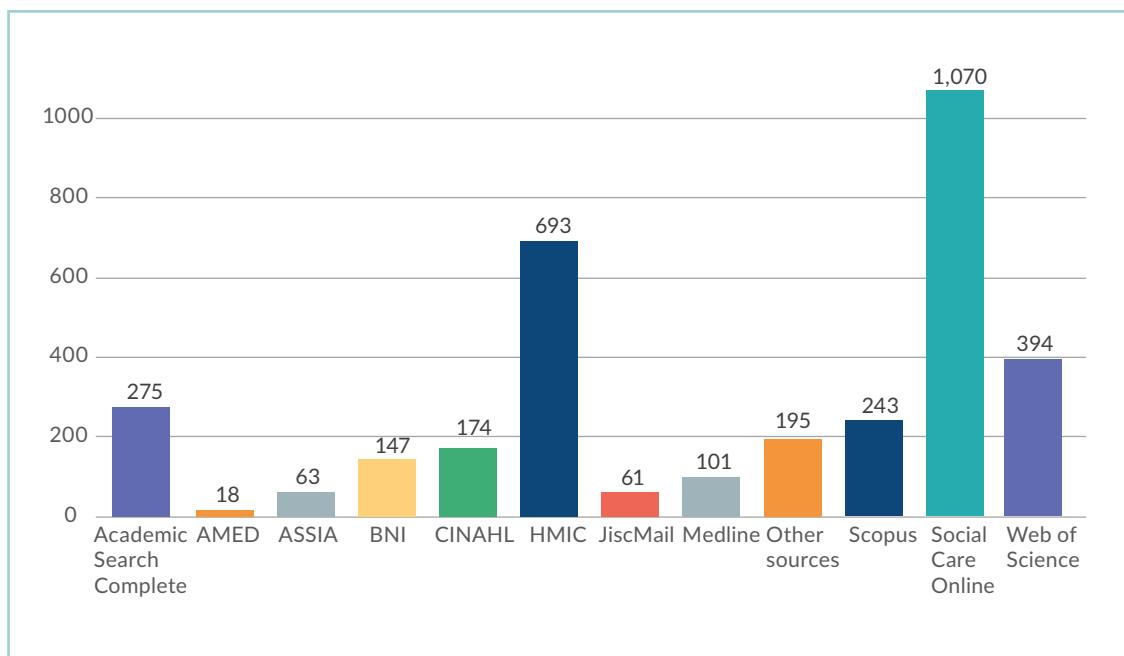
Mapping the territory

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

As Figure 1 demonstrates, 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 identified (respectively: 31%; 20% and 11%). Other data sources together contributed the remaining third of citations.

Coding of reference categories led to the identification of 17 'types' of material and resources.

FIGURE 1: References by database (n = 3,434)



These are set out in Figure 2; 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 press. 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, and this included documents which mentioned or addressed carers issues, both exclusively and within a wider context of public policy. The range of relevant resources in this category was considerable and included, for example, electronic audio visual and training materials.

'Reports' comprised the fourth highest category (193) and is a miscellaneous collection of academic reports of research published by universities and departments; by think tanks and policy research bodies (such as the King's Fund, the Joseph Rowntree Foundation and SCIE) and by government departments, quangos and other agencies (including Carers UK, the Princess Royal Trust for Carers, Age UK and the Children's Society).

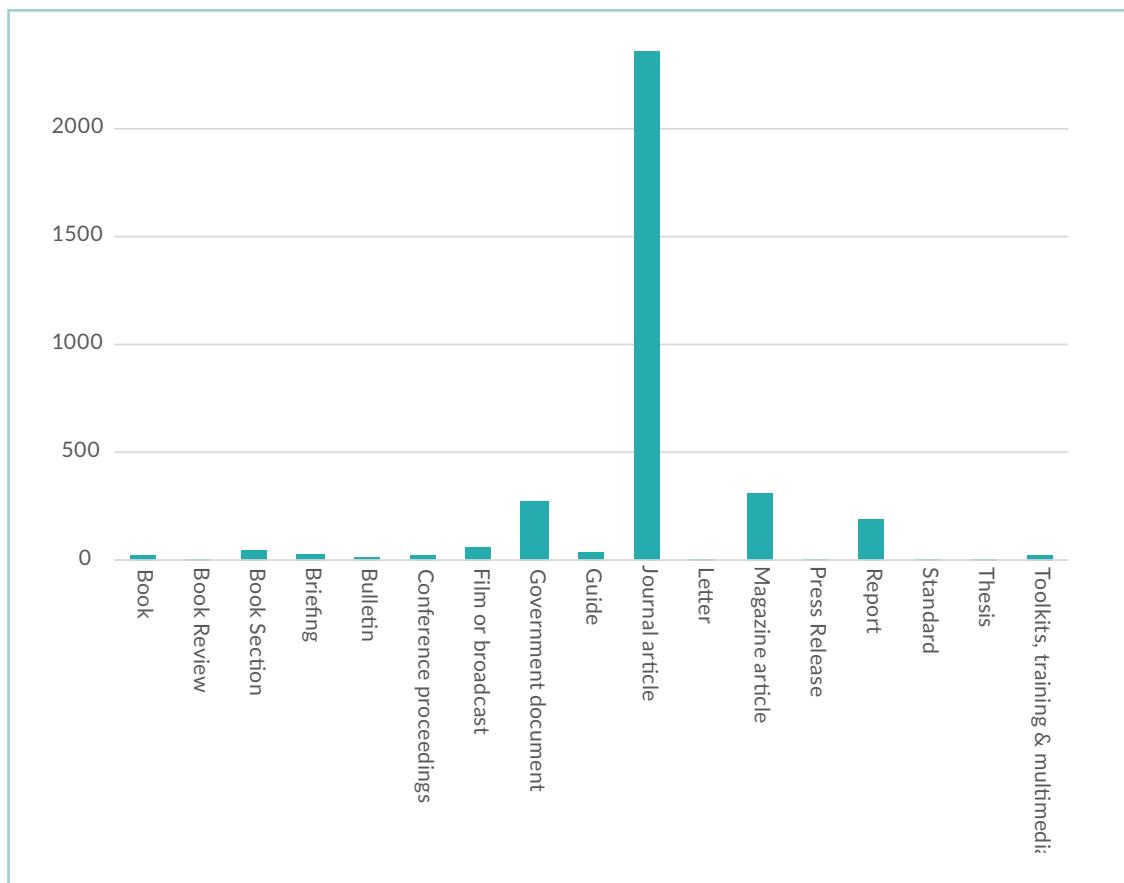
Many of the documents exist primarily in electronic form, rather than only in traditional print.

There is also a growing number of digital materials emerging including computer programmes, toolkits and e-training, films and broadcasts.

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 and interventions. Most non-academic resources – including reports, briefings, standards, toolkits and training materials – are focused on directly informing the improvement of practice.

The distribution of themes between categories was as follows:

FIGURE 2: Reference types (n = 3,434)



- 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%);
- Impact of care: the consequences and sequela of caring (39%);
- Support and carers: the provision and impact of general and specific help and support (16%).

Table 1 presents a glossary defining the categories and each of the themes. Although the four categories were not absolute (e.g. some of the themes under 'Impact of care' also intersected with 'Support and carers'), in general they discriminated well and offered a lens to analyse the topography of the extensive landscape.

TABLE 1: Categories and definitions of themes

SUPPORT AND CARERS

1	Assessment	Assessment of carers' needs.
2	Care Act evaluation	Focusing on the implementation of the 2014 Care Act and considering the impact on and implications for carers.
3	Carer support	Addressing carers' needs for support, or specific services/interventions intended to support carers.
4	Cash for care	Direct Payments, personal budgets and similar arrangements that provide cash to the carer to organise support on their own behalf and/or that of the person cared for.
5	Respite	Services and interventions intended to provide respite or a break for the carer and/or the person cared for.
6	Social support and networks	The nature of family, friends and wider community networks able to support carers.
7	Social work education	The involvement of carers in shaping social work education and training, and the importance of carers issues being reflected in course content.
8	Technology and telecare	Use of telecare, technology, telematics, robotics, electronic tracking etc. and applications for carers and those they support.
9	Training and carers	Training for carers, and involvement of carers in training of care providers and others.
10	Value of care	The notional value of care provided by carers, and the value attributed to caring (monetary and other).

TYPE OF CARE

11	AIDS/HIV	Caring associated with the needs of people with AIDS/HIV.
12	Cancer	Caring for people who have cancer.
13	Caring for older people	Caring for older people, and the needs associated with ageing.
14	Complex needs	Caring for people who have multiple and/or complex care needs.
15	Dementia	Caring for people with dementia.
16	End of life	The particular caring needs and issues associated with end of life and palliative care.
17	Intellectual disability	Caring for people with an intellectual disability, and carers who have a intellectual disability.
18	Long term conditions	The particular care needs and issues for carers of people with chronic long term conditions.
19	Mental health	Caring for people with mental health needs, and the mental health needs of carers.
20	Nature of care	What caring involves – what care is provided.
21	Stroke survivors	Caring for people who have had a stroke.

TABLE 1: Categories and definitions of themes (continued)

IMPACT OF CARE

22	Abuse and care	Caring relationships can sometimes be abusive, for the cared for and/or the carer.
23	Bereavement	The impact of bereavement on carers.
24	Burden of care	The experience of caring as a burden.
25	Care costs	The costs of caring and the economic impact of care.
26	Carer depression	Depression in carers as a result of caring.
27	Carers and health	The impact of caring on carers' health and wellbeing.
28	Carers and employment	The impact of caring on carers' labour force participation, and implications for employers.
29	Carers needs	Carers' needs for support in caring.
30	Conflict in caring	Boundaries, tensions and trade-offs in caring relationships.
31	Crisis	Crisis in the supply of care, and in carers' capacity to continue caring.
32	Emotional and physical impact	The impact of caring on individual carers.
33	Entering residential care	The decision to place a person in residential care and the impact on carers as they continue to care in a new context.
34	Ethical issues in caring	Ethical issues and dilemmas that arise in care.
35	Lifecycle and care	The transitions to care over the life course.
36	Measuring and evaluation	Outcomes and measuring impact of care.
37	Post-caring	What happens to carers when the caring situation ends.
38	Psychological impact	Psychological impact of caring; and psychological interventions aimed at improving well-being.
39	Quality of life	The quality of life of carers and those they care for – the positive and negative effects of caring.
40	Resilience and coping	Carers' resilience, and the strategies they adopt in coping.
41	Risks in care	Practical and psychological risks in caring situations for both carers and those they care for.
42	Satisfaction and caring	The satisfactions people derive from caring, or satisfaction with particular support.
43	Social exclusion	The impact of caring on social inclusion and participation.
44	Stress and strain	The emotional costs of caring and the experience of related stress.
45	Longitudinal study	Longitudinal investigation of carers and caring situations.

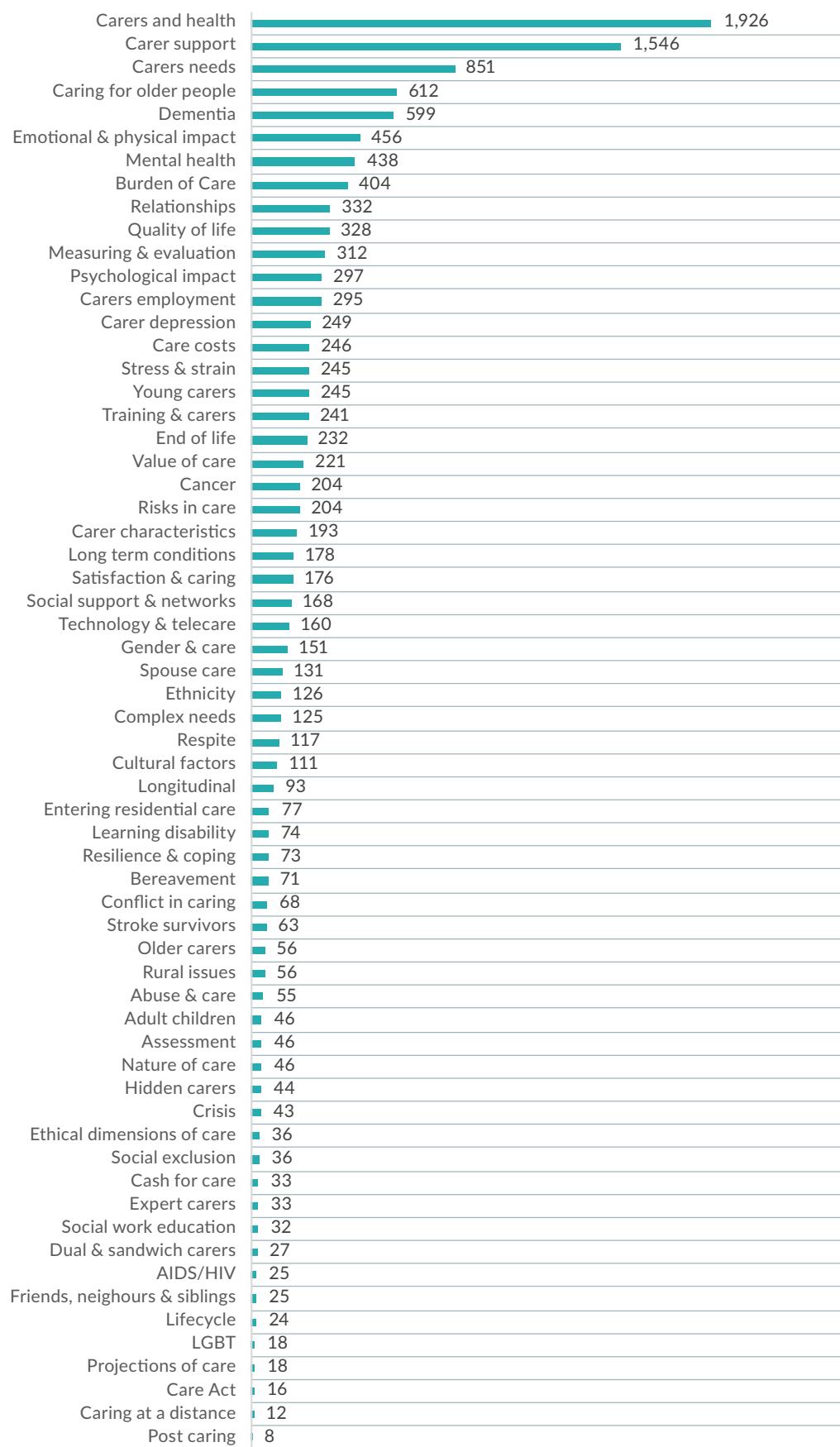
TABLE 1: Categories and definitions of themes (continued)

CARER VARIABLES

46	Adult children	Adults caring for parents/in-laws, and parents caring for adult children with disabilities.
47	Carer characteristics	The characteristics and features of carers in different situations and relationships.
48	Caring at a distance	Long distance care, and managing care when not co-resident or in propinquity.
49	Cultural factors	Cultural and social factors that affect caring situations and relationships.
50	Ethnicity	Specific aspects of caring in BME communities.
51	Expert carers	Carers as experts in the needs of those they care for.
52	Friends, neighbours and siblings	Carers supporting friends, neighbours or siblings.
53	Gender and care	Gender differences and similarities in carers.
54	Hidden carers	The challenges of identifying and finding carers who are hidden or hard to reach.
55	LGBT	The caring situations of LGBT carers and those they support.
56	Older carers	Ageing carers and their needs.
57	Projections of carer supply	The future of care; predicting supply and demand factors.
58	Relationships and care	The multiple relationships in caring including parents; children; siblings; intergenerational care; mutual support; non-kin care, and other caring dyads.
59	Sandwich carers	The specific situation of carers with simultaneous responsibilities for parents and children, and for managing care alongside other demands.
60	Rural issues	Particular issues and challenges for carers in rural areas.
61	Spouse care	Caring for a spouse/partner and co-dependency.
62	Young carers	Young people – children and young adults – who are caring for other family members and are often hidden from view; their needs and support.

Figure 3 presents the frequencies of all the themes. As references could appear under multiple themes, the total number of smart group entries was larger than the number of discrete references (13,373 smart group allocations of 3,434 items). Charting the frequencies of themes in this way provided an overview of dimensions of caring that have attracted considerable attention and those that may be relatively under-explored. It is also a reflection of research funding and other priorities to date.

FIGURE 3: Thematic Frequency (n = 13,373)



By far the largest number of thematic references are to 'Carers and health', which includes the sub-themes of 'Health impact'; 'Carers'/caregivers' health' and 'Health consequences'. The 12 most, and least, frequently identified themes are summarised in Table 2. As this shows seven of the most frequently identified themes are concerned with aspects of the impact of caregiving; half of the least frequently identified themes addressed carer variables.

Documenting this patterning revealed where there are gaps and deficits in knowledge, where there appears to be considerable existing evidence and knowledge, and where future efforts relating to research, policy development and service commissioning might most fruitfully be directed.

TABLE 2: Most and least frequently identified themes

Top 12 themes	No.of refs	Bottom 12 themes	No.of refs
Carers and health	1,926	Cash for care	33
Carer support	1,546	Expert carers	33
Carers' needs	851	Social work education and carers	32
Caring for older people	612	Dual and sandwich carers	27
Dementia care	599	AIDS/HIV and carers	25
Emotional and physical impact	456	Friends. neighbours and sibling carers	25
Mental health	438	Caring and the lifecycle	24
Burden of care	404	Projections and care demography	18
Relationships	332	Lesbian Gay Bisexual and Transgender carers	18
Quality of life	328	The Care Act and carers	16
Measuring and evaluation	312	Caring at a distance	12
Psychological impact	297	Post-caring	8

Scoping the knowledge

In the following four Sections, using the four-fold categorisation of the themes, the nature of carer-related knowledge is examined. This analysis highlights some of the major issues and questions.

1. Carer variables

As outlined above, the themes that are clustered under the heading of 'Carer variables' all relate to carers characteristics and features of carers. The key issues and questions that emerged were around relationships and care; young carers; adult children as carers; older carers, spouse and partner care; gender and care; ethnicity and carers; hidden carers. These are discussed below.

RELATIONSHIPS AND CARE

The largest number of references occurred under the sub-heading of 'Relationships and care' (332), and are indicative of the complexity and multi-dimensional nature of care and caregiving.

All care takes place within a relationship – typically a dyadic one. There are a range of such dyads; they can be between parent and child; between spouses or partners; between siblings, or between friends or other non-kin carers (Sebern and Whitlatch 2007). The majority of research and intervention studies on family care focus on only one person from the care dyad. For instance in work on spouse carers supporting a partner with Multiple Sclerosis, the complex emotional relationship of responsibility these carers experience has led to a conceptualisation of caring around 'caring as worrying' (Cheung and Hocking 2004). However, this focus on one member means that the way "each participant affects and is affected by the other" (Sebern and Whitlatch 2007) in a dyadic process is overlooked.

While the nature of pre-existing relationships can have a positive or negative influence on willingness to provide care (Lyonette and Yardley 2003) caring can also both reflect the nature of a given relationship, and impact on and change the nature, quality and dynamics of that relationship. This is particularly the case of caring for people with dementia and caregiving for stroke survivors. In both situations there are often personality and behavioural changes, and the impact on family dynamics can be particularly challenging (Abilitt *et al.* 2009). A survey by the Carers Week Partnership (2013) reported that 7 in 10 of respondents were not prepared for the impact on relationship they experienced with the person they cared for. Nearly six out of ten respondents had experienced difficulties in this relationship, although some (two out of five) reported an improvement in their relationship (such as becoming closer). The survey findings also highlight the impact on wider relationships, with breakdown in other family relationships and fractured friendships being reported by respondents.

Exploration of caring relationships includes the issue of relationship identity; being a carer can overshadow and fundamentally alter previous relationship identities (Lyonette and Yardley 2003). The literature revealed that people, and particularly older people caring for a spouse or partner, can find a carer identity difficult to assume or to distinguish from the normal expectations and roles of family and partner relations (Corden and Hirst 2011). Non-identification, or late self-identification as a carer can be significant, especially when it impacts on access to services and support, or to benefits such as Disability Living Allowance and Carers Allowance.

Other analyses focus on 'networks' rather than dyads to conceptualise and understand caring relationships. Rutherford and Bowes's (2014) analysis, for example, of British Household Panel Survey data together with qualitative interviews of older people and carers mapped 'networks of informal care' to better understand and describe the complexity and nuanced nature of caring (see also Keating *et al.* 2003). They distinguish between 'social', 'support' and 'care-giving' networks, and consider the extent to which social networks "evolve into care-giving networks when a member has an increased care need" (Keating *et al.* 2003). Nocon and Pearson (2000) similarly focus on the role of friends and neighbours in supporting older people, recognising that such

support "generally appears to be different in quantity and kind from that provided by family carers", although there is a 'fuzzy boundary' between neighbourliness, friendship and care. With reference to carers of people with dementia, Charlesworth and colleagues (2007) found that these carers are likely to experience reduced social networks because of fewer opportunities to socialise and the stigma they felt from caring for someone living with this condition. Hence, they are more likely to report less social interaction and fewer friendships than non-carers.

However, despite all these insights there are significant gaps in knowledge and understanding of these relationship dynamics:

- Blieszner (2006) points out that most gerontological research mainly addresses caregiving by spouses and adult children. As a result, less is known about caregiving by siblings, extended kin, and friends; how needed care is provided to ever-single persons and those who are estranged from relatives;
- there has been relatively little attention paid to following relationships over extended periods of time, which again is particularly relevant to older people and a lifetime of relationships.

Care by siblings can be associated with young carers, but another dimension concerns adult sibling carers of people with intellectual disabilities for whom the transition to the role of primary carer typically occurs late in the lifecycle. In their USA based qualitative study, Coyle and colleagues (2014) identified a set of challenges associated with the transition of care from parent to sibling carer for adult sibling carers of people with intellectual and development disabilities (IDD). The similarities between the experiences of these sibling carers and those of older carers who are adult children or spouses include stress reported by participants, life choices triggered or necessitated by the caring role (including retirement from paid employment), and "Intrafamily struggles and negotiations that were required in establishing and maintaining supports within the family system" (p.310). The experience of caring for adults ageing with disability was recognised to be both similar to, and different from that of caring for people ageing into disability.

Taggart *et al.* (2012) point out that the needs of ageing family carers and of older people with intellectual disabilities reflect the increased life expectancy for people with intellectual disabilities, and mean that they are now more likely to live with a family member who will also have additional support needs. The illness or death of a parent is often the trigger for unplanned challenges and dilemmas for siblings and other relatives suddenly confronting ongoing care for their family member.

As has been noted, much of the focus of research on care has been on the relational aspects of care-giver and cared for, but this dyad is often nested within wider family and social networks of caring relationships. The negotiation of caring responsibilities and decisions particularly between siblings concerning who takes on major caring responsibilities, or how these are shared, is one aspect of this wider context. Leinonen's (2011) research with Finnish adult child carers found that while in many cases siblings were described either as entirely absent or as providing occasional backup, some interviewees reported that caring for the parent(s) was shared with their other siblings. Consequently, three main patterns of responsibility between siblings were identified: absence; backup; and togetherness.

YOUNG CARERS

Young carers are officially defined as children and young people aged under 18 who help to look after a relative with a condition, disability, illness, mental health condition or a drug or alcohol problem. The 2011 census found 177,918 children and young people aged 5–17 in England and Wales had caring responsibilities (2.1% of the cohort), typically young carers are helping care for a parent or sibling. Some estimates put the figures much higher, and the Carers Trust (2016), for example, cites the figure of about 700,000 young carers in the UK. Despite young carers representing a small proportion of the total carer population (five million people aged 16 and over in England, and 12 per cent of adults), it is clear that research interest and campaigning efforts are being increasingly directed towards young carers, as reflected in the analysis presented here in

which the theme of young carers was the second most prevalent within the category of carer variables.

The 'discovery' of young carers in research and related literature, both in the UK and internationally (Becker 2007), is reflected in the work that has been undertaken in estimating prevalence, but also in more in-depth and qualitative exploration of the experiences of young carers and the impact of caring on their lives, particularly on their education.

Critical analysis has highlighted the need to challenge representations of young carers as 'victims' or 'heroes' and to understand the impact of caring on their lives and the implications for their own wellbeing (Aldridge 2008). There has been particular focus on the situation of children and young people caring for parents with mental health problems, and the worry young carers often experience about the consequences – both for themselves and for the family member they care for – of asking for help (Aldridge 2002, 2006).

The consequences of caring for young people can include psychological and physical stress, social isolation, and educational under-achievement (Hounsell 2013). Nonetheless, research has also found positive outcomes associated with caregiving, including self-worth, satisfaction in caregiving and a sense of maturity (Charles 2011).

The experiences of young carers are in many ways similar to those of carers of any age, but as Bolas and colleagues (2007) emphasise, the impact of caring is more complex as it typically occurs at a time of major change and challenge associated with adolescence. The negative impact on young carers' educational attendance and achievement also has enduring consequences for their subsequent employment prospects, with young adult carers being less likely to be in education, training or employment (Hounsell 2013).

Much of the focus on young carers has been on those caring for sick or disabled parents, and the 'parentified child' is a recurrent theme to describe and analyse the role reversal that can occur with children assuming adult responsibilities (Earley and Cushway 2002).

The dominant paradigm of young carers research has been criticised on several fronts for the assumptions it makes about the nature of disability and the implied inadequacy of disabled parents. Banks *et al.* (2001), for example, review the shortcomings of various models and suggest that alternative conceptual frameworks are required that allow consideration of children and young people in a more complex and inclusive way and within the context of their family. While supporting young carers is vital, it is recognised in much of the discourse that there are risks that support serves as "propping up exploitative caring arrangements" (p.812). Adequate support to the sick or disabled person is essential to relieve caring demands, and particularly personal care that both children and their families view as inappropriate (Dearden and Becker 2004).

ADULT CHILDREN AS CARERS

Traditionally it is care by adult children, particularly those born in the 'baby boomer' generation (1945–54), that has been most closely associated with the concept of the carer. Most informal care for older people in England is provided either by an adult child, a spouse, or both. Care by an adult child is particularly important for people aged over 85, where the likelihood of having a surviving spouse is considerably reduced (Pickard 2008). The future availability of care by adult children is expected to decline for a number of reasons including smaller families; increased childlessness among future cohorts of older people; the decline of co-residence of adult children and their parents, and the continued increase in women's employment.

In their scoping review, Bastawrous and colleagues (2015) explore the unique aspects of care by adult children in terms of the role reversal aspects of relationships, and consider how changes in the parent-child dynamic can impact negatively on health and wellbeing. They identified the features of the demands on adult child carers (ACCs), and specifically the number of different demands arising from a range of relationships and potentially giving rise to role conflict in ways that were not the case for spousal carers.

Gans *et al.* (2013) have explored the 'trade-off' between caring for children and caring for parents. They argue that in previous generations childcare and parental care were independent periods of care. Hence adult children were relatively free of childcare responsibilities by the time they needed to care for older family members. However, demographic trends now mean that childcare and parental care are likely to overlap. Not only is this a reflection of delayed childbearing but also of the lengthening of adolescence, with young adults delaying their independence for economic and other reasons, and meaning that middle-aged parents may continue to support their 'boomerang children' for extended periods. This concept of the 'sandwich generation' of women with caring responsibilities for children and parents was coined in the 1980s. Although studies at that time found a low likelihood for women to be in this position, current demographic trends mean that the simultaneous provision of support to more than one generation has, and will, become more prevalent (Gans, *et al.* 2013). Indeed, more recent research suggests that in Britain one third of women aged 55–69 are providing care to both younger and older generations. Further exploration of conflicting demands in the three-generation configuration involved is required and it is important that such exploration is not limited by reliance on cross-sectional data (Grundy and Henretta 2006).

Juggling the demands of caring for children and other relatives with paid employment is a key dimension of this 'sandwich care' (Evandrou and Glaser 2004). Work undertaken by Carers UK and Employers for Carers (2014) has also illuminated these challenges and emphasised that "one in seven people in the workplace are likely to have caring responsibilities and that many of these employees may be juggling multiple caring roles". Some of the implications of combining different role responsibilities are also addressed elsewhere in this report when considering the impact of care.

OLDER CARERS, SPOUSE AND PARTNER CARE

As might be expected, there is considerable overlap between knowledge and research on spouse (and partner) care and that on older carers. Moreover, with continued population ageing, the role of the older spouse carer is expected to be increasingly important (Pickard *et al.*, 2000). Evidence shows that there are important differences between older carers and other carers; older carers are typically spouses or cohabitantes, and are more heavily involved in care than non-resident carers (Milne and Hatzidimitriadou 2003). In addition, they are coping with more complex health needs in the person they support, often with multiple co-morbidity, and are more likely to also have their own health and disability challenges (McGarry and Arthur 2001). Indeed, Torge (2014) argues that while demographic changes mean that older people with disabilities increasingly provide care, how older spousal carers with disabilities and impairment experience caregiving has been relatively neglected in research. Older and spouse carers are also particularly likely to need to cope with the demands not just of their partner's physical infirmity, but also of cognitive decline, behavioural change and communication difficulties, for example when associated with dementia and strokes. In the case of the latter, the transition to the role of carer can be sudden and dramatic with no prior warning, and carers in such situations often experience significant strain and psychiatric morbidity (Draper and Brocklehurst 2007).

The distinctive nature of spousal care has important implications for older carers. As Milne and Hatzidimitriadou (2003) point out, within marriage, caring is seen by the carer and cared-for as an extension of the mutuality and interdependence of their marital roles and these roles are often indistinguishable. This underlines both the difficulties that can arise in identifying older carers when they do not conceptualise their role in this way, but also points to the reality that much spousal care – particularly in later life – has at least a component of co-dependency and mutual support.

As with any caring dyad, spousal carers cope in different ways and despite the 'burden of care' that many undoubtedly experience, caring can also bring satisfactions and enable people to continue to value what is often a relationship of very long-standing.

Understanding the distinctive characteristics of older carers has implications for the nature and manner of professional support. The 'choice' to become a carer, or to continue caring, for example may have little meaning "in the context of relationships characterised by lifelong obligations and reciprocity" (Pickard *et al.* 2000, p.742). The sense of obligation is also likely to mean that older carers are reluctant to ask for help or to admit that they are struggling to cope.

However, not all older carers are providing support to a spouse or partner; with longer life expectancy, ageing carers are also to be found with life-long responsibilities for their disabled adult children (particularly for people with intellectual disabilities), and often with no plans for the future despite carers being aged in their 70s or older (Bowey and McLaughlin 2007). This group of carers are uniquely distinguished by the duration of their caring, alongside concerns about their own health status and ageing, and about the future care of their son or daughter after their own death or incapacity (Perkins and Haley 2013).

GENDER AND CARE

Caring has long been seen as an activity predominantly undertaken by women, particularly by those in middle age, and that women commit more time to caregiving than men. However, despite the fact that among those aged over 70 a higher proportion of men are carers, and they are more heavily time committed to care-giving (typically for a spouse), the significance of men as carers in later life has received less attention (Dahlberg *et al.* 2007).

Milne and Hatzidimitriadou's (2003) work on older husbands as carers highlights not only the existence of this often-overlooked group, but the fact that there are clear differences in the experiences of older men and women in being a carer and the meaning of caring, such that older husband carers are "widely regarded as wonderful" (p.7). In their exploration of Swedish adult daughters' perceptions of the caring undertaken by their fathers, Eriksson *et al.* (2013) found the daughters valued their fathers' softer side and the care that they provided to a spouse, but they also drew attention to the cost that such feminisation had for their fathers in their wider social relations, particularly with other men, and the contradictions that caring and gender role identity produced (Eriksson *et al.* 2013).

Del Bono and colleagues (2009) challenge the relationship between gender and caring in later life. They argue that the apparent difference is due to gender differences in marital status; as older men are more likely to be married, and married people are more likely to be carers, there are higher levels of caring among older men. Once differences in marital status are accounted for, the relationship between gender and care provision among older people is overturned. Moreover, these gender differences are likely to reduce or disappear in the future. This is because there will be a decrease in the percentage of married men and a significant increase in the number of single, divorced or separated women.

A further dimension of gender and care concerns care in the context of Lesbian Gay Bisexual and Transgender relationships, which until recently has been largely absent from the care discourse (Manthorpe 2003) and research (Willis *et al.* 2011). Research which has been undertaken has highlighted these carers' difficulties in being accepted as 'next of kin', and being excluded from crucial discussion and decision making in end of life care (Price 2005).

ETHNICITY AND CARERS

A further aspect of variation in the diverse carer population concerns ethnicity, and as with some other variables, this is a dimension that is often regarded as 'hidden' or where carers are deemed 'hard to reach'. Caring occurs in all communities and relationships, and while there are shared and common features in the experience of all carers, there are also distinctive elements in the experience of different BME communities, and reflecting different cultural and social expectations and assumptions. For example, there are distinctive issues around language and communication needs; culturally appropriate services and support; and the barriers created by implicit and explicit racism and prejudice (Katbamna *et al.* 2002). Black Asian and Minority Ethnic (BAME) may also face more challenges than other carers because of the way that cultural barriers, stereotypes and

language can increase their chances of poorer health, poverty and social exclusion (Carers UK 2011).

At the same time, black and minority ethnic carers are not a homogenous group, and there is considerable diversity between and within communities. Greenwood *et al.* (2015) emphasise that there are both shared and unique experiences, and reasons for not using services, for example, may apply to many ethnic groups, including the white majority.

Assumptions about the patterns of kinship networks within and between generations in minority ethnic communities may tend towards the view that 'they look after their own', but this has come under critical scrutiny from a range of research. Exploration of informal support in South Asian communities, for example found carers no more likely than those from other communities to be supported by wider kinship and social networks (Katbamna *et al.* 2004). Lawrence *et al.*'s (2008) study of attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK identified both 'traditional' and non-traditional' caregiver ideologies. A traditional ideology was associated with seeing caring as 'natural, expected and virtuous', and in turn, this informed a feeling of fulfilment in caring, experience of strain, and attitudes towards support services. The authors found that the majority of the South Asian, half of the Black Caribbean, and a minority of the White British participants had a traditional ideology. The implications of such findings for support will vary depending on traditional/non-traditional ideologies. For instance, Lawrence *et al.* (2008) argue that the former may need help to see services as supporting not substituting for their own input, and to understand that professional help is not needed because of a failure to fulfil family responsibilities, while carers with non-traditional ideologies may find fewer intrinsic rewards in caregiving and may attach greater value to being able to remain in employment and protect other social roles.

Somerville's (2001) study of Bangladeshi family carers' experience of palliative care also drew attention to the sense of family duty to the point of declining help from formal services, and under-lined the isolation experienced by carers lacking wider family members and networks in the UK.

A further aspect of ethnicity and care concerns the relationship between care and migration within the European Community. Work undertaken by Ackers (2004), for example, argues the case for an evidence-based approach to European policy making which addresses the complex and fluid relationships between mobility and care. The impact of the vote to leave the European Union in the 2016 referendum remains to be understood in this context.

HIDDEN CARERS

The nature of caring means that almost by definition much of it is hidden from view and takes place behind closed doors; nonetheless, some caring relationships are less visible – or expected – than others. The terminology of 'hidden carers' is widely used to refer to two phenomena. On the one hand, it can refer to carers failing to identify themselves as such (and often not perceiving themselves as 'carers' but simply as doing their duty to a parent, partner, child or other relative) and thereby remaining hidden from or unknown to services. It is also frequently used to describe the challenges of identifying and locating specific sub-sets of carers – most often including elderly or disabled carers; young carers; rural carers; men; carers from black and minority ethnic groups, and carers in other groups that may be 'below the radar', including those in LGBT relationships. These carers can remain hidden because of a lack of awareness on the part of health, education, care and support services that fail to identify these carers as they are not attuned to recognising them or have limited cultural awareness of their existence. For carers, this lack of recognition means they fail to have access to support and services that may assist them in their multiple roles and unmet needs.

Carduff *et al.* (2014) emphasised that barriers to carer identification are two-fold – those that stem from carers themselves, and those arising from services (in their research focusing on primary care). This means that improvement strategies need to address both dimensions, namely

supporting carers to self-identify and request help, and also encouraging services to be proactive in seeking out carers and reducing barriers to access.

Good practice guides and resources issued by various organisations have focused on the importance of raising professionals' awareness and understanding of carers and their needs generally and for groups of hidden and marginalised carers specifically (RCGP and Princess Royal Trust for Carers 2008, Gray and Robinson 2009). However, Greenwood *et al.*'s (2010) exploration of GPs' awareness of carers showed that despite GPs recognising the importance of supporting carers and being pro-active in doing so, there was a gap between aspiration and reality.

2. Type of care

The approach to the discussion of the second category 'Type of care' (namely the nature of needs of the cared for person, and the features of the care situation) will be the same as in the previous section on carer variables, namely to highlight the key features in the literature.

As already established, carers are extremely diverse. Who they are providing support to, and the reasons for needing care, are similarly varied. However, in the review the most frequently identified types of care – in descending order – are associated with:

- Older people
- Dementia
- Mental health
- End-of-life
- Cancer
- Long-term conditions (including neurological conditions).

Less frequently identified are references associated with caring for people with multiple and complex needs, with an intellectual disability, with AIDS/HIV, and for stroke survivors.

None of these groups is mutually exclusive and there are considerable areas of overlap within and between categories, particularly between dementia and older people, but also between older people and intellectual disabilities, and mental health. Given the significance of both caring for parents and of spouse care, it is not surprising that so much of the review materials relate to dementia and older people.

Tensions in caring relationships may arise particularly around questions of identity and autonomy. This has been explored in relation to 'care' in mental health. A characteristic of some mental health conditions is their fluctuating nature, and people may remain well for long periods. This means that they do not need to be cared for all the time. This changing picture challenges traditional discourses on care in terms of the 'regular and substantial' definition as used in policies and legislation. Caring can also lead to conflicting needs of carers and users of service as their roles change between periods of distress and wellbeing. For instance with Bipolar disorder, people can experience a shift from being partners, to an asymmetrical balance of responsibilities or roles (Henderson 2002).

In addition, when the carer is 'professionalised' by services and is seen as the expert in 'caring for' the person with mental health needs, this can have a 'devastating impact on partnerships' and relationships. This is particularly the case where there may be disagreement within a relationship about a diagnosis and therefore the need (or lack of it) for care. Another potential source of relationship difficulty for carers of people living with mental health problems is the conflict they experience because of their ambivalent status within mental health policy; multiple additional roles may be demanded of them, namely advocates, gatekeepers and proxy decision-makers. Whether they can simultaneously fulfil all of these is questionable, is likely to require some

significant compromises on their part, and potentially creates situations in which the incompatibility of these roles creates stress (Henderson 2002, Keywood 2003).

Similar tensions and potential conflicts have also been identified in the intellectual disability field. Williams and Robinson (2001) identified three major sources of conflict or disagreement between carers and a family member with an Intellectual disability: the need for a break from caring; the need to speak for their relative; and concern over behaviour. Pilnick *et al.* (2011) also highlight the long-standing recognition of the difficulties that can arise in transition planning for young adults with intellectual disabilities. Tensions arise between carers' concerns for their adult child (and indeed for their own lives) and aspirations for choice and self-determination.

The tensions between care and protection are also increasingly recognised in relation to caring for people with dementia. Askham *et al.* (2007) identify three kinds of conflicting social relationship likely to be found when people with dementia are cared for at home: custodial care, an intimate relationship and home life. A related debate is emerging around the use of telemonitoring, particularly in caring for people with dementia. Draper and Sorell (2013) for example, have drawn attention to the ethical tensions that can arise. Ganyo and colleagues (2011) have similarly identified ethical concerns around the use of telecare for remote monitoring and surveillance, including falls detection, highlighting issues relating to autonomy, privacy, benefit and the use of resources. Godwin (2012) has argued that the complexity of using assistive technology (AT) in dementia care necessitates individualised, person-centred ethical assessment. White and Montgomery's (2014) exploratory study of the ethical issues experienced by carers in making decisions about electronic tracking to manage wandering behaviour by people with dementia, found carers prioritising safety over liberty and autonomy.

It is important to recognise, as the discussion above has explored, that the interests and preferences of carers and those they care for are not always identical and – at times – may be contradictory or at least in tension with one another. This is likely to be a feature of all caring relationships, regardless of the reasons for care, but the dissonance is more apparent in situations where there is some cognitive impairment or mental illness. Recognising the interdependencies of the needs of carers and those they care for in a dyadic relationship requires the areas of tension and conflict to be acknowledged and managed.

3. Impact of care

As the charts earlier in this report demonstrated, the impact of care on carers is the single largest category of all analyses and represents almost 40 per cent of all themes identified. While every caring situation is distinctive, there are many aspects of caring which are common to all or most carers. As many commentators point out, caring is a complex experience that can impact on all aspects of a person's life. Identifying that there may be physical, emotional or psychological impacts is often referred to using the shorthand of the 'burden of care' and the considerable literature on this topic features in the first part of this section. This term is not used in a pejorative sense, rather, it is used to convey that there are many ways in which caring is demanding, arduous, stressful and costly in physical and psychological wellbeing as well as in practical and personal terms.

The other key issues that emerged from the analysis of this category that are also discussed in this section are Satisfactions of caring; Resilience and coping, Carers and employment; Health impact of caring.

BURDEN OF CARE

Various assessment tools to measure carer burden have been developed for use in both research and clinical or practical support contexts. Charlesworth, Tzimoula, and Newman (2007) point out that some of the early measures in particular have been criticised for shortcomings such as being theoretically incoherent; having poor psychometrics, an implicit assumption that carers' experience of burden is explained by the care-recipient's levels of impairment; being 'patient/user-centred' as opposed to 'carer-centred'; a lack of sensitivity to change; and, a use of summary scores that mask the underlying sources of burden.

More recent measures such as the Carers Assessment of Difficulties Index (CADI) are generally seen to provide robust measures of the multi-dimensional nature of care burden, reflecting both the frequency of potentially stressful events (objective burden), and the carer's perception of their stressfulness (subjective burden) (Charlesworth *et al.* 2007). Further development of the CADI has subsequently produced related indices of the CASI (Carers Assessment of Satisfaction Index) and CAMI (Carers Assessment of Managing Index).

Deeken *et al.* (2003) carried out a review of instruments developed to measure carer burden, needs and quality of life – three categories that in terms of measures have largely been developed separately despite there being considerable interaction between them. A recurrent theme identified in their review reinforces findings from other studies, namely the complexity of carers' responses to the demands placed on them.

The development of instruments to assess dimensions of carer burden can have multiple applications. While there is clearly an important contribution to theoretical and research understanding, as Deeken *et al.* (2003) comment, there is a relative dearth of studies using instruments to test outcomes linked to interventions and their effects on carers. If assessment instruments are to be robust and useful to both researchers and practitioners Deeken *et al.* argue clinical assessment tools must be refined and there needs to be further research about caregiver interventions in order for practitioners to effectively intervene.

Much of the 'burden' focus in the literature and carer discourse comes from exploration of dementia carers who are generally found to experience higher levels of burden. This might be expected given the symptoms that can often accompany dementia including: behavioural disturbance and distress, confusion and cognitive impairment, wandering, incontinence, and physical dependency. However, Campbell and colleagues's (2008) multiple regression analysis found that a person's level of cognitive function; the level of help required for everyday living; behavioural and psychological symptoms were not significant contributors to carer burden. Indeed, it was not objective severity variables that impacted on the sense of burden, but carers' subjective interpretation of their experiences and their self-efficacy. The implications of the study

challenge assumptions about dementia carers' burden, and underline the issues to explore with carers in assessment and to ensure an understanding of individual circumstances.

De la Cuesta-Benjumea's (2011) qualitative research with women in Spain providing care for relatives with advanced dementia has drawn attention to the importance of coping strategies in removing oneself from the caring identity to act on other identities, and 'taking leave' from the life of care-giving. Such findings add insight to the nature of respite and the "importance of connecting with other selves for the relief of burden" (p.1794).

SATISFACTIONS OF CARING

One of the variables that can impact on subjective experience of burden concerns the satisfactions that may be derived from caring. Iecovich (2011) refers to the "gain and strain" theory of caregiving, and points out that while burden has been widely investigated, less attention has been directed towards satisfaction. Examples of existing findings are:

- quality of relationship can have a significant impact on both caregiving burden and satisfaction (Iecovich 2011);
- carers who identified more positive feelings were less likely to report depression, burden or poor health (Cohen *et al.* 2002);
- the most significant predictors of carer satisfaction were better relationship quality and a greater intrinsic motivation to care (Lyonette and Yardley 2003).

Negative consequences of caring are known to be associated with poor outcomes (including mortality) for the carer, and increased likelihood of permanent institutional admission for the care recipient. If increasing the satisfactions from caring can reduce carer burden, there would seem to be particularly valuable insights gained from a greater understanding of the interplay between these dimensions. However, as with much carer research, longitudinal analyses (as opposed to the use of cross-sectional data) are required to fully understand the effects of satisfactions on caring, which positive aspects might be more important than others, and how we might support and help enhance these.

RESILIENCE AND COPING

That some carers manage the multiple demands of caring better than others has led to explorations of different coping strategies and how they relate to experiences of 'care burden' in order to identify how best to support carers and enhance their resilience. Conceptualisation of coping strategies in many studies draws on the work of Lazarus and Folkman (1984) who defined coping as:

constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that appraised as taxing or exceeding the resources of the person (p.141).

'Coping' therefore refers to the 'thoughts and acts' that carers bring to solving problems and thereby reducing stress. These coping strategies are usually classified as emotion-focused, and problem-focused; and approach or avoidance. This theoretical framework provided the basis for the later development of the Carer's Assessment of Managing Index – CAMI (Nolan *et al.* 1995).

The concept of 'resilience' in managing the demands of caring receives particular attention in the mental health and psychology literature. Analysis of spousal dementia carers' capacity to be resilient, and the factors that facilitate or impede them indicates resilience is a multidimensional construct, rooted in individual, community and societal levels (Donnellan *et al.* 2015).

Variables that influence carers' coping strategies have been identified. Lockeridge and Simpson (2013), for example, explored younger carers coping with caring for a partner with young onset

dementia. There is evidence that younger carers experience greater emotional distress than carers of older people with dementia, and that they experience greater difficulty coping with associated challenging behaviour. However, younger carers have been relatively overlooked in research into the subjective experience of caring for people with young onset dementia.

One of the features of caring that is common to many situations is that of uncertainty, but this is arguably a particular aspect of caring for people who have experienced strokes. Greenwood *et al.* (2009) point out that the suddenness of stroke, the diverse nature of effects, and the unpredictability of recovery often means responses from clinicians are 'vague', adding to the uncertainty and stress of carers. Important aspects of carers coping strategies appeared to be accepting uncertainty but also recognising the positive aspects of situations; carers who had previous experience of caregiving were more likely to consciously adopt positive coping strategies and to do so at an earlier stage (following routines; taking things slowly; accepting the situation; keeping a sense of humour, and identifying positives). Quinn and colleagues (2014) meta-synthesis of qualitative research on how spouses cope and adjust to caring for a partner following a stroke highlighted similar points and their desire for better stroke-related information and practical training to assist them. The study identified seven themes relating to how spouses adapt and cope: seeking information; searching for own space and well-being; suffering in silence; putting one's own needs aside; adapting to a changed role; social support, and hope and optimism.

CARERS AND EMPLOYMENT

How caring impacts on employment and the significance of employment in carers' lives are important not only on the individual level, but also in wider societal and economic terms. Enabling carers to remain in or return to employment has been a focus of government policy since the first National Carers Strategy of 1999 and in all subsequent iterations (Employers for Carers/Department of Health Task and Finish Group 2013).

Studies about ways of supporting carers to work and care have shown that work-related flexibility (such as in working part-time hours) in facilitating the juggling of competing demands was often less helpful than it appeared. 'Informal flexibility' was valued as being more useful, including being contactable at work which gave carers greater peace of mind and enabled them to focus more effectively on their work. Such informal arrangements however, were predicated on trust between carers and their employers, which was not always the general experience (Vickerstaff *et al.* 2009).

A programme of pilot projects to explore initiatives supporting carers to remain in or return to employment was funded by a consortium of government departments including the DH, DWP and GEO from 2015 to May 2017. The Carers in Employment (CiE) programme is being independently evaluated by the Institute for Employment Studies, but their report was not yet available at the time of the scoping study. Nine sites were funded and their focus was on one or more of three key areas: information advice and guidance; assistive technology, and employer support and training. Carers and employment remains an under-researched topic.

HEALTH IMPACT OF CARING

While the health impact of caring is the most frequently identified theme, a majority of these references are, in fact, less to do with carers' health *per se* than they are associated with the health of the person cared for. Nonetheless, as much of the literature emphasises, these two dimensions are inextricably linked.

The physical and psychological health of carers is a concern on many fronts. Moreover, as previously discussed, many carers are older people (half of co-resident carers of older people) and likely to have their own health care needs. Given the increased complexity of conditions that are being managed in the community and in people's own homes, carers are also increasingly involved in carrying out skilled or complex and intimate health care tasks, particularly those relating to continence care.

There are multiple reports and examples of research findings documenting that caring is likely to be associated with inequalities in physical and psychological health. However, the impact of caring on carers' health is multi-dimensional and complex. Evidence indicates that the relationship between caregiving and health is neither linear nor causal, and typically the impact is mediated by a range of factors. These include the intensity of care (carers providing at least 20 hours of support a week are at greater risk); being co-resident carers, spouse carers and female competing demands carers face (e.g. the simultaneous demands of paid employment, caring and other family responsibilities); individuals' coping skills and resources, as well as by the support they receive more widely (Hirst 2004, Glaser *et al.* 2005, Vlachantoni *et al.* 2013). Vlachantoni *et al.* (2013) distinguished between factors identified in cross-sectional and longitudinal analysis. The former is more likely to highlight the role of the carer's and the cared-for person's demographic and socioeconomic characteristics, and of specific characteristics and nature of the care provided (e.g. duration, level). In contrast, longitudinal analysis shows that while informal care is not associated per se with adverse health and mortality outcomes, particular types and durations of caring have negative outcomes.

The analysis of the impact of care in this section highlights the difficulties in distinguishing between objective and subjective dimensions, causes from consequences and the complexities of impact more generally. However, the identification of risk factors is important for the identification of groups of carers who are most likely to experience adverse effects, and informing policy and practice in supporting carers.

4. Support and carers

As the charts presented in Section 3 demonstrated, of the four categories of material identified in the scoping review, support for carers attracted the least attention amongst our themes. While it is important to emphasise that many materials and resources cover more than one category, nonetheless it is true to say that there has been relatively greater attention directed to understanding the nature of caregiving, the characteristics and experiences of carers, and the consequences of caring on their lives, than to examining what makes a difference or which interventions can be judged to be (cost) effective. Nonetheless understanding carers' needs and how best they can be supported are vital objectives that need to be informed by evidence and knowledge. This section considers the key findings on support for carers, both in terms of the support needs carers identify, and in their experience of specific interventions and their effectiveness.

CARERS NEEDS AND ASSESSMENT

In recent years, there has been unprecedented policy commitment to carer support. More specifically, there has been a focus on the importance of addressing carers' needs in national carers strategies and legislation, including the Care Act 2014. As outlined in the Introduction to this report, this latest legislation consolidates previous legislative requirements and introduces a parity of esteem between carers and service users, strengthening carers' rights to an assessment of need and placing a new duty on local councils to fund support to meet carers' eligible needs, as well as entitling them to relevant information and advice.

Although the emphasis on assessing carers' needs has increased, translation into practice continues to be challenging. For example, the number of carers' assessments carried out has been both low overall and variable between councils. Scourfield (2005) suggests that 'bureaucratic incompetence' and poor professional awareness might offer part of the explanation, but more fundamental is the 'ambiguity' experienced by professionals dealing with competing messages and conflicting issues. Seddon and Robinson (2015) have also identified the issue of practitioner ambivalence towards carer assessment despite the changing policy and legislative context giving greater recognition and rights to carers; fears of not being able to deliver services due to cutbacks are a key source of such ambivalence.

Despite the fact that the aspirations and expectations of the 2014 Care Act are laudable and, as yet, it is early days since the legislation, analysis undertaken by the Carers Trust as to the difference the Care Act is making to carers' experience is not altogether encouraging (Carers Trust 2016). For example:

69% of carers responding to our survey noticed no difference since its introduction and many expressed frustration and anger at the lack of support they received in their caring role. Our survey of carers found that too many carers were unaware of their rights, 65% of carers who responded to our survey had not received assessments under the new Care Act. Our survey made some carers aware of their rights for the first time. The quality of Care Act assessments is cause for concern, 34% of carers responding to our survey felt that their carers' assessment was not helpful (p.4).

The annual survey of the 'state of caring' undertaken by Carers UK also provides insight to the reality of carers' new rights (Carers UK 2016). This showed that the widespread pressure on health and care services meant that carers are still struggling to get the support that they need to care, work and have a life outside caring. Carers often experienced considerable delays in getting an assessment, and over half (53%) felt their experience of an assessment was poor. This was because there was insufficient consideration of their ability and willingness to provide care, and their support needs in relation to juggling care with training or education, or remain in or return to work alongside caring.

INTERVENTIONS TO SUPPORT CARERS

Increasingly, policy and research attention has been directed at examining interventions to support carers and identifying what works. This is reflected in a recent carer policy development; in support of the new national Carers Strategy the Department of Health and Social Care commissioned an economic analysis modelling the implications of unpaid care provision over the next 20 years, and estimating the impact of policy interventions to support carers. At the time of writing, the report on this analysis had not yet been published.

Although evaluating the effectiveness of interventions is complex and the evidence is generally inconclusive and of variable quality, the scoping review showed there were also some examples of interventions where evidence is more conclusive. These were interventions for dementia carers and psychosocial interventions. In order to capture these findings, they are therefore presented below under three subheadings: Evaluating the effectiveness of interventions; Interventions for dementia carers; and Psychosocial interventions.

Evaluating the effectiveness of interventions

As mentioned above, the evidence from evaluations of interventions is also often far from conclusive and research varies in quality. A range of studies can be used in illustration. The first is Arksey *et al.*'s (2004) review of respite services and short-term breaks for dementia carers which found the evidence "mixed and at times contradictory" (p.8). For example, although there was limited evidence of the effectiveness and cost-effectiveness of respite care and 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. While they point out that lack of evidence of effectiveness should not necessarily be interpreted as evidence of ineffectiveness, Arksey *et al.* (2004) argue that the absence of firm conclusions and the apparent contradictions in some of the findings clearly indicate that this area is highly complex and that there are methodological issues. They also comment that it may be unrealistic to expect use of respite services to indicate substantial effects for carers, especially for carers who delay the use of services until there has been a significant deterioration in the care recipient's condition.

Likewise, in their systematic review of different models of community-based respite for frail older people and their caregivers, Mason *et al.* (2007) also found that the existing evidence does not

allow any firm conclusions about effectiveness or cost-effectiveness to be drawn. They point to the gaps in evidence and the lack of good quality, controlled evaluations for all types of respite care, highlighting the urgent need for robust research that has greater potential to inform current policy and practice.

Lopez-Hartmann *et al.*'s (2012) more recent systematic review focused on the effectiveness of different types of interventions targeting carers of frail elderly people. Their conclusions were similarly cautious in terms of the effect of caregiver support interventions. Mixed or inconclusive evidence about the effectiveness of services has also been identified for other groups of carers, such as carers of people with mental health problems (Arksey *et al.* 2002).

In their meta-review of international evidence on interventions to support carers Parker *et al.* (2010) argue that while the strongest evidence of effectiveness was in relation to education, training and information for carers (which were found to increase carers' knowledge and abilities as carers), there was little other clear evidence of the effectiveness of any of the interventions included in the reviews. Parker *et al.* (2010) also highlighted the poor quality of research, particularly in terms of it often being based on "small numbers, testing interventions that have no theoretical 'backbone', with outcome measures that may have little relevance to the recipients of their interventions" (p.67).

In the updated version of the 2010 review, sixty one systematic reviews were included and interventions such as carer champions, respite care, resilience programmes and health checks were evaluated (Thomas *et al.*, 2016). It transpired that respite care was the only intervention that had been robustly evaluated to date. Evidence for interventions that may have a positive effect was identified for carers of people with dementia, carers of people with cancer, and carers helping stroke survivors. These interventions included caregiver support groups; telephone counselling; educational programmes; art therapy; meditation-based interventions; computer-mediated interventions; cognitive reframing; couple-based interventions; and psychosocial interventions.

In their conclusions, Thomas *et al.* (2016) emphasise that:

- in many cases the findings are inconclusive, contradictory or beset with methodological weaknesses in the original studies;
- there is no 'one size fits all' intervention to support carers;
- there remains a dearth of good quality primary research about the effectiveness of most support interventions for carers (and there are particular gaps in the evidence relating to young carers and those from minority groups). This, they believe, reflects the "lack of underpinning theories of change or intervention logic that would allow the right questions about the right outcomes to be asked" (p.97).

Although the complexity of evaluating the effectiveness of interventions, as demonstrated above, in part reflects the diversity of the carer population and that individual circumstances can vary in ways that make a difference to resources and outcomes, there are several other contributory factors. One is rooted in the nature of the dyadic caring relationship; while services may be developed to support carers specifically (such as respite and breaks from caring), services provided to support a person needing care (such as home care) may also benefit the carer.

There are also underlying methodological challenges related, including how methodological differences and the use of different outcomes measures and variables often make it difficult to compare results between studies. In addition, specific measures of effectiveness employed in evaluations may be quite different from the subjective perceptions of carers. Conclusions about effectiveness therefore need to address what constitutes effectiveness from the carers' viewpoint as much as from apparently objective measures.

Interventions for dementia carers

There have been a number of studies on interventions for dementia carers which have produced more definitive results. These have focused on the following interventions:

- professionally-led support groups. Chien *et al.*'s (2011) meta-analysis of professionally-led support groups for caregivers of people with dementia found them to be "significantly effective";
- meditation-based interventions. Hurley and colleagues (2014) identified eight studies of meditation-based interventions for carers of people with dementia. They found that longer-term follow-up of results suggests that the short-term gains are not always maintained, suggesting that interventions may wish to provide 'booster' sessions to support carers in their meditation-based practice;
- psychosocial information and communication technology (ICT) interventions: These interventions typically use DVDs, CD-ROMs, computer programmes or the internet and are aimed at both providing carers of people with dementia with information and also improving their wellbeing and coping skills. A review by McKechnie *et al.* (2014) found the evidence on effectiveness to be mixed but generally positive. However, because interventions were complex and had multiple components, it wasn't always possible for the authors to disentangle the efficacy of various factors. Limitations in the studies were also a consideration, particularly in terms of poorly defined aims and the absence of control groups. Although the availability of home computers is continuing to expand rapidly, not everyone has access to such resources, nor to high speed broadband. Some groups of carers (including older carers) are likely to be disadvantaged in having unequal access to, or expertise in the use of technology required for ICT interventions (Carers UK 2012);
- educational programmes for carers of older people with dementia. Marim *et al.* (2013) conducted a systematic review of educational programmes for carers of older people with dementia, but focused only on randomized controlled trials. They found there was evidence that this type of intervention is more effective than others in reducing the burden of care.

Psychosocial interventions

The scoping review that is the subject of this report showed there is an increasing emphasis on psychosocial interventions. Waldron *et al.* (2013) reviewed psychosocial interventions to improve outcomes for carers of people with cancer while Regan *et al.* (2012) examined such interventions directed at couples affected by cancer and Cheng *et al.* (2014) reviewed psychosocial interventions for stroke survivors and their carers. The evidence emerging from such research is positive. For example, Waldron *et al.* (2013) concluded that there is evidence that interventions targeting communication and education can improve carers' quality of life.

Other studies have focussed on 'Cognitive reframing' – a particular element of psychosocial interventions which can be used with carers and others to identify and modify negative beliefs and interpretations. Vernooij-Dassen *et al.* (2011) reviewed the findings across 11 studies and found positive effects over 'usual care' for psychological morbidity (anxiety, depression) and distress, but no effects for coping or self-efficacy, carer burden, reaction to the relative's behaviour, or institutionalisation.

The findings by Thomas *et al.* (2016) on the possible value of a range of psychosocial interventions to support carers raises the issue of attention to innovative and new models of support more generally, and particularly to models that use RCT methods for evaluation and explore the impact over a sustained period of time. One such intervention worth highlighting is START, not least because it is the first trial to show longer term positive impact. The STrAtegies for RelaTives (START) intervention used a manual-based therapy delivered by supervised psychology graduates without clinical qualifications, and has been described by Knapp *et al.* (2013). Coping strategy therapy sessions taught carers techniques to better understand the behaviour of the person with

dementia they cared for, to manage behaviour, change unhelpful thoughts, promote acceptance, relax and engage in meaningful activities. Initial evaluation (over an eight-month period) found the intervention to be cost effective and showed positive outcomes in carers' affective symptoms and quality of life. Longer term follow-up showed similarly positive results in terms of improving carers' depression and anxiety symptoms and quality of life, in the short term and for up to 24 months later (Livingstone *et al.* 2014). Furthermore, at two-year follow-up carers in the 'treatment as usual' control group "were seven times more likely to have clinically significant depression than in the START intervention group" (Livingstone *et al.* 2014, p.546).

Conclusions

Sections three to seven of this report have provided an overview of the parameters and content of the research and knowledge relating to carers as captured by the scoping review. The state of knowledge on carers is rich, diverse and multi-faceted, and the report has presented key themes while acknowledging that there are multiple other dimensions within the knowledge base. In this final section we offer some conclusions for policy, practice and research in relation to carers. However, we begin by highlighting below the key messages that we have identified throughout the review.

KEY MESSAGES

- The number of carers continues to rise and people will increasingly experience one or more periods of caregiving during a lifetime.
- Knowledge and evidence about carers is extensive and varied, and comes from a wide variety of sources directed at different audiences with diverse needs and interests. These sources include: official government statistics; academic research; and from bodies representing carers. It also covers a vast array of subjects encompassing theoretical and conceptual models, professional practice development, and the voices and lived experience of carers.
- Although there are similarities in the experiences of carers, caring and carers are extremely diverse and involve all sections and age groups of the population.
- 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.
- All care takes place in a relationship, and every relationship is different, featuring unique strengths and challenges, and typically resulting in complex and sometimes ambivalent emotions associated with caring, including identifying 'care' beyond the expectations of a normative activity. 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 particular deficits in relation to BAME carers and LGBT groups.
- The profile of 'young carers' has grown considerably in recent years as they have attracted the focus of research, but they remain a small proportion of total carers.
- Older carers (i.e. over 65 years old) continue to be relatively invisible in policy, practice and research and are less likely to identify themselves as carers because of the context of their relationship which is characterised by long-term reciprocity, mutuality and interdependence.
- There are emerging 'sandwich care' generation issues: adult child 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 – reflecting the extension of dependency of adolescents/young adults and their economic dependence on parents.

- Just as carers are diverse, so the nature of their caring situation varies, but the most frequently identified topics in the evidence and knowledge are concerned with older people and dementia. Mental health – 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 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, but this language may be pejorative and unidimensional in many circumstances and needs to be seen entwined with the satisfactions and intrinsic benefits of caring that many experience. This is not to promote a rose-tinted view of caring, but to acknowledge the complexity and multiple dimensions that need to be recognised as co-existing within caring relationships and interdependencies.
- How carers cope – and how they can be taught appropriate coping strategies – is attracting more attention and results are promising in terms of improved wellbeing for carers, although 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. Around half of all carers are in paid employment, and caring responsibilities are a major reason for premature withdrawal from the labour market (particularly for women). Support for carers in employment is a complex territory without any quick fix and flexibility may not be offered to carers in low paid, or low skilled work compared with those in more professional and managerial roles. Equally, focusing on supporting working age carers is of no benefit to many of the most heavily committed carers who are retired.
- Much of what we know about carers is about their characteristics, e.g. their lives, and the nature and duration of the care they give, and less is known about interventions that support carers in general and specifically which 'work' for which carers. However, lack of evidence of effectiveness is not evidence of ineffectiveness.
- Evidence about what services and support can benefit carers is equivocal and some of the findings – such as on respite care – are contradictory. The quality and focus of research needs to be developed to more effectively explore what works for which carers and in what circumstances. 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). Comparative studies of the effectiveness and cost-effectiveness of interventions are also needed.
- There is not a quick fix or a one-size-fits-all model for supporting carers (given the diversity discussed), so 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 – what is being measured, and whether the measures are most appropriate needs to be considered. However, assessment of effectiveness must address the dyadic context in which care takes place; without attention to both sides there are risks that any conclusions are distorted or risk causing negative unintended consequences.
- A major shortcoming in much of the research is the reliance on cross-sectional evidence because of the absence of longitudinal datasets (with some minor exceptions). The need to examine the impact and experience of caring over time, and the nature of caring through the life cycle has long been recognised, and the capacity to do so would be much enhanced by the availability of robust longitudinal data.

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH FROM THIS REVIEW

This report has identified multiple areas around carers experiences, what makes a difference to them and which groups (and sub-groups) of carers are likely to be under particular strain and pressure. These have a number of implications for policy, practice and research; as explained in the introduction, the scoping review report is being used to underpin two other resources that will be accessible, useable and dynamic in order to inform a wide range of carer-interested parties across carer policy, practice and research.

In terms of specifically informing policy and practice the factors that may make the most difference to carers, and those they care for, may not be the standard service 'offer'. Evidence on respite services, for example, is at best equivocal, but breaks from care are often valued by carers. Building carers' resilience and enabling them to develop strategies to manage the stress and pressure they experience appears to be an important area to develop further. At the same time, this cannot be an excuse for failing to provide practical help and support, and these two components need to be developed in tandem.

For the research community, and those that commission research, in addition to the need to for more longitudinal data, there are also some important conclusions about the nature of the evidence base and knowledge about carers. Milne and Larkin (2015) have previously identified the bifurcated nature of care-related knowledge, with two separate and distinctive paradigms, namely 'Gathering and Evaluating', and 'Conceptualising and Theorising'. Their analysis indicated that the former paradigm:

is closely aligned to the dominant discourse about caring in the UK and primarily focuses on profiling the nature and extent of care-giving, assessing its impact and evaluating the effectiveness of carer-related policy and services (p.5).

The scoping review of carer-related research and knowledge demonstrated that much of this body of work is focused on: describing and quantifying the carer population profile in terms of numbers and characteristics; documenting the impact and sequela of care-giving within a 'burden of care' narrative, and – to a lesser extent – evaluating support for carers, usually within relatively narrow cost-effectiveness parameters of 'what works' in enabling carers to continue caring.

Milne and Larkin's second paradigm of '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).

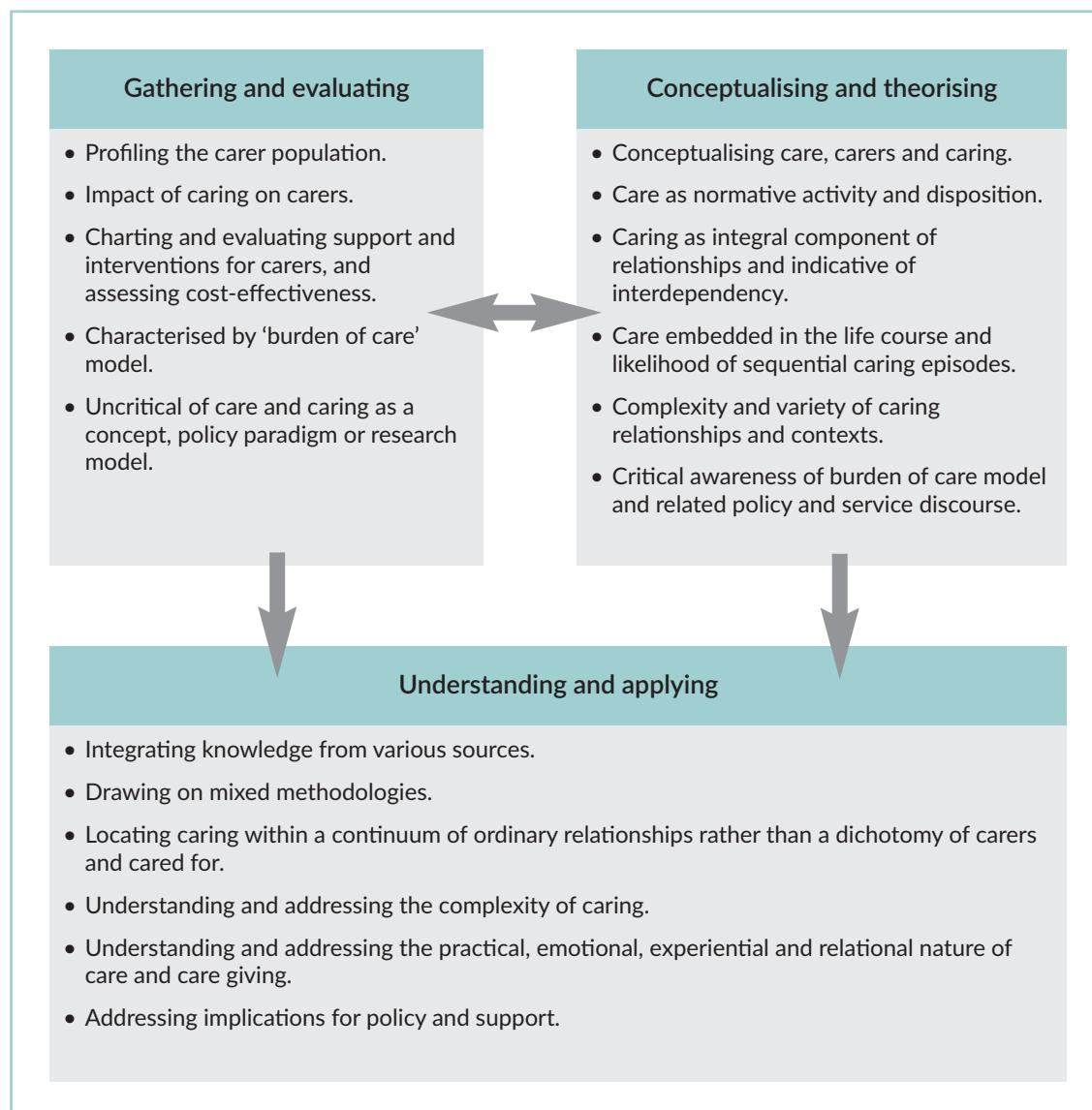
While the term 'carer' is in widespread use and generally understood in popular, research and policy discourses, it is not universally embraced or owned, even by many putative carers for whom it is integral to the nature of a dyadic relationship. Furthermore, the appropriateness of the term is contested, not least because of the complexity of inter-dependency and reciprocity within relationships which render the carer/cared for distinction a false dichotomy.

Milne and Larkin's conclusion that there are two separate research paradigms operating in the field of carer-related knowledge, which have different perspectives and approaches resonates with the current review. As we have described and discussed, there is no shortage of knowledge and research about carers, but the overall contribution may indeed be less than the sum of the parts, and certainly less than it could be with appropriate synergies exploited and greater awareness and understanding of the respective contributions of different approaches. Figure 4 outlines an integrated research and knowledge paradigm under the title of 'Understanding and Applying'. This model seeks to bring together the features and distinctive components of the two dominant paradigms which have tended to be in some tension if not diametrically opposed.

This paradigmatic issue is of more than academic importance. Indeed, it is central to the conceptual understanding of carers and caring within the health and social care system. Reference was made earlier in this report to the tensions and contradictions that have existed in the development both of research and in the underlying assumptions informing policy and practice. The implementation of the 2014 Care Act does not remove these challenges, and arguably the introduction of 'parity of esteem' for carers once again raises the issue of balancing the interests and choices of carers with those of people with disabilities or support needs. Failure to address this explicitly, or to assume that the interests always coincide, does not recognise the complexity and inter-connectivity of caring relationships for either party. The assumptions, beliefs and understandings about carers and caring that underpin policy in social care generally, and carers strategies in particular, need to be made transparent. As Arksey and Glendinning (2007) have pointed out:

This would mean that the common and separate choices and interests of both carers and the people cared for are not neglected (...). By incorporating support to both carers and care recipients, policy measures have the potential to facilitate increased choice for both groups (p.173).

FIGURE 4: Towards an integrated research and knowledge paradigm



The present review is one attempt to locate a synthesis of knowledge within an integrated paradigm. In place of the frequently fragmented and partial nature of research and evidence, we have sought to identify and understand knowledge drawn from a wide range of sources and approaches. We have not attempted to classify material along a hierarchy, nor to assess the quality of individual studies. We have also rejected adopting the dominant narrative of much research which typically addresses caring outwith the context of any relationship, and which risks constructing carers' needs in a separate and simplified manner that may be antagonistic to the needs of those they care for. Instead, our integrated paradigm has sought to illuminate the complexity of knowledge about care and caring and to understand the interdependencies inherent in relationships.

It is of ongoing importance that the state of knowledge about carers and their lived experience should be maintained and extended. It is also crucial to address the deficits in existing knowledge and to direct attention towards expanding the evidence base, while recognising that such evidence comes in many forms.

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