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# Seeing the Wood for the Trees

Carer-related research and knowledge: A scoping review

Melanie Henwood, Mary Larkin and Alisoun Milne  
Submitted to NIHR SSCR May 2017



Melanie Henwood Associates  
Health & Social Care Consultancy



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## Executive Summary

1. An NIHR-SSCR funded scoping review was undertaken on carer-related evidence and knowledge between April and December 2016. The objectives of the review had two complementary purposes: first, to provide a unique and comprehensive detailed mapping of what is known about carers and caring, and second in partnership with SCIE to provide a platform for a dynamic, searchable digital resource to be readily accessible to a full range of interested stakeholders.
2. While there is a great deal of research and evidence available about carers, it is generally fragmented, located in a variety of places and difficult to access. For the first time, the scoping review aims – uniquely - to bring together the knowledge in one place and for it to be accessible via a single portal.
3. The timing of the review has regard to the tasks associated with the implementation of the Care Act 2014, and the new duties it introduces in giving carers parity of esteem, strengthening carers' rights to an assessment and to information and advice, and requiring local councils to meet carers' eligible needs.
4. In this report we explore the background to the review in terms of the research and policy context before introducing the scoping review. The origins of academic research interest in carers in the 1980s and 1990s were largely based in sociological and feminist literature that identified the gendered nature of caring. This approach was also characterised by a conceptual separation of carers and cared for people, with care seen largely as the instrumental support of one person 'doing care' to another. Critical response to this model came in part from disabled people who rejected the passive recipient role and instead drew attention both to interdependence and – at times – conflicting interests.
5. The understanding of carers in the emergence of policy is also explored, including the implications of seeing carers as resources, or as entitled to support in their own right. Such considerations continue to be relevant in the context of the implementation of the 2014 Care Act and the stated objective of giving carers parity of esteem.
6. The review was undertaken by searching 10 key electronic bibliographic databases supplemented by additional web searches. In addition to mainstream academic materials, the review was concerned to identify and capture wider resources, 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.

7. Analysis of the resources adopts a selective thematic approach, highlighting the themes of particular significance in terms of frequency and attention. Caring is extremely diverse and involves 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.
8. 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.
9. Knowledge about 'hard to reach' groups – notably BAME and 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 are of increasing importance, 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.
10. 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.
11. 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 different strategies are required in different employment contexts.
12. 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 interventions do not appear successful against specified outcome criteria, carers may report positive subjective benefit from the process and experience of interventions.

13. The scoping review is intended to inform policy, practice and research. However, it does not offer an oracle or an index of solutions. Evidence is complicated and nuanced and almost all the conclusions need to be seen within specific caveats. However, as the review highlights, the current state of knowledge shines a light on areas that require attention and priority.
14. Conclusions about the current state of knowledge need also to inform future research and commissioning. Deficits in knowledge need to be addressed, with priority given to expanding the evidence base through using appropriate methodologies and models. We offer a model that attempts to integrate previously separate research paradigms; which acknowledges and incorporates the complexity of knowledge about care and care giving, and that seeks to understand the interdependencies inherent in caring relationships. Finally, much of the research evidence is cross-sectional and offers a 'snapshot' of a point in time; the value of developing robust longitudinal research in caring has long been recognised, and this review once again strengthens that argument.
15. For the first time, this review has used a scoping methodology to identify and classify the wide and diverse carer-related knowledge base. It is not offered as a definitive or final overview of this territory, which is dynamic and evolving. However, we have created a unique foundation for a resource that can be expanded and developed, lending itself to further analysis and exploration.



# 1 Introduction

- 1.1 The terms 'carer' and 'caregiver' are used throughout this review to refer to people who provide care and support, on an unpaid basis to people (children and adults) who are sick, disabled, frail or elderly, and which enables them to live as independently as possible in their own homes and in the community. In earlier years, the term 'informal carer' was often used to describe this type of carer, but 'carer' alone is now in more frequent usage (and 'caregiver' is the preferred term in the USA). It is important, however, to distinguish carers from people who are employed in social care (as care assistants, home care workers etc.) and who are paid to undertake personal care and support. While care workers are vital to enabling people to maintain their independence, they are part of a care economy and the issues surrounding their employment (terms and conditions, training and qualifications, regulation etc.) are of a different order to those relating to unpaid carers.
- 1.2 In using these terms, we recognise that they are not without controversy. Molyneaux et al, for example, have presented a critique on the adoption of the term 'carer', concluding that it is "ineffective and that its continued use should be reconsidered" (Lloyd, 2006; Molyneaux, Butchard, Simpson, & Murray, 2011). Lloyd has similarly drawn attention to the risks and limitations of reserving the term 'carer' to refer exclusively to unpaid carers (Lloyd, 2006). We recognise that caring is often a reciprocal relationship, and indeed this is a theme which runs throughout this report. We also accept that caring needs to be viewed through the lens of different relationships (such as parent, spouse, child etc.). However, the suggestion that in place of the term 'carer' "*descriptions of the caring relationship*" would be both more useful and acceptable to those concerned is one perspective among many, and there is no consensus about the adoption of an alternative lexicon. Our use of carer terminology does not imply lack of awareness of the contested nature of the word, nor of its lack of precision.
- 1.3 As we will explore in this report, there is growing interest in carers and caregiving in national and international research, and in a wider public discourse. An extensive body of research and knowledge has accrued since the 1980s, and particularly so in more recent years. The nature of this knowledge is diverse, and while it strongly features academic papers and research articles, it also includes: a disparate collection of 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 similar range of individuals, organisations, research centres and departments; third sector bodies and government departments and quangos. This richness and diversity is to be celebrated; however, precisely because of the disparate and wide-ranging nature of this knowledge, it is highly fragmented and compartmentalised. There has not previously been an attempt to comprehensively map and analyse this body of knowledge, or to delineate the contours of this landscape. This is precisely the focus of the present scoping review.

- 1.4 Carers are typically – although not always – family members, most often caring for a parent/parent-in-law; a spouse or partner; a child, sibling or other relative. Research into carers and knowledge about the caring life cycle has developed significantly in the past three decades. At the same time, carers have increasingly been acknowledged within policy and practice, both in national legislation and local implementation. It should not be assumed that this greater ‘carer awareness’ means that carers are therefore fully recognised and well supported, and particular groups of carers (notably older carers and also young carers) are often overlooked and poorly supported (Carers UK, 2015b)
- 1.5 The 2011 population census indicated that 6.5 million people in the UK are carers, an increase of 11% since the previous census of 2001 (Carers UK, 2015a). There is considerable ‘churn’ in the carer population, and each year more than 2.1 million people become carers and a similar number end their caring responsibilities (Hirst, 2014). It is estimated that 3 in 5 people will be carers at some point in their lives.
- 1.6 Around 4 million carers are caring for less than 20 hours each week, but 1.4 million people are providing at least 50 hours a week. The middle 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. Carers are engaged in a wide variety of help and support, from companionship and ‘keeping an eye’ on someone, to intensive personal and physical care. People caring for longer hours each week (typically those in the same household) are the most likely to be providing personal care.
- 1.7 Carers are most likely to care for a close family member such as a parent (33%), followed by 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 the middle aged 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.

- 1.8 This scoping review has distinctive objectives. For the first time ever a review has been designed to scope out and synthesise what is known about carers, bringing together disparate sources and materials to provide a unique and comprehensive review of carer-related knowledge and evidence. This is intended to inform and provide a resource for: researchers (and research funders); national and local policy development and practice, as well as for carers themselves, and for frontline support workers. Potentially this is a very large remit. We are focusing on research evidence, but also on wider knowledge, or what is often termed as 'grey literature'. Understanding what is known about carers is important for two major reasons:
- It enables the research community to overcome the fragmentation of existing knowledge and to look comprehensively to identify areas where evidence is thin or lacking and for future research to be targeted accordingly; and to avoid duplication of research investment.
  - It is vital that people who are most closely involved in policy and practice that impacts on carers are informed and knowledgeable and understand the implications of evidence for arranging the most appropriate support for carers.
- 1.9 The project had two primary aims. First, to comprehensively scope existing carer-related research evidence and knowledge, and thereby to provide a comprehensive and informed synthesis of what is known about carers, and to reflect on the range, type and nature of evidence. The resulting scoping review will support the second aim which is to enable an accessible digital evidence resource to be developed in partnership with and hosted by SCIE, that can be readily updated and maintained. Before we introduce our approach, methodology and analysis, we begin by setting the scene and exploring the background and context to the emergence of carers both as a focus of research, and also as the subject of legislation, policy and practice.
- 1.10 Implementation of Part 1 of the Care Act 2014 took effect in April 2015. This is a landmark piece of legislation for carers and integral to its effective implementation is synthesis of, and increased access, to carer-related information and knowledge for carers, people who use services and social care workers (ADASS, 2015; Carers UK, 2014).

- 1.11 The Care Act 2014 substantially replaces and consolidates existing 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 (2014) legally entitles carers to information and advice (HM Government, 2014; Larkin & Mitchell, 2016). The implications of the Act for enhancement of social care practice are significant: relevant stakeholders include: commissioners, care workers, social workers; carers themselves; carers' organisations, carers' support workers, people who use services and personal assistants.
- 1.12 The rise of carers as a focus of research and analysis paralleled (and arguably led) the growing recognition of carers within public policy. In Britain that development can be tracked from the mid-1980s. The review focuses on knowledge and resources produced since 2000, however, these need to be understood against the background of earlier research and analysis. In the UK much of the early theorising about caring came from academic feminist studies and sociological perspectives that identified the gendered nature of caring, associating the role of carer with women's social identity and their unpaid labour within the home (Finch & Groves, 1980, 1983; Graham, 1983; Ungerson, 1987; Walmsley, 1993). Indeed, some of the earliest studies of the experience of caring and nature of support for carers were undertaken by the Equal Opportunities Commission (Equal Opportunities Commission, 1980, 1984).
- 1.13 In the 1980s much of the focus of research conceptualised care as the instrumental support of one person 'doing care' to another, with the 'carer' and 'cared for' as a dichotomised pairing. This model came to be challenged not only because it was seen as a white middle-class perspective which failed to recognise class and race dimensions (Walmsley, 1993), but also because it addressed only one side of the care equation and tended to portray disabled people as passive recipients, and whose interests – particularly in terms of maintaining independent lives in the community – were depicted as antithetical to those of feminists (Morris, 1991).
- 1.14 Since the 1990s the critique – not least from disabled people - that caring may be characterised by interdependence, and that the boundary between carer and cared for can be fluid and shifting, has attracted increasing recognition and is a recurrent theme in this review (Larkin & Milne, 2013).
- 1.15 Twigg drew attention to the 'ambiguous position' occupied by carers within the social care system which, she argued, creates confusion in the relationship. Her analysis

identified three dominant practice models: carers as resources; carers as co-workers; and carers as co-clients (Twigg, 1989). This provided the foundation for the subsequent widely cited typology of caring with the addition of a fourth model of 'superseded carers' (Twigg & Atkin, 1995). Twigg and Atkin saw the dominant model operating in frontline practice as that of carers as a resource in which they provide the taken-for-granted support for a person, and where the interests of carers themselves are marginal. Where carers are perceived as co-workers, there is recognition of their contribution as partners in care, and of the need to maintain their well-being, but only in instrumental terms to enable the continuation of their caring. Where carers are co-clients they are seen as needing support in their own right, while in the final model of superseded carers, support is provided which can mean that the carer's role is no longer necessary.

- 1.16 The assumptions which lie behind each of the categories, and the tensions which they reveal in locating carers as part of the care system continue to resonate (Manthorpe, Illife, & Alison, 2003), and we return to some of these issues at the end of the review.
- 1.17 Since the 1990s there has been increasing recognition in policy and service development for ever increasing numbers of family carers across the UK. 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 strategic vision for recognising, valuing and supporting carers. Some key benchmarks in the emergence of carer policy can be identified and are summarised in Table 1.1.
- 1.18 To date, there have 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, 2010a; HM Government, 1999, 2008; Moran, Arksey, Glendinning, Jones et al., 2012). At the time of writing (March 2017) the latest iteration of a new National Carers Strategy was awaited from government. It is anticipated that this strategy will build on previous models and will focus *inter alia* on: raising awareness of the contribution of carers, and building more carer-friendly communities; recognising the diversity of carers and caring situations; and supporting carers in the most intensive circumstances, who are providing the greatest care and

who are at particular risk of crisis causing a breakdown in the caring situation. The findings of this review should inform implementation of the strategy and be of value in focusing attention on the evidence and knowledge base that should underpin policy and practice developments.

**Table 1.1: The UK Carers Policy Timeline 1995 - 2016**

<b>Policy Development</b>	<b>Date</b>	<b>Main Provisions</b>
<b>Carers (Recognition &amp; Services) Act</b>	<b>1995</b>	The first ever UK legislation for carers, giving those providing 'regular and substantial care' the right to an assessment of their own needs.
<b>Caring about Carers, first National Strategy</b>	<b>1999</b>	To enhance the quality of life of all carers by means of improved information, support and care. Introduced a new Carers Grant for local authorities to support carers to have breaks.
<b>Carers and Disabled Children Act</b>	<b>2000</b>	Gave councils powers to provide services directly to carers; gave carers the right to an assessment independently of the person they care for; enabled local authorities to make Direct Payments to carers; increased councils' flexibility to offer short breaks.
<b>Carers (Equal Opportunities) Act</b>	<b>2004</b>	Introduced a duty on councils to inform carers of their rights to an assessment of their own needs; required councils to take account of carers' wishes to undertake employment, education, training and leisure activities.
<b>Work and Families Act</b>	<b>2006</b>	Extended the right to request flexible working to employees caring for adults.
<b>'New Deal for Carers'</b>	<b>2006</b>	Announced in the White Paper 'Our health, our care, our say' alongside a commitment to update and extend the PM's Strategy for Carers. Other parts of the 'New Deal' were a national information service for carers; a 'Caring with Confidence' training programme; and additional funding to local authorities for emergency home-based respite for carers in crisis.

<b>Policy Development</b>	<b>Date</b>	<b>Main Provisions</b>
<b>Carers at the Heart of the 21<sup>st</sup> Century, updated National Strategy</b>	<b>2008</b>	<p>Set out a vision that by 2018 “carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.”</p> <p>In particular five strategic outcomes:</p> <ul style="list-style-type: none"> <li>• Carers will be respected as expert care partners, with access to services to support them.</li> <li>• Carers will be able to have a life of their own alongside caring;</li> <li>• Carers will be supported so they are not forced into financial hardship;</li> <li>• Carers will be supported to stay mentally and physically well and treated with dignity;</li> <li>• Children and young people will be protected from inappropriate caring and have the support they need.</li> </ul>
<b>Recognised, Valued, Supported (Next steps for the Carers Strategy)</b>	<b>2010</b>	<p>Four priority areas identified:</p> <ul style="list-style-type: none"> <li>• Identification and recognition;</li> <li>• Realising and releasing potential;</li> <li>• A life outside caring;</li> <li>• Supporting carers to stay healthy.</li> </ul>
<b>Care Act</b>	<b>2014</b>	<p>The Care Act, 2014 consolidates much earlier legislation on care. It also gives carers new rights, and ‘parity of esteem’ with those they are caring for. From April 2015 carers have a right to an assessment if they appear to have needs (removing the need for care to be regular and substantial), and if they meet eligibility criteria they are entitled to support. Local authorities have new duties to promote wellbeing both for carers and those they care for. Clause 2 of the Act also places a duty on local authorities to prevent, reduce and delay needs for care and support. Clause 4 requires local authorities to establish an information and advice service on care and support (including for carers); there is also a duty to provide independent advocacy if</p>

<b>Policy Development</b>	<b>Date</b>	<b>Main Provisions</b>
		needed to support people in assessment and support planning.
<b>Carers Strategy Call for Evidence Consultation</b>	<b>2016</b>	Consultation launched in March 2016 (until 30 June) with a call for evidence to better understand the needs of carers and what can be done to support them to “enjoy a happy and healthy life alongside caring.”

- 1.19 The expectations and aspirations of carer-related policy and legislation need also 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 & Milne, 2013; Larkin & Mitchell, 2016; Needham, 2011, 2014). Nonetheless studies show many carers - such as the growing number of older carers - are still routinely overlooked and unsupported (Buckner & Yeandle, 2011; Glasby, Ham, Littlechild, & McKay, 2010; Pickard, King, & Knapp, 2016; Ridley, Hunter, & Rosengard, 2010). 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). Arksey and Glendinning have concluded that both the concept and practice of choice is “highly problematic” for carers (Arksey & Glendinning, 2007). An emphasis on choice, they suggest, ignores the complex dynamics of care-giving relationships and “conflates the needs and opinions of carers and the people they support into a single (implicitly harmonious) unit.” The tensions and contradictions between the interests of carers and those they support, and between the respective carers’ and disability political movements, remain unresolved.
- 1.20 This brief overview provides the background to our study; we turn now to outline the approach and methodology.



## 2 Approach and Methodology

- 2.1 A scoping review methodology was deliberately selected as the most appropriate for charting and synthesising a range of evidence and knowledge of considerable breadth and depth. In adopting a 'scoping review' model, we followed the approach developed by Arksey and O'Malley (Arksey & O'Malley, 2005), while recognising that scoping reviews are "a relatively new approach for which there is not yet a universal study definition or definitive procedure" (Pham, Rajic, Greig, Sargeant et al., 2014). Arksey and O'Malley helpfully distinguished between the general approach of a scoping review and a systematic review in the following terms:

*"First a systematic review might typically focus on a well-defined question where appropriate study designs can be identified in advance, whilst a scoping study tends to address broader topics where many different study designs might be applicable. Second, the systematic review aims to provide answers to questions from a relatively narrow range of quality assessed studies, whilst a scoping study is less likely to seek to address very specific research questions nor, consequently, to assess the quality of included studies."* (Arksey and O'Malley, 2005, P.20)

- 2.2 A scoping study not only adopts a different approach and methodology compared with a systematic review, but it has a different purpose and objectives. Pham et al again offer the following exposition:

*"First, the purpose of a scoping review is to map the body of literature on a topic area, whereas the purpose of a systematic review is to sum up the best available research on a specific question. Subsequently, a scoping review seeks to present an overview of a potentially large and diverse body of literature pertaining to a broad topic, whereas a systematic review attempts to collate empirical evidence from a relatively smaller number of studies pertaining to a focused research question."* (P.372)

- 2.3 Daudt et al have also contributed to applying and adapting Arksey and O'Malley's framework (Daudt, Van Mossel, & Scott, 2013), and proposed this definition:

*"Scoping studies aim to map the literature on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking and research."* (P.8)

- 2.4 Arksey and O'Malley's framework identified various reasons why a scoping study might be undertaken:

- To examine the extent, range and nature of research activity.
- To determine the value of undertaking a full systematic review (i.e. a preliminary mapping of the literature).
- To summarise and disseminate research findings.
- To identify research gaps in the existing literature.

2.5 They suggest that the first two purposes are part of an ongoing process of reviewing “the ultimate aim of which is to produce a full systematic review”, while the second two types “*suggest that the scoping study might be conceived as a method in its own right – leading to the publication and dissemination of research findings in a particular field of inquiry*” (P.22). Subsequent debate and discussion of these objectives by other researchers has confirmed the view that scoping studies are

*“often misinterpreted to be a less rigorous systematic review, when in actual fact they are a different entity.”* (Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010) P.10

2.6 Our scoping study can be located within types 3 and 4: we are concerned with summarising and disseminating research (and knowledge), and identifying gaps in the existing evidence.

2.7 Arksey and O'Malley's framework had five main stages and a sixth they suggested was 'optional'. Subsequent commentary on the approach by other researchers has tended to conclude – as indeed did we - the consultation stage should be built in from the outset, although with room for interpretation about how it is achieved. The process between the stages they suggest is not linear but iterative, and may require reflexive repetition of different stages in order to cover the literature comprehensively. The stages are as follows:

- Identifying the research question.
- Identifying relevant studies.
- Study selection.
- Charting the data.
- Collating, summarising and reporting the results.

- Consultation exercise (optional)
- 2.8 There were a number of challenges in applying this framework to the present study. The ‘research question’ under consideration was one we had stated in extremely broad terms i.e. *“to comprehensively scope existing carer-related evidence and knowledge.”* This reflected our objective to draw together as much knowledge as possible from across the carer territory, but also to focus more broadly than looking only at research studies. This was a deliberate strategy, but it created significant challenges and logistical demands. Other recent scoping studies, although broad in approach, are quite specific in focus – looking at particular interventions or initiatives (Arksey & O'Malley, 2005; Brien et al., 2010; Daudt et al., 2013; Levac, Colquhoun, & O'Brien, 2010; Pham et al., 2014), Arksey and O'Malley, for example were addressing the effectiveness and cost-effectiveness of services to support carers of people with mental health problems. They identified 3,867 references, and 204 articles were selected for inclusion in the review.
- 2.9 The present scoping study, by contrast, was broad in both approach *and* focus; we were concerned not only with areas of practice or interventions, *but with the entire world of carers and their lives*. Our references and analysis were correspondingly wide
- 2.10 A scoping study is wide-ranging and seeks to map key concepts across a range of sources and types of evidence available. Indeed, the *breadth* of the approach is a distinguishing characteristic. The implications of this are significant. In the past, it has perhaps been assumed that a scoping study is a *rapid* alternative to a systematic review (Mays, Roberts, & Popay, 2001). Arksey and O'Malley challenged this perspective, and advanced the argument that a scoping review is both an entity in its own right, but not inherently quick or cheap.
- 2.11 All the scoping studies cited above used research teams with at least three full time equivalent researchers, and some employed large multi-disciplinary teams. Our study did not have such resources, being largely undertaken by one researcher. As such, we believe the resulting study offers a resource that is extremely useful, but which inevitably has some inherent limitations associated with the timeframe and resources available. An extended study would have allowed for an even wider ranging study and for greater depth of analysis. The logistical and practical demands of undertaking the study were considerable, particularly given the relatively limited resources and time available for the work. However, the resulting review has produced a resource that is wide-ranging, extremely rich in detail and that addresses multiple themes.

2.12 Inclusion criteria for the study were the following:

- Material published since 2000.
- Material available in the English language.
- Material focused on the care of adults.

2.13 The review searched for resources meeting the above inclusion criteria and where the title or abstract included 'carer' or 'caregiver'. Additional searches were undertaken using keywords which had been identified on *a priori* grounds including 'young carers'; 'older carers'; 'carers and health'; 'carers and employment'; and 'end of life care'. It was apparent that the generic search criteria were successfully identifying a wide range of references and citations and that these additional categories merely resulted in duplication. Searches were undertaken between June and December 2016. The following electronic bibliographic databases were searched:

- Academic Search Complete
- AMED
- ASSIA
- BNI
- CINAHL
- HMIC
- MEDLINE
- SCOPUS
- Social Care Online
- Web of Science

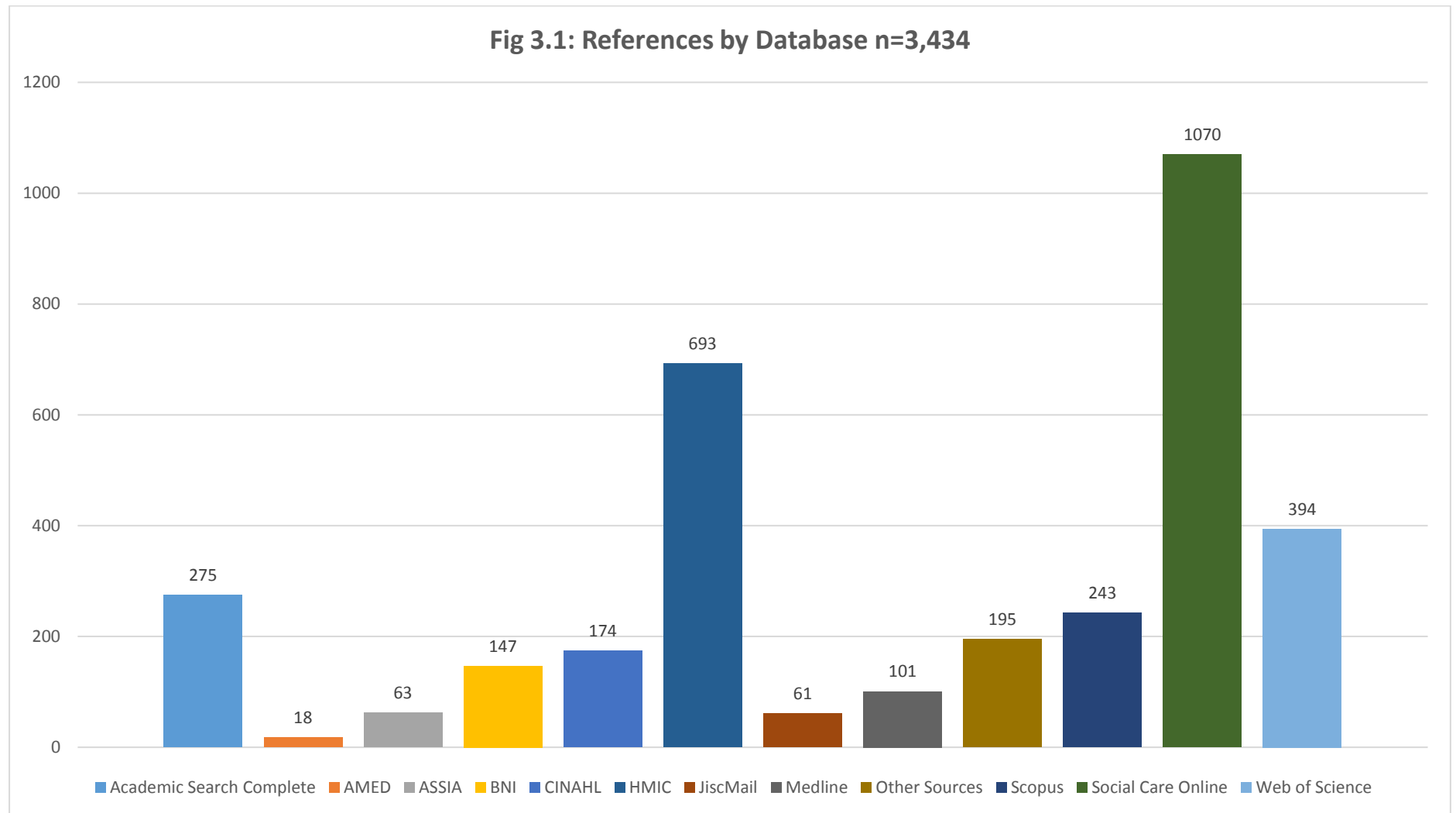
2.14 In addition, the resources from the JiscMail research email discussion list were searched, and miscellaneous other searches were undertaken in following reference lists. All materials were captured and saved using EndNote data management software, duplicates were removed and irrelevant materials screened out. In the following section, we map the range and type of material captured.

### **3 Mapping the territory**

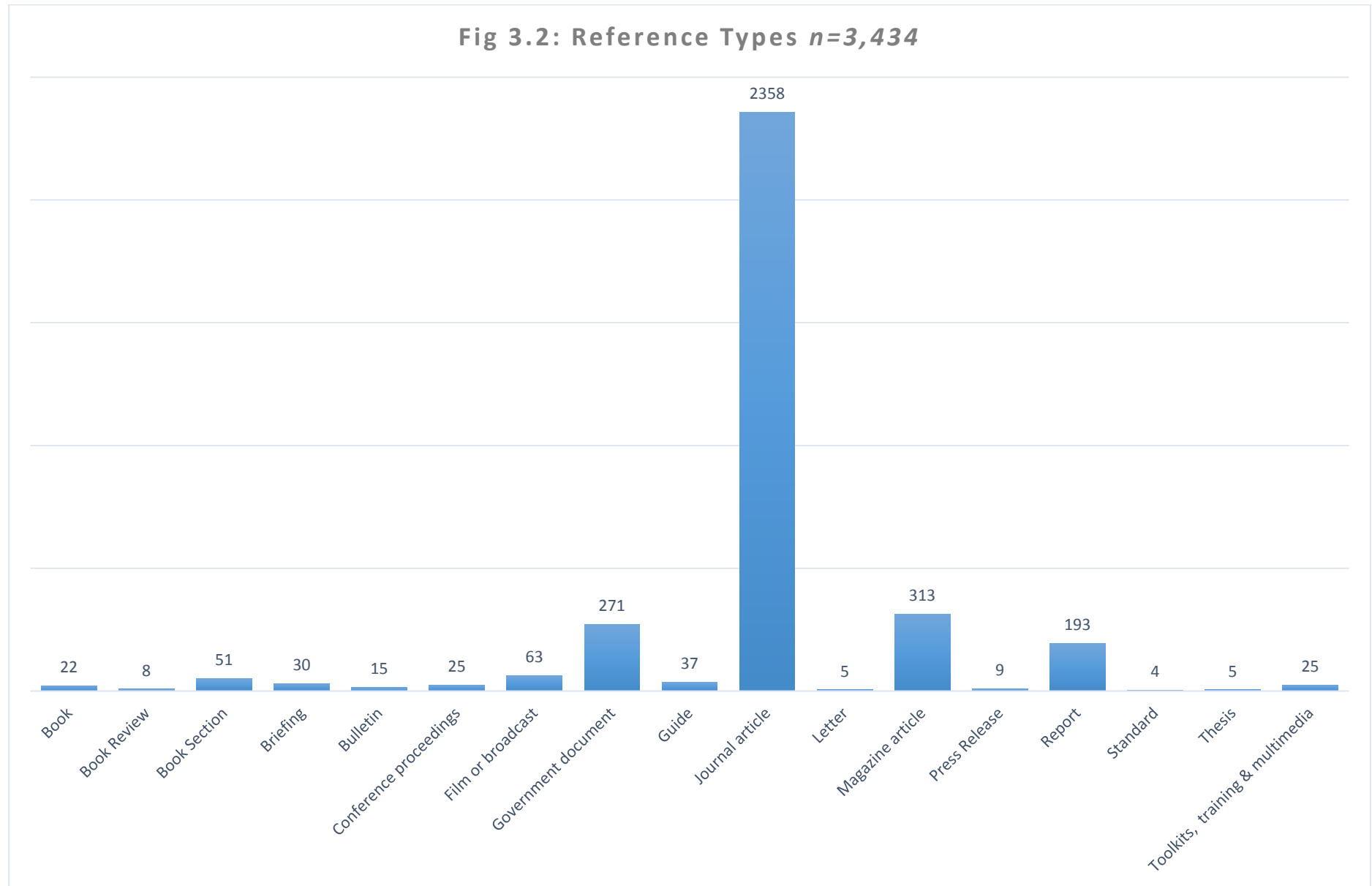
- 3.1 Sections 1 and 2 have presented the aims and objectives of the review and outlined the methodology that has been adopted in developing this scoping review. We turn now to address the findings of the review. We begin by summarising the major dimensions of the review findings, before examining themes and issues in greater detail.

#### **An introduction to the data**

- 3.2 After applying the inclusion criteria and removing duplicates, the review captured 3,434 references. The full reference list is presented in Appendix 1. The figures below indicate the distribution of material by source, and by type.
- 3.3 As Figure 3.1 demonstrates, three databases were especially productive (Social Care Online; HMIC; and Web of Science) and together accounted for more than 60 per cent of all references captured (respectively: 31%; 20% and 11%). Other data sources together contributed the remaining third of citations.
- 3.4 Materials were classified into 17 'types', but the top four categories together account for more than 90% of all classifications. Far and away the leading category (accounting for almost 70% of citations) was that of 'Journal Articles'. These were mainly peer reviewed articles in academic journals, but also included scholarly reflections and discussions of issues in other types of output. Other articles – particularly those identified in the professional and 'trade' press, which either report on events or developments, or which offer opinions on carer issues, were not included in this total and instead were coded as 'Magazine articles' (the second highest category at 313). 'Government Documents' represent the third highest category (271) and were gathered from across the GB Government as well as from the Northern Ireland Executive, the Scottish Executive, and the Welsh Assembly (and some from international resources).



**Fig 3.2: Reference Types  $n=3,434$**



- 3.5 Not all the government items are concerned exclusively – or even mainly – with carers, but they reference them as part of a wider focus on social care and related matters, and together these documents comprise an important part of the context to understanding the carer discourse. ‘Reports’ comprise the fourth highest category (193) and are a miscellaneous collection which includes 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; SCIE etc.) and by government departments, Quangos and agencies). The category also includes a wider grey literature including reports issued by major bodies representing carers (including Carers UK; the Princess Royal Trust for Carers; Age UK; the Children’s Society etc.).
- 3.6 It is important to understand that the coding of reference types is not always absolute, and although each item has been assigned only one type, some have blurred edges and could fit more than one category. For example, it may be somewhat arbitrary to decide whether a resource is classified as a ‘Guide’ or as ‘Toolkits, training and multimedia’. To a considerable extent, the materials have been enabled to classify themselves, and resources that self-describe as a ‘guide’ or a ‘toolkit’ have been classed as such. Multimedia materials, toolkits and similar resources typically originate from third sector organisations, from specialist training companies, and from SCIE.
- 3.7 Increasingly, many of the resources and ‘documents’ exist only in electronic form rather than in traditional print. Moreover, there are also a range of digital materials emerging including computer programmes; toolkits and e-training; web-based resources; films and broadcasts. The range of material and of diverse types of resource also underlines the different audiences to whom they are directed. Thus, much of the academic literature might be seen as contributions to developing the theoretical discourse on carers, and promoting debate of policy and practice issues. Other categories, including reports, briefings, standards, toolkits and training materials are focused more on the improvement of services and support and delivering best practice. In classifying the material across the 17 types, no attempt has been made to establish a hierarchy or to imply that any given type is ‘better’ or ‘superior’ to any other. Rather, the point is to understand the complexity of knowledge about carers, and to underline the importance of different materials and resources existing and being accessible to a wide range of audiences with diverse needs and interests. Some of these will be carers themselves seeking information or advice about their own situation and needs.



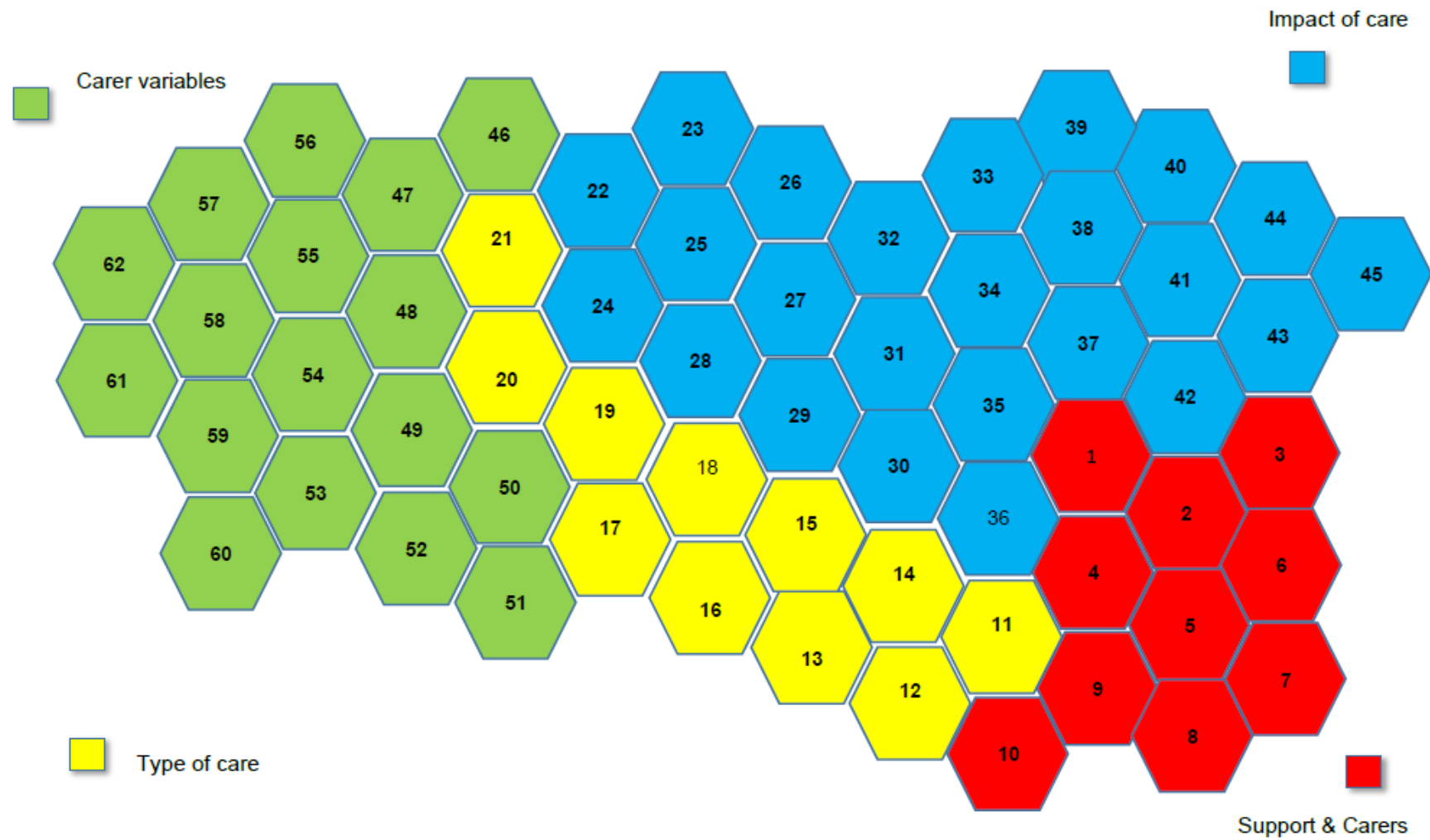
## Themes and Issues

3.8 The resources were coded and categorised into 62 themes. These were derived from keyword analysis of all references and identification of recurrent topics and issues. Dynamic 'Smart Groups' were then generated within EndNote to capture each cluster of references under all the headings. The themes, in turn, were classified within four major 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.

3.9 There is some blurring of the edges and the categories are not absolute. For example, some of the themes under 'impact of care' will also blend into 'support', but in general the four categories discriminate well and cumulatively describe the full landscape of the knowledge and literature. Figure 3.3 presents a visual representation of the distribution of themes between categories, while Table 3a presents a glossary defining the categories and each of the themes.

Figure 3.3: Themes classified by Category  $n=62$



**Table 3a: Glossary of Terms – Categories and definitions of themes**

<b>Support &amp; carers</b>	
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	Refers to 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 & 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 & telecare	Use of telecare, technology, telematics, robotics, electronic tracking etc. and applications for carers and those they support.
9. Training & 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).
<b>Type of Care</b>	
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. Learning disability	Caring for people with a learning disability, and carers who have a learning 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.
<b>Impact of Care</b>	
22. Abuse & 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.

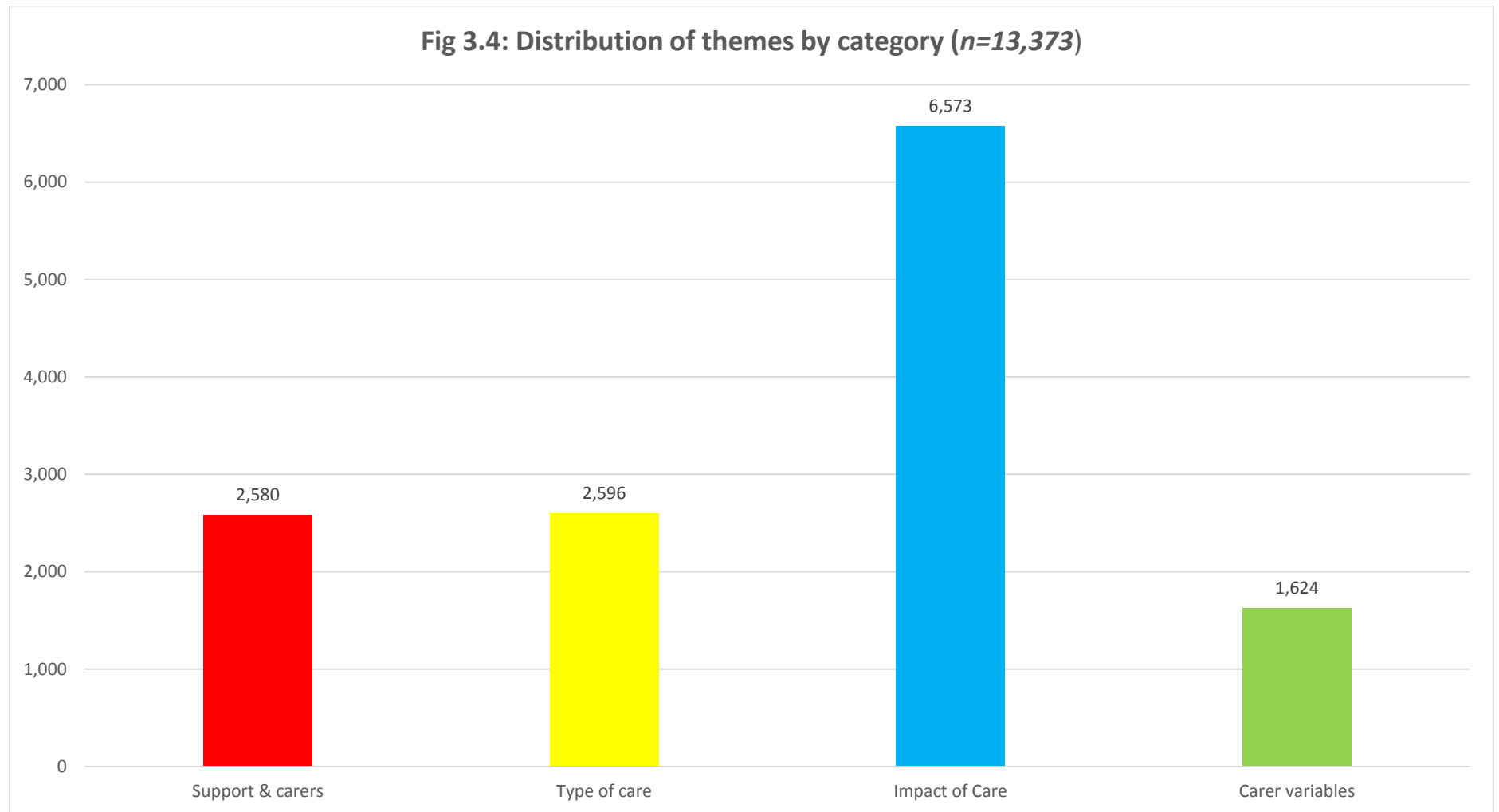
36. Measuring and evaluation	Outcomes and measuring impact of care.
37. Post-caring	What happens to carers when the caring situation ends.
38. Psychological impact	Psychological impact of caring; and psychological interventions aimed at improving well-being.
39. Quality of life	The quality of life of carers and those they care for – the positive and negative effects of caring.
40. Resilience & 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 & 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 & strain	The emotional costs of caring and the experience of related stress.
45. Longitudinal study	Longitudinal investigation of carers and caring situations.
<b>Carer Variables</b>	
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 & siblings	Carers supporting friends, neighbours or siblings.
53. Gender & 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 & 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.

3.10 The 'honeycomb' diagram demonstrates the number of themes distributed across the four categories, so:

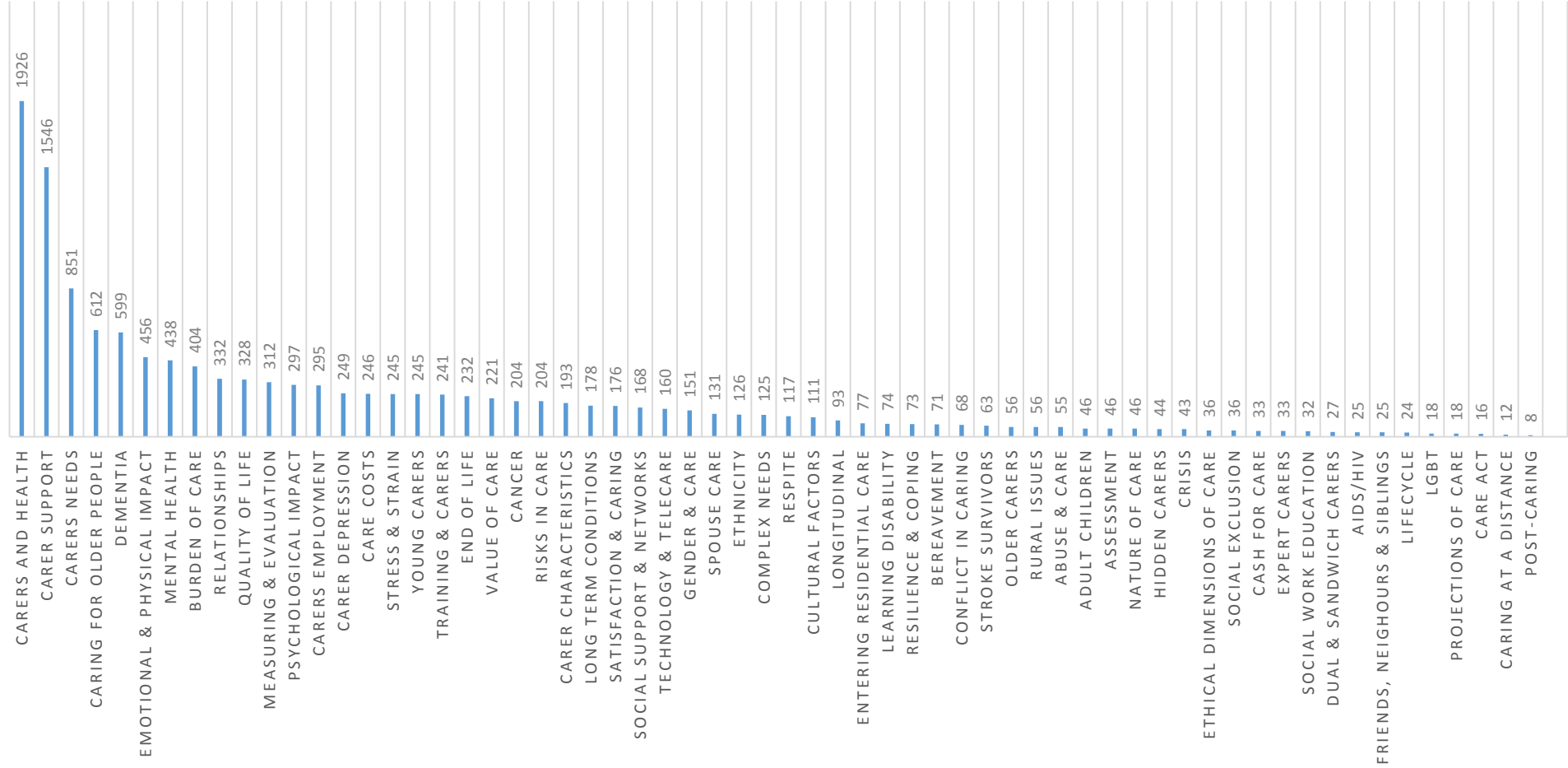
- 27 per cent address **carer variables**;
- 18 per cent are concerned with the **type of care**;
- 39 per cent explore the **impact of caring**;
- And 16 per cent of themes are to do with **support and carers**.

3.11 However, Figure 3.4 presents a slightly different picture by looking at how the themes are distributed across the categories. References can appear under multiple themes; so, the overall total of attributions (that is, the 13,373 'Smart Group' allocations) is far greater than the number of discrete references (3,434) because each source is counted every time it appears under one of the 62 themes. While the 'Impact of Care' remains the leading category accounting for around 50% of attributions, 'Carer Variables' which account for 27% of identified themes, actually represent just 12% of all reference attributions, while Support & Carers, and Type of Care which respectively accounted for 16 and 18 per cent of themes, both account for just under 20 per cent of all attributions. Figure 3.5 outlines the complete distribution of themes by frequency.





**Fig 3.5: Thematic Frequency N=13,373**



- 3.12 The pattern of distribution is strikingly varied. 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'. Some of these references will reflect the health of people being cared for, but a very large number are concerned with carers' own health and well-being. Of the dozen most frequently identified themes, 7 (58%) are concerned with aspects of the impact of caregiving; half of the least frequently identified themes addressed variables in the carer population. The 12 most and least frequently identified themes are summarised below:

**Table 3b: Most and least frequently identified themes**

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

- 3.13 This charting of frequencies is intrinsically interesting and begins to enable us to map out the terrain of research and knowledge on carers. Documenting the peaks and troughs reveals the areas that have attracted considerable focus and those that are relatively under-explored; it is also a reflection of research funding, and policy, priorities to-date. This is not necessarily an argument for giving equal attention to all aspects of caring, but it *does* allow us to better understand where the gaps and deficits in knowledge are likely to be found; where there appears to be considerable evidence

and knowledge, and where future analysis, exploration, policy prioritising and research commissioning might most fruitfully be directed.

- 3.14 We turn now to examine the nature of knowledge in greater depth, and we do so by using the four-fold categorisation to cluster the themes.

## **4 Scoping the Knowledge: a) Carer Variables**

- 4.1 As we have described earlier, this is *not* a systematic review, and following Arksey and O'Malley (Arksey & O'Malley, 2005), our prime concern has been to map the body of literature and knowledge on the topic of carers, rather than – as a systematic review would do – summing up the best available research on a specific question. Nonetheless, peeling back the layers and examining the knowledge in more detail allows us to explore the territory in more granular detail. It is not possible to individually review and analyse all 62 themes that are identified; however, by looking through the lens of the four categories some of the major themes, issues and questions can be highlighted. Sections four to seven of the report provide the analysis and narrative for each of the categories in turn.
- 4.2 The themes that are clustered under the heading of 'Carer variables' all relate to characteristics and features of carers themselves. The largest number of references occur under the sub-heading of 'Relationships and care' (332), and are indicative of the complexity and multi-dimensional nature of care and caregiving. However, all the references under this heading also appear under other classifications that provide a more specific or detailed analysis.

### **Relationships and Care**

- 4.3 All care takes place within a relationship, and typically that is a dyadic relationship, whether between parent and child; between spouses or partners; between siblings, or between friends or other non-kin carers. Caring both reflects the nature of a given relationship, but can also impact on and change the nature and quality of that relationship. Being a carer can overshadow and fundamentally alter previous relationship identities; while the nature of pre-existing relationships can have a positive or negative influence on willingness to provide care (Lyonette & Yardley, 2003).
- 4.4 Almost all the items captured within this sub-heading (95%) are Journal Articles and reflect academic investigation of caring relationships, and qualitative study of people's experiences. For example, Asabø et al examine how the spouses of people with COPD accommodate and integrate their role as carers with that of spouses, and the tensions and conflicts this creates (Aasbø, Solbraekke, Kristvik, & Werner, 2016) The authors propose the use of the concept of 'biographical we' as a way people strive to maintain a sense of continuity in their lives. Identifying as a carer can create

ambivalence and discomfort; the literature reveals that people can find a carer identity difficult to assume or to distinguish from the normal expectations and roles of family and partner relations (Corden & Hirst, 2011). Caring for a spouse or partner is predominantly – but not exclusively – the experience of older people, and:

*“As couples age, both partners are more likely to need and give support, and the boundaries between providing and receiving care can be blurred.”* (Corden and Hirst, 2011, P.219)

- 4.5 Non-identification, or late self-identification as a carer can be significant particularly when it impacts on access to services and support, or to benefits such as Disability Living Allowance and Carers Allowance. Corden and Hirst point to the need for further research to better understand the circumstances associated with adoption of a carer identity, and the implications the identify has both for the person’s experience of care giving, but also in their use or take-up of services (Corden and Hirst, 2011, P.237).
- 4.6 The focus on relationships has been explored through various lenses, but particularly around caring for people with dementia, and care giving for stroke survivors. In both situations there are often personality and behavioural changes, and the impact on family dynamics is particularly challenging (Ablitt, Jones, & Muers, 2009). The meaning of caring has also been conceptualised around ‘caring as worrying’; exploring the complex emotional relationship of responsibility among spouse carers supporting a partner with MS for example (Cheung & Hocking, 2004).
- 4.7 The impact of caring on relationships is likely to be similar in many contexts, but there are distinctive aspects in respect of young carers (i.e. children and young people who assume premature responsibilities in caring for other family members, usually a parent). These issues will be considered more fully below, however, the negative impact on psychosocial development of young people is a matter of particular concern (Collins & Bayless, 2013).
- 4.8 Evidence on the impact of caring on relationships is also a finding of survey work undertaken by the Carers Week Partnership which reported that more than 7 in 10 (71 per cent) of respondents were not prepared for the change in relationship they experienced with the person they cared for. Nearly six out of ten respondents had experienced difficulties in their relationship with the person they cared for, although some (two out of five) reported *an improvement in their relationship* (such as by becoming closer). The survey findings also point to the impact on wider relationships,

with breakdown in other family relationships and fractured friendships (Carers Week Partnership, 2013)

- 4.9 How people become carers is often complex, and we will examine issues around self-identification elsewhere. But, who cares within families, and why one person rather than other family members become involved speaks to the complexity of relationships and the range of dyads involved. Sebern and Whitlatch point out that while family care intrinsically involves (at least) two people, the majority of research and intervention studies on family care focus on only one person from the care dyad, but in a dyadic process “each participant affects and is affected by the other” (Sebern. & Whitlatch, 2007)
- 4.10 Other analyses focus on ‘networks’ rather than dyads to conceptualise and understand caring relationships. Keating et al, for example, 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, Otfinowski, Wenger, Fast, & Derksen, 2003). Nocon and Pearson 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 (Nocon & Pearson, 2000).
- 4.11 Charlesworth et al explored the relationship between caring and social networks among carers of people with dementia. Carers are likely to experience reduced social networks because of fewer opportunities to socialise and because of the stigma of caring; carers are generally likely to report less social interaction and fewer friendships than non-carers (Charlesworth, Tzimoula, Higgs, & Poland, 2007).
- 4.12 Analysis indicated that carers with private restricted networks (i.e. with the least regular contact with family, friends or neighbours) were most likely to make use of a befriending intervention., and this group was seen as precisely the one “for whom gaining such a relationship would have made a notable difference in their social network type and level of social isolation” (Charlesworth et al., 2008, P.42). The authors suggest that one practice implication of the findings would be to take account of network types when undertaking carer assessments:

*“These could take account of whether informal networks were likely to continue to provide appropriate levels of types of support and whether home-based service support could complement network functions.” (P.42)*

- 4.13 Lapierre and Keating’s secondary analysis of the 1996 General Social Survey of Canada distinguished between friend and neighbour carers who differed both in terms of their characteristics and in the nature of support provided (Lapierre & Keating, 2013). However, such analysis has limitations as the authors acknowledge, reflecting the variables and definitions used in the original study and not providing – for example – information about the people being supported by this non-kin care. The data also provide limited insight to the nature of the caring relationship:

*“In this study we were able to describe only those neighbours and friends who became involved in care-giving, leaving remaining gaps in our understanding of how friends and neighbours contribute to the informal care sector. We do not know anything about the history of these relationships prior to the provision of care, or how these individuals emerged as carers. Future research needs to place non-kin carers within the context of the social and care networks of care recipients to determine the extent to which contributions of friends and neighbours are contingent on network composition.” (Lapierre and Keating, 2013, P.1464)*

- 4.14 Rutherford and Bowes’s analysis 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 (Rutherford & Bowes, 2014).

- 4.15 Despite the complexity of relationships, and the changes which occur over a lifetime, there are significant gaps in knowledge and understanding of these dynamics. Blieszner, for example, points out that gerontological research is ‘unbalanced’:

*“Most of that work addresses caregiving by spouses and adult children, but studies of caregiving by siblings, extended kin, and friends are less prevalent. Less is known about how needed care is provided to ever-single persons and those who are estranged from relatives than to those experiencing more normative family settings as they age.” (Blieszner, 2006)*

- 4.16 Similarly, 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.

- 4.17 Care by siblings can be associated with young carers, but another dimension concerns adult sibling carers of people with learning disabilities for whom the transition to the role of primary carer typically occurs late in the lifecycle. Coyle et al examined this transition through qualitative research with adult sibling carers of people with intellectual and development disabilities (I/DD) in the USA and identified “a unique set of challenges for sibling carers of adults with I/DD associated with the transition of care from the parent to the sibling carer” (Coyle, Kramer, & Mutchler, 2014). The ageing process was seen to permeate the care providing role, both in terms of the ageing of the person with learning disabilities but also of the sibling carer and other family members:

*“They key finding of our study is that aging of the family system as a whole (parents, care recipient with I/DD, sibling carer, and other non-care providing siblings) shapes the transition in unique ways.” (Coyle et al, 2014, P.309).*

- 4.18 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.

- 4.19 Taggart et al point out that the needs of ageing family carers and of older people with intellectual disabilities reflect the greater life expectancy for people with learning disabilities, and mean that they are now more likely to live with a family member who will also have additional support needs (Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). 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. Their qualitative research in Northern Ireland with 112 parent and sibling carers revealed the lack of planning typically given to questions about future care despite carers experiencing ‘unremitting apprehension’:

*“Contemplating future planning was emotive and disturbing, with many carers reporting not wanting to explore this complex topic. Despite constant worry about what would happen to their relative when they could no longer care, many carers in this study had failed to develop a plan for the future care of their relative.” (Taggart et al, 2012, P.228)*



- 4.20 Some carers *had* apparently made plans whereby siblings would take over care responsibilities, but these generally appeared fragile, or indeed merely ‘aspirational’:

*“These parents had not directly discussed the future care options of their son/daughter with intellectual disability with other family members. The carers were therefore hoping or expecting that these non-disabled siblings would take on this caring role when they died.” (P.227)*

- 4.21 As has been noted previously, 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 research with Finnish adult child carers (Leinonen, 2011) identified three main patterns of responsibility between siblings: absence; backup; and togetherness. While various rationales were offered to account for differential sibling responsibilities (such as different child care and employment commitments), interviewees recognised the mediating role of relationships:

*“They stress the relational nature of human life course: the lives of the family carers were linked with the lives of other actors involved in a care relationship. The interviewees stressed that either the relationship between adult children and parent(s) or the relationships among the siblings influenced the division of care duties.” (P.324)*

- 4.22 Turning from the wide category of ‘relationships and care’ to the finer detail of knowledge about the nature of carers, the major dimensions that are distinguished are: young carers; spouse carers; older carers; adult children; gender and ethnicity.

## **Young Carers**

- 4.23 Young carers are officially defined as children 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 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, 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.

- 4.24 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. The Young Carers Research Group (YCRG) was founded at Loughborough University in 1992 and is associated with a lot of the initial identification of the phenomenon of young carers. Similarly, the members of the National Young Carers Coalition (notably The Children’s Society and Carers Trust) – established in 2008 – feature prominently in campaigning and in highlighting the situation of young carers.
- 4.25 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 failure of many services to address the needs of both the cared for person and the young carer has been identified, as has the assumption that children are automatically at risk where there is severe parental mental illness.
- 4.26 The consequences of caring for young people can include psychological and physical stress; social isolation, and educational under achievement (Charles, 2011) (Hounsell, 2013). Nonetheless, research has also found positive outcomes associated with caregiving, including self-worth, satisfaction in care-giving and a sense of maturity (Charles, 2011). Bolas et al have similarly identified the multidimensional experience of young people as carers including:
- “Searching for meaning; feeling isolated from others and actively withdrawing from their social worlds; and attempting to integrate caring into their self-concepts and everyday lives.”* (Bolas, van Wersch, & Flynn, 2007) P.845
- 4.27 The experiences of young carers are in many ways similar to those of carers of any age, but Bolas et al emphasise the complexity of impact particularly 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).

4.28 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 & Cushway, 2002).

4.29 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, 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 (Banks, Cogan, Deeley, Hill et al., 2001). One of the particular challenges to the conceptualisation of 'young carers' concerns the conclusion in much analysis that children with caring responsibilities need support in managing these, whereas Banks et al point out:

*"Critics question the criteria for being classified as a young carer. At the same time, they maintain that far from supporting young carers in taking on responsibility for another family member, the emphasis should be on pressurising local authorities to support families adequately so that the role of the young carer becomes redundant."* (Banks, 2001, P.810)

4.30 While supporting young carers is vital, it is recognised in much of the discourse that there are risks that support effectively institutionalises responsibilities and serves as "propping up exploitative caring arrangements" (Banks, 2001, 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 & Becker, 2004). Getting the right balance in supporting young carers and those they care for is often emphasised within a 'whole family approach', but this recognises that there are inherent tensions and contradictions between different interests, and within the context of a wider social, economic and political context (Frank, 2002).

## **Adult Children as Carers**

- 4.31 Care by adult children, particularly those born in the 'baby boomer' generation (1945-54) is the model that has traditionally been most closely associated with the concept of the carer. Ogg and Renaut point out that compared to their parents at the same stage of the life course, people born between 1945-54 were more likely to have at least one parent still alive, and were also likely to have living siblings (Ogg & Renaut, 2006). Their analysis of data from the Survey of Health, Ageing and Retirement in Europe (SHARE) confirmed the continuing importance of support from adult children in both Northern and Southern European countries, although in the latter there was closer proximity of generations (more shared households) and a greater likelihood of providing daily care or support.
- 4.32 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. The supply of spouse care – as explored below – is expected to continue to increase as improved male mortality reduces the number of widowed women (Pickard, 2008).
- 4.33 Pickard's analysis and projections of supply of intensive care to disabled older people by their adult children in England indicates a growing 'care gap' between the demand for care and its supply with effect from 2017. The vast majority (around 90 per cent) of those providing intense care to parents (i.e. of more than 20 hours per week) are themselves aged under 65, and increasing the provision of care will intensify demands on these working age carers.
- 4.34 Bastawrous et al 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 (Bastawrous, Gignac, & Kapral, 2015). Their scoping review 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 was not the case for spousal carers:

*“While the findings suggest that wellbeing is not impacted by the number of roles an ACC occupies, the combination and quality of these roles can result in limitations on time that lead to role conflicts.” (Bastawrous et al, 2015, P.463)*

- 4.35 The other factor mediating ACC wellbeing was identified as the quality of the parent-child relationship. However, it is unclear from the literature how relationships change and influence wellbeing over time, and the authors point to the importance of a longitudinal focus in future work to inform understanding “of the changes that take place in the parent child relationship and multiple role involvement across the care-giving trajectory” (P.449).

- 4.36 Gans et al have explored the ‘trade-off’ between caring for children and caring for parents; they argue that in previous generations adult children were relatively free of childcare responsibilities by the time they needed to care for older family members (Gans, Lowenstein, Katz, & Zissimopoulos, 2013).

*“However, current demographic trends reflect the changed timing of the two formerly independent periods of care – childcare and parental care – creating a potential overlap.” (P.456)*

- 4.37 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 of the time found a low likelihood for women to be in this position. More recent research suggests that in Britain one third of women aged 55-69 are providing care to both younger and older generations (Grundy & Henretta, 2006). On the basis of current demographic trends Gans et al conclude that this simultaneous provision of support to more than one generation will become more prevalent.

- 4.38 Grundy and Henretta point out that having dependent young children while also caring for parents is rare, and requires both delayed child bearing and early onset of illness or disability in parents. Nonetheless:

*“Much more common are families in which the potential call for simultaneous support comes from adult but still partly dependent children and from elderly parents. Adults, particularly women, in late middle age are the most likely to face these two-way commitments.” (Grundy & Henretta, 2006, P.709)*

- 4.39 Exchanges of help among three generations, they argue “will become increasingly important as these family arrangements become more common”. Grundy and Henretta identify the need for more research around these complex issues, particularly recognising the limitations of cross-sectional data. Further exploration is also required to better understand the trade-offs in helping one or other generation.

*“..an important constraint on help that involves giving money or spending time is that it involves scarce resources, trade-offs and opportunity costs. Unlike affection or emotional closeness, spending money or time on one generation implies that someone or some others – the other generation, the donor, or their spouse or partner – receives or retains less.”* (Grundy & Henretta, 2006, P.720)

- 4.40 Evandrou and Glaser’s analysis of major data sets (British Household Panel Study; Family and Working Lives Survey; General Household Surveys, and the longitudinal Retirement Survey) also analysed the generation caught in the middle between simultaneous work and family roles, but concluded this pattern “remains atypical in Britain” (Evandrou & Glaser, 2004).

*“However, a higher proportion of mid-life individuals hold multiple roles at some point in their life course than at a single point in time. In addition, comparison across birth cohorts shows that multiple role occupancy is increasing, and it is likely that the proportion of men and women who juggle work and family responsibilities will continue to rise.”* (Evandrou & Glaser, 2004, P.787)

- 4.41 The extended period of responsibility for adult children, particularly those that return to share the parental home for extended periods, is lengthening the period of parental responsibility “into and beyond mid-life”. The impact of this on quality of life (financial and physical/mental wellbeing) requires further attention.

- 4.42 Some of the implications of combining different role responsibilities are also addressed elsewhere in this report when considering the impact of care, but it is clear that juggling the demands of caring for children and other relatives with paid employment is a key dimension of this ‘sandwich care’. Work undertaken by Carers UK and Employers for Carers 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” (Carers UK/Employers for Carers, 2014).

## Older carers, Spouse and Partner care

4.43 As might be expected, there is considerable overlap between knowledge and research on spouse (and partner) care and that on older carers. Moreover, with the continued ageing of the population, the role of the older spouse carer is expected to be increasingly important (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). Older carers differ from other carers in some important respects; analysis of data has found strong correlations between type of relationship and type of household, which in turn has an impact on the nature of care. Thus, co-resident carers are typically spouses or cohabitantes, and are more heavily involved in care than non-resident carers (Milne & Hatzidimitriadou, 2003b).

4.44 Older carers have tended to be relatively invisible in both research and policy, but the importance of supporting them should be compelling:

*“Older carers can be distinguished from other groups of carers in a number of unique ways: they are more likely to live with the person they care for, care-giving is likely to take place within the context of a long-term relationship and there is a greater chance of carers having health problems of their own. Dementia is also more likely to be a feature of caring in later life.”*

And

*“There is clearly a high level of devotion to caring amongst many co-resident older carers; they often provide intensive care over a long period of time in very demanding circumstances with little or no support from services.”* (Milne and Hatzidimitriadou, 2003, P.12).

4.45 Older carers and spouse carers are 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 that are associated with dementia and with the incidence of 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 & Brocklehurst, 2007). Social isolation can be a particular consequence for both carers and stroke survivors because of the physical and psychological impact of the condition (Quinn, Murray, & Malone, 2014) (Cheater, 2008). Spousal care is distinguished, Milne and Hatzidimitriadou observe, by

*“its mutuality and interdependence with the carer/cared for roles being indistinguishable from one another. Caring within marriage, unlike most other caring relationships, tends to be regarded by carer and cared for as an extension of the intimacy and companionship that characterises marriage.”* (Milne and Hatzidimitriadou, 2003, P.7)

- 4.46 This underlines both the difficulties that can arise in identifying 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. However, when the nature and quality of the spousal relationship is fundamentally changed by the circumstances of caring (such as in caring for a partner with dementia), carers may experience particular stress and care burden (Davis, 2011). The quality of the care relationship, and the perception of mutuality, are important predictors of people’s capacity to sustain caring (Shim, Landerman, & Davis, 2011).

- 4.47 How older spousal carers with disabilities and impairment experience caregiving has been relatively neglected in research, but the complexity of spousal care is apparent:

*“From a demographic perspective where people are living longer, older people and especially older people with disabilities might represent the bulk of society’s informal caregivers, and they need to be further recognized and acknowledged not only as receivers of social care but also as providers of invaluable care.”* (Torge, 2014)

- 4.48 Understanding the meaning attached by couples to mutual caregiving and why it may be preferable to other sources of help requires careful and flexible response, as Torge also comments:

*“..health care professionals need to be sensitive to the dynamics of the couple relationship and carefully explore the couple’s preferences for how formal support can best be provided in ways that honour and sustain the integrity of the couple relationship.”* (Torge, 2014 P.221).

- 4.49 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. How people cope with the demands of their role; how they develop resilience, and what differences there are between older spousal carers and others are areas where further exploration is needed (Greenwood & Smith, 2016).



- 4.50 Older carers are typically coping with more complex health needs in the person they support, often with multiple comorbidity, and in addition are more likely to also have their own health and disability challenges.(McGarry & Arthur, 2001). Older carers are more likely to be caring for someone with dementia, and:

*“it is very likely that they carry out a wide range of care-giving activities including health care and nursing-type activities as well as much care-giving of an intimate or personal nature.”* (Pickard, Glendinning, & Shaw, 2000)

- 4.51 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. Simultaneously, services are rarely offered to people proactively with the result that older carers are too often left to cope with highly demanding and difficult personal care tasks. Lack of breaks from caring are also likely to lead to a crisis in care-giving but older carers are unwilling to make use of respite services that are institutional in style, and which they find unacceptable (Pickard & Glendinning, 2001).

- 4.52 Not all older carers are providing support to a spouse or partner, and with longer life expectancy, ageing carers are also to be found with life-long responsibilities for their disabled adult children (particularly for people with learning disabilities), and often with no plans for the future despite carers being aged in their 70s or older (Bowey & McLaughlin, 2007). Perkins and Haley point to this “unique population of carers” 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 & Haley, 2013). Interestingly, as with spousal carers there is some evidence of mutual care and support and:

*“The roles of carer and care recipient may evolve over time and become rather blended as both carer and care recipient age.”* (Perkins & Haley, 2013, P.342)

- 4.53 The finding of reciprocity in both emotional and tangible support in dyads of carer and care recipient existed irrespective of the severity of learning disability, and was a “potentially promising predictor of carer wellbeing.”

## Gender and Care

- 4.54 Many aspects of gender and care arise in relation to employment and attempts to balance caring responsibilities and paid employment, and these issues are explored elsewhere in the paper. Here we consider changing understanding of gender and caring more broadly. Caring has long been seen as activity predominantly undertaken by women, particularly by those in middle age, and that women commit more time to caregiving than men. While the predominance of women as carers is well documented and understood, the significance of men as carers in later life has received less attention, but 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) (Dahlberg, Demack, & Bamba, 2007).
- 4.55 Milne and Hatzidimitriadou's exploration of 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" (Milne & Hatzidimitriadou, 2003a).

*"Caring offers older husbands considerable benefit, status and self-esteem, and accords these men both a role and a vehicle for reciprocity within marriage and an expression of commitment to their wives." (P.402)*

- 4.56 Eriksson et al described a slightly different scenario from research in Sweden that explored adult daughters' perceptions of the caring undertaken by their fathers. Daughters apparently 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, Sandberg, Holmgren, & Pringle, 2013).
- 4.57 Analysis by Del Bono et al challenges the relationship between gender and caring in older life and concludes that the apparent difference is due to differences in marital status (Del Bono, Sala, & Hancock, 2009) Moreover, this is likely to change in the future:

*"In particular, the share of single and especially of divorced or separated women will increase substantially, while the percentage of married men will decrease. These trends imply that gender differences in the provision of care which are mainly due to*

*differences in marital circumstances are likely to be significantly reduced or disappear altogether.” (P.272)*

- 4.58 A further dimension of gender and care concerns care in the context of LGBT relationships, which until recently has been largely absent from the care discourse. Manthorpe (Manthorpe, 2003) points out that “certain relationships have dominated discussions about informal carers and those receiving care”, and in particular the early focus was on the model of the ‘spinster daughter’, then moved to the ‘sandwiched’ adult woman with demands both for her children and her aged parents/in-laws, and latterly attention has moved to spouse care:

*“The family is the linking relationship between all such models, whether constructed by marriage or blood tie. Other relationships remain neglected, both conceptually and in terms of practice in community care.” (Manthorpe, 2003 P.753)*

- 4.59 The formation of the Lesbian and Gay Carers Network of the Alzheimer’s Society arose in the 1990s from the efforts of one gay man caring for a partner with a diagnosis of pre-senile dementia who had found images of caring did not reflect his own experience (Newman, 2005). The needs of older gay and lesbian people have also been largely overlooked in the wider nursing literature; indeed, research which has been undertaken has highlighted people’s difficulties in being accepted as ‘next of kin’, and being excluded from crucial discussion and decision making in end of life care (Price, 2005).

- 4.60 Willis et al (2011) undertook a scoping study of the territory and pointed to the “negligible amount of social work and social care research” specifically concerned with issues for LGBT carers. Such previous work as there has been has focused largely on specific care needs, such as for carers of people with dementia or with AIDS/HIV (Willis, Ward, & Fish, 2011). Areas identified for further investigation include the following:

*“Prime issues include the heteronormative assumptions encountered from health care professionals about sexual subjectivities and relationships; the absence presence of LGBT carers in organisational data collection and monitoring; and the differing kinds of care practices demonstrated within transgender communities in comparison to more traditional understanding of caring relationships.” (Willis et al, 2011, P.1317)*

## Ethnicity and Carers

- 4.61 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, Ahmad, Bhakta, Baker, & Parker, 2002).
- 4.62 Work undertaken by Carers UK has also highlighted the fact that Black Asian and Minority Ethnic (BAME) carers face the same challenges as all carers,
- "but also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion."* (Carers UK, 2011)
- 4.63 Others similarly emphasise that while support for carers generally is inadequate,
- "the experience of black and minority ethnic carers tends to be compounded by structural disadvantage and the marginalisation of 'race' equality within social policy."* (Gregory, 2010)
- 4.64 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 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 (Greenwood, Habibi, Smith, & Manthorpe, 2015)
- 4.65 Much British research on the experience of people with conditions such as dementia has focused on people from white British backgrounds, and taken little account of how family members of different minority ethnic groups manage the situation or access services. Research which has been done has highlighted challenges around poor cultural and language awareness in services, and in part this is a reflection of wider equalities issues in health and care services (Forbat & Nar, 2003).
- 4.66 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, Ahmad, & Bhakta, 2004).

*"In fact, the findings challenge the pervasive assumption and stereotype that South Asian people live in self-supporting extended families, and therefore, that the support of social services is largely unnecessary."* (P.404)

4.67 The disadvantage of carers in these communities is further compounded when knowledge about and access to care and support services *"may be additionally limited in comparison to carers from the majority community"* (P.405).

4.68 Lawrence et al's study of attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK identified 'traditional' and non-traditional' caregiver ideologies (Lawrence, Murray, Samsi, & Banerjee, 2008). A traditional ideology was associated with seeing caring as 'natural, expected and virtuous', and in turn, this informed feelings 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 example, Lawrence et al 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.

4.69 The meaning and significance of mental illness and physical disability can be very different in some cultural and minority ethnic communities. Research into the experience of carers of people with dementia in Asian communities, for example, has underlined the lack of knowledge about dementia, and a view that it is part of ageing rather than a specific condition, but something which is also seen as stigmatising and shameful (St. John, 2004):

*"The illness is not conceptualised as an organic disease associated with old age, but as a result of it. This affects how families understand the needs of those with dementia and their carers. The project brought to light an almost universally negative perception*

*of dementia sufferers' behaviour, and that in the early stages symptoms are viewed as a normal part of ageing and therefore not treatable.” (St John, 2004, P.23)*

- 4.70 Similarly, Koo has drawn attention to the relative dearth of research on British Chinese carers, and in relation to carers of people with depressive illnesses he has identified the centrality of the family unit and collectivism (Koo, 2012). These values may partially account for the low take-up of support services among British Chinese carers, but compounded by views about mental illness and stigma:

*“The carers explained their reluctance to accept outside support by visiting nurses, even when the former felt overwhelmed by their responsibilities, through a profound connection between the obligation to serve ill family members and essentialist ideals of being human and maintaining ‘social dignity’ for the patient and family (...) beyond the stigma of mental illness perceived from others, and by the self, an additional shame associated with failing to fulfil an expectation within the prioritised family unit establishes a barrier to admitting the need for external support that is too high for most carers to overcome.” (Koo, 2012, P.1151)*

- 4.71 Somerville’s study of Bangladeshi family carers’ experience of palliative care also drew attention to the sense of family duty “to the point of declining help”, and also underlined the isolation experienced by carers often lacking wider family members and networks in the UK (Somerville, 2001). Furthermore:

*“The findings of the study not only highlighted the importance of family ties, but the additional anxiety these families experienced at an already difficult time, because of the problems they had obtaining visas so that family members could visit their dying relative.” (Somerville, 2001, P.245)*

- 4.72 Given the unwillingness of these carers to complain or to ask for help Somerville argued that nursing staff need to be sensitive to the particular stresses they face and able:

*“to act as the families’ advocate in obtaining increased support and in reassuring them that they do not have to struggle alone.” (Somerville, 2001, P.247)*

- 4.73 A further aspect of ethnicity and care concerns the relationship between care and migration within the European Community. In view of the current position of Britain following the 2016 the referendum to leave the European Union, these considerations are particularly current. Work undertaken by Ackers, for example, argues the case for

an evidence-based approach to European policy making “grounded in a more detailed understanding of the complex and fluid relationships between mobility and care” (Ackers, 2004).

- 4.74 Ackers’ analysis of the relationship between care, paid work and mobility presents a picture that is “highly complex, often unpredictable, and constantly under negotiation.” Families can be widely distributed across EU countries, and the rate of international partnering within the population of mobile EU nationals “typically result in a significant and complex dispersal of family relationships across international space” (P.391). Ackers also draws attention to the population of mobile younger retired people, and their role in providing care to older relatives, adult children and grandchildren:

*“These concerns remain completely absent from international migration theory. Very many of these people move at some point in time, not only to access but in order to provide unpaid care (...). Most migrants will be under pressure or wishing to move in order to provide care at some point in their lives (...) The only solution that responds directly to the unpredictable and fluid contours of the life-course and recognises the importance of care-giving to European society lies in a more inclusive approach to citizenship.”* (P.392)

- 4.75 The implications of this in a post-Brexit world have not even begun to be explored.

### **Hidden Carers**

- 4.76 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 various 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.

- 4.77 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. For example, the RCGP and the Princess Royal Trust for Carers (subsequently the Carers Trust) issued an 'action guide' for GPs and their teams, based on the underpinning belief "that patients benefit when carers are treated as partners in care" (RCGP & Princess Royal Trust for Carers, 2008). This recognises both the information and support needs of carers in their own right, as well as the expertise and knowledge the carer brings regarding the person they care for. The guide also addresses the HR aspects of this carer awareness – realising that there will be people with caring responsibilities within the primary care team.
- 4.78 Similar good practice and principles have been identified for other groups of hidden and marginalised carers. Gray and Robinson, for example, focus on the situation of young carers of people with mental health problems (Gray & Robinson, 2009).

*"Many professionals from health, social services and education are not fully aware of the challenges facing young carers for people with mental health problems. An ethos of listening, responding and dialogue must be developed, in conjunction with more partnership working and training on young carer issues, if services and young carers are to work together effectively."* (Gray & Robinson, 2009, P.105)

- 4.79 Greenwood et al's exploration of GPs' awareness of carers underlined the gap between aspiration and reality (Greenwood, Mackenzie, Habibi, Atkins, & Jones, 2010). Despite GPs recognising the importance of supporting carers, and believing they should be pro-active in doing so:

*"they frequently lack confidence and training and sometimes knowledge to do it effectively. Key issues highlighted include the identification of carers – some GPs are aware that they are not identifying all carers in their practices and would like to be guided on how best to do this. Few services are currently being offered by general practices specifically for carers despite GPs' belief that carers want their support. The few carers' registers reported here by the GPs is all the more surprising given the financial incentives to have them."* (Greenwood et al, 2010, P.104)

- 4.80 The authors point out that the potential significance of GPs to supporting carers has long been identified, and although GPs in their study agreed that carers should be



partners in care, “little progress seems to have been made”. While setting up carers registers may be an important first step, they argue that without time and knowledge to offer support to carers thus identified “raising expectations may be detrimental.” Increasing the number of carers leads or ‘champions’ within primary care teams is suggested as one way forward, but recognising the effectiveness of this role requires evaluation.

- 4.81 Carduff et al 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 strategies similarly 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 (Carduff, Finucane, Kendall, Jarvis et al., 2014). However, as we explore further below, self-identification for carers is not merely about raising awareness. The identify of carer may be viewed with reluctance or perceived as inappropriate for many reasons, not least because of the complex emotions that may be involved, and the nature of caring which is embedded within a normative relationship.
- 4.82 Knowles et al have recently proposed that carers of people with long term conditions – LTCs - (such as coronary heart disease or kidney disease) might also be considered as actual or potential hidden carers (Knowles, Combs, Kirk, Griffiths et al., 2016). Increasingly, long term conditions are approached through self-management and the authors argue that this:

*“may risk creating a new group of ‘hidden’ carers who are providing substantial support which is less stereotypically recognisable as ‘caring work’.” (P.211)*

- 4.83 In particular, qualitative interviews with carers supporting people with LTCs revealed that they did not perceive themselves as carers because of comparisons they made with what they understood other carers did, and therefore not seeing the legitimacy of their own caring that was more about emotional support than physical. There was also a level of conscious rejection of the identify of carer because of the inference that this would identify the person they supported as the dependent and ‘cared for’, while they were trying hard to maintain a sense of normal life and identity. The failure to self-identify meant that carers failed to recognise or access support that might be available to them “despite the substantial emotional and practical responsibilities undertaken.”

## **5 Scoping the Knowledge: b) Type of Care**

- 5.1 Thus far this section has provided an overview of the variables that describe the carer population. It is not possible to address each dimension in detail, and that is not the intention. Rather the purpose is to highlight the features that are especially striking or notable. The same approach is adopted in addressing the other categories of themes, and we turn now to consider briefly the type of care provided and for whom.
- 5.2 As well as carers being extremely diverse – as we have explored above – 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, and
  - Long Term Conditions (including neurological conditions).
- 5.3 Less frequently identified are references associated with caring for people with multiple and complex needs; for stroke survivors; learning disability, and AIDS/HIV. 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 learning 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.
- 5.4 The great majority of items and references in the review are concerned either with understanding and quantifying the impact of care, or with the role and contribution of support and services; both categories are explored more fully in the remainder of the paper.
- 5.5 While all caring situations are different, and caring for people with different conditions and needs also produces distinctive demands, there are also features of caring that are widespread or common across all types of caregiving. Carers may be involved in providing help with all aspects of daily life, including in practical terms; with personal care; companionship; assistance with shopping and housework; help in managing

services; managing finances and benefits; helping with paperwork, and giving medication. The impact of care and the 'burden' of care (see below) typically refers to the emotional and psychological costs and stresses of caring.

- 5.6 Caring is not without conflict, and tensions in relationships may arise particularly around questions of identity and autonomy. Henderson, for example, has explored the experience of 'care' in mental health and highlighted the conflicting needs of carers and users of services (Henderson, 2002). She comments that:

*"Models of care developed in relation to older people or physical disability do not transfer easily to mental health, perhaps because the issues surrounding personal care do not seem to apply in this area."* (P.37)

- 5.7 One characteristic of some mental health conditions – such as bi-polar disorder – is their intermittent and fluctuating nature, and people may remain well for long periods. "they are not in a permanent state of caring or being cared for." And, Henderson argues this changing picture "challenges traditional discourses on care" (P.38).

- 5.8 We have emphasised previously that care takes place within a relationship, and there can be particular difficulties in a relationship which may not fit easily in a care system in which treatment can be imposed without consent:

*"there may be disagreement within a relationship about diagnosis and therefore the need (or lack of it) for care. This may or may not be at odds with wider definitions and expectations in professional and social relationships. Many professionals assume that someone's partner is their 'carer' and work with them accordingly. 'Carers' are assumed to be on the side of the professional. For some people this is an identity they aspire to, and indeed throw themselves into. For others, an identity of 'carer' bears no similarity to their own construction of their role within a relationship."* (Henderson, 2002, P.44)

- 5.9 The role of a carer within mental health policy may occupy a particularly ambivalent status, especially when the carer is 'professionalised' by services and is seen as the expert in 'caring for' the person with mental health needs. Indeed, Henderson argues that this can have a 'devastating impact on partnerships' and relationships.

- 5.10 Keywood similarly identifies overlapping and at times conflicting roles for carers associated with mental health law reform and incapacity decisions (Keywood, 2003). Whether carers can simultaneously act as advocates, gatekeepers and proxy decision-

makers requires some significant compromises and potentially creates situations in which these multiple roles are incompatible.

- 5.11 A similar discourse is evident in international literature. Goodwin and Happell (Goodwin & Happell, 2006), for example, have presented a critique of:

*“the tendency of Australian Government policy to present consumers and carers as a collective with an apparent assumption that these needs can be met by similar initiatives”* (P.136)

- 5.12 Rather, they argue there are at times ‘conflicting agendas’, and that nursing staff experience particular conflict when trying to balance the desire of carers to be fully involved and given appropriate information, with the preferences of the consumer “to whom they owe a primary duty of care.” They conclude:

*“For the goal of current mental health policy to increase consumer and carer participation to be realized, it is crucial that policy-makers cease to view the interests of the two groups as synonymous.”* (P.141)

- 5.13 Similar tensions and potential conflicts have also been identified in the learning disability field. Williams and Robinson identified three major sources of conflict or disagreement between carers and a family member with a learning disability centred upon: the need for a break from caring; the need to speak for their relative; and concern over behaviour (Williams & Robinson, 2001). There is also long-standing recognition of the difficulties that can arise in transition planning for young adults with intellectual disabilities. Pilnick et al identify the tensions between carers’ concerns for their adult child, and indeed for their own lives, versus aspirations for choice and self-determination (Pilnick, Clegg, Murphy, & Almack, 2011).

- 5.14 The tensions between care and protection are also increasingly recognised in relation to caring for people with dementia. Askham et al identify three kinds of social relationship likely to be found when people with dementia are cared for at home: custodial care, an intimate relationship and home life (Askham, Briggs, Norman, & Redfern, 2007).

*“Homes are not total institutions, and people with dementia are not inmates. But living at home with a person with dementia brings the challenge of how to preserve home-life and an intimate relationship alongside providing care and custody (...) Living with a person with dementia is a complex balancing act that is difficult to sustain. It is in*

*constant danger of slipping towards the practices and life of a total institution, and is fraught with challenging problems for both carers and the people with dementia.” (P.21)*

- 5.15 A related debate is emerging around the use of telemonitoring, particularly in caring for people with dementia, and Draper and Sorell for example, have drawn attention to the ethnical tensions that can arise (Draper & Sorell, 2013):

*“The perspectives of carers and users may be increasingly difficult to keep in balance the more telecare enables information and control to pass from user to carer (...) For telemonitoring to qualify as care, it must be integrated into a care relationship which incorporates personal contact, and which is personalized through negotiation to take account of the interests and autonomy of all involved in the caring.” (P.372).*

- 5.16 Ganyo et al 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 (Ganyo, Dunn, & Hope, 2011). Godwin has argued that the complexity of using assistive technology (AT) in dementia care necessitates individualised, person-centred ethical assessment (Godwin, 2012). White and Montgomery’s 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 (White & Montgomery, 2014).

*“The study suggested that a decision to use electronic tracking partly reflected a need for carers to have reassurance, space from the person, and time out from the caring role. This raises questions about who the technology is for. Careful consideration is warranted of how it may be used in a way that reflects the best interests of the person with dementia as well as the needs of the carer.” (P.228)*

- 5.17 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 addressed.

## 6 Scoping the Knowledge: c) Impact of Care

- 6.1 As the charts in Section 3 demonstrated, examination of the impact of care is the single largest category of all analyses and represents almost 40 per cent of all themes identified. Caring exists in multiple forms, and involves people in different relationships, supporting people with distinctive and specific needs which make every caring situation distinctive. Nonetheless, 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 there is a considerable literature that addresses this topic. In adopting the term here, we are mindful of the potentially pejorative connotations this may have, but that is not the intention. Rather, it is to recognise 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. As O'Neill has remarked, it may be more meaningful to refer to "burdensome aspects of care" rather than to repeat the trope of carer burden (O'Neill, 2015). It is also apparent that the concept of burden is more complex than it first appears and that there are both objective and subjective dimensions.

### Burden of Care

- 6.2 Various assessment tools to measure carer burden have been developed for use in both research and clinical or practical support contexts. Charlesworth et al (Charlesworth, Tzimoula, & Newman, 2007) point out that some of the early measures in particular have been criticised for various shortcomings:

*"theoretical incoherence; poor psychometrics; an implicit assumption that carers' experience of burden is explained by levels of impairment of the care-recipient; being 'patient-centred' rather than 'carer-centred'; lacking sensitivity to change and using summary scores that mask underlying sources of burden."* (P.218)

- 6.3 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). McKee et al argue that "family care is more complex than a burden model would suggest", and that

assessment instruments therefore need to be able to reflect this complexity (McKee, Spazzafumo, Nolan, Wojszel et al., 2009). Development of work on the CADI has subsequently produced related indices of the CASI (Carers Assessment of Satisfaction Index) and CAMI (Carers Assessment of Managing Index). McKee et al undertook research with carers in the UK, Italy and Poland evaluating the use of all three indices. The subscales were found to have divergent associations with demographic and caregiving characteristics, and the CASI subscales had fewer significant associations:

*“Suggesting that satisfactions gained from caregiving might be more personal and idiosyncratic than coping strategies or burdens, and therefore not so easily explained by gross characteristics of the person such as gender, or obvious characteristics of the caregiving situation, such as co-habitation status or duration of caregiving.”* (McKee et al, P.262)

- 6.4 Use of the three indices is seen by McKee et al to have much potential as a research instrument and as an assessment model in practice settings. Together the three indices may have a particular contribution in “expanding practitioners’ understanding of the complexity of caring situations” (P.263). The importance of cultural factors on mediating caregiving satisfactions is a further variable identified by McKee et al, and also highlighted in various other studies (Chan & Chui, 2011). Sequeira’s study of satisfaction and burden among Portuguese carers (using the CADI, CAMI and CASI indices) found carers of people with dementia more vulnerable than those caring for people with physical needs only, due to higher levels of burden (associated with higher levels of difficulty and reduced satisfactions) (Sequeira, 2013).
- 6.5 Deeken et al carried out a review of instruments developed to measure carer burden; needs and quality of life – these three categories have largely been developed separately despite there being considerable overlap (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). A recurrent theme identified in their review reinforces findings from other studies, particularly in this respect:
- “the demands placed on caregivers, and their response to those demands, are not simple. Caregivers’ responses do not directly correlate with caregiver demographic characteristics or with patients’ physical or psychological health status.”* (P. 947)
- 6.6 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 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 clinicians, Deeken et al argue:

*“it is critical that the refinement of clinical assessment tools and studies about caregiver interventions must proceed so that professionals will know when and how to intervene to assist the overly burdened caregivers of their patients.”* (P.950)

- 6.7 Much of the ‘burden’ focus in the literature and carer discourse comes from exploration of those caring for people with dementia who are generally found to experience higher levels of burden. This might be expected given the characteristic symptoms that typically accompany dementia including: behavioural disturbance and distress, confusion and cognitive impairment, wandering, incontinence, and physical dependency. Any or all of which are likely to prove extremely stressful. However, Campbell et al’s 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 burden, but subjective interpretation and experience of the carers (Campbell, Wright, Job, Crome et al., 2008)

*“From the analysis it was shown that the strongest predictor of caregiver burden within the model is the caregiver’s sense of ‘role captivity’.”* (P.1082)

*“The study has shown that it is not so much the ‘objective’ load on the caregiver that leads to burden but more importantly it is in how the caregiver perceives this load in terms of their previous relationship with the patient, their own confidence and efficacy in the role and the time they have to develop and sustain their sense of self.”* (P.1083)

- 6.8 The implications of the study for practice and for carer support challenge assumptions about how carers of people with dementia experience burden, and underline the issues to explore with carers in assessment and to ensure an understanding of individual circumstances.
- 6.9 Rinaldi et al observe that it is often difficult to distinguish the factors that contribute to burden and to distress, and undertook a large study in Italy (involving 419 patients with dementia and 419 matched carers). Using the Caregiver Burden Inventory that assesses both objective and subjective burden, and found that older carers (aged over 70) and spouse carers – more than adult child carers - were particularly likely to



experience high burden (Rinaldi, Spazzafumo, Mastriforti, Mattioli et al., 2005). As they observe:

*“This is so probably because the spouse often suffers from age-associated chronic illnesses and providing care is more difficult than for an adult child when care needs increase (...) Dementia can undermine the marital relationship, so that reciprocity can be lost.” (P.173)*

- 6.10 Bruvik et al also explored whether the coping of carers accounts for differences in their experience of burden. Carers with a high external locus of control (LoC) – that is, they believe that what happens is due to factors beyond their control – experienced more burden than carers with a greater internal LoC who believed they were in control and could use more active coping strategies and problem solving approaches (Bruvik, Ulstein, Ranhoff, & Engedal, 2013). Perception of burden, and interventions that can reduce the perception, and increase the satisfactions of caring would therefore seem to be of particular importance (Sequeira, 2013)

- 6.11 De La Cuesta-Benjumea’s qualitative research with women in Spain providing care for relatives with advanced dementia has drawn attention to the importance in coping strategies of removing oneself from the caring identity, and ‘taking leave’ from the life of care-giving (De la Cuesta-Benjumea, 2011):

*“A close examination of the data shows that when caregivers act upon other identities such as being a grandmother, a wife, a mother, or a friend, they attain rest. Thus, it is of little relevance what the caregiver actually does or where she is, but it is fundamental who she is in her relations to others and the social space that she occupies.” (P.1794)*

- 6.12 Such findings add insight to the nature of respite and the “importance of connecting with other selves for the relief of burden.”

### **Satisfactions of caring**

- 6.13 One of the variables that can impact on subjective experience of burden concerns the satisfactions that may be derived from caring. Iecovich, for example, 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 satisfactions (Iecovich, 2011). If increasing satisfactions from caring can reduce carer burden, there would seem to be particularly valuable insights gained from understanding the interplay between

these dimensions. Iecovich explored 335 dyads of care recipients and their adult children who were primary caregivers in Israel, using measures of caregiver burden, satisfaction and quality of relationship. The study found that quality of relationship had the most significant impact on both caregiving burden and satisfaction.

- 6.14 Consistent with other studies, Iecovich found both burden and satisfactions to be largely subjective experiences rather than a reflection of objective difficulty or severity of caring demands, but “quality of relationships was found to affect both of them more than other variables” (P.586).
- 6.15 Cohen et al’s exploration of positive aspects of caregiving found that carers who identified more positive feelings “were less likely to report depression, burden or poor health” (Cohen, Colantonio, & Vernich, 2002). 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. Cohen et al suggest that carers reporting more positive aspects may therefore “be buffered from these negative consequences for themselves and those they care for” (P.187). As with so much carer research, however, longitudinal analyses are required to understand the effects of satisfactions on caring, and which positive aspects might be more important than others, “as we are not able to establish causality with our cross-sectional data.”
- 6.16 Pinquart and Sörensen’s meta-analysis refers to positive aspects of caring as the “uplifts” derived from such aspects as feeling useful, appreciating closeness to the person being cared for, and taking pride in the ability to handle crisis situations (Pinquart & Sorensen, 2003). They conclude that because behaviour problems are the most associated with carer stress and burden,

*“interventions that reduce behaviour problems of the care recipient and increase caregivers’ skills in handling behavioural difficulties are needed.”*

*“Second, because we did not find much evidence that perceived uplifts of caregiving may be eroded when the objective level of stress increases, psychological interventions might also focus on strengthening perceived uplifts of caregiving, for example by cognitively restructuring caregiving perceptions, strengthening positive aspects of the CG-CR relationship, and promoting appreciation by other family members.” (P.122)*

- 6.17 Sequeira's findings that carers of people with dementia experienced greater burden also underlines the significance of behavioural factors. As with other studies, the author concludes that caring is associated with a set of stressor agents which are:

*"mediated by the relationship of providing care and which may result in a greater or lesser degree of burden and/or caregiver satisfaction." (P.498)*

- 6.18 Jensen et al comment on why it is important to direct attention to the benefits and satisfactions of caring, recognising that this is complex territory and a great deal of research has been focused on burden as 'the primary or only experience of the caregiver' (Jensen, Ferrari, & Cavanaugh, 2004):

*"Therefore, the tendency to view caregiving in a negative light exists. Indeed, most studies on elder care have concentrated on burden exclusively, overlooking potential benefits caregivers perceive. Highlighting burdens affiliated with elder care, without acknowledging potential benefits provides an incomplete picture and may be detrimental to aging families. It can set up negative expectations, self-fulfilling prophecies and limit our conceptual treatment of caregiver adjustment and satisfaction." (P.88)*

- 6.19 Lyonette and Yardley (Lyonette & Yardley, 2003) found that while carer stress is independently associated with a poor relationship with the person cared for (in their study, older people), "better relationship quality and greater intrinsic motivations to care are the most significant predictors" of carer satisfaction. However, unravelling the personal aspects of predictors of stress and satisfaction is complex, as they also note:

*"Carers who report high carer stress may be likely to report a poor quality of relationship as a consequence of stress, rather than because the poor quality of relationship caused their stress. Indeed, there is the possibility that two-way effects characterise all the relationships studied in this analysis." (P. 502)*

- 6.20 Many of the other references to 'satisfaction and care' identified in the materials relate to carers' experiences with support and specific interventions, and we will return to this aspect in addressing support later in the document.

## Resilience and Coping

- 6.21 How carers deal with the multiple demands of caring raises multiple issues around coping strategies and resilience; how do some carers manage better than others and what variables are of importance? Understanding different coping strategies and how they relate to experiences of 'care burden' is important in identifying how best to support carers and enhancing their own 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."* (Lazarus & Folkman, 1984) (P.141)

- 6.22 '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, Keady, & Grant, 1995).

- 6.23 As the discussion above on 'burdens' and satisfactions of care has indicated, this is complex territory of multiple intersecting variables. Grant and Whittel (Grant & Whittel, 2000) comment that:

*"satisfactions and stresses among family carers typically co-exist in the midst of enduring and often challenging home circumstances. It seems that the realities with which families are faced are more complex and subtle than at first appears."* (P.257)

- 6.24 Their qualitative study reaffirmed that carers use a variety of problem-solving, cognitive and stress-reduction approaches to caring, and as measured using the CAMI these strategies were differentiated by gender, life stage and family structure. The authors highlight both strengths and vulnerabilities in their findings:

*"On the strengths side, there is support for the view that families demonstrate considerable resilience in their everyday coping."*

However,

*"In relation to vulnerabilities, there must be some concerns that lone carers in particular have to rely quite so much on cognitive coping strategies (...) In some important*

*respects, men appeared to have less mastery over coping than women. They were less self-confident and appeared to find it harder to derive meaningfulness from much of what was happening around them. They frequently sought to distance themselves from the situation by deferring to their female partner or by maintaining interests outside caring.” (P.272)*

6.25 Other variables can also influence carers’ coping strategies; Lockeridge and Simpson, for example, explored younger carers coping with caring for a partner with young onset dementia (Lockeridge & Simpson, 2013). 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 much research into the subjective experience of caring for people with young onset dementia given the much higher prevalence of dementia among older people and their often-elderly carers. Lockeridge and Simpson believe their study to be the first to look specifically at the coping strategies adopted by younger carers to manage changes in their relationship with their partner with dementia.

6.26 The experience of younger carers of people with early onset dementia was similar in many respects to that of carers of older people with dementia, but there were also differences. Lack of public and professional awareness and understanding of young onset dementia increased the carers’ experience of stigma. Typically, carers were motivated to protect their partner from dementia by sustaining their identity for as long as possible (involving denial of dementia and keeping the truth from their partner):

*“Younger carers adopted a range of emotion – and problem-focused coping strategies, though useful in the short-term, ultimately led to negative emotional and psychological outcomes both for carers and their partners with dementia.” (P.649)*

6.27 Lockeridge and Simpson suggest that the greater understanding of the coping strategies “may lead to the development of specific assessments and interventions for younger carers, in order to improve their psychological wellbeing.”

6.28 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 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 (Greenwood, Mackenzie,

Wilson, & Cloud, 2009). How do they manage these circumstances? Important aspects of 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).

*“Uncertainty is double-edged – it allows carers to cling onto hope that with time, their survivor might make unlikely improvements but at the same time it leaves them in limbo. The common description of ‘living day-by-day’ helps manage this because focussing on the present and on survivors’ improvements provides a framework for carers to enjoy the satisfactions derived from caring whilst avoiding focussing on the future.”* (Greenwood et al, 2009, P.131)

- 6.29 Quinn et al’s meta-synthesis of qualitative research on how spouses cope and adjust to caring for a partner following a stroke also highlighted the uncertainty and unpreparedness of carers and their desire for better stroke-related information and practical training to assist them (Quinn et al., 2014). The meta-synthesis 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.
- 6.30 Different strategies may be employed at different stages in caring, and the authors comment that spouses putting their own needs aside tended to occur early in the caregiving journey, while as time progressed there was a greater refocusing on spouses’ own needs. The authors emphasised the importance of using the meta-review findings to inform clinical practice.
- 6.31 Not all coping strategies are positive; they are a way of responding to difficult situations but may not be productive in terms of creating greater carer resilience or wellbeing. Emotional strategies such as denial come within this category, while attempting to gain control or achieving some degree of acceptance may be seen as more positive. It is also apparent that caring situations are dynamic, particularly in relation to care for people with dementia for example, where the caring ‘journey’ will evolve and change. In such situations, different coping strategies may be required at different points of the journey. Norman et al looked at how people with dementia *and* their carers perceived change, and how they managed that change (Norman, Redfern, Briggs, & Askham, 2004). As the authors comment:

*“Cognitive coping strategies are considered in the literature to be less effective than problem-solving strategies. But in our study (...) the ability of carers to perceive caregiving in a different light emerged as essential if they are to cope with the demands of caring for a person with dementia that change over time.” (P.38)*

- 6.32 ‘Change’ was thus a major feature of people’s lives, and was generally perceived negatively, but the response of people with dementia and of their carers involved a range of strategies including denial, acceptance, anger or distress. In such ways people “sought to maintain continuity or a sense of stability and security in the face of deteriorating mental function or unpredictable changes in behaviour.” This study did not explore the effects of different strategies on the wellbeing of the carer, but the findings that people have to adapt to change which can require “all their ingenuity and skill to manage” is illuminating.

- 6.33 The concept of ‘resilience’ in managing the demands of caring is one that is addressed particularly in the mental health and psychology literature. Donnellan et al adopted a qualitative approach to examine spousal dementia carers’ capacity to be resilient, and the factors that facilitate or impede them (Donnellan, Bennett, & Soulsby, 2015). Their analysis indicates findings on “individual, community and societal levels, which suggest that resilience is a multidimensional construct” (P.938). They conclude that:

*“a resilient carer is someone who stays positive in the face of care demands and actively maintains and preserves their relationship and loved one’s former self. Resilient carers have access to and use services such as respite care and may actively engage with innovative schemes that aim to ‘give back’ to others in similar situations. Resilient carers are knowledgeable and well supported by family but especially friends, with whom they share this knowledge. Support group friends share emotional and practical advice and reassurance that may help the carer manage their role better.” (P.938)*

## **Carers and Employment**

- 6.34 We have referred at various points in the report to carers who face multiple role demands, and a key dimension of this is the situation of people who are combining caring responsibilities with paid employment. How caring impacts on employment, and the importance of employment in carers lives are important not only on the individual level, but also in wider 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.

- 6.35 Arksey's analysis of carers and the workplace points to double edged nature of combining work and care (Arksey, 2002). Thus, research indicates the positive impact:

*"employment provides an income and pension rights, it helps to maintain social networks, it offers a temporary relief from the caring role, it enhances self-esteem, and it offers the opportunity to share concerns with colleagues. It can have beneficial effects on carers' physical health and on their emotional well-being. Carers who are in paid work may be less vulnerable to social exclusion."* (P.152)

However,

*"Conversely, studies have also suggested that combining work and care can be difficult. The adverse effects on carers include: lethargy, tiredness and lack of concentration; worry about caring responsibilities at work; and stress brought on by trying to manage the often incompatible roles of employee and carer, each with its own pattern of conflicting demands and expectations."* (P,152)

- 6.36 For some people managing the essential tension between these push and pull factors can become impossible, leading to withdrawal from the labour market, 'early' retirement, or the adoption of new approaches to employment (such as self-employment) that allow greater flexibility. Arksey's analysis unusually brought together the perspectives and experiences both of carers and of employers (much research in this area has focused only on the carers' experience of employment). The findings from both perspectives indicate that there is "no single or simple solution to the issue of supporting carers in the workplace." However, it appeared that women were more likely than men who were carers to have their needs acknowledged, while the research also suggested that there may be a relationship between seniority and opportunities to combine work and care, although the nature of this relationship needed further exploration. Arksey concluded:

*"it has been shown repeatedly that caring, and supporting carers, is either absent from or not high on the agenda of many employers."* (P.159)

- 6.37 The fact that carers form a relatively small proportion of the workforce may account for the lack of awareness of employers; but given the turnover in the caregiver population,



many more people will experience caring responsibilities at some point in their working lives.

- 6.38 Pickard's review of literature on carers of older people and employment carried out for the Audit Commission commented that most carers of older people are of working age, with almost half being aged between 45 and 64 (Pickard, 2004). Around one quarter of women and nearly a fifth of men aged 45 to 59 are carers, and most of these are caring for older relatives (parents or in-laws). As Pickard comments:

*"Although informal carers form a relatively small minority of the workforce at any one point in time, a higher proportion of the workforce is likely to provide informal care at some stage of their working lives."* (P.3)

- 6.39 Work commissioned by the Department for Work and Pensions from the Social Policy Research Unit at the University of York explored the "aspirations and decisions of carers about caring, work and pensions" (Arksey, Kemp, Glendinning, Kotchetkova, & Tozer, 2005). Their study (involving a literature review and qualitative research) indicated that most carers wish to work and are reluctant to stop, and that the consequences of giving up work to care can be profound and enduring:

*"Many employed carers find it difficult to care at the same time; it appears to become more difficult once people provide over 20 hours of care per week. It is co-resident, rather than extra-resident, carers who face the biggest obstacles. Interrupted or short working careers, or moving from full-time to part-time work, have implications for earnings and subsequent pension entitlements, especially if the caring episode last for many years."* (P.1)

- 6.40 More recent evidence suggests that the critical threshold for carers leaving employment may be lower than previous estimates. Pickard et al found that carers providing care for 10 or more hours per week are at risk of leaving employment (King & Pickard, 2013; NIHR School for Social Care Research, 2012). An important finding from the qualitative work by Arksey et al was the complexity of carers' decision making about giving up or remaining in employment. These decisions appeared to be revisited as circumstances changed and reflected the interaction of multiple variables, many of which were beyond the carers' control. At the time of their study it appeared that carers were unlikely to benefit from flexible solutions in their employment:

*"most carers appear to have little access to potential carer-friendly workplace policies and practices, and even where they do exist carers can feel unable to take advantage*

*of them. Most employers, in particular those in the private sector, give little consideration to care-friendly work practices.” (Arksey et al, 2005 P.2)*

- 6.41 In recent years there has been increasing attention to research and information gathering around carers and employment matters, not least from the Action for Carers and Employment (ACE National) partnership led by Carers UK, through work commissioned from the Centre for Social Inclusion (Yeandle, Bennett, Buckner, Shipton, & Suokas, 2006), and from the Carers, Employment and Services study commissioned by Carers UK from the University of Leeds (Yeandle & Buckner, 2007). At the same time, these matters have risen up the policy agenda and achieved greater recognition and traction, partly as a reflection of wider family-friendly policy and practice, and greater flexible working.
- 6.42 Yeandle et al identify the ‘multi-faceted rationale’ underpinning these developments, but highlighting in particular the business case, that is, the costs of developing and implementing policies and practices “are considerably outweighed by productivity gains and reduced operating costs” (Yeandle et al, 2006, P.7).
- 6.43 Vickerstaff et al were commissioned by the Department for Work and Pensions in 2008 to undertake qualitative research to examine and understand what employment support is needed for carers to take up, and remain in, employment (Vickerstaff, Loretto, Milne, Alden et al., 2009). The authors commented that their findings confirmed many of the findings from previous studies, highlighting the importance of working for carers in terms of income but also satisfaction. Similarly, the study confirmed the restrictions that caring placed on carers’ opportunities to work, but also provided a more detailed and in-depth understanding of some of the challenges in combining working and caring:
- “Despite unanimous agreement of the importance of work in our study sample, it was clear that combining working and caring was far from easy. The key themes raised were balancing/juggling, stress and guilt. Respondents who worked found themselves constantly having to balance their work requirements with the needs of their cared for person. This was viewed as a source of great stress.” (Vickerstaff et al, 2009, P.121)*
- 6.44 The study revealed the importance of work-related flexibility in facilitating the juggling of competing demands, although the unpredictable nature of caring meant that flexibility – such as in working fixed part time hours – was often less helpful than it appeared. ‘Informal flexibility’ was particularly valued for 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.

- 6.45 The importance of employers being more carer-aware and carer-friendly was underlined. The fact that it was not unusual for carers to keep their caring responsibilities a secret at work was revealing:

*“This may be a choice, for example, in order to keep a clear line between work and caring and to preserve a space in which the carer can escape their caring role, but for most it was out of fear of the reaction they would get from their employer.” (Vickerstaff et al, 2009, P.127)*

- 6.46 Greater carer-awareness on the part of employers would not only support carers to disclose their situation but would also encourage employers to be alert to signs of potential carer-related stress signs among their workforce:

*“Those on long-term sick, or with an emerging pattern of absences may be desperately trying to balance the demands of caring and working and modifications to work patterns might enable them to remain in work.” (P.128)*

- 6.47 In 2012 a Task and Finish Group was established between the Department of Health and Employers for Carers to explore ways in which carers can be supported to combine work and care (Employers for Carers/Department of Health Task & Finish Group, 2013). The report from the group set out the belief that supporting carers in this way is “not only a problem, but also an economic opportunity”:

*“Supporting people to combine work and care has now become an economic as well as a social imperative. There are significant costs to individuals and families, to employers and business and to the wider economy of carers feeling that they have few options other than to leave work. Some carers choose not to work in order to focus on their caring responsibilities, but many carers feel unable to work because they are not getting the help they need at work, and more still feel they are not getting the help they need from formal care and support services.” (P.8)*

- 6.48 The social and economic gains to be made from supporting carers ‘to juggle their work and family lives’ are identified across several fronts:

- *“individuals and families will not face the financial, health and social disadvantage of being outside the labour market;*
- *Employers will realise quantifiable benefits, including retention of skills and experience, increased employee resilience in terms of health, productivity and engagement, and better results through improved performance;*
- *The economy will benefit from improved output at lower cost, higher public revenues and a reduced benefits bill;*
- *There will be a new and previously unrealised opportunity to turn the need for public investment in care services on its head and grow a vibrant, technology-enabled care sector that supports individuals and families, employers and business, while delivering benefits for the whole economy.” (P.9)*

6.49 This would seem to offer a compelling case, but in practice it is evident that translating these aspirations into reality has some way to go. Nonetheless, many employers are recognising the issues and the Task and Finish Group identified case studies from employers showcasing good practice. 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. The CiE programme has been coordinated and supported by SCIE.

## **Health Impact of Caring**

6.50 So far in this section addressing the impact of caring we have highlighted the ‘burden’ of care, the satisfactions of caring, and the various factors that help carers to cope. Despite the multiple themes identified under the category of ‘Impact of Care’, it is clear that many of them are subsumed within the general focus of ‘burden’. For example, carer depression; emotional and physical impact; psychological impact, and stress and strain are all dimensions of burden. However, it is worth exploring the health impact of caring in more detail, not least because this appeared to be – by some distance – the most frequently identified theme. However, the great 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.

6.51 The health of carers is a concern on many fronts, both because of risk of physical injury (particularly from lifting and handling), and from the psychological and mental health strain of constant and long term caring. Moreover, as we have 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.

6.52 The relationship between caring and health is not straightforward. Glaser et al point out that the issue is increasingly about multiple family and work commitments of older adults (i.e. the simultaneous demands of paid employment, caring and other family responsibilities) (Glaser, Evandrou, & Tomassini, 2005). As they comment, there are two opposing theoretical models regarding the impact of multiple roles on physical and psychological health:

*"Role enhancement theory suggests that those involved in multiple roles (e.g. spouse, parent and employee) are in better health than those with fewer work and family responsibilities. Role strain theory postulates that multiple roles are associated with poor health outcomes."* (P.470-71)

6.53 Using analysis of the longitudinal Retirement Survey Glaser et al found "few statistically significant relationships" between simultaneous role occupancy and health. At the individual level their analyses showed a positive relationship between employment and health, and "mixed results" on the relationship between caring and health.

6.54 Hirst's study of health inequalities and caring used analysis of the British Household Panel Survey and found caring most likely to be associated with inequalities in mental and emotional health. These findings are consistent with other literature that shows carers are more likely than non-carers to report psychological symptoms of stress such as anxiety and depression (Hirst, 2004). However:

*"Despite firm evidence for the existence of caring-related inequalities, the findings indicate that most carers do not have additional health problems that could be attributable to their caring responsibilities. Although a substantial minority of carers present poor physical, emotional and mental health, morbidity levels in the carer*

*population are, in large measure, no different than would be observed if the same people were not providing unpaid care.” (Hirst, 2004, P.18)*

- 6.55 Nonetheless, there are substantial variations within the care population and carers providing more intensive support for greater durations report “much higher than expected levels of distress.”

*“The findings of this study show the challenge to public health policy that tackling the inequalities associated with caregiving represents. Although the vast majority of carers do not present additional health problems because of their caring activities, the adverse effects of caregiving on carers’ psychological well-being are quantifiable and significant. They are most pronounced around transitions into and out of care and in the more demanding care situations. The risk for psychological distress increases with involvement in and intensity of caring activities.” (P.27)*

- 6.56 The greater risk of emotional and psychological distress that exists for a ‘substantial minority’ of carers can be identified. Carers providing at least 20 hours of support a week are at greater risk, so too are women who are carers and caring for a spouse or partner is “particularly associated with additional health problems beyond those that might be attributable to other determinants of health.”

- 6.57 Understanding the health effects of caring is complex, and the evidence indicates that the relationship between caregiving and health impact is neither linear nor causal, and typically the impact is mediated by individuals’ coping skills and resources, as well as by the support they receive more widely. However, the identification of risk factors is important in identifying the groups of carers who are most likely to experience adverse effects.

- 6.58 Certainly, there is considerable evidence that carers report adverse health effects. For example, the partnership of eight national charities involved in Carers Week undertook a survey in 2012 of almost 3,400 carers, exploring the impact of caring on their health and well-being (Carers UK, 2012a).

*“The findings of the survey illustrate that for many people caring can impact negatively on an individual’s physical and mental health; 83 per cent of carers stated that caring has had a negative impact on their physical health and 87 per cent of carers stated that caring has had a negative impact on their mental health.” (P.2)*

6.59 In particular, carers reported experiencing anxiety or stress; depression; injury such as back pain; high blood pressure, and the deterioration of an existing condition. Carers also report neglecting their own health, or inadequately looking after themselves (missing appointments, delaying treatments and not following healthy lifestyles) because of the demands of caring. The financial demands of caring, particularly if carers have left paid employment or reduced their hours of work due to the needs to provide care, were identified as a further source of stress and worry.

6.60 Similarly, the Carers Trust (Carers Trust, 2016b) has commented that:

*“Caring is a risk factor for children and young people’s mental health, which continues to be little understood and often invisible to professionals and policy makers.” (P.4)*

6.61 The nature of the relationship in care dyads is one of the mediating factors that can also impact on health and well-being. Confusingly perhaps, closeness of dyadic relationships appears to predict both beneficial *and* adverse carer outcomes. Fauth et al found that closeness between carers and people with dementia is related to better outcomes when viewed cross-sectionally, but poorer outcomes when viewed longitudinally (Fauth, Hess, Piercy, Norton et al., 2012):

*“Our findings that higher levels of current closeness predicted declines in affect and mental health for the caregiver and that a greater loss in the relationship (from pre-to post-dementia) predicted poorer physical health over time, together support that poorer relationship quality and loss in the relationship may serve as sources of stress for caregivers, negatively affecting their physical health and psychological well-being.” (P.708)*

6.62 Vlachantoni et al's review of care, health and mortality (Vlachantoni, Evandrou, Falkingham, & Robards, 2013) also distinguished between cross-sectional and longitudinal analysis, and drew two key conclusions:

*“Firstly, the cross-sectional analysis of data shows mixed associations between informal care provision and poor health outcomes for the carer. Such research highlights the importance of the demographic and socio-economic characteristics of the carer and the person cared for, and of the specific characteristics and nature of the care provided (e.g. duration, level). Secondly, longitudinal analysis, which typically benefits from a longer timeframe to follow up the impact of caring, shows that informal care provision is not per se associated with adverse health and mortality outcomes,*

*nevertheless particular types and durations of caring have shown negative outcomes.”*  
(P.114)

- 6.63 As the discussion above has indicated, the impact of caring on carers is multi-dimensional and complex. There is extensive evidence and knowledge – particularly from qualitative exploration – of the ways in which the experience of caring impacts on people’s lives. We have explored how the ‘burden of care’ discourse has evolved and the importance of distinguishing between apparently objective and subjective variables. In unpacking the concept of ‘impact’ we have also paid attention to the positive and valued aspects of caring, and to the variables which appear to influence carers’ capacity to cope and build resilience. At several points in this analysis we have highlighted the difficulties in distinguishing causes from consequences. In addressing the health impact of caring we have examined how the complexities of impact are exemplified.
- 6.64 There are multiple reports and examples of research findings that document carers reporting physical, emotional and psychological impacts of caring. However, there is limited evidence that these are disproportionately experienced by carers relative to people who are not carers. Nonetheless, analysis *has* identified the factors that create greater health risks for carers which are associated with intensity of care, particularly for co-resident carers spouse carers. Such insights are important in informing policy and practice in supporting carers, and particularly in identifying carers who are at greater risk of negative impact, and who are facing the most intense demands, and may require specific interventions to avert crises.
- 6.65 We turn now to consider the review’s findings on support and carers, both in terms of the support needs carers identify, and in their experience of specific interventions and their effectiveness.



## **7 Scoping the Knowledge: d) Support & Carers**

- 7.1 How carers can best be supported is a central question. It was at the heart of the government's 2016 consultation to inform the new Carers Strategy, recognising that carers may need a range of support from services and from the benefits system to enable them to live well whilst caring for someone else. As the charts presented earlier demonstrated, of the four over-arching categories of material identified in the scoping review, support for carers attracted the least attention. 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.
- 7.2 These are important questions, but in the light of the foregoing analysis it is also evident that this is complex territory; carers are extremely diverse, their experiences have shared but also unique characteristics, and identifying 'what works' oversimplifies the question. However, understanding carers' needs and how best they can be supported are vital objectives that need to be informed by evidence and knowledge.

### **Carers Needs & Assessment**

- 7.3 The importance of addressing carers' needs has been the focus both of national carers strategies and of legislation, culminating in the most recent Care Act 2014. As we outlined in Section 1, the 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. Support for carers has increasingly come to mean more than recognising carers' existence and helping them to continue caring; it is also about supporting them to live a fulfilled life outside caring, as Larkin and Milne observe, for example (Larkin & Milne, 2013):

*"While these have aspired to increase carers' rights across the board, their specific aims are to: improve carers' levels of support; help them to fulfil their educational potential and combine paid work and care; acknowledge their value and importance,*

*ensure that they are treated with dignity and respect by health and social care professionals; improve their access to information and provide them with opportunities to be involved in service design and delivery as well as professional training.” (P.5)*

- 7.4 Nicholas has similarly commented that in attempting to define or assess outcomes for carers, it is essential to appreciate the nature of caregiving, and that traditional concepts of caring (focusing on stress and burden) tended to emphasise relieving strain and preventing breakdown in caring relationships (Nicholas, 2003). However:

*“While the difficulties of caring can indeed be considerable, achievement of normal life goals (for example, to work or not, to enjoy a social life), choice and independence are as valid for carers as they are for users of services and arguably offer a more positive framework for measuring outcomes.” (P.33)*

- 7.5 Despite the increased attention directed towards assessing carers’ needs, translating this into practice is not straightforward. Take-up of carers’ assessments, for example, has been both low overall and variable between councils. Scourfield suggests that ‘bureaucratic incompetence’ and poor professional awareness might offer part of the explanation, but more fundamentally is the ‘ambiguity’ experienced by professionals dealing with “competing messages and conflicting issues” (Scourfield, 2005).

*“Practitioners work in such a maelstrom of competing discourses, for example, users’ rights, carers’ rights, risk, abuse, efficiency, adult protection, independent living, empowerment, partnership and so on, that there is a genuine feeling of confusion and of being deskilled in their work with carers.” (P.26)*

- 7.6 Seddon and Robinson 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 (Seddon & Robinson, 2015). They suggest that this ambivalence:

*“stems largely from the perceived lack of new types of support for carers following the completion of a separate carer assessment. The continued reliance on traditional social care provision, including home care and respite care, means that practitioners remain cautious about raising carer expectations and identifying support needs, which traditional services do not address. In particular, they are hesitant to discuss the emotional and relational aspects of caring, and explore carers’ associated support needs.” (P.17)*

- 7.7 These are important issues because they underline the continuing challenges to translating policy into practice “despite the unprecedented commitment to carer support” achieved in legislative reform and policy aspiration. Seddon and Robinson’s analysis indicates that in part the difficulty lies in user and carer assessment being regarded in practice as unrelated processes, but the conceptual and theoretical progress that has been made in understanding caregiving over the last 25 years, they argue, offer significant insights that need to inform assessment and effective support planning:

*“Our findings highlight the need for tools that facilitate a narrative approach to care assessment and provide a platform for carers to reflect on the affective and relational aspects of caring, as well as their future aspirations in and beyond their caring role.”*  
(P.21)

- 7.8 In our analysis above of the impact of caring, we highlighted the dynamic and complex nature of caring; and the insights that have emerged in conceptualising caring. It would appear that there is a considerable gap in translating this understanding into meaningful carer assessment practice.

- 7.9 The aspirations and expectations of the 2014 Care Act may be considerable. The Government’s own explanation of changes in care and support as a result of the Act state the following:

*“Since April 2015, changes to the way care and support is provided in England mean you may be eligible for support, such as a direct payment to spend on the things that make caring easier; or practical support, like arranging for someone to step in when you need a short break. Or you may prefer to be put in touch with local support groups so you have people to talk to.*

*The council covering the area where the person you care for lives can help you find the right support and you can ask them for a carers’ assessment. A carers’ assessment will look at the different ways that caring affects your life and work out how you can carry on doing the things that are important to you and your family. Your physical, mental and emotional wellbeing will be at the heart of this assessment. As a result, you may be eligible for support from the council, who will also offer you advice and guidance to help you with your caring responsibilities. You can have a carers’ assessment even if the person you care for does not get any help from the council, and they will not need to be assessed.”* (Great Britain Department of Health, 2014)

- 7.10 These are, as yet, early days since the legislation, but it is pertinent to ask what difference the Care Act is making to carers' experience. Analysis undertaken by the Carers Trust is not altogether encouraging (Carers Trust, 2016a). 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)*

- 7.11 The annual survey of the 'state of caring' undertaken by Carers UK also provides insight to the reality of carers' new rights, particularly in the context of reductions in social care expenditure and widespread pressure on health and care services (Carers UK, 2016)

*"The results show that the spirit of the Care Act 2014 and the Children and Families Act 2014 have not become a reality for all – and carers are struggling to get the support from health and care services that they need to care, work and have a life outside caring." (P.5)*

- 7.12 31% of carers responding to the survey reported having had an assessment of the impact of caring in the previous year:

*"Only a minority of those have an assessment in the last year (35%) were told how to get all the information and advice about their caring role they felt they needed, with 1 in 5 (22%) saying they received little or no helpful information or advice and felt they did not know where to go for support with caring." (P.8)*

- 7.13 Carers often experienced considerable delays in getting an assessment, and the experience of those who had an assessment was often poor:

*"over half (53%) of carers felt that their ability and willingness to provide care was not properly or insufficiently considered in their assessment or the support they received (...) The area which most carers found was not properly considered as part of the assessment or the support received was the support needed to juggle care with training or education. This was followed by support needed to remain in or return to*

*work alongside caring – in fact 74% of working age carers did not feel that this was sufficiently considered as part of the assessment.” (P.10)*

## **Interventions to Support Carers**

7.14 Increasingly, attention has been directed to examining interventions to support carers and identifying what works, but it is clear that this is a complex issue and evidence is far from conclusive. Services developed specifically to support carers include respite and breaks from caring; at the same time, services provided to support a person needing care (such as home care) may indirectly benefit the carer. In support of the new national Carers Strategy the Department of Health commissioned an economic analysis modelling the implications of unpaid care provision over the next 20 years, and estimating the impact of alternative policy interventions to support carers. At the time of writing, the report had not yet been published (Brimblecombe, Fernandez, Knapp, Rehill, & Wittenberg, 2016).

7.15 Arksey et al reviewed respite services and short term breaks for carers of people with dementia and found the evidence “mixed and at times contradictory” (Arksey, Jackson, Croucher, Weatherly et al., 2004):

*“Overall, however, the review found that on the basis of the outcome measures used and on the service that was offered, evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks is limited.” (P.8)*

Alongside this, however:

*“In contrast, there was considerable qualitative evidence from carers (and some from care recipients) of the perceived benefits of the use of respite services. It would be wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective.” (P.8)*

7.16 In addition to reviewing the literature, Arksey et al also included consultation with national statutory and voluntary bodies and with carers themselves, and the findings from this highlighted the importance of not viewing respite in isolation from wider ‘underpinning factors’:

- Knowledgeable and supportive doctors.
- Appropriate management of the condition.

- Responsive social services.
- Fair and understandable benefits/charging systems.
- Supportive carers' networks.
- Helpful family, friends and neighbours.
- Well-coordinated services.

7.17 Arksey et al comment that the absence of firm conclusions from their review, and the apparent contradictions in some of the findings, point to the complexities of this area, as well as to methodological issues. As they also observe, it may be unrealistic to expect use of respite services to indicate substantial effects for carers, *"especially in the case of those carers who delay the use of services until quite late in the progression of the care recipient's disease"* (P.108).

7.18 Furthermore, specific measures of effectiveness and cost-effectiveness employed in evaluations may be quite different from the subjective perceptions of carers. While there may have been little evidence in measures such as reduced stress, depression or burden, carers nonetheless reported high levels of satisfaction.

*"The consultation also suggests that carers see the benefits of respite in quite broad terms which are as much about general quality of life for both carers and care recipients as they are about specific indicators of health."* (P.113)

7.19 Conclusions about effectiveness therefore need to address what constitutes effectiveness from the carers' viewpoint as much as from apparently objective measures.

7.20 Mason et al point out that respite care "is not a discrete intervention but encompasses a range of services" intended to provide temporary relief to the carer (Mason, Weatherley, Spilsbury, Golder et al., 2007). Their systematic review examined the effectiveness and cost-effectiveness of different models of community-based respite for frail older people and their caregivers. Their findings were very similar to those of Arksey et al, thus they observed:

*"Evidence from this review suggests that respite for caregivers of frail elderly people generally has a small effect upon caregiver burden and caregiver mental and physical health. There is tentative evidence that some caregivers benefit more than others, but caregiver satisfaction levels for all types of respite are generally high, and caregivers appear to be more satisfied with respite than with usual care."* (P.297)

7.21 The authors comment that the existing evidence does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn “and is unable to inform current policy and practice.” 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.

7.22 Lopez-Hartmann et al’s more recent systematic review focused on the effectiveness of different types of interventions targeting carers of frail elderly people (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012). The conclusions were similarly cautious:

*“Some evidence exists for the effectiveness of respite care, interventions at individual caregiver level, group support and information and communication technology. Overall, the effect of caregiver support interventions is small and also inconsistent between studies.” (P.12)*

7.23 Methodological differences, and the use of different outcomes measures and variables make it difficult to compare results between studies.

7.24 Mixed or inconclusive evidence has also been identified for other groups of carers. For example, Arksey et al reviewed the literature on services to support carers of people with mental health problems (Arksey, O'Malley, Baldwin, & Harris, 2002). They found:

*“A lack of clear evidence to support any specific interventions, although it is obvious that almost all studies have been able to identify some positive outcomes of services provided.” (P.92)*

7.25 In 2010 Parker et al undertook a meta-review of international evidence on interventions to support carers (Parker, Arksey, & Harden, 2010), and updated the analysis in 2016 with the inclusion of sixty one systematic reviews (Thomas, Dalton, Harden, Eastwood, & Parker, 2016). The 2010 meta-review was commissioned by the Department of Health to inform the work of the Standing Commission on Carers, summarising the main findings on support and interventions for carers, and identifying gaps and weaknesses in the evidence base. 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. However,

*“Beyond this, there is little secure evidence about any of the interventions included in the reviews. We must emphasise that this is **not** the same as saying that these*

*interventions have no positive impact. Rather, what we see here is poor quality research, often 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."* (Parker et al, 2010, P.67)

- 7.26 The updated review of 2016 (Thomas et al, 2016) was commissioned by NIHR, and in addition to updating the evidence about how best to support carers given the implementation of the 2014 Care Act, it was hoped that the review might also evaluate interventions such as carer champions, respite care, resilience programmes and health checks. In the event, "of these interventions only respite care has been subject to systematic review to date" (P.90). The findings from the meta-review confirmed that there is no 'one size fits all' intervention to support carers:

*"However, what seems clear is that contact with others outside the carers' normal networks (whether professional or other carers) may be beneficial, regardless of how delivered (...) there is potential for effective support in specific groups of carers. This includes shared learning, cognitive reframing, meditation, and computer-delivered psychosocial interventions for carers of people with dementia; psychosocial interventions, art therapy, and counselling for carers of people with cancer. Counselling may also help carers of people with stroke. The effectiveness of respite care remains a paradox, given the apparent conflict between the empirical evidence and views of carers."* (P.xx)

- 7.27 The best evidence for interventions "that may have an effect on carers" was defined by the authors as evidence where analysis was based on more than one study, where quality of the primary studies was appraised and reported to be moderate or above for at least two studies, where the intervention type was clearly defined, and where the results of the synthesis were not mixed or inconsistent (P.94). 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 were summarised in these terms:

*"For carers of people with dementia:*

- *Opportunities to share with and learn from others (whether carers or professionals) may have a positive impact on depression and anxiety, and on subjective burden.*
- *Opportunities to reframe the way they think about dementia may have a positive impact on mental health and subjective burden and stress.*



- *Learning meditation techniques may have a positive impact on depression.*
- *Psychosocial interventions delivered via a computer may have a positive impact on depression and anxiety and on subjective burden and stress.*

*For carers of people with cancer:*

- *Psychosocial interventions may have a positive impact on carers' physical and psychological 'distress' and quality of life.*
- *Art therapy may have a positive impact on carers' mental health.*
- *Counselling may have a positive impact on relationship functioning.*

*For carers of people with stroke:*

- *Counselling may have positive impact on family functioning.” (Thomas et al, 2016, P.97).*

7.28 The tentative nature of findings should not come as a surprise. Carers are heterogenous and managing highly individual, complex and demanding situations; it might be expected that effective interventions would be similarly diverse. However, it is also apparent that it remains extremely difficult to disentangle the components of an intervention and to identify the features that are making a difference. As the authors remark:

*“Given the restricted lives some carers lead **any** contact may have beneficial effects. Alternatively, the evidence could reflect the real value of being able to share experiences with and learn from others, whether carers or professionals; but this benefit does appear to be regardless of how the sharing and learning is achieved.” (P.96)*

7.29 Thomas et al emphasise that 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). Furthermore, the conundrum of respite care remains with a lack of evidence of effectiveness, and both the meta-reviews found some evidence of negative impact for carers of people with dementia, alongside qualitative evidence indicating that carers attach value to respite care. Thomas et al point to the variability in quality of respite but also to the emergence of new models (including, for example,

memory cafes) which have not been fully evaluated. They conclude that *“primary research that explores what type of respite is better or worse, for whom, and in relation to outcomes that carers themselves think are valuable is urgently needed”* (P.98).

- 7.30 The evidence for interventions that may have an effect on carers is worth exploring here. The main types identified by Thomas et al, and summarised above, were caregiver support groups; telephone counselling; educational programmes; art therapy; meditation-based interventions; computer-mediated interventions; cognitive reframing; couple-based interventions; and psychosocial interventions. Some of the findings of the systematic reviews which informed this conclusion are explored below. It is evident in many cases that findings are inconclusive, contradictory or beset with methodological weaknesses in the original studies.

- 7.31 Chien et al's meta-analysis of professionally-led support groups for caregivers of people with dementia found them to be “significantly effective” (Chien, Chu, Guo, Liao et al., 2011). Educational and psychoeducational groups have different effects:

*“This result might suggest that educational groups can immediately provide useful information, such as caregiving skills, ways of self-adjustment, knowledge for handling legal issues, role play, and discussion, and thus facilitate caregivers finding available resources that can reduce their burden in patient care quickly. Psychoeducational groups not only provide practical information on patient care but also focus on caregivers’ psychological and emotional status as well as establishing a social supportive network, and are more effective at improving caregivers’ psychological well-being and depression.”* (P.1096)

- 7.32 The distress and burden of caring for someone with dementia have been well rehearsed; interventions that address the psychological needs of these carers are therefore of potential value. Hurley et al identified eight studies of meditation-based interventions for carers of people with dementia (Hurley, Patterson, & Cooley, 2014). The studies demonstrated:

*“significant improvements in depression among dementia caregivers, consistent with the application of such interventions to other populations with depression (...). additionally, the interventions have been shown to alleviate burden (...). Consequently, it appears that meditation-based interventions offer a feasible and effective intervention for dementia caregivers experiencing burden or depression.”* (P.286)

- 7.33 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.
- 7.34 The review by McKechnie et al focused on psychosocial information and communication technology (ICT) interventions (that is, using DVDs, CD-ROMs, computer programmes or the internet), aimed at both providing carers of people with dementia with information and also improving their wellbeing and coping skills (McKechnie, Barker, & Stott, 2014). Sixteen papers, representing 14 empirical studies, were included in the review. The interventions were “varied and multifaceted, with a range of different outcome measures.” However, most measured impact on carer burden/stress and depression.
- 7.35 The review 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 absence of control groups. Nonetheless, the use of computer-mediated interventions for carers is expanding and McKechnie et al conclude that:
- “it would be beneficial to carers, and also to services – in terms of reaching more carers as well as potential cost saving implications – for this medium of intervention to be developed so that more individuals can benefit.”*
- “More research is, however, needed in order to ensure that interventions are maximally effective. Research needs to consider the effects of interventions on people of different ethnicities and carer-care recipient relationships, as there is evidence that differential effects exist between groups.” (P.1634)*
- 7.36 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, 2012b)
- 7.37 Marim et al also conducted a systematic review of educational programmes for carers of older people with dementia, but focusing only on randomized controlled trials (Marim, Silva, Taminato, & Barbosa, 2013). They found:

*“evidence “to support this type of intervention as being more effective than usual care in reducing the burden of caregivers of patients with dementia.” (P.274)*

- 7.38 Waldron et al reviewed psychosocial interventions to improve outcomes for carers of people with cancer (Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013), while Regan et al examined such interventions directed at couples affected by cancer (Regan, Lambert, Girgis, Kelly et al., 2012), and Cheng et al reviewed psychosocial interventions for stroke survivors and their carers (Cheng, Chair, & Chau, 2014). Waldron et al commented that:

*“The present findings lend further support to the existing body of literature suggesting that interventions targeting communication and education have an impact on improving caregiver quality of life.” (P.1203)*

And

*“Overall, the present review suggests that support and education may be the most valued and effective tools for improving caregiver QoL. The largest (although small) effect sizes were for supportive-educational interventions focusing on a wide range of issues including family involvement, optimistic attitude, coping skills, uncertainty reduction, and symptom management. These treatment combinations have not been widely researched within the field of cancer caregiving, and perhaps a combination of support, information, and skills training may achieve significant gains to improve the QoL of adult cancer caregivers.” (P.1206)*

- 7.39 Regan et al found the effects of couple-based psychosocial interventions similar to those reported for patient only or carer only interventions, however:

*“Couple-based interventions tended to have the greatest impact on improving outcomes such as couple communication, psychological distress, relationship functioning.” (P.9)*

- 7.40 The authors conclude that:

*“In summary, the findings from this review suggest that there are clear benefits to be gained following the implementation of a couple-based intervention. Although more work is needed, there is enough evidence to be confident that these interventions show promising results in reducing distress and improving coping and adjustment to a cancer diagnosis or to cancer symptoms.” (P.12)*

- 7.41 Cheng et al found evidence on the effects of psychosocial interventions for stroke caregivers was limited, and the effectiveness of different types of interventions could not be ascertained because of the limitations of studies available. However:

*“There is a trend that psychoeducation, consisting of training in problem solving and stress coping, offered by telephone, reduced the depression level and improved the sense of competency of caregivers, although the summary of the effect was not statistically significant. In addition, equipping caregivers with caregiving skills had a more favourable effect on reducing the use of healthcare resources of stroke survivors.” (P.42).*

- 7.42 ‘Cognitive reframing’ refers to a particular element of psychosocial interventions; Vernooij-Dassen et al point out that a key problem for carers of people with dementia lies in understanding and responding to the person’s behaviour, and carers frequently experience anger, anxiety, guilt, depression and other negative emotions as a consequence (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011). Cognitive reframing can be used as a psychological intervention with carers to identify and modify negative beliefs and interpretations. Reviewing the findings across 11 studies the authors 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 authors advise that the conclusions should be treated with caution, but suggest that in clinical practice:

*“cognitive reframing could be a useful additional tool in individualised support for carers of people with dementia.” (P.11)*

- 7.43 The findings by Thomas et al 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 (Knapp, King, Romeo, Schehl 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 8 month period) found the intervention

to be cost effective and showed positive outcomes in carers' affective symptoms and quality of life. Knapp et al conclude that:

*"An intervention that is cost neutral, even over a relatively short period, and which significantly improves carer mental health and quality of life should be made more widely available."* (P.6)

- 7.44 Livingstone et al reported on longer term follow-up which showed similarly positive results (Livingston, Barber, Rapaport, Knapp et al., 2014):

*"START (...) improved carers' depression and anxiety symptoms and quality of life not only in the short term, but also up to 24 months later. This is the first trial to show such results."* (P.546)

- 7.45 Furthermore, at 2-year follow-up carers in the 'treatment as usual' (TAU) control group:

*"were seven times more likely to have clinically significant depression than in the START intervention group."* (P.546)

- 7.46 For both groups, social care and care home costs rose over time for the person with dementia as their condition deteriorated. Residential costs increased in both groups, but with a greater increase in TAU than in START "although this result was not statistically significant." Monitoring of the impact on residential admissions is continuing for five years. The conclusions from the evaluation to-date are clear:

*"The START intervention is clinically effective in the long term, improving carer mood and quality of life for 2 years. It does not raise costs, and it is cost effective in terms of both carer and patient outcomes with respect to NICE cost thresholds."* (P.547)

- 7.47 The authors argue that a cost-neutral intervention such as START "should be made widely available."

- 7.48 In this section of the paper we 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 been selective in presenting key themes while acknowledging that there are multiple other dimensions within the knowledge base. At the same time, while we know a lot about the lives, experiences and characteristics of carers, we still are able to offer relatively few conclusions about the evidence of 'what works'. In part this reflects the enormous variability in the carer population and the fact that individual

circumstances can vary in ways that make a difference to resources and outcomes. However, it also reflects the focus of much research around carers to-date, and the need for further work to explore in finer detail what works for which carers and in what circumstances.

## **8 Conclusions**

- 8.1 In this final section we offer some conclusions for policy and practice in relation to carers, and for research. However, we begin by highlighting below the key messages that we have identified throughout the review.

### **Key Messages**

- Knowledge and evidence about carers in the UK and more widely is extensive and varied, and comes from a wide variety of sources including: official government statistics; academic research; and from bodies representing the experiences and voices of carers.
- Caring is extremely diverse and involves all sections and age groups of the population; people are increasingly likely to experience one or more periods of caregiving during a lifetime.
- There are similarities in the experiences of carers but at the same time all caring is unique. All care takes place in a relationship, and every relationship is different, featuring distinctive strengths and weaknesses, positive and negative dimensions, and typically resulting in complex and ambivalent emotions associated with caring, and with 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.
- Most care is provided for older people, and typically by adult children or by a spouse/partner. Co-resident carers are the most likely to be spouses or partners and are the most heavily involved in care, while also being more likely to have their own health needs.
- Older carers continue to be relatively invisible in policy, practice and research 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 newly 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 themes 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 particular considerations here.
- The impact of caring covers a wide range of themes – from abuse and care, through conflict in caring, ethnical issues, risks and resilience and stress and strain. 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 is highly pejorative and one dimensional and needs to be seen alongside the satisfactions and intrinsic benefits of caring. 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 also 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). The business case for employers to support carers is one that has been made, but it 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 elderly and retired.

- Much of what we know about carers is about their characteristics; 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. 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).
- There is not a quick fix or a one-size-fits-all model, 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.
- There is a great deal of knowledge on a vast array of subjects under the ‘carer umbrella’. That knowledge comes from a wide range of sources – from theoretical and conceptual models; from professional practice development, and - most importantly – from the voices and lived experience of carers.
- Providing the overview of evidence and knowledge enables us to go from the big picture to the small and to maximise the value of the cumulative weight of knowledge. It is important to keep sight of all aspects of caring and not to ‘salami slice’ care or focus disproportionately on sub-groups to the detriment of others.

## Implications for Policy, Practice & Research

- 8.2 As we explored at the beginning of the report, the objectives of the review were two-fold; both to map carer-related knowledge and evidence, but also to create a resource that would be accessible, useable and dynamic in order to inform a wide range of carer-

interested parties. We believe there is considerable value in having undertaken this unique review; and that for the first time this offers a report and associated data resource that will be of benefit to a wide range of audiences seeking information and knowledge on different aspects of carers and caring.

- 8.3 However, the resource is not an oracle and will not provide simple solutions for policy makers or practitioners wanting to identify short-cuts or easy answers to caring dilemmas. There is no single panacea, but there are multiple areas in which knowledge of carers' experiences and of *what makes a difference to them*, can and should inform policy and practice. Moreover, the current state of knowledge is able to identify critical pinch points and to highlight groups (and sub-groups) of carers that are likely to be under particular strain and pressure and where attention should be prioritised.
- 8.4 As we have explored, 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 generally 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 parallel.
- 8.5 For the research community, and those that commission research, there are also some important conclusions. It is illuminating to reflect on the *nature* of the evidence base and knowledge about carers. Milne and Larkin have previously identified the bifurcated nature of carer-related knowledge, with two separate and distinctive paradigms, namely 'Gathering and Evaluating', and 'Conceptualising and Theorising' (Milne & Larkin, 2015). 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)

- 8.6 As this scoping review has also demonstrated, much of the carer-related knowledge 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.

- 8.7 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)

- 8.8 As we acknowledged in Section 1, while the term 'carer' is in widespread use and generally understood in popular, research and policy discourse, 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 to some extent at least contested, not least because of the complexity of inter-dependency and reciprocity within relationships which render the carer/cared for distinction as a false dichotomy.

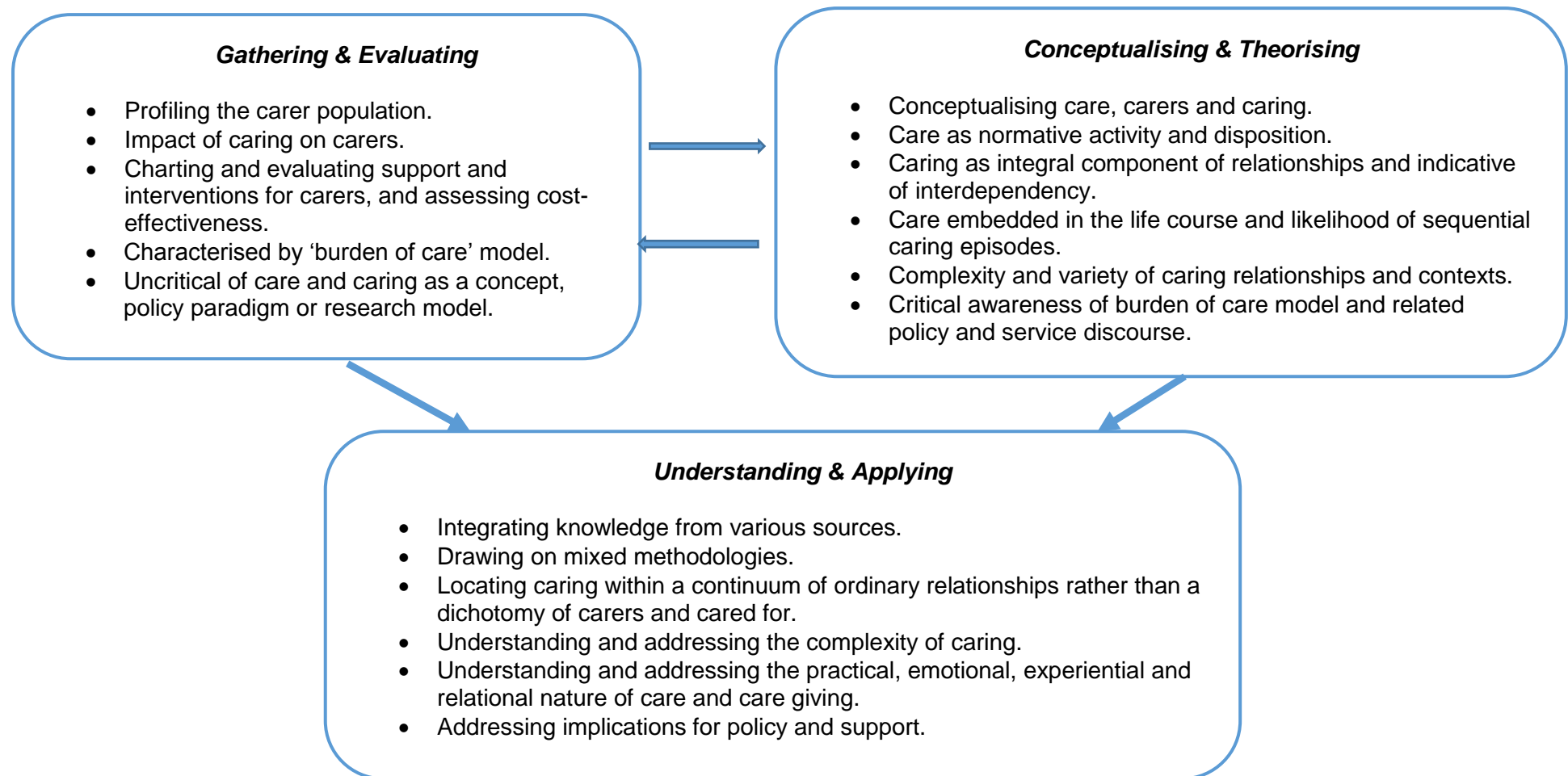
- 8.9 Milne and Larkin's conclusion that there are two separate research paradigms operating in carer-related knowledge, which have different perspectives and approaches, finds considerable traction and resonance within the current review. As we have described and discussed, there is no shortage of knowledge 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 8.1 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.

- 8.10 This 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. In Section 1 we explored 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 have pointed out (Arksey & Glendinning, 2007):

*“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)*

**Fig. 8.1: Towards an integrated research & knowledge paradigm**



- 8.11 We can see the present review as one attempt to locate itself 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 and counterpoints inherent in relationships.
- 8.12 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.
- 8.13 Finally, a major shortcoming in much of the research – and one that is repeatedly identified by academics – 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.
- 8.14 This review has, for the first time, used a scoping methodology to identify and classify the wide and diverse carer-related knowledge base. We do not claim to offer a definitive or final overview of this territory, since by its nature it is dynamic and evolving. However, we have created a unique foundation for a resource that can be expanded and developed and which lends itself to further analysis and exploration.

## References

- Aasbø, G., Solbraekke, K. N., Kristvik, E., & Werner, A. (2016). Between disruption and continuity: challenges in maintaining the 'biographical we' when caring for a partner with a severe, chronic illness. *Sociology of Health & Illness*, 38(5), 782-796.
- Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: a systematic review of the influence of relationship factors. *Aging and Mental Health*, 13(4), 497-511.
- Ackers, L. (2004). Citizenship, migration and the value of care in the European Union. *Journal of Ethnic and Migration Studies*, 30(2), 373-396.
- ADASS. (2015). *Distinctive, valued, personal: why social care matters - the next five years*. London: ADASS
- Aldridge, J. (2002). *Children caring for parents with severe and enduring mental illness*. Loughborough University
- Aldridge, J. (2006). The Experiences of Children Living with and Caring for Parents with Mental Illness. *Child Abuse Review*, 15(2), 79-88.
- Aldridge, J. (2008). All Work and no Play? Understanding the Needs of Children with Caring Responsibilities. *Children & Society*, 22(4), 253-264.
- Arksey, H. (2002). Combining informal care and work: supporting carers in the workplace. *Health & Social Care in the Community*, 10(3), 151-161.
- Arksey, H., & Glendinning, C. (2007). Choice in the context of informal care-giving. *Health & Social Care In The Community*, 15(2), 165-175.
- Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Newbronner, E., & Baldwin, S. (2004). *Review of respite services and short-term breaks for carers of people with dementia*. London: NCCSDO
- Arksey, H., Kemp, P., Glendinning, C., Kotchetkova, I., & Tozer, R. (2005). *Carer's aspirations and decisions around work and retirement*. Department for Work and Pensions
- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
- Arksey, H., O'Malley, L., Baldwin, S., & Harris, J. (2002). *Services to support carers of people with mental health problems : overview report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*. NCCSDO
- Askham, J., Briggs, K., Norman, I., & Redfern, S. (2007). Care at home for people with dementia: as in a total institution? *Ageing & Society*, 27(1), 3-24.
- Banks, P., Cogan, N., Deeley, S., Hill, M., Riddell, S., & Tisdall, K. (2001). Seeing the invisible children and young people affected by disability. *Disability and Society*, 16(6), 797-814.
- Bastawrous, M., Gignac, M., & Kapral, M. (2015). Factors that contribute to adult children caregivers' well-being : a scoping review. *Health Soc Care Community*, 23(5), 449-466.
- Becker, S. (2007). Global Perspective on Children's Unpaid Caregiving in the Family. *Global Social Policy*, 7(1), 23-50.
- Blieszner, R. (2006). A lifetime of caring: Dimensions and dynamics in late-life close relationships. *Personal Relationships*, 13(1), 1-18.



- Bolas, H., van Wersch, A., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology & Health, 22*(7), 829-850.
- Bowey, L., & McLaughlin, A. (2007). Older carers of adults with a learning disability confront the future: Issues and preferences in planning. *British Journal of Social Work, 37*(1), 39-54.
- Brien, S. E., Lorenzetti, D., Lewis, S., Kennedy, J., & Ghali, W. A. (2010). Overview of formal scoping review on health system report cards. *Implementation Science, 5*(2).
- Brimblecombe, N., Fernandez, J., Knapp, M., Rehill, A., & Wittenberg, R. (2016). *Unpaid care in England: Future Patterns and Potential Support Strategies*. London: PSSRU, LSE/ESHCRU
- Bruvik, F., Ulstein, I., Ranhoff, A., & Engedal, K. (2013). The effect of coping on the burden in family carers of persons with dementia. *Aging and Mental Health, 17*(8), 973-978.
- Buckner, L., & Yeandle, S. (2011). *Valuing Carers 2011: Calculating the value of carers' support*. London: Carers UK
- Campbell, P., Wright, J. O., J., Job, D., Crome, P., Bentham, P., Jones, L., & Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International Journal Of Geriatric Psychiatry, 23*(10), 1078-1085.
- Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., & Murray, S. A. (2014). Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Family Practice, 15*(48).
- Carers Trust. (2016a). *Care Act for Carers. One Year on*. Carers Trust/University of Birmingham
- Carers Trust. (2016b). *Invisible and in distress: prioritising the mental health of England's young carers*. Carers Trust
- Carers UK. (2011). *Half a million voices : improving support for BAME carers*. Carers UK
- Carers UK. (2012a). *In sickness and in health : a survey of 3,400 UK carers about their health and well-being*. Carers UK and 7 other charities
- Carers UK. (2012b). *Care and technology in the 21st century*. Carers UK
- Carers UK. (2014). *Care Act 2014*. London: Carers UK
- Carers UK. (2015a). *Facts about Carers*. London: Carers UK
- Carers UK. (2015b). *Caring into later life: the growing pressure on older carers*. London: Carers UK
- Carers UK. (2016). *State of Caring*. Carers UK
- Carers UK/Employers for Carers. (2014). *Supporting employees who are caring for someone with dementia*. Carers UK/Employers for Carers
- Carers Week Partnership. (2013). *Prepared to care? : exploring the impact of caring on people's lives*.
- Chan, C., & Chui, E. (2011). Association between cultural factors and the caregiving burden for Chinese spousal caregivers of frail elderly in Hong Kong. *Aging and Mental Health, 15*(4), 500-509.
- Charles, G. (2011). Bringing Young Carers Out of the Shadows. *Reclaiming Children & Youth, 20*(3), 26-30.
- Charlesworth, G., Tzimoula, X., Higgs, P., & Poland, F. (2007). Social networks, befriending and support for family carers of people with dementia. *Quality in Ageing, 8*(2), 37-44.

- Charlesworth, G., Tzimoula, X., & Newman, S. (2007). Carers Assessment of Difficulties Index (CADI): Psychometric properties for use with carers of people with dementia. *Aging & Mental Health*, 11(2), 218-225.
- Cheater, F. M. (2008). Carers living with stroke survivors who were incontinent had minimal social interaction and felt socially isolated. *Evidence Based Nursing*, 11(2), 64-64 61p.
- Cheng, H., Chair, S., & Chau, J. (2014). The effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors: A systematic review and meta-analysis. *Patient Education and Counseling*, 95, 30-44.
- Cheung, J., & Hocking, P. (2004). Caring as worrying: the experience of spousal carers. *Journal of Advanced Nursing*, 47(5), 475.
- Chien, L.-Y., Chu, H., Guo, J.-L., Liao, Y.-M., Chang, L.-I., Chen, C.-H., & Chou, K.-R. (2011). Caregiver support groups in patients with dementia: a meta-analysis. *Int J Geriatr Psychiatry*, 26, 1089-1098.
- Cohen, C., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal Of Geriatric Psychiatry*, 17(2), 184-188.
- Collins, J., & Bayless, S. (2013). How caring for a parent affects the psychosocial development of the young *Nursing Children & Young People*, 25(10), 16-21.
- Corden, A., & Hirst, M. (2011). Partner care at the end-of-life : identity, language and characteristics. *Ageing & Society*, 31(2), 217-242.
- Coyle, C., Kramer, J., & Mutchler, J. (2014). Aging together: sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4), 302-312.
- Dahlberg, L., Demack, S., & Bambra, C. (2007). Age and gender of informal carers: a population-based study in the UK. *Health and Social Care in the Community (Print edition)*, 15(5), 439-445.
- Daudt, H. M. L., Van Mossel, C., & Scott, S. J. (2013). Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework' *Medical Research Methodology*, 13(48).
- Davis, L. L. (2011). The nature and scope of stressful spousal caregiving relationships. *Journal of Family Nursing*, 17(2), 224-240.
- De la Cuesta-Benjumea, C. (2011). Strategies for the relief of burden in advanced dementia care-giving. *J Adv Nurs*, 67(8), 1790-1799.
- Dearden, C., & Becker, S. (2004). *Young carers in the UK : the 2004 report*. Carers UK/The Children's Society
- Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K., & Ingham, J. M. (2003). Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management*, 26(4), 922-953.
- Del Bono, E., Sala, E., & Hancock, R. (2009). Older carers in the UK: are there really gender differences? New analysis of the Individual Sample of Anonymised Records from the 2001 UK Census. *Health and Social Care in the Community*, 17(3), 267-273.
- Department of Health. (2010a). *Recognised, valued and supported: Next steps for the Carers Strategy*. London: TSO.
- Department of Health. (2010b). *Carers and Personalisation:: improving outcomes* London: Department of Health.

- Donnellan, W., Bennett, K., & Soulsby, L. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? a qualitative study. *Aging and Mental Health*, 19(10), 932-939.
- Draper, H., & Sorell, T. (2013). Telecare, remote monitoring and care *Bioethics*, 27(7), 365-372.
- Draper, P., & Brocklehurst, H. (2007). The impact of stroke on the well-being of the patient's spouse: an exploratory study. *Journal of Clinical Nursing*, 16(2), 264-271.
- Earley, L., & Cushway, D. J. (2002). The Parentified Child. *Clinical Child Psychology & Psychiatry*, 7(2), 163.
- Employers for Carers/Department of Health Task & Finish Group. (2013). *Supporting working carers : the benefits to families, business and the economy : final report of the carers in employment task and finish group* London: Carers UK
- Equal Opportunities Commission. (1980). *The experience of caring for elderly and handicapped dependents*. Manchester: EOC
- Equal Opportunities Commission. (1984). *Carers and services: a comparison of men and women caring for dependent elderly people*. Manchester: EOC
- Eriksson, H., Sandberg, J., Holmgren, J., & Pringle, K. (2013). His helping hands -adult daughter's perceptions' of fathers with caregiving responsibility. *European Journal of Social Work*, 16(2), 235-248.
- Evandrou, M., & Glaser, K. (2004). Family, work and quality of life: changing economic and social roles through the lifecourse. *Ageing and Society*, 24(5), 771-791.
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging and Mental Health*, 16(6), 699-711.
- Finch, J., & Groves, D. (1980). Community care and the family: A case for equal opportunities? *Journal of Social Policy*, 9(4), 487-501.
- Finch, J., & Groves, D. (1983). *A Labour of Love: Women, work and caring*: Routledge.
- Forbat, L., & Nar, S. (2003). Dementia's cultural challenge. *Community Care*(25.9.03), 38-39.
- Frank, J. (2002) Making it work : good practice with young carers and their families. Children's Society/Princess Royal Trust for Carers.
- Gans, D., Lowenstein, A., Katz, R., & Zissimopoulos, J. (2013). Is There a Trade-Off Between Caring for Children and Caring for Parents? *Journal of Comparative Family Studies*, 44(4), 455-471.
- Ganyo, M., Dunn, M., & Hope, T. (2011). Ethical issues in the use of fall detectors. *Ageing & Society*, 31(8), 1350-1367.
- Glasby, J., Ham, C., Littlechild, R., & McKay, S. (2010). *The case for social care reform - the wider economic and social benefits*. University of Birmingham: HSMC/Institute of Applied Social Studies
- Glaser, K., Evandrou, M., & Tomassini, C. (2005). The health consequences of multiple roles at older ages in the UK. *Health Soc Care Community*, 13(5), 470-477.
- Godwin, B. (2012). The ethical evaluation of assistive technology for practitioners: a checklist arising from a participatory study with people with dementia, family and professionals. *Journal of Assistive Technologies*, 6(2), 123-135.

- Goodwin, V., & Happell, B. (2006). Conflicting agendas between consumers and carers: the perspectives of carers and nurses. *International Journal of Mental Health Nursing*, 15(2), 135-143.
- Graham, H. (1983). Caring: A labour of love. In J. Finch & D. Groves (Eds.), *A Labour of Love: women, work and caring*. London: Routledge & Kegan Paul.
- Grant, G., & Whittel, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: the relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disabilities*, 13(4), 256-275.
- Gray, B., & Robinson, C. (2009). Hidden Children: Perspectives of Professionals on Young Carers of People with Mental Health Problems. *Child Care in Practice*, 15(2), 95-108.
- Great Britain Department of Health. (2014). *Care and support: what's changing?* London: Great Britain. Department of Health.
- Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health Soc Care Community*, 23(1), 64-78.
- Greenwood, N., Mackenzie, A., Habibi, R., Atkins, C., & Jones, R. (2010). General practitioners and carers: a questionnaire survey of attitudes, awareness of issues, barriers and enablers to provision of services. *BMC Family Practice*, 11, 100-107.
- Greenwood, N., Mackenzie, A., Wilson, N., & Cloud, G. (2009). Managing uncertainty in life after stroke: a qualitative study of the experiences of established and new informal carers in the first 3 months after discharge. *International Journal of Nursing Studies*, 46(8), 1122-1133 1112p.
- Greenwood, N., & Smith, R. (2016). The oldest carers: A narrative review and synthesis of the experiences of carers aged over 75 years. *Maturitas*, 94, 161-172.
- Gregory, C. (2010). *Improving health and social care support for carers from black and minority ethnic communities*.
- Grundy, E., & Henretta, J. C. (2006). Between elderly parents and adult children : a new look at the intergenerational care provided by the 'sandwich generation'. *Ageing & Society*, 26(5), 707-722.
- Health and Social Care Information Centre. (2010). *Survey of Carers in Households 2009/10*. London: The NHS Information Centre for Health and Social Care
- Henderson, J. (2002). Experiences of 'care' in mental health. *Journal of Adult Protection*, 4(3), 34-45.
- Hirst, M. (2004). *Health inequalities and informal care : end of project report*. University of York: Social Policy Research Unit
- Hirst, M. (2014). Transitions into and out of unpaid care. York: Social Policy Research Unit University of York.
- HM Government. (1999). *Caring About Carers: A National Strategy for Carers*. London: TSO.
- HM Government. (2008). *Caring at the Heart of 21st Century Families and Communities: A caring system on your side*. London: TSO.
- HM Government. (2014). *Care Act 2014*. London: TSO.
- Hounsell, D. (2013). *Hidden from View: The experiences of young carers in England*. The Children's Society

- Hurley, R., Patterson, T., & Cooley, S. (2014). Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature. *Aging & Mental Health*, 18(3), 281-288.
- Iecovich, E. (2011). Quality of relationships between care recipients and their primary caregivers and its effect on caregivers' burden and satisfaction in Israel. *Journal of Gerontological Social Work*, 54(6), 570-591.
- Jensen, C., Ferrari, M., & Cavanaugh, J. (2004). Building on the benefits: assessing satisfaction and well-being in elder care. *Ageing International*, 29(1), 88-110.
- Katbamna, S., Ahmad, W., & Bhakta, P. (2004). Do they look after their own? Informal support for South Asian carers. *Health and Social Care in the Community (Print edition)*, 12(5), 398-406.
- Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2002). Supporting South Asian carers and those they care for: the role of the primary health care team. *The British Journal Of General Practice: The Journal Of The Royal College Of General Practitioners*, 52(477), 300-305.
- Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors : a case for care networks. *Ageing & Society*, 23(1), 115-127.
- Keywood, K. (2003). Gatekeepers, proxies, advocates?: the evolving role of carers under mental health and mental incapacity law reforms. *Journal of Social Welfare and Family Law*, 25(4), 355-368.
- King, D., & Pickard, L. (2013). When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England. *Health & Social Care in the Community*, 21(3), 303-314.
- Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaprt, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E., Cooper, C., & Livingston, G. (2013). Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrategies for RelaTives) study): a pragmatic randomised controlled trial. *BMJ*, 347(f6342), 1-12.
- Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community*, 24(2), 203-213.
- Koo, K. (2012). Carers' representations of affective mental disorders in British Chinese communities. *Sociology of Health & Illness*, 34(8), 1140-1155.
- Lapierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing and Society*, 33(8), 1442-1468.
- Larkin, M., & Milne, A. (2013). Carers and Empowerment in the UK: A Critical Reflection. *Social Policy and Society*, 13(1), 25-38.
- Larkin, M., & Mitchell, W. (2016). Carers, choice and personalisation: What do we know? *Social Policy and Society*, 15(2), 189-205.
- Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK. *Br J Psychiatry*, 193(3), 240-246.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal and Coping*: Springer Publishing.
- Leinonen, A. M. (2011). Adult children and parental care-giving: making sense of participation patterns among siblings. *Ageing and Society*, 31(2), 308-327.

- Levac, D., Colquhoun, H., & O'Brien, K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(69).
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Romeo, R., Livingston, D., Mummery, C., Walker, Z., Hoe, J., & Cooper, C. (2014). Long-term clinical and cost-effectiveness of psychological intervention for family carers of people with dementia: a single-blind, randomised, controlled trial. *The Lancet Psychiatry*, 1(7), 539-548.
- Lloyd, L. (2006). Call us carers: limitations and risks in campaigning for recognition and exclusivity. *Critical Social Policy*, 26(4), 945-960.
- Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: how younger carers cope. *Dementia: the International Journal of Social Research and Practice*, 12(5), 635-651.
- Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly : a systematic review. *Int J Integr Care*, 12(10 August).
- Lyonette, C., & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing & Society*, 23(4), 487-506.
- Manthorpe, J. (2003). Nearest and dearest?: the neglect of lesbians in caring relationships. *British Journal of Social Work*, 33(6), 753-768.
- Manthorpe, J., Illife, S., & Alison, E. (2003). Testing Twigg and Atkin's typology of caring : a study of primary care professionals' perceptions of dementia care using a modified focus group method. *Health and Social Care in the Community*, 11(6), 477-485.
- Marim, C., Silva, V., Taminato, M., & Barbosa, D. (2013). Effectiveness of educational programs on reducing the burden of caregivers of elderly individuals with dementia: a systematic review. *Rev. Latino-Am Enfermagem*, 21, 267-275.
- Mason, A., Weatherley, H., Spilsbury, K., Golder, S., Arksey, H., Adamson, J., & Drummond, M. (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Journal of the American Geriatrics Society*, 55(2), 290-299.
- Mays, N., Roberts, E., & Popay, J. (2001). Synthesising research evidence. In N. Fulop, P. Allen, A. Clarke, & N. Black (Eds.), *Studying the organisation and delivery of health services: research methods*. London: Routledge.
- McGarry, J., & Arthur, A. (2001). Informal caring in later life: a qualitative study of the experiences of older carers. *Journal of Advanced Nursing*, 33(2), 182-189.
- McKechnie, V. B., C.;Stott, J., Barker, C., & Stott, J. (2014). Effectiveness of computer-mediated interventions for informal carers of people with dementia - a systematic review. *International Psychogeriatrics*, 26(10), 1619-1637.
- McKee, K., Spazzafumo, L., Nolan, M., Wojszel, B., Lamura, G., & Bien, B. (2009). Components of the difficulties, satisfactions and management strategies of carers of older people: a principal component analysis of CADI-CASI-CAMI. *Ageing & Mental Health*, 13(2), 255-264 210p.
- Milne, A., & Hatzidimitriadou, E. (2003a). "Isn't he wonderful?" Exploring the contribution and conceptualisation of older husbands as carers. *Ageing Int*, 28(389).
- Milne, A., & Hatzidimitriadou, E. (2003b). The 'Caring in later life' report : a secondary analysis of the 1995 General Household Survey. *Quality in Ageing*, 3(3), 3-15.

- Milne, A., & Larkin, M. (2015). Knowledge generation about care-giving in the UK : a critical review of research paradigms. *Health Soc Care Community*, 23(1), 4-13.
- Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing & Society*, 31, 422-437.
- Moran, N., Arksey, H., Glendinning, C., Jones, K., Netten, A., & Rabiee, P. (2012). Personalisation and carers: Whose rights? Whose benefits? *British Journal of Social Work*, 42(3), 461-479.
- Morris, J. (1991). Us and them? Feminist research, community care and disability. *Critical Social Policy*, 11(33), 22-39.
- Needham, C. (2011). Personalisation: from story-line to practice. *Social Policy and Administration*, 45(1), 54-68.
- Needham, C. (2014). The spaces of personalisation: place and distance in caring labour. *Social Policy and Society*, 14(3), 357-369.
- Newman, R. (2005). Partners in care: being equally different: lesbian and gay carers. *Psychiatric Bulletin*, 29(7), 266-267.
- Nicholas, E. (2003). An outcomes focus in carer assessment and review: value and challenge. *British Journal of Social Work*, 33(1), 31-47.
- NIHR School for Social Care Research. (2012). Overcoming barriers: unpaid care and employment in England *Research Findings* (pp. 4). London: NIHR School for Social Care Research.
- Nocon, A., & Pearson, M. (2000). The roles of friends and neighbours in providing support for older people. *Ageing & Society*, 20(3), 341-367.
- Nolan, M., Keady, J., & Grant, G. (1995). CAMI: A basis for assessment and support with family carers. *Br J Nurs*, 4(14), 822-826.
- Norman, I., Redfern, S., Briggs, K., & Askham, J. (2004). Perceptions and management of change by people with dementia and their carers living at home. *Dementia: the International Journal of Social Research and Practice*, 3(1), 19-44.
- Ogg, J., & Renault, S. (2006). The support of parents in old age by those born during 1945-1954 : a European perspective. *Ageing & Society*, 26(5), 723-743.
- Parker, G., Arksey, H., & Harden, M. (2010). *Meta review of international evidence on interventions to support carers*. Social Policy Research Unit/Centre for Reviews and Dissemination
- Perkins, E. A., & Haley, W. E. (2013). Emotional and Tangible Reciprocity in Middle- and Older-Aged Carers of Adults With Intellectual Disabilities. *Journal of Policy & Practice in Intellectual Disabilities*, 10(4), 334-344.
- Pham, M. T., Rajic, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research Synthesis Methods*, 5, 371-385.
- Pickard, L. (2004). *Caring for older people and employment : a review of the literature prepared for the Audit Commission*. Audit Commission/PSSRU
- Pickard, L. (2008). *Informal care for older people provided by their adult children : projections of supply and demand to 2041 in England*. PSSRU
- Pickard, L., King, D., & Knapp, M. (2016). The 'visibility' of unpaid care in England. *Journal of Social Work*, 16(3), 263-282.

- Pickard, L., Wittenberg, R., Comas-Herrera, A., Davies, B., & Darton, R. (2000). Relying on informal care in the new century? Informal care for elderly people in England to 2031. *Ageing and Society*, 20(6), 745-772.
- Pickard, S., & Glendinning, C. (2001). Caring for a relative with dementia : the perceptions of carers and CPNs. *Quality in Ageing and Older Adults*, 2(4), 3-11.
- Pickard, S., Glendinning, C., & Shaw, S. (2000). Health care professionals' support for older carers. *Ageing & Society*, 20(6), 725-744.
- Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just being selfish for my own sake . . .': balancing the views of young adults with intellectual disabilities and their carers in transition planning. *Sociological Review*, 59(2), 303-323.
- Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta- analysis. *Journals of Gerontology Series B Psychological Sciences and Social Sciences*, 58(2), 112-128.
- Price, E. (2005). All but invisible: older gay men and lesbians. *Nurs Older People*, 17(4), 16-18.
- Quinn, K., Murray, C., & Malone, C. (2014). Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. *Disability and Rehabilitation*, 36(3), 185-198.
- RCGP, & Princess Royal Trust for Carers. (2008) Supporting Carers: An action guide for general practitioners and their teams. (pp. 59): RCGP.
- Regan, T., Lambert, S., Girgis, A., Kelly, B., Kayser, K., & Turner, J. (2012). Do couple-based interventions make a difference for couples affected by cancer? A systematic review. *BMC Cancer*, 12(279).
- Ridley, J., Hunter, S., & Rosengard, A. (2010). Partners in care? Views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment, Scotland) Act 2003. *Health and Social Care in the Community*, 18(5), 474-482.
- Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M. C., Cherubini, A., Abate, G., Bartorelli, L., Bonaiuto, S., Capurso, A., Cucinotta, D., Gallucci, M., Giordano, M., Martorelli, M., Masaraki, G., Nieddu, A., Pettenati, C., Putzu, P., Tammaro, V. A., Tomassini, P. F., Vergani, C., Senin, U., & Mecocci, P. (2005). Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study. *International Journal of Geriatric Psychiatry*, 20(2), 168-174.
- Rutherford, A., & Bowes, A. (2014). Networks of informal caring: a mixed-methods approach. *Canadian Journal On Aging = La Revue Canadienne Du Vieillissement*, 33(4), 473-487.
- Scourfield, P. (2005). Understanding why carers' assessments do not always take place. *Practice: Social Work in Action*, 17(1), 15-28.
- Sebern., M., & Whitlatch, C. (2007). Dyadic relationship scale: A measure of the impact of the provision and receipt of family care. *The Gerontologist*, 47(6), 741-751.
- Seddon, D., & Robinson, C. (2015). Carer assessment : continuing tensions and dilemmas for social care practice. *Health Soc Care Community*, 23(1), 14-22.
- Sequeira, C. (2013). Difficulties, coping strategies, satisfaction and burden in informal Portuguese caregivers. *Journal of Clinical Nursing*, 22(3-4), 491.



- Shim, B., Landerman, L. R., & Davis, L. L. (2011). Correlates of care relationship mutuality among carers of people with Alzheimer's and Parkinson's disease. *Journal of Advanced Nursing*, 67(8), 1729-1738.
- Somerville, J. (2001). Palliative care: the experience of informal carers within the Bangladeshi community. *International Journal of Palliative Nursing*, 7(5), 240-247.
- St. John, T. (2004). Hidden shame : a review of the needs of Asian elders with dementia and their carers in a Kent community. *Journal of Integrated Care*, 12(3), 20-26.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, M. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16(3), 217-234.
- Thomas, S., Dalton, J., Harden, M., Eastwood, A., & Parker, G. (2016). *Updated Meta-Review of Evidence on Support for Carers*. NIHR HS&DR:
- Torge, C. J. (2014). Freedom and Imperative Mutual Care Between Older Spouses With Physical Disabilities. *Journal of Family Nursing*, 20(2), 204-225.
- Twigg, J. (1989). Models of Carers: How do social care agencies conceptualise their relationship with informal carers? *Journal of Social Policy*, 18(1), 53-66.
- Twigg, J., & Atkin, K. (1995). *Carers Perceived, Policy and practice in informal care*. Buckingham: Open University Press.
- Ungerson, C. (1987). *Policy is Personal: Sex, gender and informal care*: Routledge.
- Vernooij-Dassen, M., Draskovic, I., McCleery, J., & Downs, M. (2011). *Cognitive reframing for carers of people with dementia (review)*. Cochrane Library
- Vickerstaff, S., Loretto, W., Milne, A., Alden, E., Billings, J., & White, P. (2009). *Employment support for carers* (9781847126306). London: The Stationery Office
- Vlachantoni, A., Evandrou, M., Falkingham, J., & Robards, J. (2013). Informal care, health and mortality. *Maturitas*, 74(2), 114-118.
- Waldron, E., Janke, E., Bechtel, C., Ramirez, M., & Cohen, A. (2013). A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psycho-Oncology*, 22, 1200-1207.
- Walmsley, J. (1993). Contradictions in Caring: reciprocity and interdependence. *Disability, Handicap & Society*, 8(2), 129-141.
- White, E., & Montgomery, P. (2014). Electronic tracking for people with dementia: an exploratory study of the ethical issues experienced by carers in making decisions about usage. *Dementia: the International Journal of Social Research and Practice*, 13(2), 216-232.
- Williams, V., & Robinson, C. (2001). More than one wavelength : identifying, understanding and resolving conflicts of interest between people with intellectual disabilities and their family carers. *Journal of Applied Research in Intellectual Disabilities*, 14(1), 30-46.
- Willis, P., Ward, N., & Fish, J. (2011). Searching for LGBT carers: mapping a research agenda in social work and social care. *British Journal of Social Work*, 41(7), 1304-1320.
- Yeandle, S., Bennett, C., Buckner, L., Shipton, L., & Suokas, A. (2006). *Who cares wins: the social and business benefits of supporting working carers* (1843872196). London - 20/25 Glasshouse Yard London EC1A 4JT: Carers UK
- Yeandle, S., & Buckner, L. (2007). *Carers, employment and services: Time for a new social contract?* Carers UK/University of Leeds

## Appendix 1: Bibliographic Sources

## Overview

This appendix draws together the 3,434 items that were identified in the scoping review. It classifies them into 17 types of reference for ease of identification, and these are organised alphabetically.

## Books

- Aldridge, J., & Becker, S. (2004). *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*. University of Bristol: Policy Press.
- Andrews, B., & Becker, S. (2000). *Young Carers in Their Own Words*. London: Calouste Gulbenkian Foundation.
- Barrett, J. (2000). *Information Needs of Elderly, Disabled People and Their Carers*: Disability Information Trust.
- Burau, V., Theobald, H., & Blank, R. H. (2007). *Governing Home Care: A Cross-National Comparison*.
- Cavaye, J. (2006). *Hidden Carers*: Dunedin Academic Press.
- Chamberlayne, P., & King, A. (2000). *Cultures of Care: Biographies of Carers in Britain and the Two Germanies*: Policy Press.
- Cooper, H., & Geyer, R. (2007). *Riding the Diabetes Rollercoaster: A New Approach for Health Professionals, Patients and Carers*: Radcliffe.
- Dearden, C. (2000). *Growing up Caring: Vulnerability and Transition to Adulthood: Young Carers' Experiences*. Leicester: Youth Work Press.
- Fink, J. (2004). *Care: Personal Lives and Social Policy*. Bristol: Policy Press.
- Forbat, L. (2005). *Talking About Care: Two Sides to the Story*. Bristol: The Policy Press.
- Great Britain Parliament. House of Commons. Public Accounts Committee. (2009). *Supporting Carers to Care: Forty-Second Report of Session 2008-09: Report, Together with Formal Minutes, Oral and Written Evidence*. London: Stationery Office.
- Lynch, T. (2008). *"But I Don't Want Eldercare!": Helping Your Parents Stay as Strong as They Can as Long as They Can* (1st ed.). Denver, Colo: The Legal Center for People with Disabilities and Older People.
- McErlean, S. (2001). *Younger People with Dementia and Their Carers*. Norwich: School of Social Work and Psychosocial Studies.
- Mo McPhail (Ed). (2008). *Service User and Carer Involvement: Beyond Good Intentions*. Edinburgh: Dunedin Academic Press.
- Moore, M., Patient, M., & Skelton, J. (2000). *Enabling Future Care*: Venture Press.
- Olson, R. E. (2015). *Towards a Sociology of Cancer Caregiving: Time to Feel*: Routledge.
- Payne, S., & Ellis-Hill, C. (2001). *Chronic and Terminal Illness: New Perspectives on Caring and Carers*: OUP.
- Smith, P. (2000). *Carers' Needs: The Voluntary Sector Perspective*. London: Emap Healthcare.
- Soar, J. (2008). *Information Management in Healthcare - Gaps and Opportunities*.
- Wales National Assembly. (2010). *Proposed Carers Strategies (Wales) Measure (as Introduced): January 2010*. Cardiff: Wales. National Assembly.
- WHO. (2011). *Assistance and Support*.
- Williams, V., & Robinson, C. (2000). *In Their Own Right: The Carers Act and Carers of People with Learning Disabilities*: Policy Press.

## Book Reviews

*Cambridge Law Journal* volume 71 issue 3 Cover and Back matter. (2012) (Vols. 71). Cambridge University Press.

Busby, N. (Ed.) (2013) *Edinburgh Law Review* (Vols. 17). Edinburgh University Press.

Grant, G. (Ed.) (2004) *Journal of Social Policy* (Vols. 33).

Haslam, M. (Ed.) (2010) *Community Care*. Reed Business Information Limited.

Herring, J. (Ed.) (2013) *Journal of Social Welfare & Family Law* (Vols. 35). Routledge.

Jenkins, R. (Ed.) (2010) *Learning Disability Practice* (Vols. 13). RCNi.

Morley, D. (Ed.) (2003) *Community Care*. Reed Business Information Limited.

Stewart, A. (Ed.) (2014) *Social & Legal Studies* (Vols. 23).

## Book Chapter

Addington-Hall, J. M., & Higginson, I. (2011). Discussion. In J. M. Addington Hall & I. Higginson (Eds.), *Palliative Care for Non-Cancer Patients*: Oxford University Press.

Ager, W. (2008). Issues of power in service user and carer involvement: partnership, processes and outcomes. In M. McPhail. (Ed.), *Service user and carer involvement: beyond good intentions*. Edinburgh: Dunedin Academic Press.

Anderson, B. (2011). Palliative Care and Dementia: Is a Good Death Possible at Home? In S. E. Plunkett (Ed.), *Palliative and Nursing Home Care: Policies, Challenges and Quality of Life* (pp. 131-143): Nova Science.

Angelidis, P., & Vellidou, E. (2011). Independent: Technology Supported Autonomous Living. In J. C. Lin, & K. S. Nikita (Eds), *Wireless Mobile Communication and Healthcare* (Vol. 55, pp. 69-76).

Anka, A. (2016). Service User and Carer Assessment of Social Work Students. In I. Taylor, M. Bogo, M. Lefevre, & B. Teater (Eds.), *Routledge International Handbook of Social Work Education* (pp. 286-297): Routledge.

Arksey, H., & Corden, A. (2009). Policy initiatives for family carers. In P. Hudson, & S. Payne, (Ed.), *Family carers in palliative care: A guide for health and social care professionals* (pp. 55-71). Oxford: OUP.

Baldwin, S., & Hirst, M. (2002). Children as carers. In J. Bradshaw (Ed.), *The Well-being of Children in the UK* (pp. 153-166). London: Save the Children.

Bayer, A., & Sinclair, A. (2009). Supporting the Family and Informal Carers. In A. J. Sinclair (Ed.), *Diabetes in Old Age: Third Edition* (pp. 443-452): John Wiley & Sons.

Bhattacharyya, S., & Benbow, S. M. (2015). Carers of People with Dementia and the Use of Assistive Technologies. In F. Xhafa, P. Moore, & (Eds.), *Advanced Technological Solutions for E-Health and Dementia Patient Monitoring* (pp. 12-35): IGI Global.

Carrera, F., Pavolini, E., Ranci, C., & Sabbatini, A. (2013). Long-Term Care Systems in Comparative Perspective: Care Needs, Informal and Formal Coverage, and Social Impacts in European Countries. In C. Ranci & E. Pavolini (Eds.), *Reforms in Long-Term Care Policies in Europe: Investigating Institutional Change and Social Impacts* (Vol. 9781461445029, pp. 23-52): Springer.

Carretero, S., Garcés, J., & Ródenas, R. (2010). How to Secure the Future of the Mental Health of Families in Charge of Their Elders. In D. M. Montez (Ed.), *Psychiatric Research Trends: Dreams and Geriatric Psychiatry* (pp. 27-45): Nova Science.

Chambers, P. (2005). Working across the Interface of Formal and Informal Care of Older People. In R. Carnwell & J. Buchanan (Eds.), *Effective Practice in Health and Social Care*: McGraw-Hill Education.

Chang, L. R., Kitson, A., & Petch, A. (2006). Who's Going to Care? In Z. S. Morris, L. R. Chang, S. Dawson, & P. Garside (Eds.), *Policy Futures for UK Health, 2006*: Radcliffe.

Chen, H. L. (2014). Meeting the Care Needs of Older People: Long-Term Care Practice in England, the Netherlands, and Taiwan. In M. M. Mervio (Ed.), *Contemporary Social Issues in East Asian Societies: Examining the Spectrum of Public and Private Spheres* (pp. 219-233): ICI Global.

Copeland, J. R. M., Abousaleh, M. T., & Blazer, D. G. (2002). Informal Carers and Their Support. In D. Buck (Ed.), *Principles and Practice of Geriatric Psychiatry*. Chichester, UK: Chichester, UK: John Wiley and Sons, Ltd.

- Dearden, C. (2000). Listening to Children: Meeting the Needs of Young Carers. In H. Kemshall & R. Littlechild (Eds.), *User Involvement and Participation in Social Care: Research Informing Practice*. Jessica Kingsley.
- Glendinning, C. (2006). Paying Family Caregivers: Evaluating Different Models. In C. Glendinning & P. A. Kemp (Eds.), *Cash and Care: Policy Challenges in the Welfare State* (pp. 127-140). Bristol: Policy Press.
- Glendinning, C. (2014). Supporting Older People and Carers. In P. Rossall & J. Goodwin (Eds.), *Services for Older People: What Works: Age UK*.
- Glendinning, C., & Arksey, H. (2008). Informal care. In P. M. Alcock, M and Rowlingson, K (Ed.), *The Student's Companion to Social Policy* (pp. 219-225). Oxford: Blackwell.
- Gori, C. (2007). The Commodification of Care: The Italian Way. In C. Ungerson & S. Yeandle (Eds.), *Cash for Care in Developed Welfare States*. Basingstoke: Palgrave Macmillan.
- Gray, L. C., Cullen, D. J., & Lomas, H. B. (2012). Regulating Long-Term Care Quality in Australia. In V. Mor, T. Leone, & A. Maresso (Eds.), *Regulating Long-Term Care Quality: An International Comparison* (pp. 149-179): Cambridge.
- Greenwood, R., Marsden, J., Playford, D., Stevenson, V., & Ward, N. (2009). Restorative and Rehabilitation Neurology. In C. Clarke, R. Howard, & M. Rossor (Eds.), *Neurology: A Queen Square Textbook* (pp. 645-673): Wiley.
- Haritou, M., & Koutsouris, D. (2015). Home Care Systems for the Management of Patients with Mental Disorders: The 'Aladdin' Experience. In D. I. Fotiadis (Ed.), *Handbook of Research on Trends in the Diagnosis and Treatment of Chronic Conditions* (pp. 382-411): IGI Global.
- Hepworth, D., & Arksey, H. (2000). Assessing Carers' Needs. In J. Harris, L. Froggett, & L. Paylor (Eds.), *Reclaiming Social Work: The Southport Papers, Volume 1*: Venture Press.
- Hirst, M. (2004). The British Household Panel Survey: A Longitudinal Perspective on Informal Care. In S. Becker & A. Bryman (Eds.), *Understanding Research for Social Policy and Practice*. Bristol: The Policy Press.
- Hofdijk, J. (2011). Patient Centered Integrated Clinical Resource Management. In A. Moen, S. K. Andersen, J. Aarts, & P. Hurlen (Eds.), *User Centred Networked Health Care* (Vol. 169, pp. 996-999): IOS Press.
- Jenkins, S., & Draper, H. (2014). Robots and the Division of Healthcare Responsibilities in the Homes of Older People. In M. Beetz, B. Johnston, & M. A. Williams (Eds.), *Social Robotics* (Vol. 8755, pp. 176-185).
- Jester, R. (2008). Preparing and Supporting Informal Carers. In R. Jester (Ed.), *Advancing Practice in Rehabilitation Nursing* (pp. 82-92): Wiley.
- Keefe, J., Glendinning, C., & Fancey, P. (2008). Financial payments for family carers: policy approaches and debates. In A. a. P. Martin-Matthews, J (Ed.), *Ageing and Caring at the Intersection of Work and Home Life* (pp. 185-206). London: Lawrence Erlbaum Associates.
- Koffman, J., & Snow, P. (2011). Informal Carers of Dependants with Advanced Disease. In J. M. Addington Hall & I. Higginson (Eds.), *Palliative Care for Non-Cancer Patients*: Oxford Scholarship Online.
- Lejsal, M. (2014). Participation: (re)interpretation of a core value in the Czech social care of the frail elderly *Psychology and Psychiatry, Sociology and Healthcare, Education, Vol II* (pp. 615-621).
- Martin, C. (2007). Cash for Care in the French Welfare State: A Skilful Compromise? In C. Ungerson & S. Yeandle. (Eds.), *Cash for Care in Developed Welfare States*: Palgrave.
- McSloy, N. (2008). Expert knowledge: a carer's perspective. In M. McPhail (Ed.), *Service user and carer involvement: beyond good intentions*. Edinburgh: Dunedin Academic Press.

- Meiland, F. J. M., Jonker, C., & Dröes, R. M. (2012). Predictors of effective support for carers of persons with dementia *Dementia: Non-Pharmacological Therapies* (pp. 239-258).
- Mitchell, W., Brooks, J., & Glendinning, C. (2014). Personalisation: Where Do Carers Fit? In C. Needham & J. Glasby (Eds.), *Debates in Personalisation* (pp. 65-74). Bristol: Policy Press.
- Nicholas, E. (2001). Implementing an outcomes approach in carer assessment and review. In H. Qureshi (Ed.), *Outcomes in Social Care Practice*. University of York: Social Policy Research Unit.
- Pantazis, C. (2006). Gender, Poverty and Social Exclusion. In C. Pantazis, D. Gordon, & R. Levitas (Eds.), *Poverty and Social Exclusion in Britain the Millennium Survey* Bristol: Policy Press.
- Peters, M., Fitzpatrick, P., & Jenkinson, C. (2011). Carers and Neurogenerative Disease. In C. Jenkinson, M. Peters, & M. B. Bromberg (Eds.), *Quality of Life Measurement in Neurodegenerative and Related Conditions* (pp. 114-138): Cambridge University Press.
- Pijl, M. (2002). Chapter 2: The Support of Carers and Their Organisations in Some Northern and Western European Countries In J. Brodsky, J. Habib, & M. Hirschfeld (Eds.), *Key Policy Issues in Long-Term Care* (pp. 25-60): World Health Organization.
- Pijl, M. (2007). Contracting One's Family Members: The Dutch Care Allowance. In C. Ungerson & S. Yeandle (Eds.), *Cash for Care in Developed Welfare States* Palgrave Macmillan.
- Qureshi, H., Arksey, H., & Nicholas, E. (2003). Carers and assessment. In K. Stalker (Ed.), *Reconceptualising Work with Carers: new directions for policy and practice* (pp. 72-95). London: Jessica Kingsley.
- Rogers, H. (2000). Breaking the Ice: Developing Strategies for Collaborative Working with Carers of Older People with Mental Health Problems. In H. Kemshall & R. Littlechild (Eds.), *User Involvement and Participation in Social Care: Research Informing Practice* London: Jessica Kingsley.
- Sabat, S. R. (2011). Maintaining the Self in Dementia. In J. Hughes, M. Lloyd-Williams, & G. Sachs (Eds.), *Supportive Care for the Person with Dementia*: Oxford University Press.
- Schneider, U. (2007). Mixed Blessings: Long-Term Care Benefits in Germany. In C. Ungerson & S. Yeandle (Eds.), *Cash for Care in Developed Welfare States* Palgrave Macmillan.
- Seddon, D. (2005). Care and Caregiving in the Context of Intermediate and Continuing Care. In B. Roe & R. Bee (Eds.), *Intermediate and Continuing Care: Policy and Practice*. Oxford: Blackwell.
- Seddon, D. (2005). Care and caregiving in the context of intermediate and continuing care. In B. R. a. R. Bee (Ed.), *Intermediate and continuing care: policy and practice*. Oxford: Blackwell.
- Srinivasa Murthy, R. (2008). Approaches to Suicide Prevention in Asia and the Far East. In K. Hawton & K. van Heerington (Eds.), *The International Handbook of Suicide and Attempted Suicide* (pp. 631-643): Wiley.
- Tarum, H., & Kutsar, D. (2015). The Impact of the Policy Framework on the Integration of Informal Carers into the Labour Market in Tartu, Estonia. In D. Kutsar & M. Kuronen (Eds.), *Local Welfare Policy Making in European Cities* (Vol. 59, pp. 195-208): Springer.
- Twigg, J. (2000). The changing role of users and carers. In B. Hudson (Ed.), *The changing role of social care* London: Jessica Kingsley.
- Vontas, A., Moumtzi, V., & Urwin, G. (2015). Spinning Off Business Activities for Care Giver Support: The Discover Attempt. In P. D. Bamidis, I. Tarnanas, L. Hadjileontiadis, & M. Tsolaki (Eds.), *Handbook of Research on Innovations in the Diagnosis and Treatment of Dementia* (pp. 414-425): IGI.



Wiles, R. (2007). The Role of Carer in Chronic Disease and End of Life Care. In I. Kandel, P. Schofield, & J. Merrick (Eds.), *Aging and Disability Research and Clinical Perspectives* Victoria, BC: Trafford Publishing.

Yeandle, S., & Ungerson, C. (2007). Conceptualizing Cash for Care: The Origins of Contemporary Debates. In C. Ungerson & S. Yeandle (Eds.), *Cash for Care in Developed Welfare States*: Palgrave, Macmillan.

## Briefing

Arksey, H. (2000). *Carers' Needs and the Carers Act*. Social Policy Research Unit University of York.

Arksey, H., Corden, A., Glendinning, C., & Hirst, M. (2006). *Carers and the Management of Financial Assets in Later Life*. Research Works: Social Policy Research Unit University of York.

Carers UK. (2002). *Hospital Discharge Practice Briefing*. Carers UK.

Carers UK. (2011). *BAME Families and Personalisation: A Person-Centred Approach: Making Personalisation Successful for Black Asian Minority Ethnic (BAME) Families and Communities*. Carers UK.

Carers UK. (2012). *Hospital Discharge and BAME Carers*. Carers UK.

Carers UK. (2013). *Evidence-Based Planning and Delivery of Local Support for Carers: Findings and Feedback from a Survey of Local Authority Carers' Leads in England*. Carers UK.

Carers UK. (2015). *Emergency Budget: What It Means to Carers. On the Day Briefing*. Carers UK.

Dearden, C., & Becker, S. (2000). *Young Carers' Transitions into Adulthood*. Joseph Rowntree Foundation.

Family Policy Studies Centre. (2000). *Long-Term Care and the Family*. Family Policy Studies Centre.

Glendinning, C., & Bell, D. (2008). *Rethinking Social Care and Support: What Can England Learn from Other Countries?* Social Policy Research Unit University of York.

Health Services Research Department, Institute of Psychiatry King's College London, & Rethink. (2006). *Sharing Mental Health Information with Carers: Pointers to Good Practice for Service Providers* London - London School of Hygiene and Tropical Medicine,

Hepworth, D. (2003). *Assessment and Support for South Asian Carers*. Research Works: Social Policy Research Unit University of York.

Hoffmann, F., & Rodrigues, R. (2010). *Informal Carers: Who Takes Care of Them?* European Centre for Innovation: European Centre for Innovation.

Holmes, R., & McMullen, K. (2004). *The Costs of Care: The Impact of the Fairer Charging Policy on Disabled and Older People and Their Carers in England*. Coalition on Charging.

Holzhausen, E. (2001). *"You Can Take Him Home Now": Carers' Experiences of Hospital Discharge*. Carers National Association.

Hutton, S., & Hirst, M. (2001). *Informal Care over Time*. Research Works: Social Policy Research Unit University of York.

Kennedy, S., Bird, L., & J., S. (2011). *Improving Support for Older People Looking After Someone with Advanced Cancer*. University of Nottingham: Macmillan Cancer Support.

Mitchell, W., Brooks, J., & Glendinning, C. (2013). *Carers and Personalisation. Research Findings*: NIHR School for Social Care Research.

Moriarty, J. (2011). *Black and Minority Ethnic People with Dementia and Their Access to Support and Services*, SCIE.

NCCSDO. (2002). *Services to Support Carers of People with Mental Health Problems: Briefing Paper*. NCCSDO.

- NCCSDO. (2004). *A Proper Break: Effective Respite Services for Carers of People with Dementia*. NCCSDO.
- NCCSDO. (2005). *Access to Health Care for Carers*. NCCSDO.
- Pickard, L. (2006). *What Are the Most Effective and Cost-Effective Services for Informal Carers of Older People?* Ripfa Outline 4: Research in Practice for Adults RIPFA.
- Rodrigues, R., Schulmann, K., Schmidt, A., Kalavrezou, N., & Matsaganis, M. (2013). *The Indirect Costs of Long-Term Care*, Research Note 8/2013. European Commission.
- Schmidt, A. E., Fuchs, M., & Rodrigues, R. (2016). *Juggling Family and Work - Leaves from Work to Care Informally for Frail or Sick Family Members - an International Perspective*. European Centre Policy Brief September 2016: European Centre.
- SCIE. (2005). *The Health and Well-Being of Young Carers*. Research Briefing 11: SCIE.
- Social Care Institute for Excellence. (2011). *Personal Budgets Briefing: Learning from the Experiences of Older People and Their Carers*, SCIE.
- Social Care Institute for Excellence. (2015). *Co-Production and Participation: Paying People Who Receive Benefits*, SCIE.
- The Children's Society. (2016). *There's Nobody Is There - No One Who Can Actually Help?* The Children's Society.
- The Joanna Briggs Institute. (2012). *Caregiver Burden of Terminally-Ill Adults in the Home Setting*. The Joanna Briggs Institute.

## Bulletin

Giving carers the right to claim support. (2000). *Reportage* (Vol. 6, pp. 4). London: Age Concern.

Weekly PQs - Wales/Cymru. (2006). *Education Parliamentary Monitor Weekly Bulletin* (pp. 10-10): Education Publishing Worldwide Ltd.

Weekly Written PQs. (2016). *Education Parliamentary Monitor* (pp. 1-46): Education Publishing Worldwide Ltd.

Buckner, L., & Yeandle, S. (2006). *More than a job: working carers: evidence from the 2001 Census* (pp. 4). Leeds: University of Leeds.

Clarke, B., Coryton, D., Coryton, J., Coryton, T., & Waterman, C. (2014). Weekly Debates Scotland *Education Parliamentary Monitor* (pp. 1-3): Education Publishing Worldwide Ltd.

Glendinning, C. (2009). Cash for Care: implications for Carers. In G. Association (Ed.), *Health and Ageing Newsletter* (21 ed.).

Great Britain Office for National Statistics. (2012). *National bereavement survey (VOICES) 2011: England* (pp. 16p.). London: Great Britain. Office for National Statistics.

Great Britain Office of National Statistics. (2013). *National bereavement survey (VOICES) 2012: England* (pp. 18). London: Great Britain. Office for National Statistics.

Great Britain Office of National Statistics. (2014). *National survey of bereaved people (VOICES), 2013* (pp. 24). Newport: Great Britain. Office for National Statistics.

Greenwood, N. (2014). Talking to carers of stroke survivors to understand ethnic differences *NIHR School for Social Care Research*.

Gridley, K., Brooks, J., & Glendinning, C. (2012). *Good support for people with complex needs: what does it look like and where is the evidence?* (pp. 4): NIHR School for Social Care Research.

Hirst, M. (2014). *Transitions into and out of Unpaid Care*. In Social Policy Research Unit University of York.

Mitchell, W. (2014). *How local authorities allocate resources to carers through personal budgets*, NIHR.

NIHR School for Social Care Research. (2012). Overcoming barriers: unpaid care and employment in England *Research Findings* (pp. 4). London: NIHR School for Social Care Research.

Pickard, L. (2009). *Informal care for older people by their adult children: Projections of supply and demand to 2041 in England*. PSSRU.

## Conference Proceedings

Alzougool, B., Chang, S., & Gray, K. (2007). *Modelling the information needs of informal carers*. Paper presented at the ACIS 2007 Proceedings - 18th Australasian Conference on Information Systems.

Alzougool, B., Chang, S., & Gray, K. (2009). *A taxonomy of information needs of informal carers: An empirical investigation*. Paper presented at the HEALTHINF 2009 - Proceedings of the 2nd International Conference on Health Informatics.

Apostolidis, H., Tsiatsos, T., Karagkiozo, K., & Tsolaki, M. (2016). *Supporting distant psycho-educational activities with a bio-feedback device*. Paper presented at the Proceedings of the 10th pan-hellenic and international conference ICT in education.

Baharin, H., Mühlberger, R., & Loch, A. (2009). *Mutuality: A key gap in the move to telecare*. Paper presented at the ACM International Conference Proceeding Series.

Bamidis, P. D., Antoniou, P., Sidiropoulos, E., & Lee, A. (2014). *Using simulations and experiential learning approaches to train carers of seniors*. Paper presented at the 2014 IEEE 27th International Symposium on Computer-Based Medical Systems.

Boyd, K. J., Nugent, C., Donnelly, M., Bond, R., Sterritt, R., & Hartin, P. (2014). *An investigation into the usability of the STAR training and re-skilling website for carers of persons with dementia*. Paper presented at the Conference proceedings: Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society. Annual Conference.

Cavaye, J. (2015). *The health and wellbeing of former carers of older people*. Paper presented at the 44th BSG Conference, Ageing in Changing Times; Challenges and future prospects, Newcastle Upon Tyne.

Chouvarda, J., Philip, N. Y., Natsiavas, P., Kilintzis, V., Sobnath, D., Kayyali, R., Henriques, J., Paiva, R. P., Raptopoulos, A., Chetelat, O., & Maglaveras, N. I. (2014). *WELCOME - Innovative Integrated Care platform using Wearable Sensing and Smart Cloud Computing for COPD patients with Comorbidities*. Paper presented at the 2014 36th Annual International Conference of the IEEE Engineering in Medicine and Biology Society.

Davis, H., Pedell, S., Lorca, A. L., Miller, T., & Sterling, L. (2014). *Researchers as proxies for informal carers: Photo sharing with older adults to mediate wellbeing*. Paper presented at the Proceedings of the 26th Australian Computer-Human Interaction Conference, OzCHI 2014.

De Reuver, M., & Keijzer-Broers, W. (2016). *Trade-offs in designing ICT platforms for independent living services*. Paper presented at the 2015 IEEE International Conference on Engineering, Technology and Innovation/ International Technology Management Conference, ICE/ITMC 2015.

Felea, M. G., Crivoi, P., & Covrig, M. (2013). *Educational Outcomes in the Rehabilitation of Elderly Patients with Diabetes Mellitus*. Paper presented at the Logos Universality Mentality Education Novelty.

Gosman-Hedstrom, G. (2003). *Burden of care in elderly people one year after acute stroke - The Goteborg 70+Stroke Study*. Paper presented at the Proceedings of the 2nd World Congress of the International Society of Physical and Rehabilitation Medicine - Isprm.

Gui, N., Sun, H., De Florio, V., & Blondia, C. (2007). *A service-oriented infrastructure for mutual assistance community*. Paper presented at the 2007 IEEE International Symposium on a World of Wireless, Mobile and Multimedia Networks, WOWMOM.

Hanson, J., & Percival, J. (2006). *Differing perspectives on telecare: An attitudinal survey of older people, professional care workers and informal carers*. Paper presented at the Designing Accessible Technology.

- Hirst, M. (2005). *Promoting carers' health*. Paper presented at the Proceedings of the Conference on Carers' Health: Working for a positive future.
- Kayyali, R., Nabhani-Gebara, S., Hesso, I., Siva, R., Kaimakamis, E., Vaes, A. W., Spruit, M. A., Chang, J., Costello, R., Philip, N., Pierscioneck, B., & Maglaveras, N. (2016). *User profiling for coordinated and integrated care*. Paper presented at the 3rd IEEE EMBS International Conference on Biomedical and Health Informatics, BHI 2016.
- Nabhani-Gebara, S., Kayyali, R., Philip, N., Pierscioneck, B., Sobnath, D., Kaimakamis, E., Perantoni, E., Chang, J., Davies, N., Siva, R., D'Arcy, S., Vaes, A., & Spruit, M. (2015). *WELCOME project: What do stakeholders want? in depth analysis of COPD patients, carers and healthcare professional views*. Paper presented at the Proceedings of the 2014 4th International Conference on Wireless Mobile Communication and Healthcare - "Transforming Healthcare Through Innovations in Mobile and Wireless Technologies", MOBIHEALTH 2014.
- Rodgers, P. A., Tennant, A., & Dodd, K. (2014). *Disrupting health and social care by design*. Paper presented at the 9th International Conference on Design and Emotion 2014: The Colors of Care.
- Sánchez-González, P., Oropesa, I., Moreno-Sánchez, P., Martínez-Moreno, J. M., García-Novoa, J., & Gómez, E. J. (2014). *AMELIE: Authoring multimedia-enhanced learning interactive environment for e-health contents*. Paper presented at the IFMBE Proceedings.
- Schroeter, C., Mueller, S., Volkhardt, M., Einhorn, E., Huijnen, C., van Den Heuvel, H., van Berlo, A., Bley, A., & Gross, H. M. (2013). *Realization and user evaluation of a companion robot for people with mild cognitive impairments*. Paper presented at the Proceedings - IEEE International Conference on Robotics and Automation.
- Smith, K. (2014). *Supporting carers through intelligent technology*. Paper presented at the International Conference on Intelligent User Interfaces, Proceedings IUI.
- Stavropoulos, T. G., Meditskos, G., Andreadis, S., & Kompatsiaris, I. (2015). *Real-time health monitoring and contextualised alerts using wearables*. Paper presented at the Proceedings of 2015 International Conference on Interactive Mobile Communication Technologies and Learning, IMCL 2015.
- Steffen, S. (2009). *S09-05 Beyond family burden - the complexities of carer roles*. Paper presented at the European Psychiatry.
- Valero, M. A., Vadillo, L., Penalver, A., Pau, I., Gago, E., Martin, M., Gonzalez, M., & Portillo, E. (2007). *An implementation framework for smart home telecare services*. Paper presented at the Proceedings of Future Generation Communication and Networking, Workshop Papers, Vol 2.
- Yeandle, S. (2015). *The impact of the carers' movement on policy and practice at international level*. University of Ulster.

## Film or Broadcast

- Alzheimer's Society (Writer). (2010). *Voices from the Shadows: Stories from People Living with Dementia*. London: Alzheimer's Society.
- Arigho, B., & Strahan, K. (Writers). (2006). *'Listen to What I'm Saying': Person Centred Care and the Single Assessment Process*. London: Age Exchange.
- Austin, A., & Tyrrell, I. (Writers). (2008). *Demystifying Autism and Asperger's Syndrome: Help for Parents, Carers, Teachers and Others Interested in Autistic Spectrum Disorder*. Chelvington: HG Publishing.
- Barnardo's (Writer). (2006). *Reality Check: A Participation Toolkit for Adults Working with Young People Leaving Care*. Ilford: Barnardo's.
- Bond, L., & Farrell, Z. (Writers). (2007). *Needs of the Service User*. London: BVS.
- Bond, L., & Farrell, Z. (Writers). (2007). *Principles of Person Centred Care: Part 1*. London: BVS.
- Bond, L., & Farrell, Z. (Writers). (2007). *Principles of Person Centred Care: Part 2*. London: BVS.
- Bond, L., & Farrell, Z. (Writers). (2007). *Raising Concerns and Whistleblowing*. London: BVS.
- Bond, L., & Farrell, Z. (Writers). (2007). *Role of the Home Carer*. London: BVS.
- BVS (Writer). (2007). *Understanding Dementia*. London: BVS.
- Care Council for Wales (Writer). (2010). *Digital Stories for Dementia Care and End of Life Care*. Care Council for Wales.
- Challenging Behaviour Foundation (Writer). (2007). *Communication and Challenging Behaviour*. Chatham: Challenging Behaviour Foundation.
- Davies, A., & Tipper, P. (Writers). (2008). *Carers' Journeys*. Leeds: Care Services Improvement Partnership.
- Dawkins, S., & Polding, C. (Writers). (2006). *Caring One-to-One: Supporting Independent Living*. Coventry: Penderels Trust.
- Duffy, J., Martinez-Roman, M., & Zavissek, D. (Writers). (2013). *An Exploration of International Innovation in Service User Involvement across Three Countries*.
- Fain-Binda, V. (Writer). (2009). *Life with Two Hats: Part 1. -*: Viviana Fain-Binda.
- Fain-Binda, V. (Writer). (2009). *Life with Two Hats: Part 2. -*: Viviana Fain-Binda.
- Fain-Binda, V. (Writer). (2009). *Life with Two Hats: Part 3. -*: Viviana Fain-Binda.
- Foundation for People with Learning Disabilities (Writer). (2003). *Learning with Families: A Training Resource*. London: Mental Health Foundation.
- Foundation for People with Learning Disabilities (Writer). (2010). *Mutual Caring: Multimedia Resources*. London: Foundation for People with Learning Disabilities.
- Great Britain Department of Health (Writer). (2011). *Personal Health Budgets: Stories from People in the Pilot Programme*. London: Great Britain. Department of Health.
- Great Britain Department of Health (Writer). (2015). *Dementia Support Workers: Bath and North East Somerset*. London: Great Britain. Department of Health.
- Great Britain Department of Health Valuing People Support Team (Writer). (2010). *Turn Your Life Around: Person Centred Planning and Families*. London: Great Britain. Department of Health. Valuing People Support Team.

- Home Farm Trust (Writer). (2008). *The Mental Capacity Act 2005 Explained: For People with Learning Disabilities, Families, Carers and Staff*. London: Great Britain. Department of Health.
- Ipsos Ethnography Centre of Excellence (Writer). (2015). *Living Independently with Long Term Conditions: An Ethnographic Investigation: Interim Findings*. London: Ipsos Mori.
- NHS East of England (Writer). (2011). *A Personal Approach: To Healthcare Professionals*. Cambridge: NHS East of England.
- NHS East of England (Writer). (2011). *A Personal Approach: To Patients and Carers*. Cambridge: NHS East of England.
- Parkinson's Disease Society (Writer). (2007). *Being There*. London: Parkinson's Disease Society.
- Pool, J., & Bond, L. (Writers). (2004). *Dementia Care in the Care Home*. London: BVS.
- Pool, J., & Bond, L. (Writers). (2004). *Dementia Care in the Domiciliary Setting*. London: BVS.
- Rethink (Writer). (2008). *Combating Stigma*. London: Rethink.
- Scottish Consortium for Learning Disability (Writer). (2011). *Food for Thought: People with Learning Disabilities and Family Carers Share Their Experiences of Healthy Eating*. Glasgow: Scottish Consortium for Learning Disability.
- Shared Care Network (Writer). (2010). *Short Break Carers: Be the Big Difference*. Bristol: Shared Care Network.
- Skelton, G. (Writer). (2013). *An Interview with Gerry Skelton on Social Work and Spirituality*.
- Social Care Institute for Excellence (Writer). (2009). *Personalisation for Older People: Residential Care*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2009). *Personalisation for Older People: Supported Housing*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2009). *Rapidly Declining Early-Onset Dementia: Living at Home with Nursing Support*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2010). *Principles of Participation*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2010). *Supporting Carers: The Carer*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2010). *Supporting Carers: The Commissioner*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2010). *Supporting Carers: The Social Worker*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2011). *Participation in Dementia Care Planning*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2011). *Prevention: Reablement*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *End of Life Care: Supporting the Carers*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *The Role of Carers and Families in Reablement*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Case Study: Anglia Ruskin University*. London: Social Care Institute for Excellence.



- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Case Study: Bucks New University*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Case Study: Kingston University and St George's University London*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Case Study: Leeds University*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Participation: Access, Payment and Support*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Participation: Hopes for the Future*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Participation: User and Carer Participation in Social Work*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2012). *Social Work Education Participation: What's Happening in Four Universities?* London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2014). *Challenging Behaviour and Learning Disabilities: Independent Living*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2014). *Dementia: Participation in Development of Dementia Care*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2014). *Early Onset Dementia: Living at Home with Nursing Support*. London: Social Care Institute for Excellence.
- Social Care Institute for Excellence (Writer). (2014). *End of Life Care: Why Supporting Family Carers Is Vital*. London: Social Care Institute for Excellence.
- Thompson, M. J. (Writer). (2007). *Managing Challenging Behaviour*. London: BVS.
- Tibbitts, A. (Writer). (2004). *The Relationship between Brain and Behaviour in Dementia: You're the Expert*. Torquay: Torbay Partnership Committee.
- Values into Action and Telesafe Association (Writer). (2001). *Telesafe 2: A Video Resource Pack on Safety: For Use with People with Learning Difficulties and Their Carers*. London: Values into Action; Telesafe Association.
- Walker, M. (Writer). (2007). *Welcome to the Family*. Bristol: Shared Care Network.
- Walker, M., & Boss, P. (Writers). (2007). *A Warm Welcome*. Bristol: Shared Care Network.
- Waring, A. (Writer). (2005). *What Do You See?* Fittleworth: Looking for Magic.

## Government Documents

Banks, P., Gallagher, E., Hill, M., & Riddell, S. (2002). *Young Carers: Assessment and Services; Literature Review of Identification, Needs Assessment and Service Provision for Young Carers and Their Families*. (0 7559 3414 8). Edinburgh: Scotland. Scottish Executive Central Research Unit.

Behan, D., & Flory, D. (2011). *NHS Support for Social Care: 2010/11-2012/13*. London: Great Britain. Department of Health.

Blow, E., & Baker, C. (2015). *Dementia: Statistics on Prevalence and Improving Diagnosis, Care and Research*. London: Great Britain. Parliament. House of Commons Library.

Byron, A., Knibbs, S., & Dickman, A. (2009). *Disability and Carers Service Customer Service Survey 2008*. (978 1 84712 580 4). London: Great Britain. Department for Work and Pensions.

Calderwood, B., & Harker, L. (2008). *New Deal for Carers: Income Task Force Report*. London: Great Britain. Department of Health.

Care Services Improvement Partnership. (2007). *Consultation on Guidance on 'Finding a Shared Vision of How People's Mental Health Problems Should Be Understood'*. London: Great Britain. Department of Health.

Clwyd, A., & Hart, T. (2013). *A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture*. London: Great Britain. Department of Health.

Department of Health. (2008). *What the End of Life Care Strategy Means for Patients and Carers*. (End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life.).

Department of Health. (2010). *Adult Autism Strategy Consultation: A Summary of the Submissions Received in Response to the Online Consultation*. London.

Department of Health. (2010). *New Strategy Will Help Identify Carers Earlier*.

Department of Health. (2015). *Supporting Carers to Stay in Paid Employment*.

Department of Health. (2016). *How Can We Improve Support for Carers?* London: Department of Health.

*Education Parliamentary Monitor*. (2010). Debates in the House of Commons. (1366302X). Education Publishing Worldwide Ltd.

Employer panel for caregivers. (2015). *When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers*. Government of Canada.

G8 Dementia Summit London. (2013). *Global Action against Dementia: G8 Dementia Summit Declaration*. London: Department of Health.

G8 Dementia Summit London. (2013). *Global Action against Dementia: G8 Dementia Summit Communique*. London: Department of Health.

Granville, S., Mulholland, S., & Fawcett, J. (2015). *Carers Legislation: Analysis of Consultation Responses*. (9781785441424). Edinburgh: Scotland. Scottish Government Social Research.

Great Britain Cabinet Office. (2014). *Carers Social Action Support Fund: Guidance Notes*. London: Great Britain. Cabinet Office.

Great Britain Department for Constitutional Affairs. (2007). *Mental Capacity Act 2005 Code of Practice: Laid before Parliament in Draft February 2007, Pursuant to Sections 42 and 43 of the Act*. (978 0 11 703734 2). London: Stationery Office.

Great Britain Department for Education. (2014). *Young Carers' Draft Regulations: Government Consultation*. London: Great Britain. Department for Education.

Great Britain Department for Education. (2015). *Consultation on Young Carers' Draft Regulations: Government Response*. London: Great Britain. Department for Education.

Great Britain Department for Work and Pensions. (2010). *The Pension, Disability and Carers Service: Business Plan 2010/11*. (978 1 84712 724 2). London: Great Britain. Department for Work and Pensions.

Great Britain Department of Health. (2000). *Reforming the Mental Health Act: Part II; High Risk Patients*; Presented to Parliament by the Secretary of State for Health and the Home Secretary by Command of Her Majesty December 2000. (0 10 150162 5). London: Stationery Office.

Great Britain Department of Health. (2000). *Helping You to Stay Independent: A Guide to Long-Term Care Services and Benefits for People Who Live at Home*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2000). *Reforming the Mental Health Act: Part I; the New Legal Framework*; Presented to Parliament by the Secretary of State for Health and the Home Secretary by Command of Her Majesty December 2000. (0 10 150162 5). London: Stationery Office.

Great Britain Department of Health. (2000). *Better Care, Higher Standards: A Charter for Long-Term Care*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2000). *Promoting Independence: Partnership, Prevention and Carers Grants; Conditions and Allocations 2000/2001*. (017622). London: Great Britain. Department of Health.

Great Britain Department of Health. (2000). *A Quality Strategy for Social Care*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2000). *A Quality Strategy for Social Care: Executive Summary*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2001). *A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*; a White Paper Presented to Parliament by the Secretary of State for Health by Command of Her Majesty March 2001. (0 10 150862 X). London: Stationery Office.

Great Britain Department of Health. (2002). *Intermediate Care: Moving Forward; National Service Framework for Older People Supporting Implementation*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2002). *National Service Framework for Older People Interim Report on Age Discrimination*, April 2002. London: Great Britain. Department of Health.

Great Britain Department of Health. (2002). *Developing Services for Carers and Families of People with Mental Illness*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2003). *Making Change Happen: The Government's Annual Report on Learning Disability 2003; Easy Read Version*. (0 10 292120 2). Norwich: Stationery Office.

Great Britain Department of Health. (2003). *Making Change Happen: The Government's Annual Report on Learning Disability 2003*. (0 10 292120 2). Norwich: Stationery Office.

Great Britain Department of Health. (2003). *A Practical Guide for Disabled People or Carers: Where to Find Information, Services and Equipment*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2003). *Delivering Race Equality; a Framework for Action; Mental Health Services Consultation Document*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2003). *New Ways of Working in Stroke Care: Examples of New or Extended Roles for Those Involved with the Care of Stroke Victims and Their Carers*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2004). *The Community Care Assessment Directions 2004*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2004). *Making Partnership Work for Patients, Carers and Service Users: A Strategic Agreement between the Department of Health, the NHS and the Voluntary and Community Sector*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2004). *The National Service Framework for Mental Health: Five Years On*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2006). *From Values to Action: The Chief Nursing Officer's Review of Mental Health Nursing*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2007). *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2008). *Carers at the Heart of 21st-Century Families and Communities*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2008). *Carers Grant: 2008-2011: Guidance*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2008). *A Guide to Receiving Direct Payments from Your Local Council: March 2008 Update*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2008). *Consultation on Direct Payment Regulations*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2008). *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life: Executive Summary*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2008). *Making the CPA Work for You*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *End of Life Care Strategy: First Annual Report*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *A Summary of Changes to Direct Payments*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *Shaping the Future of Care Together: Equality Impact Assessment*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *Equal Access? A Practical Guide for the NHS: Creating a Single Equality Scheme That Includes Improving Access for People with Learning Disabilities*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *Carers Strategy Demonstrator Sites Project Funding Allocations 2009/10*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2009). *Guidance on Direct Payments: For Community Care, Services for Carers and Children's Services: England 2009*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Essence of Care 2010: Benchmarks for Safety*. (978 0 11 322883 6). London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Amendment to Paragraph 119 of the Guidance on Direct Payments 2009*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Recognised, Valued and Supported: Next Steps for the Carers Strategy*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Carers and Personalisation: Improving Outcomes*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *End of Life Care Strategy: Second Annual Report*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Essence of Care 2010: Benchmarks for Communication*. (978 0 11 322875 1). London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Essence of Care 2010: Benchmarks for the Prevention and Management of Pain*. (978 0 11 322877 5). London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Carers Strategy Demonstrator Sites Project Funding Allocations 2010/11*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2010). *Prioritising Need in the Context of Putting People First: A Whole System Approach to Eligibility for Social Care: Guidance on Eligibility Criteria for Adult Social Care, England 2010*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2011). *Better Care at Home and in Care Homes: Contract Inserts*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2011). *Template Action Plan to Improve Care for People with Dementia in the Community*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2012). *Reforming the Law for Adult Care and Support: The Government's Response to Law Commission Report 326 on Adult Social Care*: Presented to Parliament by the Secretary of State for Health July 2012. (9780101837927). London: Stationery Office.

Great Britain Department of Health. (2012). *Caring for Our Future: Reforming Care and Support*: Presented to Parliament by the Secretary of State for Health July 2012. (9780101837828). London: Stationery Office.

Great Britain Department of Health. (2012). *Caring for Our Future: Progress Report on Funding Reform*: Presented to Parliament by the Secretary of State for Health July 2012. (9780101838122). London: Stationery Office.

Great Britain Department of Health. (2012). *Caring for Our Future: Reforming Care and Support: Equality Analysis*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2012). *Caring for Our Future: Reforming Care and Support: Easy Read Version of the Government's White Paper on Care and Support*. London: Stationery Office.

Great Britain Department of Health. (2012). *Caring for Our Future: Reforming Care and Support: Impact Assessments Summary Document*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2012). *Caring for Our Future: Summary of Responses*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2012). *Government Response to the House of Commons Health Committee Report on Social Care* (Fourteenth Report of Session 2010-12). (9780101838023). London: Stationery Office.

Great Britain Department of Health. (2013). *Government Response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities*. London: Department of Health.

Great Britain Department of Health. (2013). *Draft National Minimum Eligibility Threshold for Adult Care and Support: A Discussion Document*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2014). *Care and Support: What's Changing?* London: Great Britain. Department of Health.

Great Britain Department of Health. (2014). *Carers Strategy: Second National Action Plan 2014 - 2016*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2015). *Voice, Choice and Control: How Registered Nurses, Care and Support Staff in the Care Sector Can Support People to Achieve These Aims*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2015). *No Voice Unheard, No Right Ignored: Key Themes from the Consultation Responses*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2015). *Statutory Guidance for Local Authorities and NHS Organisations to Support Implementation of the Adult Autism Strategy*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2015). London: Great Britain. Department of Health. *The Government Response to the Consultation on Revised Statutory Guidance to Implement the Strategy for Adults with Autism in England*

Great Britain Department of Health. (2015). *Mental Health Act 1983: Code of Practice*. (9780113230068). Norwich: Great Britain. Department of Health.

Great Britain Department of Health. (2016). *Joint Declaration on Post-Diagnostic Dementia Care and Support*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2016). *Dementia 2020 Citizens' Engagement Programme: Toolkit for Engaging People with Dementia and Carers*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2016). *Making a Difference in Dementia: Nursing Vision and Strategy*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2016). *Joint Declaration on Post-Diagnostic Dementia Care and Support*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2016). *Our Commitment to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care*. London: Great Britain. Department of Health.

Great Britain Department of Health. (2016). *Prime Minister's Challenge on Dementia 2020: Implementation Plan*. London: Great Britain. Department of Health.

Great Britain Department of Health, & Alzheimer's Society. (2011). *Simple Ways to Help Someone Living with Dementia*. London: Great Britain. Department of Health.

Great Britain Department of Health, & Association of Directors of Adult Social Services. (2009). *National Dementia Strategy Objective 6: Improved Community Personal Support: Think Tank Report*. London: Great Britain. Department of Health.

Great Britain Department of Health, & Great Britain Department of the Deputy Prime Minister. (2002). *Housing and Support Options for People with Learning Disabilities: Draft*. London: Great Britain. Department of Health.

Great Britain Department of Health Carers Policy Team. (2010). *Recognised, Valued and Supported: Next Steps for the Carers Strategy: Response to the Call for Views*. London: Great Britain. Department of Health.

Great Britain Department of Health Social Services Inspectorate. (2002). *Improving Older People's Services: Policy into Practice; Key Messages for Service Managers and Practitioners*. London: Great Britain. Department of Health. Social Services Inspectorate.

Great Britain Government Equalities Office. (2009). *A Fairer Future: The Equality Bill and Other Action to Make Equality a Reality*. London: Great Britain. Government Equalities Office.

Great Britain Home Office. (2007). *Keep an Eye Open for Bogus Callers: A Guide for Carers and Care Professionals*. London: Great Britain. Home Office.

Great Britain House of Commons Work and Pensions Committee. (2005). *The Disability and Carers Service: Oral Evidence: Wednesday 19 October 2005: Mr Terry Moran and Ms Vivien Hopkin*. (0 215 02742 6). London: Stationery Office.

Great Britain House of Commons. Health Committee. (2004). *Palliative Care: Fourth Report of Session 2003-04; Volume 2; Oral and Written Evidence*. (0 215 01872 9). London: Stationery Office.

Great Britain House of Commons. Health Committee. (2004). *Palliative Care: Fourth Report of Session 2003-04; Volume 1; Report Together with Formal Minutes*. (0 215 01869 9). London: Stationery Office.

Great Britain House of Commons. Health Committee. (2012). *Social Care: Fourteenth Report of Session 2010-12: Volume 1: Report, Together with Formal Minutes*. London: Great Britain. House of Commons.

Great Britain House of Commons. Health Committee. (2012). *Social Care: Fourteenth Report of Session 2010-12: Volume 2: Oral and Written Evidence*. London: Great Britain. House of Commons.

Great Britain House of Commons. Health Committee. (2012). *Social Care: Fourteenth Report of Session 2010-12: Volume Iii Additional Written Evidence*. London: Great Britain. House of Commons.

Great Britain Office of the Deputy Prime Minister Social Exclusion Unit. (2005). *Excluded Older People: Social Exclusion Unit Interim Report*. London: Great Britain. Office of the Deputy Prime Minister.

Great Britain Parliament. (2004). *Carers (Equal Opportunities) Bill*. (0 215 70345 6). London: Stationery Office.

Great Britain Parliament. (2004). *Carers (Equal Opportunities) Act 2004: Chapter 15; Explanatory Notes*. (0 10 561504 8). London: Stationery Office.

Great Britain Parliament. (2014). *Care Act 2014: Chapter 23*. (9780105423140). Norwich: TSO.

Great Britain Parliament All Party Parliamentary Group on Dementia. (2012). *Unlocking Diagnosis: The Key to Improving the Lives of People with Dementia*. London: Great Britain. Parliament. All Party Parliamentary Group on Dementia.

Great Britain Parliament All-Party Parliamentary Group on Dementia. (2011). *The £20 Billion Question: An Inquiry into Improving Lives through Cost-Effective Dementia Services*. London: Great Britain. Parliament. All Party Parliamentary Group on Dementia.

Great Britain Parliament House of Commons Work and Pensions Committee. (2008). *Valuing and Supporting Carers: Government Response to the Committee's Fourth Report of Session 2007-08: First Special Report of Session 2008-09*. London: Stationery Office.



Great Britain Parliament House of Lords. (2007). *Mental Health Bill (HL)*: June 2007. (978 0 10 843630 7). London: Stationery Office.

Great Britain Parliament Joint Committee on Human Rights. (2008). *A Life Like Any Other? Human Rights of Adults with Learning Disabilities: Seventh Report of Session 2007-08: Volume 2: Oral and Written Evidence* (HL 40-li; Hc 73-li). (978 0 10 401240 6). London: Stationery Office.

Great Britain Parliament Joint Committee on Human Rights. (2008). *A Life Like Any Other? Human Rights of Adults with Learning Disabilities: Seventh Report of Session 2007-08: Volume 1: Report and Formal Minutes* (HL 40-l; Hc 73-l) London: Stationery Office.

Great Britain Parliament Joint Committee on Human Rights. (2014). *Legislative Scrutiny: Care Bill: Eleventh Report of Session 2013-14: Report, Together with Formal Minutes*. London: Stationery Office.

Great Britain Parliament. House of Commons. (2004). *Carers (Equal Opportunities) Bill [as Amended in Standing Committee C]*. (0 215 70380 4). London: Stationery Office.

Great Britain Parliament. House of Commons. Health Committee. (2015). *End of Life Care: Fifth Report of Session 2014-15*. London: TSO.

Greengross, S., & Shersby, J. (2008). *New Deal for Carers: Equalities Task Force Report*. London: Great Britain. Department of Health.

Harkins, J., & Dudleston, A. (2006). *Scottish Household Survey Analytical Topic Report: Characteristics and Experiences of Unpaid Carers in Scotland*. (0 7559 6254 0). Edinburgh: Scotland. Scottish Executive. Social Research.

Harkins, J., & Dudleston, A. (2006). *Scottish Household Survey Analytical Topic Report: Characteristics and Experiences of Unpaid Carers in Scotland: Research Findings*. (0 7559 6255 9). Edinburgh: Scotland. Scottish Executive. Social Research.

HM Government. (2003). Social Services, England: *The Community Care (Delayed Discharges Etc.) Act (Qualifying Services) (England) Regulations 2003*. (0 11 045839 7). London: Stationery Office.

HM Government. (2003). *Community Care (Delayed Discharges Etc.) Act 2003: Chapter 5*. (0 10 540403 9). London: Stationery Office.

HM Government. (2008). *Caring at the Heart of 21st Century Families and Communities: A Caring System on Your Side*. London: TSO.

HM Government. (2014). *Children and Families Act 2014: Chapter 6*. (9780105406143). Norwich: TSO.

House of Commons Committee of Public Accounts. (2008). *Improving Services and Support for People with Dementia: Sixth Report of Session 2007-08: Report, Together with Formal Minutes, Oral and Written Evidence*. (9780215038197). London: Stationery Office.

Joint Improvement Team. (2006). *Connecting Partnerships: A Framework for Supporting Leadership, Effective Management and Service Innovations across Health and Social Care Partnerships*. Edinburgh: Scotland. Scottish Executive.

Joint Improvement Team. (2011). *Telecare to 2012: An Action Plan for Scotland*. (978 1 78045 064 3). Edinburgh: Scotland. Scottish Government.

- Kidner, C. (2008). *Kinship Care*. Edinburgh: Scotland. Scottish Parliament.
- Killeen, J. (2006). *Guardianship and Intervention Orders - Making an Application: A Guide for Carers*. (0 7559 5002 X). Edinburgh: Scotland. Scottish Executive.
- Killeen, J. (2007). *Adults with Incapacity (Scotland) Act 2000: Guardianship and Intervention Orders - Making an Application: A Guide for Carers*. (978 0 7559 5393 6). Edinburgh: Scotland. Scottish Executive.
- Lamb, N. (2014). *How the Government Is Supporting Carers*. London: Department of Health.
- Law Commission. (2008).. London: Law Commission. *Adult Social Care: Scoping Report: Summary*
- Law Commission. (2008). *Adult Social Care: A Scoping Report*. London: Law Commission.
- Law Commission. (2010). *Adult Social Care: A Consultation Paper*. London: Law Commission.
- Law Commission. (2011). *Adult Social Care: Consultation Analysis*. London: Law Commission.
- Law Commission. (2011). *Adult Social Care: Summary of Final Report*. London: Law Commission.
- Law Commission. (2011). *Adult Social Care*. (9780102971682). London: Stationery Office.
- Law Commission. (2015). *Mental Capacity and Deprivation of Liberty: A Consultation Paper*. (9780108561634). London: Law Commission.
- McLean, J., & Whitehead, I. (2008). *Evaluation of the Scottish Recovery Indicator Pilot in Five Health Board Areas*. (978 0 7559 7211 1). Edinburgh: Scotland. Scottish Government Social Research.
- Muir, C., & Webber, J. (2008). *New Deal for Carers: Revision of the Prime Minister's 1999 Strategy on Carers: Health and Social Care Taskforce Report*. London: Great Britain. Department of Health.
- National Assembly for Wales. (2001). *Caring About Carers: A Strategy for Carers in Wales: The First Report*. National Assembly for Wales.
- National Assembly for Wales. (2002). *Caring About Carers: A Strategy for Carers in Wales: The Second Report*. National Assembly for Wales.
- National Information Board. (2014). *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens: A Framework for Action*. London: Great Britain. Department of Health.
- National Information Board. (2015). *Personalised Health and Care 2020: Work Stream 2.2 Roadmap: Give Care Professional and Carer Access to All the Data They Need*. Leeds: National Information Board.
- NHS England Patients Information Directorate. (2013). *Transforming Participation in Health and Care: "The NHS Belongs to Us All"*. Leeds: NHS England.

Northern Ireland Department of Health. (2016). *Improving and Safeguarding Social Wellbeing: A Strategy for Social Work 2012-2022. Governance System for Stage 2 Delivery*. Belfast: Northern Ireland. Department of Health.

Northern Ireland Department of Health Social Services and Public Safety. (2004). *Direct Payments: Legislation and Guidance for Boards and Trusts*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2005). *Guidance on Accounting and Monitoring Requirements for Payments Made under the Carers and Direct Payments Act (Northern Ireland) 2002*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2005). *Developing a Strategy and Action Plan to Promote Equality and Human Rights: Stakeholder Consultation Workshop Outcome Report: 29 November 2005*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2005). *Best Practice, Best Care: The Quality Standards for Health and Social Care*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2005). *Carers' Assessment and Information Guidance*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2006). *Personal Social Services: Development and Training Strategy 2006-2016*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2006). *Caring for Carers: Recognising, Valuing and Supporting the Caring Role*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2006). *The Quality Standards for Health and Social Care: Supporting Good Governance and Best Practice in the HPSS*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2008). *Standards for Adult Social Care Support Services for Carers*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2010). *Adult Safeguarding in Northern Ireland: Regional and Local Partnership Arrangements*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2010). *Living Matters Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2012). *Delivering the Bamford Vision: The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability: Action Plan 2012-2015*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2013). *Service Framework for Older People*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2013). *The Autism Strategy and Action Plan: Summary of Public Consultation Feedback, Findings and Impact Report*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Department of Health Social Services and Public Safety. (2015). *Service Framework for Learning Disability*. Belfast: Northern Ireland. Department of Health Social Services and Public Safety.

Northern Ireland Executive Department of Health Social Services and Public Safety. (2013). *The Autism Strategy (2013-2020) and Action Plan (2013-2016)*. Belfast: Northern Ireland. Northern Ireland Executive.

Northern Ireland Health and Social Care Board. (2013). *Transforming Your Care: Vision to Action: A Post Consultation Report*. Belfast: Northern Ireland. Health and Social Care Board.

Opinion Leader Research. (2009). *Overarching Report of Findings from the Adult Autism Strategy Consultation Activities*. London: Great Britain. Department of Health.

Opinion Research Services. (2016). *Research to Support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010...Part 1 Final Report: Local Primary Mental Health Support Services*. (9781473455887). Cardiff: Wales. Welsh Government.

Opinion Research Services. (2016). *Research to Support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010...Part 4 Final Report: Mental Health Advocacy*. (9781473455917). Cardiff: Wales. Welsh Government.

Opinion Research Services. (2016). *Research to Support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010... Part 2 Final Report: Coordination of and Care and Treatment Planning for Secondary Mental Health Users*. (9781473455894). Cardiff: Wales. Welsh Government.

*Parliamentary Monitor*. (2015). *Weekly Debates -- Westminster*. (1366302X). Education Publishing Worldwide Ltd.

*Parliamentary Monitor*. (2016). *Weekly Written PQs*. (1366302X). Education Publishing Worldwide Ltd.

Roberts, G., Jones, E., & Rhisiart, D. A. (2011). *Giving Voice to Older People: Dignity in Care Welsh Language Toolkit*. (978 0 7504 6431 4). Cardiff: Wales. Welsh Assembly Government.

Scottish Consortium for Learning Disability. (2007). *The New Mental Health Act: An Easy Read Guide*. (978 0 7559 5253 3). Edinburgh: Scotland. Scottish Executive.

Scottish, E. (2001). *Renewing Mental Health Law: A Policy Statement*. (1 7559 0198 3). Edinburgh: Stationery Office.

Scottish Executive. (2000). *The Same as You? A Review of Services for People with Learning Disabilities*. (0 7480 9378 8). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2000). *Council Tax in Scotland: A Guide for People Who Have Special Needs and Their Carers*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2001). *Scottish Community Care Statistics 2000*. (0 7559 0111 8). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2001). *Financial Provision and Direct Payments 2001*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2001). *Scottish Executive's Response to the Report of the Joint Future Group*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2002). *Growth and Development National Overview: Social Work Services for the 21st Century; the Report of the Chief Inspector of Social Work Service for Scotland*. (0 7559 0505 9). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2002). *Growth and Development: Social Work Services for the 21st Century; the Report of the Chief Officer of Social Work Services for Scotland*. (0 7559 0394 3). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2002). *National Care Standards: Hospice Care*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2002). *National Care Standards: Care Homes for Older People*. (0 7559 0319 6). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2002). *Scottish Community Care Statistics 2001*. (0 7559 0564 4). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2002). *Statistics Release: Home Care Services; Scotland 2002*. Edinburgh: Scotland. Scottish Executive National Statistics.

Scottish Executive. (2002). *National Care Standards: Short Breaks and Respite Care Services for Adults*. (0 7559 0367 6). Scotland. Scottish Executive.

Scottish Executive. (2002). *National Care Standards: Adult Placement Services*. (0 7559 0364 1). Edinburgh: Stationery Office.

Scottish Executive. (2003). *Statistics Release: Home Care Services, Scotland 2003*. Edinburgh: Scotland. Scottish Executive National Statistics.

Scottish Executive. (2003). *Scottish Community Care Statistics 2002*. (0 7559 0940 2). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2004). *Nursing People with Cancer in Scotland: A Framework*. (0755909151). Edinburgh: The Stationery Office.

Scottish Executive. (2006). *The Same as You? Partnership in Practice Agreements 2004-2007: National Overview and Next Steps*. (0 7559 6313 X). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2006). *Delivering for Health: Delivering for Mental Health: Establishing Acute Inpatient Forums and Improving Care*. (0 7559 6398 9). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2006). *NHS Carer Information Strategies: Minimum Requirements and Guidance on Implementation*. Scotland. Scottish Executive.

Scottish Executive. (2006). *The New Mental Health Act: Rights of Carers*. (0 7559 4971 4). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2006). *Scottish Executive Response to Care 21 Report: The Future of Unpaid Care in Scotland*. (0 7559 5066 6). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2006). *Delivering for Health: Delivering for Mental Health National Standards for Crisis Services*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2006). *Having Your Say? The Same as You? National Implementation Group: Report of the Advocacy Sub Group*. (0 7559 4979 X). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2007). *Living Well with Long-Term Conditions: Report of the Open Space Events Held in Glasgow, Tuesday 13 February 2007 and Aberdeen, Thursday 15 March 2007*. (978 0 7559 5487 2). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2007). *Rehabilitation and You: A Guide to Rehabilitation Services in Scotland*. (978 0 7559 5404 9). Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2007). *National Practitioner Conference 20 June 2007 BLCC Halbeath Dunfermline: Conference Report*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive. (2007). *Co-ordinated, Integrated and Fit for Purpose: A Delivery Framework for Adult Rehabilitation in Scotland*. (978 0 7559 5301 1). Edinburgh: Scotland. Scottish Executive.

Scottish Executive Chief Nursing Officer. (2007). *Rights, Relationships and Recovery: The National Review of Mental Health Nursing in Scotland: Annual Report of Progress Prepared by the National Implementation Group for the Chief Nursing Officer*. (978 0 7559 5469 8). Edinburgh: Scotland. Scottish Executive.

Scottish Executive Education Department, Social Work Services Unit, Care 21 Change Innovation, & Office for Public Management. (2006). *The Future of Unpaid Care in Scotland: Headline Report and Recommendations*. (0 7559 4876 9). Edinburgh: Scotland. Scottish Executive.

Scottish Executive Education Department, Social Work Services Unit, Care 21 Change Innovation, & Office for Public Management Innovation. (2006). *The Future of Unpaid Care in Scotland: Appendices 1-5*. (0 7559 4993 5). Edinburgh: Scotland. Scottish Executive.

Scottish Executive Health and Social Care Ministerial Steering Group. (2004). *National User and Carer Outcomes and Local Improvement Targets for the Joint Future Agenda*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive Health Department. (2000). *Help for Carers (Scotland)*. Edinburgh: Scotland. Scottish Executive.

Scottish Executive Substance Misuse Division Effective Interventions Unit. (2002). *Supporting Families and Carers of Drug Users: A Review; Summary*. Edinburgh: Scotland. Scottish Executive. Substance Misuse Division. Effective Interventions.

Scottish Executive Substance Misuse Division Effective Interventions Unit. (2002). *Support for the Families and Carers of Drug Users: A Review of the Literature*. (0 7559 0648 9). Edinburgh: Scotland. Scottish Executive. Substance Misuse Division. Effective Interventions.

Scottish Executive Substance Misuse Division Effective Interventions Unit. (2002). *Supporting Families and Carers of Drug Users: A Review*. (0 7559 0632 2). Edinburgh: Scotland. Scottish Executive. Substance Misuse Division. Effective Interventions.

Scottish Government. (2005). *The New Mental Health Act: A Guide to Emergency and Short-Term Powers: Information for Service Users and Their Carers*. (0 7559 4827 0). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2007). *Consultation on Respite Care Guidance*. (978 0 7559 1589 7). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2007). *National Minimum Information Standards for All Adults in Scotland for Assessment, Shared Care and Support Plan, Review and Carers Assessment and Support: Consultation on the Compendium of Standards*. (978 0 7559 1624 5). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2007). *Mental Health in Scotland: Closing the Gaps - Making a Difference: Commitment 13*. (978 0 7559 6887 9). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2008). *Adults with Incapacity (Scotland) Act 2000: Guardianship and Intervention Orders: Making an Application: A Guide for Carers*. (978 0 7559 5640 1). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2008). *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland*. (978 0 7559 5889 4). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2008). *Principles and Standards of Citizen Leadership by the Changing Lives User and Carer Forum Including What Is Citizen Leadership? A Report by the User and Carer Panel of the 21st Century Social Work Review*. (978 0 7559 5712 5). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2008). *Guidance on Short Breaks* (Ccd 4/2008). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2009). *The Adult Support and Protection (Scotland) Act 2007: "What It Means to Me" - Report of a User and Carers Conference*. (978 0 7559 7411 5). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2010). *Caring Together: The Carers Strategy for Scotland 2010-2015*. (978 0 7559 9484 7). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2010). *Self-Directed Support: A Draft Bill for Consultation*. (978 0 7559 9889 0). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2010). *Good Practice Carers and Young Carers Stories: Caring Together and Getting It Right for Young Carers: The Carers and Young Carers Strategy for Scotland 2010-2015*. (978 0 7559 9503 5). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2010). *Consultation on Draft Social Care Procurement Scotland Guidance: Summary Paper Service User and Carer Involvement*. (978 0 7559 9217 1). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2011). *Adults with Incapacity (Scotland) Act 2000: Code of Practice for Continuing and Welfare Attorneys*. (978 1 78045 144 2). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2012). *Mental Health Strategy for Scotland 2012-15*. (9781780459950). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2012). *Integration of Adult Health and Social Care in Scotland: Consultation Analysis Report*. Edinburgh: Scotland. Scottish Government.

Scottish Government. (2013). *The Keys to Life: Improving Quality of Life for People with Learning Disabilities*. (9781782566366). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2014). *Statutory Guidance to Accompany the Social Care (Self-Directed Support) (Scotland) Act 2013*. (9781784123482). Edinburgh: Scotland. Scottish Government.

Scottish Government. (2015). *Scottish Government Response to 'Carers Legislation: Consultation Proposals: January 2014'*. Scotland. Scottish Government.

Scottish Government. (2015). *National Health and Wellbeing Outcomes: A Framework for Improving the Planning and Delivery of Integrated Health and Social Care Services*. Edinburgh: Scotland. Scottish Government.

Scottish Government User and Carer Forum. (2007). *Citizen Leadership Report and Principles and Standards of Citizen Leadership*. Edinburgh: Scotland. Scottish Government.

Social Work Inspection Agency. (2010). *Performance Improvement Handbook 2010-11*. Edinburgh: Social Work Inspection Agency.

Strategy on Carers Health & Social Care Taskforce. (2008). *New Deal for Carers: Revision of the Prime Minister's 1999 Strategy on Carers: Health and Social Care Taskforce Report*.

Traynor, J., Walker, A., & Great Britain Office for National Statistics. (2003). *People Aged 65 and Over: Results of a Study Carried out on Behalf of the Department of Health as Part of the 2001 General Household Survey*. (0 11 621 653 0). London: Stationery Office.

Wales National Assembly. (2003). *Challenging the Myth; "They Look after Their Own"; Carers Services; Access Issues for Black and Minority Ethnic Carers in Wales; Executive Summary*. (0 7504 9949 4). Cardiff: Wales. National Assembly.

Wales National Assembly. (2003). *Challenging the Myth; "They Look after Their Own"; Black and Minority Ethnic (BME) Carers; Directory*. (0 7504 9951 6). Cardiff: Wales. National Assembly.

Wales National Assembly. (2003). *Domiciliary Care: Implementation of Regulations and National Minimum Standards*. Cardiff: Wales. National Assembly.

Wales National Assembly. (2003). *BME Carers: Challenging the Myth; "They Look after Their Own"; a Good Practice Guide*. (0 7504 9950 8). Cardiff: Wales. National Assembly.

Wales Social Services Inspectorate for Wales. (2005). *Thematic Inspection of Health and Social Services for Adults Who Require Hospital Inpatient Treatment for Physical Ill-Health in Wales*. (0 7504 3875 4). Cardiff: WALES. Social Services Inspectorate for Wales.

Ward, C. (2001). *Family Matters: Counting Families In*. London: Great Britain. Department of Health.

Waters, C., & Portes, J. (2008). *New Deal for Carers: Employment Task Force Report*. London: Great Britain. Department of Health.



Welsh Assembly Government. (2003). *Caring About Carers: A Strategy for Carers in Wales: The Third Report*. (0 7504 3188 1). Cardiff: Wales. Welsh Assembly Government.

Welsh Assembly Government. (2004). *Learning Disability Strategy: Section 7 Guidance on Service Principles and Service Responses*. Cardiff: Wales. Welsh Assembly Government.

Welsh Assembly Government. (2006). *Caring About Carers: A Strategy for Carers in Wales: The Third Report: Summary Document*. (0 7504 3188 1). Cardiff: Wales. Welsh Assembly Government.

Welsh Assembly Government. (2007). *Statement on Policy and Practice for Adults with a Learning Disability*. Cardiff: Wales. Welsh Assembly Government.

Welsh Assembly Government. (2010). *Explanatory Memorandum to the Proposed Carers Strategies (Wales) Measure*: January 2010. Cardiff: Wales. Welsh Assembly Government.

Welsh Assembly Government. (2011). *Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments (Wales) Guidance 2011*. Cardiff: Wales. Welsh Assembly Government.

Welsh Assembly Government. (2012). *Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales*. (978 0 7504 7440 5). Cardiff: Wales. Welsh Assembly Government.

Welsh Government. (2011). *Carers Strategies (Wales) Measure 2010: Guidance Issued to Local Health Boards and Local Authorities*. Cardiff: Welsh Government.

Welsh Government. (2011). *Summary of the Direct Payments Guidance 2011*. (978 0 7504 6719 3). Cardiff: Welsh Government.

Welsh Government. (2012). *Together for Mental Health: Delivery Plan 2012-16*. Cardiff: Welsh Government.

Welsh Government. (2012). *Together for Mental Health: A Cross-Government Strategy for Mental Health and Wellbeing in Wales*. Cardiff: Welsh Government.

Welsh Government. (2013). *Well-Being Statement for People Who Need Care and Support and Carers Who Need Support*. Cardiff: Welsh Government.

Welsh Government. (2013). *The Carers Strategy for Wales 2013*. Cardiff: Welsh Government.

Welsh Government. (2014). *Social Services and Well-Being (Wales) Act 2014*. Cardiff: Welsh Government.

Welsh Government. (2014). *The National Outcomes Framework for People Who Need Care and Support and Carers Who Need Support, 2014-15: Working Document*. Cardiff: Welsh Government.

Welsh Government. (2014). *Together for Mental Health: Annual Report 2013-14*. Cardiff: Welsh Government.

Welsh Government. (2015). *Social Services and Well-Being (Wales) Act 2014: Part 3 Code of Practice (Assessing the Needs of Individuals)*. Cardiff: Wales. Welsh Government.

Welsh Government. (2015). *Social Services and Well-Being (Wales) Act 2014: Part 4 Code of Practice (Meeting Needs)*. Cardiff: Wales. Welsh Government.

- Welsh Government. (2015). *Social Services and Well-Being (Wales) Act: Assessing and Meeting Needs*. Cardiff: Welsh Government.
- Welsh Government. (2015). *Social Services and Well-Being (Wales) Act: Assessment and Support for Carers*. Cardiff: Welsh Government.
- Welsh Government. (2015). *Social Services and Well-Being (Wales) Act 2014: Part 4 and 5 Code of Practice (Charging and Financial Assessment)*. Cardiff: Wales. Welsh Government.
- Welsh Government. (2015). *Social Services and Well-Being (Wales) Act 2014: Part 2 Code of Practice (General Functions)*. Cardiff: Wales. Welsh Government.
- Welsh Government. (2015). *Consultation on the Revision of the Mental Health Act 1983 Code of Practice for Wales*. Cardiff: Welsh Government.
- Welsh Government. (2016). *Research to Support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010. Part 3 Final Report: Assessments of Former Users of Secondary Mental Health Services*. (9781473455900). Cardiff: Wales. Welsh Government.
- Welsh Government. (2016). *Together for Mental Health Delivery Plan: 2016-19: Consultation Document*. Cardiff: Wales. Welsh Government.
- Welsh Government. (2016). *Recording Measurement of Personal Outcomes: Part 3 Personal Outcome Guidance: (Issued under the National Assessment and Eligibility Tool)*. Cardiff: Wales. Welsh Government.
- Welsh Government. (2016). *Refreshed Autistic Spectrum Disorder Strategic Action Plan*. (9781473482104). Cardiff: Wales. Welsh Government.
- Welsh Government. (2016). *The National Outcomes Framework for People Who Need Care and Support and Carers Who Need Support*. Cardiff: Wales. Welsh Government.
- Welsh Government. (2016). *A Bulletin on the Personal Well-Being of People Who Need Care and Support and Carers Who Need Support, 2014-15*. Cardiff: Wales. Welsh Government.
- Welsh Government. (2016). *Together for Mental Health: Delivery Plan: 2016-19*. Wales. Welsh Government.
- Welsh Government Eligibility Technical Group. (2014). *Options for the Eligibility Framework for Care & Support under Regulations Stemming from the Social Services and Well-Being (Wales) Act 2014: Revised Final Draft 13 June 2014*. Cardiff: Welsh Government.
- White, C. (2013). *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and Comparison with 2001*. Newport: Great Britain. Office for National Statistics.
- Whitfield, G., Waring, A., Goode, J., Phung, V.-H., Hill, K., & Sutton, L. (2011). *Customers' Experiences of Contact with the Pension, Disability and Carers Service: Research Summary*. London: Great Britain. Department for Work and Pensions.

## Guide

Allison, S. (2004) *Carers and confidentiality in mental health: issues involved in information sharing*. Suffolk Carers.

Blunden, R. (2002) *How good is your service to carers? A guide to checking quality standards for local carer support services*. London: King's Fund; 2002.

BMA. (2009) *Working with carers: guidelines for good practice*. (Rev June 2009 ed., pp. 13). London: British Medical Association.

BMA Committee on Community Care. (2007) *Working with carers: guidelines for good practice*.

Carers Trust. (2013) *Commissioning for carers: key principles for clinical commissioning groups*.

Cass, E. (2007) *Implementing the Carers (Equal Opportunities) Act 2004. Guide* (Rev. Ed. ed.). London: Social Care Institute for Excellence.

CIRCLE. (2011) *Delivering Training to Carers. A practical guide based on finding from the National Evaluation of the Caring with Confidence Programme*. University of Leeds: CIRCLE: Centre for International Research on Care, Labour and Equalities.

De Filippis, M. L., Craven, M. P., & Denning, T. (2014) *Informal carer role in the personalisation of assistive solutions connected to aspirations of people with dementia*. Vol. 8868. *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)* (pp. 236-243).

Enable, S. (2006) *Being a witness: helping people with learning disabilities who go to court: a guide for carers*. (pp. 32p.). Edinburgh: Scotland. Scottish Executive.

Frank, J. (2002) *Making it work: good practice with young carers and their families*. Children's Society/Princess Royal Trust for Carers.

Great Britain Department of Health. (2005) *Telecare implementation guide*. (pp. 44p.). London: Great Britain. Department of Health. Integrating Community Equipment Services.

Hannan, R., Thompson, R., Worthington, A., & Rooney, P. (2013) *The Triangle of Care: Carers included: A guide to best practice for dementia care*. Carers Trust.

Haywood, A., Brownsell, S., Hawley, M. S., & Mountain, G. A. (2011) 'Development of an integrated telehealth system to facilitate self-management of long term conditions'. Vol. 29. *Assistive Technology Research Series* (pp. 1051-1057).

Help the Hospices. (2009) *Identifying carers' needs in the palliative setting*.

Highland Council Social Work Services, Northern Constabulary, & NHS Highland. (2005) *Protecting vulnerable adults: good practice guidance and procedures*. (Rev. ed., pp. 44p.). Inverness: Highland Council. Social Work Services.

Jee, M., & Reason, L. (2005) *Who cares? information and support for the carers of people with dementia*. (3rd ed, rev ed., pp. 96). London: Department of Health.

Kennedy, S., & Bird, L. (2011) *Older carers and involvement in research: why, what and when?*

Kerkhof, Y., Rabiee, F., & Willems, C. G. (2011) 'Memory aid to structure and support daily activities for people with dementia.' Vol. 29. *Assistive Technology Research Series* (pp. 3-9).

Levin, E. (2004) *Involving service users and carers in social work education*. SCIE.

Marshall, M. (2000) *A.S.T.R.I.D. a social and technological response to meeting the needs of individuals with dementia and their carers: a guide to using technology within dementia care*. (pp. 51).

Minhas, B. (2002) *Culturally competent care: a good practice guide for care management: developing services for black & minority ethnic older people and their carers*. Kent County Council.

National Development Team for Inclusion. (2013) *Paths to personalisation in mental health: a whole system, whole life framework*. (rev. ed. ed., pp. 84). Bath: National Development Team for Inclusion.

National Institute for Health and Care Excellence. (2013) *Tailored resource for carers and care providers on supporting people to live well with dementia*. Manchester: National Institute for Health and Care Excellence.

Newcastle Council for Voluntary Service. (2002) *How to ensure your service is responsive to the needs of carers: a guide and action planning tool for managers and staff working in the health service in Newcastle*. (pp. 20). Newcastle: Newcastle Council for Voluntary Service.

NHS England. (2014) *Bite-size guides to patient and public participation: guide 2: governance for participation*. London: NHS England.

Powell, E. (2002) *We care too: a good practice guide for people working with black carers*. (pp. 76): Afiya Trust.

Princess Royal Trust for Carers. (2004) *Focus on carers and the NHS: identifying and supporting hidden carers: good practice guide*. (pp. 40): Princess Royal Trust for Carers.

RCGP. (2008) *Supporting carers: an action guide for general practitioners and their teams*. (pp. 59): RCGP.

SCIE. (2010) *Young carers of parents with mental health issues*.

Scottish Consortium for Learning Disability (2009) *Effective engagement in social work education*. Glasgow: Institute for Research and Innovation in Social Services.

Skills for Care. (2012) *Carers in your workforce matter*. (pp. 29): Skills for Care.

Social Care Institute for Excellence. (2005) *SCIE research briefing 12: involving individual older patients and their carers in the discharge process from acute to community care: implications for intermediate care. Research briefing*. London: Social Care Institute for Excellence.

Social Care Institute for Excellence. (2011) *Improving access to social care for adults with autism. Guide*. London: Social Care Institute for Excellence.

Social Care Institute for Excellence. (2014) *Care Act: assessment and eligibility: supported self-assessment*. (Version 1 ed., pp. 8). London: Social Care Institute for Excellence.

Social Care Institute for Excellence. (2015) *Co-production in social care: what it is and how to do it (Guide)*. (pp. 71). London: Social Care Institute for Excellence.

Social Care Institute for Excellence, & Challenging Behaviour Foundation. (2011) *Challenging behaviour: a guide for family carers on getting the right support for teenagers. At a glance* (pp. 6p.). London: Social Care Institute for Excellence.

Velleman, R., & Bradbury, C. (2006) *Supporting and involving carers: A guide for commissioners and providers* National Treatment Agency for Substance Misuse.

## Journal Articles

Resources. (2004). *Research Matters* (18), 73-74.

Aasbø, G., Solbraekke, K. N., Kristvik, E., & Werner, A. (2016). Between Disruption and Continuity: Challenges in Maintaining the 'Biographical We' When Caring for a Partner with a Severe, Chronic Illness. *Sociology of Health & Illness*, 38(5), 782-796.

Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with Dementia: A Systematic Review of the Influence of Relationship Factors. *Aging and Mental Health*, 13(4), 497-511.

Ablitt, A., Jones, G. V., & Muers, J. (2010). Awareness of Carer Distress in People with Dementia. *International Journal of Geriatric Psychiatry*, 25(12), 1246-1252.

Åbom, B. M., Obling, N. J., Rasmussen, H., & Kragstrup, J. (2000). Unplanned Hospitalisation of Dying Patients. *Ugeskrift for Laeger*, 162(43), 5771.

Abstracts. (2000). Research Abstracts. *Palliative Medicine*, 14(4), 325-351.

Abstracts. (2004). Training Informal Carers of Stroke Patients Reduces Health and Social Care Costs in the Year Following a Stroke. *Evidence-Based Healthcare and Public Health*, 8(6), 345-347.

Acaster, S., Perard, R., & Chauhan, D. (2013). A Forgotten Aspect of the Nice Reference Case: An Observational Study of the Health-Related Quality of Life Impact on Caregivers of People with Multiple Sclerosis. *BMC Health Services Research*, 13(346), 8.

Ackers, L. (2004). Citizenship, Migration and the Value of Care in the European Union. *Journal of Ethnic and Migration Studies*, 30(2), 373-396.

Acton, G. J. (2002). Health-Promoting Self-Care in Family Caregivers. *Western Journal of Nursing Research*, 24(1), 73-86.

Acton, J., & Carter, B. (2016). The Impact of Immersive Outdoor Activities in Local Woodlands on Young Carers Emotional Literacy and Well-Being. *Comprehensive Child & Adolescent Nursing*, 39(2), 94-106.

Adams, T. (2001). The Conversational and Discursive Construction of Community Psychiatric Nursing for Chronically Confused People and Their Families. *Nursing Inquiry*, 8(2), 98-107.

Adams, T. (2001). The Social Construction of Risk by Community Psychiatric Nurses and Family Carers for People with Dementia. *Health, Risk and Society*, 3(3), 307-319.

Adams, T. (2003). Developing an Inclusive Approach to Dementia Care. *Practice: Social Work in Action*, 15(1), 45-56.

Adams, T. (2005). From Person-Centred Care to Relationship-Centred Care. *Generations Review*, 15(1), 4-7.

Adams, T., & Gardiner, P. (2005). Communication and Interaction within Dementia Care Triads: Developing a Theory for Relationship-Centred Care. *Dementia: The International Journal of Social Research and Practice*, 4(2), 185-205.

Adamsom, J., & Donovan, J. (2005). 'Normal Disruption': South Asian and African/Caribbean Relatives Caring for an Older Family Member in the UK. *Social Science & Medicine*, 60(1), 37-48.

Adamson, J. (2001). Awareness and Understanding of Dementia in African/Caribbean and South Asian Families. *Health and Social Care in the Community*, 9(6), 391-396.

Adcock, L. (2000). Assessing the Needs of Carers. *Journal of Community Nursing*, 14(3).

Addington Hall, J., & Armes, P. (2003). Perspectives on Symptom Control in Patients Receiving Community Palliative Care. *Palliative Medicine*, 17(7), 608-615.

- Addington-Hall, J. M., & O'Callaghan, A. C. (2009). A Comparison of the Quality of Care Provided to Cancer Patients in the UK in the Last Three Months of Life in in-Patient Hospices Compared with Hospitals, from the Perspective of Bereaved Relatives: Results from a Survey Using the Voices Questionnaire. *Palliative Medicine*, 23(3), 190-197.
- Adefila, A., Graham, S., Clouder, L., Bluteau, P., & Ball, S. (2016). Myshoes - the Future of Experiential Dementia Training? *The Journal of Mental Health Training, Education and Practice*, 11(2), 91-101.
- Adelman, R. D. (2014). Caregiver Burden: A Clinical Review. *JAMA*, 311(10), 1052-1060.
- Adeshokan, E., Radcliffe, J., & Bird, L. (2010). Meeting the Needs of Families and Carers of Acute Psychiatric Inpatients: A Nurse-Led Family Service. *British Journal of Wellbeing*, 1(4), 31-34.
- Agar, M., Currow, D. C., Shelby-James, T. M., J., P., Sanderson, C., & Abernethy, A. P. (2008). Preference for Place of Care and Place of Death in Palliative Care: Are These Different Questions? *Palliat Med*, 22(7), 787-795.
- Age Concern. (2004). Fearless in West London. *London Age*, 8-9.
- Aggar, C., Ronaldson, S., & Cameron, I. (2010). Reactions to Caregiving of Frail, Older Persons Predict Depression. *International Journal of Mental Health Nursing*, 19(6), 409-415.
- Aggar, C., Ronaldson, S., & Cameron, I. D. (2011). Self-Esteem in Carers of Frail Older People: Resentment Predicts Anxiety and Depression. *Aging and Mental Health*, 15(6), 671-678.
- Agree, E., Bissett, B., & Rendall, M. (2003). Simultaneous Care for Parents and Care for Children among Mid-Life British Women and Men. *Population Trends*, 112, 29-35.
- Aguirre, E., Spector, A., A, S., Burnell, K., & Orrell, M. (2011). Service Users' Involvement in the Development of a Maintenance Cognitive Stimulation Therapy (CST) Programme: A Comparison of the Views of People with Dementia, Staff and Family Carers. *Dementia: The International Journal of Social Research and Practice*, 10(4), 459-473.
- Ahmed, N., Ahmedzai, S. H., Bestall, J. C., Clark, D., Noble, B., & Payne, S. A. (2004). Systematic Review of the Problems and Issues of Accessing Specialist Palliative Care by Patients, Carers and Health and Social Care Professionals. *Palliative Medicine*, 18(6), 525-542.
- Ahmed, N., & Jones, I. R. (2008). 'Habitus and Bureaucratic Routines', Cultural and Structural Factors in the Experience of Informal Care - a Qualitative Study of Bangladeshi Women Living in London. *Current Sociology*, 56(1), 57-76.
- Aikaterini, K., Elissabet, V., & Venetia, N. (2012). Health-Related Quality of Life in Caregivers of Patients with Spinal Cord Injury (Sci). A Greek Review. *International Journal of Caring Sciences*, 5(3), 348-353.
- Airey, C. M., Chell, S. M., Rigby, A. S., Tennant, A., & Connelly, J. B. (2001). The Epidemiology of Disability and Occupation Handicap Resulting from Major Traumatic Injury. *Disability and Rehabilitation*, 23(12), 509-515.
- Airey, L., McKie, L., & Backett-Milburn, K. (2007). Women's Experiences of Combining Eldercare and Paid Work in the Scottish Food Retail Sector. *Health Sociology Review*, 16(3-4), 292-303.
- Akosile, C. O., Okoye, E. C., & Odunowo, O. K. (2009). Carers' Burden in Stroke and Some Associated Factors in a South-Eastern Nigerian Population. *African Journal of Neurological Sciences*, 28(2).
- Alaszewski, A., & Alaszewski, H. (2002). Towards the Creative Management of Risk: Perceptions Practices and Policies. *British Journal of Learning Disabilities*, 30(2), 56-62.

- Alcaraz, F. G., Useros, V. D., Espín, A. A., & Hidalgo, J. L. T. (2015). The Use of Social Healthcare Resources and Informal Care Characteristics Care of Immobilised Homecare Patients. *Atencion Primaria*, 47(4), 195-204.
- Aldred, H., Gariballa, S., & Gott, M. (2005). Advanced Heart Failure: Impact on Older Patients and Informal Carers. *Journal of Advanced Nursing*, 49(2), 116-124.
- Aldridge, J. (2003). We Didn't Know They Cared. *Mental Health Today*, 31-33.
- Aldridge, J. (2006). The Experiences of Children Living with and Caring for Parents with Mental Illness. *Child Abuse Review*, 15(2), 79-88.
- Aldridge, J. (2008). All Work and No Play? Understanding the Needs of Children with Caring Responsibilities. *Children & Society*, 22(4), 253-264.
- Aldridge, J., & Sharpe, D. (2007). Supporting Mum. *Mental Health Today*, 16-17.
- Alhaddad, B., Taylor, K. M. G., Robertson, T., Watman, G., & Smith, F. J. (2016). Assistance of Family Carers for Patients with COPD Using Nebulisers at Home: A Qualitative Study. *European Journal of Hospital Pharmacy-Science and Practice*, 23(3), 156-160.
- Ali, L., Ahlstrom, B. H., Krevers, B., Sjostrom, N., & Skarsater, I. (2013). Support for Young Informal Carers of Persons with Mental Illness: A Mixed-Method Study. *Issues in Mental Health Nursing*, 34(8), 611-618.
- Ali, L., Ahlstrom, B. H., Krevers, B., & Skarsater, I. (2012). Daily Life for Young Adults Who Care for a Person with Mental Illness: A Qualitative Study. *Journal of Psychiatric and Mental Health Nursing*, 19(7), 610-617.
- Ali, L., Krevers, B., Sjostrom, N., & Skarsater, I. (2014). Effectiveness of Web-Based Versus Folder Support Interventions for Young Informal Carers of Persons with Mental Illness: A Randomized Controlled Trial. *Patient Education and Counselling*, 94(3), 362-371.
- Ali, L., Krevers, B., & Skarsater, I. (2015). Caring Situation, Health, Self-Efficacy, and Stress in Young Informal Carers of Family and Friends with Mental Illness in Sweden. *Issues in Mental Health Nursing*, 36(6), 407-415.
- Al-Janabi, H., Coast, J., & Flynn, T. N. (2008). What Do People Value When They Provide Unpaid Care for an Older Person? A Meta-Ethnography with Interview Follow-Up. *Social Science and Medicine*, 67(1), 111-121.
- Al-Janabi, H., McCaffrey, N., & Ratcliffe, J. (2013). Carer Preferences in Economic Evaluation and Healthcare Decision Making. *Patient*, 6(4), 235-239.
- Allain, L., Cosis-Brown, H., Danso, C., Dillon, J., Finnegan, P., Gahhoke, S., Shamash, M., & Whittaker, F. (2006). User and Carer Involvement in Social Work Education - a University Case Study: Manipulation or Citizen Control? *Social Work Education (The International Journal)*, 25(4), 403-413.
- Allen, D. (2000). Negotiating the Role of Expert Carers on an Adult Hospital Ward. *Sociology of Health and Illness*, 22(2), 149-171.
- Allen, D. (2000). Recent Research on Physical Aggression in Persons with Intellectual Disability: An Overview. *Journal of Intellectual and Developmental Disability*, 25(1), 41-57.
- Allen, J., Annells, M., Clark, E., Lang, L., Nunn, R., Petrie, E., & Robins, A. (2012). Mixed Methods Evaluation Research for a Mental Health Screening and Referral Clinical Pathway. *Worldviews on Evidence-Based Nursing*, 9(3), 172-185.
- Allen, J., Annells, M., Nunn, R., Petrie, E., Clark, E., Lang, L., & Robins, A. (2011). Evaluation of Effectiveness and Satisfaction Outcomes of a Mental Health Screening and Referral Clinical Pathway for Community Nursing Care. *Journal of Psychiatric and Mental Health Nursing*, 18(5), 375-385.

- Allen, S., & Ciambone, D. (2003). Community Care for People with Disability: Blurring Boundaries between Formal and Informal Caregivers. *Qualitative Health Research*, 13(2), 207-226.
- Alwin, J. (2013). Perception and Significance of an Assistive Technology Intervention the Perspectives of Relatives of Persons with Dementia. *Disability & Rehabilitation*, 35(18), 1519-1526.
- Alzougool, B., Chang, S., & Gray, K. (2015). A New Scale to Measure the State of an Informal Carer's Information Needs: Development and Validation. *Journal of Consumer Health on the Internet*, 19(3-4), 200-218.
- Alzougool, B., Chang, S. T., & Gray, K. (2013). The Nature and Constitution of Informal Carers' Information Needs: What You Don't Know You Need Is as Important as What You Want to Know. *Information Research-an International Electronic Journal*, 18(1).
- Ambrosio, L., Navarta-Sanchez, M. V., & Portillo, M. C. (2014). Living with Parkinson's Disease in the Community: Improving Assessments and Interventions. *Primary Health Care*, 24(10), 26-29 24p.
- Amir, Z., Wilson, K., Hennings, J., & Young, A. (2012). The Meaning of Cancer: Implications for Family Finances and Consequent Impact on Lifestyle, Activities, Roles and Relationships. *Psycho-Oncology*, 21(11), 1167-1174.
- Andershed, B. (2006). Relatives in End-of-Life Care - Part 1: A Systematic Review of the Literature the Five Last Years, January 1999-February 2004. *Journal of Clinical Nursing*, 15(9), 1158-1169.
- Anderson, N., & Hughes, K. D. (2010). The Business of Caring: Women's Self-Employment and the Marketization of Care. *Gender, Work & Organization*, 17(4), 381-405.
- Andren, S., & Elmstahl, S. (2002). Former Family Carers' Subjective Experiences of Burden: A Comparison between Group Living and Nursing Home Environments in One Municipality in Sweden. *Dementia: The International Journal of Social Research and Practice*, 1(2), 241-254.
- Andreouli, E., Skovdal, M., & Campbell, C. (2013). 'It Made Me Realise That I Am Lucky for What I Got': British Young Carers Encountering the Realities of Their African Peers. *Journal of Youth Studies*, 16(8), 1038-1053.
- Anfilogoff, S. (2003). Research into Practice. *Community Care* (6.11.03), 50.
- Angermeyer, M., Bull, N., & Bernert, S. (2006). Burnout of Caregivers: A Comparison between Partners of Psychiatric Patients and Nurses. *Archives of Psychiatric Nursing*, 20(4), 158-165.
- Angus, J. (2003). Community Care: Challenging the Assumption of Gratuitous Care. *ACCNS Journal for Community Nurses*, 8(2), 13-15 13p.
- Anne, A., Faithfull, S., Plaskota, M., Lucas, C., & De Vries, K. (2010). A Study of Patients with a Primary Malignant Brain Tumour and Their Carers: Symptoms and Access to Services. *International Journal of Palliative Nursing*, 16(1), 24-30.
- Antsey, I., & Antsey, M. (2005). Development of a Holistic Approach to Assisting Families with an Alzheimer's Sufferer. *Social Work Maatskaplike Werk*, 41(3), 296-305.
- Ardley, J. (2006). Ten Points for a Big Difference. *Health Service Journal* (29.06.06), 32-33.
- Argyle, C. (2016). Caring for Carers: How Community Nurses Can Support Carers of People with Cancer. *British Journal of Community Nursing*, 21(4), 180-184.
- Argyle, E. (2001). Poverty, Disability and the Role of Older Carers. *Disability & Society*, 16(4), 585-595.
- Arksey, H. (2002). Combining Informal Care and Work: Supporting Carers in the Workplace. *Health & Social Care in The Community*, 10(3), 151-161.



- Arksey, H. (2002). Rationed Care: Assessing the Support Needs of Informal Carers in English Social Services Authorities. *Journal of Social Policy*, 31(1), 81-101.
- Arksey, H. (2003). Caring Attitudes. *Community Care* (13.3.03), 40.
- Arksey, H. (2003). People into Employment: Supporting People with Disabilities and Carers into Work. *Health & Social Care in The Community*, 11(3), 283-292.
- Arksey, H. (2003). Scoping the Field: Services for Carers of People with Mental Health Problems. *Health and Social Care in the Community*, 11(4), 335-344.
- Arksey, H. (2007). Combining Work and Care: The Reality of Policy Tensions for Carers. *Benefits*, 15(2), 139-149.
- Arksey, H., & Bamford, C. (2007). Respite Care for People with Dementia: The Range of Models for Getting a Break. *Journal of Dementia Care*, 15(3), 37-39.
- Arksey, H., Corden, A., Glendinning, C., & Hirst, M. (2008). Managing Money in Later Life: Help from Relatives and Friends. *Benefits*, 16(1), 47-59.
- Arksey, H., & Glendinning, C. (2007). Choice in the Context of Informal Care-Giving. *Health and Social Care in the Community*, 15(2), 165-175.
- Arksey, H., & Glendinning, C. (2008). Combining Work and Care: Carers' Decision-Making in the Context of Competing Policy Pressures. *Social Policy & Administration*, 42(1), 1-18.
- Arksey, H., & Hirst, M. (2001). Taking Care of the Carers. *General Practitioner*, 36-37.
- Arksey, H., & Hirst, M. (2001). Why GPs Are Best Placed to Support Work of Carers. *General Practitioner*, 34-35.
- Arksey, H., & Hirst, M. (2005). Unpaid Carers' Access to and Use of Primary Care Services. *Primary Health Care Research & Development*, 6(2), 101-116.
- Arksey, H., & Lund, A. (2001). How to Support Staff Who Are Carers. *People Management*, 7(17), 44-45.
- Arksey, H., & Moree, M. (2008). Supporting Working Carers: Do Policies in England and the Netherlands Reflect 'Doulia Rights'? *Health and Social Care in the Community*, 16(6), 649-657.
- Arksey, H., & O'Malley, L. (2005). Scoping Studies: Towards a Methodological Framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
- Arksey, H., & Weatherly, H. (2004). Respite Care and Short Breaks: What Works and at What Cost? *Journal of Dementia Care*, 12(5), 33-37.
- Armstrong, M. (2000). Factors Affecting the Decision to Place a Relative with Dementia into Residential Care. *NURSING STANDARD*, 14(16).
- Armstrong, M. (2001). Admiral Nurses Are There for Carers and Patients...The Pressures Felt by Informal Carers of People with Dementia' (Art & Science January 10). *Nursing Standard*, 15(21), 31-31 31p.
- Armstrong, M. (2001). Continuing Professional Development: Dementia Care. The Pressures Felt by Informal Carers of People with Dementia. *Primary Health Care*, 11(10), 43-50 48p.
- Armstrong, M. (2001). The Pressure Felt by Informal Carers of People with Dementia. *Nursing Standard*, 15(17), 47-53.
- Armstrong, M. (2003). The Needs of Young People with Young-Onset Dementia and Their Carers. *Professional Nurse*, 18(12), 681-684.
- Armstrong-Esther, C., Hagen, B., & Sandilands, M. (2005). A Longitudinal Study of Home Care Clients and Their Informal Carers. *British Journal of Community Nursing*, 10(6), 284-291.

- Arnaert, A., Gabos, T., Ballenas, V., & Rutledge, R. D. H. (2010). Contributions of a Retreat Weekend to the Healing and Coping of Cancer Patients' Relatives. *Qualitative Health Research*, 20(2), 197-208.
- Arnberger, P., Chang, N., & Mensendier, M. (2009). Caregiving in the Pacific Rim: A Comparison of Asian and Non-Asian Caregiving Experiences. *Asia Pacific Journal of Social Work and Development*, 19(2), 38-51.
- Arora, K., & Wolf, D. (2014). Is There a Trade-Off between Parent Care and Self-Care? *Demography*, 51(4), 1251-1270.
- Arsenio, A. (2012). Supporting Families: Helping Build Resilient Children. *Relational Child & Youth Care Practice*, 25(2), 66-68.
- Ashcroft, J., Wykes, T., Taylor, J., Crowther, A., & Szmukler, G. (2016). Impact on the Individual: What Do Patients and Carers Gain, Lose and Expect from Being Involved in Research? *Journal of Mental Health*, 25(1), 28-35.
- Ashworth, M., & Baker, A. H. (2000). 'Time and Space': Carers' Views About Respite Care. *Health and Social Care in the Community*, 8(1), 50-56.
- Askey, R., Holmshaw, J., Gamble, C., & Gray, R. (2009). What Do Carers of People with Psychosis Need from Mental Health Services? Exploring the Views of Carers, Service Users and Professionals. *Journal of Family Therapy*, 31(3), 310-331.
- Askham, J. (2007). Care at Home for People with Dementia: As in a Total Institution? *Ageing & Society*, 27(1), 3-24.
- Aspinall, A. (2011). A Weight Off My Mind: Exploring the Impact and Potential Benefits of Telecare for Unpaid Carers in Scotland. *Journal of Assistive Technologies*, 5(1), 43-44.
- Assaf, R., auf der Springe, J., Siskowski, C., Ludwig, D., Mathew, M., & Belkowitz, J. (2016). Participation Rates and Perceptions of Caregiving Youth Providing Home Health Care. *Journal of Community Health*, 41(2), 326-333.
- Aubeluck, A., & Buchanan, H. (2006). Capturing the Huntington's Disease Spousal Carer Experience: A Preliminary Investigation Using the 'Photovoice' Method. *Dementia: the International Journal of Social Research and Practice*, 5(1), 95-116.
- Aubin, M., Giguère, A., Martin, M., Verreault, R., Fitch, M. I., Kazanjian, A., & Carmichael, P. H. (2012). Interventions to Improve Continuity of Care in the Follow-up of Patients with Cancer. *Cochrane database of systematic reviews (Online)*, 7.
- Austen, S., Jefferson, T., Lewin, G., Ong, R., & Sharp, R. (2015). Care Roles and Employment Decision-Making: The Effect of Economic Circumstance. *Journal of Industrial Relations*, 57(5), 665-685.
- Austen, S., & Ong, R. (2010). The Employment Transitions of Mid-Life Women: Health and Care Effects. *Ageing & Society*, 30(2), 207-227.
- Austen, S., & Ong, R. (2013). The Effects of Ill Health and Informal Care Roles on the Employment Retention of Mid-Life Women: Does the Workplace Matter? *Journal Of Industrial Relations*, 55(5), 663-680.
- Austin, L., Luker, K., Caress, A., & Hallett, C. (2000). Palliative Care: Community Nurses' Perceptions of Quality. *Quality in Health Care*, 9(3), 151-158 158p.
- Ax, S., Gregg, V. H., & Jones, D. (2002). Caring for a Relative with Chronic Fatigue Syndrome: Difficulties, Cognition and Acceptance over Time. *J R Soc Promot Health*, 122(1), 35-42.
- Ayalon, L. (2011). Abuse Is in the Eyes of the Beholder: Using Multiple Perspectives to Evaluate Elder Mistreatment under Round-the-Clock Foreign Home Carers in Israel. *Ageing and Society*, 31(3), 499-520.

- Aylward, N. (2009). 'They Just Don't Get It.'. *Adults Learning*, 21(3), 29-29.
- Aziz, N. A., Pindus, D. M., Mullis, R., Walter, F. M., & Mant, J. (2016). Understanding Stroke Survivors' and Informal Carers' Experiences of and Need for Primary Care and Community Health Services--a Systematic Review of the Qualitative Literature: Protocol. *BMJ Open*, 6(1),
- Aznar Cabrerizo, M. I., Fleming, V., Watson, H., & Narvaiza Solís, M. J. (2004). Psychosocial Needs of Informal Carers of Persons with Schizophrenia: Exploring the Role of Nurses. *Enfermeria Clinica*, 14(5), 286-293 288p.
- Baago, S. (2004). The Unrecognized Caregiver: Children of Dementia: What Kind of Care Do Young Carers Provide? *Perspectives: The Journal of the Gerontological Nursing Association*, [28] ([1]), 3-4.
- Babu, K. S., Law-Min, R., Adlam, T., & Banks, V. (2008). Involving Service Users and Carers in Psychiatric Education: What Do Trainees Think? *Psychiatric Bulletin*, 32(1), 28-31.
- Bäckström, B., & Sundin, K. (2010). The experience of being a middle-aged close relative of a person who has suffered a stroke – six months after discharge from a rehabilitation clinic. *Scandinavian Journal of Caring Sciences*, 24(1), 116-124.
- Backstrom, B., & Sundin, K. (2009). The experience of being a middle-aged close relative of a person who has suffered a stroke, 1 year after discharge from a rehabilitation clinic: A qualitative study. *International Journal of Nursing Studies*, 46(11), 1475-1484.
- Bailey, V. (2007). Satisfaction Levels with a Community Night Nursing Service. *Nurs Stand*, 22(5), 35-42.
- Baines, D., Charlesworth, S., & Cunningham, I. (2015). Changing Care? Men and Managerialism in the Non-profit Sector. *Journal of Social Work*, 15(5), 459-478.
- Bains, H., Bonell, E., & Speight, P. (2010). Carer Satisfaction with Telephone Consultations in a Community Intellectual Disability Unit. *Journal of Intellectual Disabilities*, 14(4), 259-265.
- Baker, C., Edwards, P., & Packer, T. (2003). Crucial Impact of the World Surrounding Care. *Journal of Dementia Care*, 11(3), 16-18.
- Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., Wojszel, Z. B., Nolan, M., Prouskas, C., Bien, B., & Oberg, B. (2008). Negative Impact and Positive Value in Caregiving: Validation of the Cope Index in a Six-Country Sample of Carers. *The Gerontologist*, 48(3), 276-286.
- Baldwin, M., Smith, J., Dervis, M., & Crumbie, A. (2009). Just the Job for Young Carers. *Nursing Standard*, 23(42), 28-29.
- Bamford, C., & Bruce, E. (2000). Defining the Outcomes of Community Care: The Perspectives of Older People with Dementia and Their Carers. *Ageing and Society*, 20(5), 543-570.
- Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a Diagnosis of Dementia: A Systematic Review. *International Journal of Geriatric Psychiatry*, 19(2), 151-169.
- Bangerter, L. R., Kim, K., Zarit, S. H., Birditt, K. S., & Fingerman, K. L. (2015). Perceptions of Giving Support and Depressive Symptoms in Late Life. *Gerontologist*, 55(5), 770-779.
- Banks, P. (2000). Quality Services for Carers. *Working with Older People*, 4(1), 22-24.
- Banks, P., Cogan, N., Deeley, S., Hill, M., Riddell, S., & Tisdall, K. (2001). Seeing the Invisible Children and Young People Affected by Disability. *Disability and Society*, 16(6), 797-814.
- Banks, P., & McVey, C. (2005). Overstretched? The Effect of Multiple Roles on Informal Carers Supporting Younger Stroke Survivors. *Psychology & Health*, 20, 20-21.

- Banu, N., & Mauuri, K. (2005). Determinants of the Caregiver's Appraisal in the Context of Caregiving. *Indian Journal of Social Work*, 66(3), 175-195.
- Barber, C. (2007). Informal Carers: Where Is the Support? *British Journal of Nursing*, 16(13), 769.
- Barber, C. (2009). Setting up a Male Support Group to Meet the Needs of Men Who Are Informal Carers. *Nursing Times*, 12-13.
- Barbosa, A., Figueiredo, D., Sousa, L., & Demain, S. (2011). Coping with the Caregiving Role: Differences between Primary and Secondary Caregivers of Dependent Elderly People. *Aging and Mental Health*, 15(4), 490-499.
- Barbosa, D. (2014). Culture Change. *Mental Health Today*, 28-29.
- Barbosa, F., & Matos, A. D. (2014). Informal Support in Portugal by Individuals Aged 50+. *European Journal Of Ageing*, 11(4), 293-300.
- Barbour, K. J., & Hope, S. (2013). PEACEanywhere - Implementing the Vision for Integrated Health and Social Care. *International Journal of Integrated Care (IJIC)*, 13, 1-2.
- Barnes, M., & Henwood, F. (2015). Inform with Care: Ethics and Information in Care for People with Dementia. *Ethics and Social Welfare*, 9(2), 147-163.
- Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S., & Small, N. (2005). Recruiting Older People into a Large, Community-Based Study of Heart Failure. *Chronic Illness*, 1(4), 321-329 329p.
- Barrett, D. (2012). The Role of Telemonitoring in Caring for Older People with Long-Term Conditions. *Nursing Older People*, 24(7), 21-25.
- Barron, D. N. (2007). The Emotional Costs of Caring Incurred by Men and Women in the British Labour Market. *Soc Sci Med*, 65(10), 2160-2171.
- Barrow, S., & Harrison, R. A. (2005). Unsung Heroes Who Put Their Lives at Risk? Informal Caring, Health and Neighbourhood Attachment. *Journal of Public Health*, 27(3), 292-297.
- Barrowclough, C., Lobban, F., Hatton, C., & Quinn, J. (2001). An Investigation of Models of Illness in Carers of Schizophrenia Patients Using the Illness Perception Questionnaire. *British Journal of Clinical Psychology*, 40(4), 371-385.
- Barry, M. (2011). 'I Realised That I Wasn't Alone': The Views and Experiences of Young Carers from a Social Capital Perspective. *Journal of Youth Studies*, 14(5), 523-539.
- Bartley, C., Webb, J.-A., & Bayly, J. (2015). Multidisciplinary Approaches to Moving and Handling for Formal and Informal Carers in Community Palliative Care. *International Journal of Palliative Nursing*, 21(1), 17-23.
- Bassi, M., Falautano, M., Cilia, S., Goretti, B., Grobberio, M., Pattini, M., Pietrolongo, E., Viterbo, R. G., Amato, M. P., Benin, M., Lugaresi, A., Martinelli, V., Montanari, E., Patti, F., Trojano, M., & Delle Fave, A. (2014). The Coexistence of Well- and Ill-Being in Persons with Multiple Sclerosis, Their Caregivers and Health Professionals. *J Neurol Sci*, 337(1-2), 67-73.
- Bastawrous, M., Gignac, M., & Kapral, M. (2015). Factors That Contribute to Adult Children Caregivers' Well-Being: A Scoping Review. *Health Soc Care Community*, 23(5), 449-466.
- Bastawrous, M., Gignac, M. A., Kapral, M. K., & Cameron, J. I. (2015). Adult Daughters Providing Post-Stroke Care to a Parent: A Qualitative Study of the Impact That Role Overload Has on Lifestyle, Participation and Family Relationships. *Clinical Rehabilitation*, 29(6), 592-600.
- Bath, P. A., & Bouchier, H. (2003). Development and Application of a Tool Designed to Evaluate Web Sites Providing Information on Alzheimer's Disease. *Journal of Information Science*, 29(4), 279-297.

- Batson, P., Thorne, K., & Peak, J. (2002). Life Story Work Sees the Person Beyond the Dementia. *Journal of Dementia Care*, 10(3), 15-17.
- Battaglia, M. A., Zagami, P., & Uccelli, M. M. (2000). A Cost Evaluation of Multiple Sclerosis. *Journal of Neurovirology*, 6, S191-S193.
- Bauer, J. M., & Sousa-Poza, A. (2015). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family. *Population Ageing*, 8(3), 113-145.
- Bauer, M. (2012). Relationships between Patients, Informal Caregivers and Health Professionals in Care Homes. *Evidence Based Nursing*, 15(1), 28-29.
- Bauer, M., Fitzgerald, L., Koch, S., & King, S. (2011). How Family Carers View Hospital Discharge Planning for the Older Person with a Dementia. *Dementia: the International Journal of Social Research and Practice*, 10(3), 317-323.
- Bauld, L., Chesterman, J., & Judge, K. (2000). Measuring Satisfaction with Social Care Amongst Older Service Users: Issues from the Literature. *Health and Social Care in the Community*, 8(5), 316-324.
- Baulkwill, J., Dechamps, A., Manning, J., van der Kroft, N., & Payne, M. (2012). Young Carers in Palliative Care: A Groupwork Project. *European Journal of Palliative Care*, 19(6), 296-298.
- Baxter, S. K. (2013). The Use of Non-Invasive Ventilation at End of Life in Patients with Motor Neurone Disease: A Qualitative Exploration of Family Carer and Health Professional Experiences. *Palliat Med*, 27(6), 516-523.
- Baxter, S. K., Baird, W. O., Thompson, S., Bianchi, S. M., Walters, S. J., Lee, E., Ahmedzai, S. H., Proctor, A., Shaw, P. J., & McDermott, C. J. (2013). The Impact on the Family Carer of Motor Neurone Disease and Intervention with Non-invasive Ventilation. *Journal of Palliative Medicine*, 16(12), 1602-1609.
- Baynham, J., Hardy, J., Macaulay, P., Vaz, H., & Wiley, S. (2005). Conducting a Study to Improve Information Exchange and Develop Communication Strategies for Informal Carers of Palliative Care Patients (and Patients without Carers): A Team Approach. *Nursing Monograph*, 42-47 46p.
- Beale, S., Truman, P., Sanderson, D., & Kruger, J. (2010). The Initial Evaluation of the Scottish Telecare Development Program. *Journal of Technology in Human Services*, 28(1/2), 60-73 14p.
- Beaver, K., & Witham, G. (2007). Information Needs of the Informal Carers of Women Treated for Breast Cancer. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*, 11(1), 16-25.
- Beccaro, M., Caraceni, A., & Costantini, M. (2010). End-of-Life Care in Italian Hospitals: Quality of and Satisfaction with Care from the Caregivers' Point of View—Results from the Italian Survey of the Dying of Cancer. *Journal of Pain & Symptom Management*, 39(6), 1003-1015.
- Bechelet, L., Heal, R., Leam, C., & Payne, M. (2008). Empowering Carers to Reconstruct Their Finances. *Practice: Social Work in Action*, 20(4), 223-234.
- Becker, S. (2000). Carers and Indicators of Vulnerability to Social Exclusion. *Benefits* (28), 1-4.
- Becker, S. (2001). Carers. *Research Matters*, 28-33. Community Care.
- Becker, S. (2002). Carers. *Research Matters*, 5-10. Community Care
- Becker, S. (2003). Carers. *Research Matters* 11-16. Community Care
- Becker, S. (2004). Carers. *Research Matters*, 5-10. Community Care

- Becker, S. (2007). Global Perspective on Children's Unpaid Caregiving in the Family. *Global Social Policy*, 7(1), 23-50.
- Becker, S., & Aldridge, J. (2003). Carers. *Research Matters* (15), 13.
- Becker, S., & Dearden, C. (2004). Young Carers. *Research Matters* (18), 11-18.
- Bedaf, S., Draper, H., Gelderblom, G. J., Sorell, T., & de Witte, L. (2016). Can a Service Robot Which Supports Independent Living of Older People Disobey a Command? The Views of Older People, Informal Carers and Professional Caregivers on the Acceptability of Robots. *International Journal of Social Robotics*, 8(3), 409-420.
- Beddington, A., & Unell, J. (2003). Care Direct: An Integrated Route to Help for Older People. *Generations Review*, 13(3), 18-21.
- Bee, P., Gibbons, C., & Callaghan, P. (2016). Evaluating and Quantifying User and Carer Involvement in Mental Health Care Planning (Equip): Co-Development of a New Patient-Reported Outcome Measure. *PLoS ONE*, 11(3).
- Bee, P. E., Barnes, P., & Luker, K. A. (2009). A Systematic Review of Informal Caregivers' Needs in Providing Home-Based End-of-Life Care to People with Cancer. *Journal of Clinical Nursing*, 18(10), 1379-1393 1315p.
- Begley, P. (2010). 360 Degrees of Care. *Quality in Ageing and Older Adults*, 11(4), 47-50.
- Beische, D., Hautzinger, M., Becker, C., & Pfeiffer, K. (2012). Problem-Solving Counselling for Caregivers of Stroke Survivors - an Analysis of the Addressed Topics. *PPmP Psychotherapie Psychosomatik Medizinische Psychologie*, 62(9-10), 375-382.
- Bekhet, A. K. (2013). Effects of Positive Cognitions and Resourcefulness on Caregiver Burden among Caregivers of Persons with Dementia. *Int J Mental Health Nurs*, 22(4), 340-346.
- Beland, P. (2013). Implications for Carers of Terminally Ill Patients Dying at Home. *Nursing Standard*, 28(3), 40-45.
- Bell, D., & Rutherford, A. (2013). Individual and Geographic Factors in the Formation of Care Networks in the UK. *Population Space and Place*, 19(6), 727-737.
- Bell, R. (2012). Does He Have Sugar in His Tea? Communication between People with Learning Disabilities, Their Carers and Hospital Staff. *Tizard Learning Disability Review*, 17(2), 57-63.
- Benbow, S. M. (2011). Patients' and Carers' Views on Dementia Workforce Skills. *Journal of Mental Health Training Education and Practice*, 6(4), 195-202.
- Ben-Galim, D. (2009). Who Will Care? Meeting the Care Deficit. *Public Policy Research*, 16(3), 186-191.
- Benton, T. F., Boyd, K., Kendall, M., Murray, S. A., & Worth, A. (2004). Exploring the Spiritual Needs of People Dying of Lung Cancer or Heart Failure: A Prospective Qualitative Interview Study of Patients and Their Carers. *Palliative Medicine*, 18(1), 39-45.
- Berecki-Gisolf, J., Lucke, J., Hockey, R., & Dobson, A. (2008). Transitions into Informal Caregiving and out of Paid Employment of Women in Their 50s. *Social Science & Medicine*, 67(1), 122-127.
- Berg, J., & Woods, N. (2009). Global Women's Health: A Spotlight on Caregiving. *Nursing Clinics of North America*, 44(3), 375-384.
- Berger, G., Bernhardt, T., Schramm, U., Muller, R., Lansiedel-Anders, S., Peters, J., Kratzsch, T., & Frolich, L. (2004). No Effects of a Combination of Caregivers Support Group and Memory Training/Music Therapy in Dementia Patients from a Memory Clinic Population. *International Journal of Geriatric Psychiatry*, 19(3), 223-231.

- Berg-Weger, M., & Tebb, S. S. (2003). Conversations with Researchers About Family Caregiving: Trends and Future Directions. *Generations*, 27(4), 9-16.
- Berg-Weger, M. R., McGartland, D., & Tebb, S. S. (2000). Depression as a Mediator: Viewing Caregiver Well-Being and Strain in a Different Light. *Families in Society*, 81(2), 162-173.
- Beringer, T. R. O., & Crawford, V. L. S. (2003). Admissions to Elderly Care Institutions in the United Kingdom. *Reviews in Clinical Gerontology*, 13(1), 95-101.
- Bernard, M., & Phillips, J. E. (2007). Working Carers of Older Adults. *Community, Work & Family*, 10(2), 139-160.
- Bevans, M. (2012). Caregiving Burden, Stress, and Health Effects among Family Caregivers of Adult Cancer Patients. *JAMA*, 307(4), 398-403.
- Beyer, S. (2004). Working Lives: The Role of Day Centres in Supporting People with Learning Disabilities into Employment. *Llais* (73), 3-7.
- Bhui, K., Mohamud, S., Warfur, N., Thomas, J. C., & Stansfield, S. A. (2003). Cultural Adaptation of Mental Health Measures: Improving the Quality of Clinical Practice and Research. *British Journal of Psychiatry*, 18(9), 184-186.
- Bień, B., Wojszel, Z. B., & Wilmańska, J. (2000). Care of the Frail Elderly in Population Studies. *Polski merkuriusz lekarski: organ Polskiego Towarzystwa Lekarskiego*, 9(53), 775-778.
- Bigby, C., & Ozanne, E. (2004). Comparison of Specialist and Mainstream Programs for Older Carers of Adults with Intellectual Disability: Considerations for Service Development. *Australian Social Work*, 57(3), 273-287.
- Bilotta, C., Nicolini, P., & Vergani, C. (2010). One-Year Predictors of Turnover among Personal-Care Workers for Older Adults Living at Home in Italy. *Ageing and Society*, 1-14.
- Birch, L., & Adams, J. (2008). Carers' Perceptions of Community Occupational Therapy: Short Report. *British Journal of Occupational Therapy*, 71(5).
- Bird, M., Llewellyn-Jones, R. H., & Korten, A. (2009). An Evaluation of the Effectiveness of a Case-Specific Approach to Challenging Behaviour Associated with Dementia. *Ageing and Mental Health*, 13(1), 73-83.
- Birks, J., & Harvey, R. J. (2006). Donepezil for Dementia Due to Alzheimer's Disease. *Cochrane Database of Systematic Reviews* (1).
- Biskin, S., Barcroft, V., Livingston, W., & Snape, S. (2013). Reflections on Student, Service User and Carer Involvement in Social Work Research. *Social Work Education (The International Journal)*, 32(3), 301-316.
- Biswas, A. B., Raju, L. B., & Gravestock, S. (2009). Training in Partnership: Role of Service Users with Intellectual Disability and Carers. *Psychiatric Bulletin*, 33(11), 429-432.
- Bittman, M., Hill, T., & Thomson, C. (2007). The Impact of Caring on Informal Carers' Employment, Income and Earnings: A Longitudinal Approach. *Australian Journal of Social Issues (Australian Council of Social Service)*, 42(2), 255-272.
- Bjorgvinsdottir, K., & Halldorsdottir, S. (2014). Silent, Invisible and Unacknowledged: Experiences of Young Caregivers of Single Parents Diagnosed with Multiple Sclerosis. *Scandinavian Journal of Caring Sciences*, 28(1), 38-48.
- Black, S., Gauthier, S., & Dalziel, W. (2010). Canadian Alzheimer's Disease Caregiver Survey: Baby-Boomer Caregivers and Burden of Care. *International Journal of Geriatric Psychiatry*, 25(8), 807-813.
- Blackburn, C., Read, J., & Hughes, N. (2005). Carers and the Digital Divide: Factors Affecting Internet Use among Carers in the UK. *Health & Social Care in The Community*, 13(3), 201-210.

- Blanco Toro, L., Librada Flores, S., Rocafort Gil, J., Cabo Domínguez, R., Galea Marín, T., & Alonso Prado, M. E. (2007). The Profile of Main Caregivers of Terminally Ill Patients, and an Analysis of the Risk of Suffering from Complicated Grief. *Medicina Paliativa*, 14(3), 164-168.
- Blieszner, R. (2006). A Lifetime of Caring: Dimensions and Dynamics in Late-Life Close Relationships. *Personal Relationships*, 13(1), 1-18.
- Bliss, J. (2005). Working in Partnership with Adult Informal Carers: Policy and Practice. *British Journal of Community Nursing*, 10(5), 233-235.
- Bliss, J. (2006). What Do Informal Carers Need from District Nursing Services? (Cover Story). *British Journal of Community Nursing*, 11(6), 251-256.
- Bliss, J., & While, A. E. (2014). Meeting the Needs of Vulnerable Patients: The Need for Team Working across General Practice and Community Nursing Services. *London Journal of Primary Care*, 6(6), 149-153.
- Blomgren, J. (2012). Help from Spouse and from Children among Older People with Functional Limitations: Comparison of England and Finland. *Ageing & Society*, 32(6), 905-933.
- Blustein, J., Chan, S., & Guanais, F. C. (2004). Elevated Depressive Symptoms among Caregiving Grandparents (Living with Chronic Illness). *Health Services Research*, 39(6), 1671.
- Bobinac, A. (2010). Caring for and Caring About: Disentangling the Caregiver Effect and the Family Effect. *J Health Econ*, 29(4), 549-556.
- Bocková, S., & Marečková, J. (2011). Education of Informal Caregivers in a Home Environment. Conference Proceedings of the IV. International Conference of General Nurses & Workers Educating Paramedical Staff, 12-17.
- Boland, M., Daly, L., & Staines, A. (2008). Methodological Issues in Inclusive Intellectual Disability Research: A Health Promotion Needs Assessment of People Attending Irish Disability Services. *Journal of Applied Research in Intellectual Disabilities*, 21(3), 199-209.
- Bolas, H., van Wersch, A., & Flynn, D. (2007). The Well-Being of Young People Who Care for a Dependent Relative: An Interpretative Phenomenological Analysis. *Psychology & Health*, 22(7), 829-850.
- Bolin, K., Lindgren, B., & Lundborg, P. (2008). Your Next of Kin or Your Own Career? Caring and Working among the 50+ of Europe. *J Health Econ*, 27(3), 718-738.
- Bonacci, I., & Tamburis, O. (2015). From Knowledge Transfer to Innovation Spreading: The Use of Networks in Long-Term Care. *Lecture Notes in Information Systems and Organisation*, 5, 135-148.
- Bonsang, E. (2009). Does Informal Care from Children to Their Elderly Parents Substitute for Formal Care in Europe. *J Health Econ*, 28(1), 143-154.
- Bookman, A. (2007). Family Caregivers: A Shadow Workforce in the Geriatric Health Care System? *Journal of Health Politics, Policy and Law*, 32(6), 1005-1041.
- Bordogna, M. T., & Ornaghi, A. (2012). The 'Badanti' (Informal Carers) Phenomenon in Italy: Characteristics and Peculiarities of Access to the Health Care System 1. *Journal of Intercultural Studies*, 33(1), 9-22.
- Borg, C., & Hallberg, I. (2006). Life Satisfaction among Informal Caregivers in Comparison with Non-Caregivers. *Scandinavian Journal of Caring Sciences*, 20(4), 427-438.
- Bornarova, S. (2009). User Involvement in Social Work Education: Macedonian Perspective. *Ljetopis Socijalnog Rada*, 16(2), 279-298.



- Borthwick, R., Newbronner, L., & Stuttard, L. (2009). 'Out of Hospital': A Scoping Study of Services for Carers of People Being Discharged from Hospital. *Health Soc Care Community*, 17(4), 335-349.
- Boter, H. (2004). Multicenter Randomized Controlled Trial of an Outreach Nursing Support Program for Recently Discharged Stroke Patients. *Stroke; A Journal of Cerebral Circulation*, 35(12), 2867-2872.
- Boter, H. (2004). Outreach Nurse Support after Stroke: A Descriptive Study on Patients' and Carers' Needs, and Applied Nursing Interventions. *Clin Rehabil*, 18(2), 156-163.
- Botsford, A. L., & Rule, D. (2004). Evaluation of a Group Intervention to Assist Aging Parents with Permanency Planning for an Adult Offspring with Special Needs. *Social Work: A journal of the National Association of Social Workers (NASW)*, 49(3), 423-431.
- Boumans, N. P. G., & Dorant, E. (2014). Double-Duty Caregivers: Healthcare Professionals Juggling Employment and Informal Caregiving. A Survey on Personal Health and Work Experiences. *Journal of Advanced Nursing*, 70(7), 1604-1615.
- Bourne, C., Clayton, C., & Murch, A. (2006). Cognitive Impairment and Behavioural Difficulties in Patients with Huntington's Disease. *Nursing Standard*, 20(35), 41-44.
- Bowes, A., & Bell, D. (2007). Free Personal Care for Older People in Scotland: Issues and Implications. *Social Policy and Society*, 6(3), 435-445.
- Bowes, A., & Wilkinson, H. (2003). 'We Didn't Know It Would Get That Bad': South Asian Experiences of Dementia and the Service Response. *Health Soc Care Community*, 11(5), 387-396.
- Bowey, L., & McGlaughlin, A. (2005). Adults with a Learning Disability Living with Elderly Carers Talk About Planning for the Future: Aspirations and Concerns. *British Journal of Social Work*, 35(8), 1377-1392.
- Bowey, L., & McLaughlin, A. (2007). Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning. *British Journal of Social Work*, 37(1), 39-54.
- Bowler, N., Moss, S., Winston, M., & Coleman, M. (2000). An Audit of Psychiatric Case Notes in Relation to Antipsychotic Medication and Information Giving. *British Journal of Clinical Governance*, 5(4), 212-216 215p.
- Boyd, K. J., Murray, S. A., Kendall, M., Worth, A., Benton, T. F., & Clausen, H. (2004). Living with Advanced Heart Failure: A Prospective, of Patients and Their Carers Based Study Community. *European Journal of Heart Failure*, 6(5), 585-591.
- Braathen, S. H., Sanudi, L., Swartz, L., Jurgens, T., Banda, H. T., & Eide, A. H. (2016). A Household Perspective on Access to Health Care in the Context of HIV and Disability: A Qualitative Case Study from Malawi. *Bmc International Health and Human Rights*, 16.
- Bradley, E. (2015). Carers and Co-Production: Enabling Expertise through Experience? *Mental Health Review Journal*, 20(4), 232-241.
- Bragstad, L. K., Kirkevold, M., Hofoss, D., & Foss, C. (2014). Informal Caregivers' Participation When Older Adults in Norway Are Discharged from the Hospital. *Health Soc Care Community*, 22(2), 155-168.
- Brammer, A. (2014). Carers and the Mental Capacity Act 2005: Angels Permitted, Devils Prosecuted? *Criminal Law Review*, 2014(1), 589-606.
- Bramwell, S. D., Dallard, N., & Sheppard, P. (2014). Self-Care Hub in Kirklees. *International Journal of Integrated Care (IJIC)*, 14, 35-36.
- Brand, C., Barry, L., & Gallagher, S. (2014). Social Support Mediates the Association between Benefit Finding and Quality of Life in Caregivers. *Journal of Health Psychology*, on line 9 September.

- Brand, C., Barry, L., & Gallagher, S. (2015). A Randomised Controlled Trial of Benefit Finding in Caregivers: The Building Resources in Caregivers Study Protocol. *Health Psychology Open*, July-December.
- Brand, U. (2001). Mental Health Care in Germany: Carers' Perspectives. *Acta Psychiatrica Scandinavica*, 104, 35-40.
- Brandon, D., & Maglajlic, R. (2000). Direct Payments: The Information Deficit. *Working with Older People*, 4(3), 26-27.
- Brandt, Å., Ebbelhøj, N. E., Bengtsson, S., & Fallentin, N. (2007). Review: Assistive Technology for the Benefit of Users and Carers. *Assistive Technology Research Series*, 20, 569-572.
- Brännström, M., Fürst, C. J., Tishelman, C., Petzold, M., & Lindqvist, O. (2016). Effectiveness of the Liverpool Care Pathway for the Dying in Residential Care Homes: An Exploratory, Controlled before-and-after Study. *Palliative Medicine*, 30(1), 54-63.
- Bray, Y., & Goodyear-Smith, F. (2007). A Migrant Family's Experience of Palliative Care: A Qualitative Case Study. *Journal of Hospice and Palliative Nursing*, 9(2), 92-99.
- Braye, S., & Preston-Shoot, M. (2005). Emerging from out of the Shadows? Service User and Carer Involvement in Systematic Reviews. *Evidence and Policy*, 1(2), 173-193.
- Brazil, K., Howell, D., & Bedard, M. (2005). Preferences for Place of Care and Place of Death among Informal Caregivers of the Terminally Ill. *Palliative Medicine*, 19(6), 492-499.
- Breitborde, N. J. K., Lopez, S. R., Chang, C., Kopelowicz, A., & Zarate, R. (2009). Emotional over-Involvement Can Be Deleterious for Caregivers' Health: Mexican Americans Caring for a Relative with Schizophrenia. *Soc Psychiatry Psychiatr Epidemiol*, 44(9), 716-723.
- Bremer, P., Cabrera, E., & Leio-Kilpi, H. (2015). Informal Dementia Care: Consequences for Caregivers' Health and Health Care Use in 8 European Countries. *Health Policy*, 119(11), 1459-1471.
- Brereton, L., Carroll, C., & Barnston, S. (2007). Interventions for Adult Family Carers of People Who Have Had a Stroke: A Systematic Review. *Clinical Rehabilitation*, 21(10), 867-884.
- Brereton, L., & Dawes, H. (2003). Building on Carers' Stories to Enrich Research: Lessons from a Recent Study. *Quality in Ageing*, 4(4), 11-17.
- Brereton, L., & Nolan, M. (2002). 'Seeking': A Key Activity for New Family Carers of Stroke Survivors. *Journal of Clinical Nursing*, 11(1), 22-31.
- Brewin, A. (2004). The Quality of Life of Carers of Patients with Severe Lung Disease. *Br J Nurs*, 8(13), 906-912.
- Bristow, M., Cook, R., Erzinciloglu, S., & Hodges, J. (2008). Stress, Distress and Mucosal Immunity in Carers of a Partner with Fronto-Temporal Dementia. *Ageing & Mental Health*, 12(5), 595-604 510p.
- Brittain, I., Taylor, B., & Tyler, S. (2002). Contributory Factors. *Health Service Journal* (2.5.02), 30-31.
- Brittain, K. R., & Shaw, C. (2007). The Social Consequences of Living with and Dealing with Incontinence—a Carers Perspective. *Social Science & Medicine*, 65(6), 1274-1283.
- Broady, T. (2014). What Is a Person-Centred Approach? Familiarity and Understanding of Individualised Funding Amongst Carers in New South Wales. *Australian Journal of Social Issues*, 49(3), 285-307.
- Broady, T. R., & Stone, K. (2015). "How Can I Take a Break?" Coping Strategies and Support Needs of Mental Health Carers. *Social Work in Mental Health*, 13(4), 318-335.

- Broback, G., & Berterö, C. (2003). How Next of Kin Experience Palliative Care of Relatives at Home. *European Journal of Cancer Care*, 12(4), 339-346.
- Broese van Groenou, M., Glaser, K., Tomassini, C., & Jacobs, T. (2006). Socio-Economic Status Differences in Older People's Use of Informal and Formal Help: A Comparison of Four European Countries. *Ageing & Society*, 26(5), 745-766.
- Bronson, M., & Toye, C. (2015). Providing Information for Family Carers of Hospital Patients Experiencing Dementia. *Dementia: The International Journal of Social Research and Practice*, 14(2), 267-272.
- Brown, K., & Matthews, E. (2006). Careworn Country. *Community Care* (1617), 34-35.
- Brown, K., & Young, N. (2008). Building Capacity for Service User and Carer Involvement in Social Work Education. *Social Work Education (The International Journal)*, 27(1), 84-96.
- Brownhill, S., Chang, E., Bidewell, J., & Johnson, A. (2013). A Decision Model for Community Nurses Providing Bereavement Care. *Br J Community Nurs*, 18(3), 133.
- Bruce, D. G., & Paterson, A. (2000). Barriers to Community Support for the Dementia Carer: A Qualitative Study. *International Journal of Geriatric Psychiatry*, 15(5), 451-457.
- Brusco, N. K., Watts, J. J., Shields, N., & Taylor, N. F. (2015). Is Cost Effectiveness Sustained after Weekend Inpatient Rehabilitation? 12 Month Follow up from a Randomized Controlled Trial. *BMC Health Services Research*, 15.
- Bruvik, F. K., Ulstein, I. D., Ranhoff, A. H., & Engedal, K. (2013). The Effect of Coping on the Burden in Family Carers of Persons with Dementia. *Aging and Mental Health*, 17(8), 973-978.
- Bryan, M. I. (2012). Access to Flexible Working and Informal Care. *Scottish Journal of Political Economy*, 59(4), 361-389.
- Buchanan, R. (2009). Informal Care Giving to More Disabled People with Multiple Sclerosis. *Disability & Rehabilitation*, 31(15), 1244-1256.
- Buchanan, R., & Huang, C. (2011). Health-Related Quality of Life among Informal Caregivers Assisting People with Multiple Sclerosis. *Disability & Rehabilitation*, 33(2), 113-121.
- Buchanan, R. J., & Huang, C. (2012). Caregiver Perceptions of Accomplishment from Assisting People with Multiple Sclerosis. *Disability & Rehabilitation*, 34(1), 53-61.
- Buchanan, R. J., Radin, D., & Huang, C. (2010). Burden among Male Caregivers Assisting People with Multiple Sclerosis. *Gend Med*, 7(6), 637-646.
- Buck, H., & McMillan, S. (2008). The Unmet Spiritual Needs of Caregivers of Patients with Advanced Cancer. *Journal of Hospice and Palliative Nursing*, 10(2), 91-99.
- Buckland, M., Frost, B., & Reeves, A. (2006). Liverpool Telecare Pilot: Telecare as an Information Tool. *Inform Prim Care*, 14(3), 191-196.
- Bulley, C., Shiels, J., Wilkie, K., & Salisbury, L. (2010). Carer Experiences of Life after Stroke – a Qualitative Analysis. *Disability & Rehabilitation*, 32(17), 1406-1413.
- Bullock, K., Crawford, S., & Tennstedt, S. (2003). Employment and Caregiving: Exploration of African American Caregivers. *Social Work: A journal of the National Association of Social Workers (NASW)*, 48(2), 150-162.
- Bungay, H., & Alaszewski, A. (2003). Handle with Care. *Health Service Journal* (31.7.07), 28-29.
- Burnell, K., Hoe, J., Miranda, C., Aguirre, E., Streater, A., Charlesworth, G., & Orrell, M. (2009). Introducing "Support at Home: Interventions to Enhance Life in Dementia (Shield)": Five Year Research Programme Funded by the National Institute for Health Research. *Generations Review*, 19(2).

- Burns, A., Denning, T., & Baldwin, R. (2001). Care of Older People: Mental Health Problems. *British Medical Journal* (31.3.01), 789-791.
- Burns, A., Guthrie, E., Marino-Francis, F., Busby, C., Morris, J., Russell, E., Margison, F., Lennon, S., & Byrne, J. (2005). Brief Psychotherapy in Alzheimer's Disease: Randomised Controlled Trial. *British Journal of Psychiatry*, 187(2), 143-147.
- Burns, A., & Rabins, P. (2000). Carer Burden in Dementia. *International Journal of Geriatric Psychiatry*, 15(S1), 9-13.
- Burns, C. M., W, L. T., Abernethy, A., & Currow, D. (2010). Young Caregivers in the End-of-Life Setting: A Population-Based Profile of an Emerging Group. *J Palliat Med*, 13(10), 1225-1235.
- Burns, C. M., Abernethy, A. P., Dal Grande, E., & Currow, D. C. (2013). Uncovering an Invisible Network of Direct Caregivers at the End of Life: A Population Study. *Palliat Med*, 27(7), 608-615.
- Burns, C. M., Dixon, T., Broom, D., Smith, W. T., & Craft, P. S. (2003). Family Caregiver Knowledge of Treatment Intent in a Longitudinal Study of Patients with Advanced Cancer. *Supportive Care in Cancer*, 11(10), 629-637.
- Burrows, A., & Gannon, K. (2013). An Evaluation of Health and Well-Being Checks for Unpaid Carers. *Journal of Integrated Care*, 21(3), 148-156.
- Burt, J., & Raine, R. (2006). The Effect of Age on Referral to and Use of Specialist Palliative Care Services in Adult Cancer Patients: A Systematic Review. *Age and Ageing*, 35(5), 469-476.
- Burt, J., Shipman, C., Richardson, A., Ream, E., & Addington-Hall, J. (2009). The Experiences of Older Adults in the Community Dying from Cancer and Non-Cancer Causes: A National Survey of Bereaved Relatives. *Age and Ageing*, 39(1), 86-91.
- Burton, M. (2008). Grounding Constructions of Carers: Exploring the Experiences of Carers through a Grounded Approach. *British Journal of Social Work*, 38(3), 493-506.
- Burton, M., Reed, H., & Chamberlain, P. (2011). Age-Related Disability and Bathroom Use. *Journal of Integrated Care*, 19(1), 37-43.
- Burton-Smith, R., McVilly, K. R., M., Y., Parmenter, T. R., & Tsutsui, T. (2009). Quality of Life of Australian Family Carers: Implications for Research, Policy and Practice. *Journal of Policy and Practice in Intellectual Disabilities*, 6(3), 189-198.
- Buschenfeld, K., Morris, R., & Lockwood, S. (2009). The Experience of Partners of Young Stroke Survivors. *Disability and Rehabilitation*, 31(20), 1643-1651.
- Buswell, M., Amado, S., Goodman, C., William, J., Fleming, J., Lumbard, P., & Prothero, L. (2015). Does Dementia Matter: Is Dementia an Important Factor in 999 Call-Outs to Older People? *Emergency Medicine Journal*, 32(6), e14-15 11p.
- Butcher, H. K. (2001). The Experience of Caring for a Family Member with Alzheimer's Disease. *Western Journal of Nursing Research*, 23(1), 33-55.
- Buys, L., Aird, R., & Miller, E. (2012). Active Ageing among Older Adults with Lifelong Intellectual Disabilities: The Role of Familial and Nonfamilial Social Networks. *Families in Society*, 93(1), 55-64.
- Byrt, R. (2013). Forensic Nursing Interventions with Patients with Personality Disorder: A Holistic Approach. *Journal of Forensic Nursing*, 9(3), 182-188.
- Cabin, W. D. (2008). Moving toward Medicare Home Health Coverage for People with Alzheimer's Disease. *Journal of Gerontological Social Work*, 51(1/2), 77-86.

- Cabrera, M., & Özcivelek, R. (2009). ICT for Independent Living Services. *Assistive Technology Research Series*, 23, 216-234.
- Cadell, S. (2003). Trauma and Growth in Canadian Carers. *AIDS Care*, 15(5), 639-648.
- Cairns, D., Brown, J., Tolson, D., & Darbyshire, C. (2014). Caring for a Child with Learning Disabilities: Over a Prolonged Period of Time: An Exploratory Survey on the Experiences and Health of Older Parent Carers Living in Scotland. *Journal of Applied Research in Intellectual Disabilities*, 27(5), 471-480.
- Cairns, D., Tolson, D., Brown, J., & Darbyshire, C. (2013). The Need for Future Alternatives: An Investigation of the Experiences and Future of Older Parents Caring for Offspring with Learning Disabilities over a Prolonged Period of Time. *British Journal of Learning Disabilities*, 41(1), 73-82.
- Cameron, I. D., Aggar, C., & Robinson, A. L. (2011). Assessing and Helping Carers of Older People. *British Medical Journal* (24.9.11), 630-633.
- Cameron, J., Cheung, A., Streiner, D. L., Coyte, P. C., & Stewart, D. (2011). Stroke Survivor Depressive Symptoms Are Associated with Family Caregiver Depression During the First 2 Years Post-stroke. *Stroke*, 42(2), 302-306.
- Cammack, V., & Byrne, K. (2013). The Facebook Effect. *The Health Service Journal*, 123(6370), 28-29.
- Campbell, H. E., Stokes, E. A., Bargo, D., Logan, R. F., Mora, A., Hodge, R., Gray, A., James, M. W., Stanley, A. J., Everett, S. M., Bailey, A. A., Dallal, H., Greenaway, J., Dyer, C., Llewelyn, C., Walsh, T. S., Travis, S. P. L., Murphy, M. F., & Jairath, V. (2015). Costs and Quality of Life Associated with Acute Upper Gastrointestinal Bleeding in the UK: Cohort Analysis of Patients in a Cluster Randomised Trial. *BMJ Open*, 5(4).
- Campbell, J. (2007). Understanding Social Support for Patients with Cancer. *Nursing Times* (5.06.07), 28-29.
- Campbell, P., Wright, J., Ovebode, J., Job, D., Crome, P., Bentham, P., Jones, L., & Lendon, C. (2008). Determinants of Burden in Those Who Care for Someone with Dementia. *International Journal of Geriatric Psychiatry*, 23(10), 1078-1085.
- Campbell, T., & Hately, J. (2000). Clinical Update. The Management of Nausea and Vomiting in Advanced Cancer. *International Journal of Palliative Nursing*, 6(1), 18-25 17p.
- Campbell, T., & Hately, J. (2000). The Management of Nausea and Vomiting in Advanced Cancer. *International Journal of Palliative Nursing*, 6(1), 18.
- Canning, A. H. M., O'Reilly, S. A., Wressell, L. R. S., Cannon, D., & Walker, J. (2009). A Survey Exploring the Provision of Carers' Support in Medium and High Secure Services in England and Wales. *Journal of Forensic Psychiatry & Psychology*, 20(6), 868-885.
- Cannuscio, C. C., Colditz, G. A., Rimm, E. B., Berkman, L. F., Jones, C. P., & Kawachi, I. (2004). Employment Status, Social Ties, and Caregivers' Mental Health. *Social Science & Medicine*, 58(7), 1247.
- Cantegreil-Kallen, I., Turbelin, C., Angel, P., Flahault, A., & Rigaud, A.-S. (2006). Dementia Management in France: Health Care and Support Services in the Community. *Dementia: The International Journal of Social Research and Practice*, 5(3), 317-326.
- Canty-Mitchell, J., Austin, J., & Jaffee, K. (2004). Behavioral and Mental Health Problems in Low-Income Children with Special Health Care Needs. *Archives of Psychiatric Nursing*, 18(3), 79-87.
- Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a Conceptual Framework of Positive Aspects of Caregiving in Dementia. *Dementia*, 9(3).

- Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., & Murray, S. A. (2014). Understanding the Barriers to Identifying Carers of People with Advanced Illness in Primary Care: Triangulating Three Data Sources. *BMC Family Practice*, 15.
- Carduff, E., Jarvis, A., Highet, G., Finucane, A., Kendall, M., Harrison, N., Greenacre, J., & Murray, S. A. (2016). Piloting a New Approach in Primary Care to Identify, Assess and Support Carers of People with Terminal Illnesses: A Feasibility Study. *BMC Family Practice*, 17(1).
- Carers Week Partnership. (2013). Prepared to Care? Exploring the Impact of Caring on People's Lives.
- Caress, A. (2010). Promoting the Health of People with Chronic Obstructive Pulmonary Disease: Patients' and Carers' Views. *J Clin Nurs*, 19(3-4), 564-573.
- Carey, L. M., & Matyas, T. A. (2008). Effectiveness of Sensory Discrimination Training When Delivered by Family Members: A Pilot Study. *Brain Impairment*, 9(2), 140-151.
- Carey, M. (2006). Selling Social Work by the Pound? The Pros and Cons of Agency Care Management. *Practice (09503153)*, 18(1), 3-15 13p.
- Carey, M. (2008). Everything Must Go? The Privatization of State Social Work. *British Journal of Social Work*, 38(5), 918-935.
- Carey, M. (2009). Happy Shopper? The Problem with Service Users and Carer Participation. *British Journal of Social Work*, 39(1), 179-188.
- Carlisle, C. (2000). The Search for Meaning in HIV and AIDS: The Carers' Experience. *Qualitative Health Research*, 10(6), 750-765 716p.
- Carlos, A., Pinto, M., Paula, R., Antonio, O., Ana, A., & Claudia, C. (2011). The Burden of the Informal Carers of the Dependent Individual in the Domiciliary Context. *Psychology & Health*, 26, 75-75.
- Carmichael, F., & Charles, S. (2003). The Opportunity Costs of Informal Care: Does Gender Matter? *Journal of Health Economics*, 22(5), 781-803.
- Carmichael, F., Charles, S., & Hulme, C. (2010). Who Will Care? Employment Participation and Willingness to Supply Informal Care. *Journal of Health Economics*, 29(1), 182-190.
- Carmichael, F., & Ercolani, M. G. (2016). Unpaid Caregiving and Paid Work over Life-Courses: Different Pathways, Diverging Outcomes. *Social Science & Medicine*, 156, 1-11.
- Carmichael, F., & Hulme, C. (2008). Are the Needs of Carers Being Met? *Journal of Community Nursing*, 4-12.
- Carmichael, F., Hulme, C., Sheppard, S., & Connell, G. (2008). Work - Life Imbalance: Informal Care and Paid Employment in the UK. *Feminist Economics*, 14(2), 3-35.
- Carpenter, I., Gambassi, G., Topinkova, E., Schroll, M., Finne-Soveri, H., Henrard, J. C., Garms-Homolova, V., Jonsson, P., Frijters, D., Ljunggren, G., Sørbye, L. W., Wagner, C., Onder, G., Pedone, C., & Bernabei, R. (2004). Community Care in Europe. The Aged in Home Care Project (Adhoc). *Aging Clinical and Experimental Research*, 16(4), 259-269.
- Carpentier, N. (2005). Support Network Transformations in the First Stages of the Caregiver's Career. *Qual Health Res*, 15(3), 289-311.
- Carpentier, N. (2010). Using the Life Course Perspective to Study the Entry into the Illness Trajectory: The Perspective of Caregivers of People with Alzheimer's Disease. *Social Science & Medicine*, 70(10).
- Carpentier, N., & Ducharme, F. (2003). Care-Giver Network Transformations: The Need for an Integrated Perspective. *Ageing & Society*, 23(4), 507-525.

- Carretero Gómez, S., Garcés Ferrer, J., & Monsonís Payá, I. (2012). Social Inclusion for the Mental Health of Informal Caregivers of Alzheimer Disease's Patients: The Role of Reemployment Strategies of Socially Excluded. *European Psychiatry*, 27, 1-1.
- Carretero Gómez, S., Garcés Ferrer, J., & Monsonís Payá, I. (2012). Social Inclusion for the Mental Health of Informal Caregivers of Alzheimer Disease's Patients: The Role of Reemployment Strategies of Socially Excluded. *European Psychiatry*, 27, 1-1.
- Carretero, S., Centeno, C., & Stewart, J. (2013). Telecare and Telehealth for Informal Carers: A Research in 12 Member States on Their Benefits and Policy Role for the Success. *International Journal of Integrated Care*, 13.
- Carretero, S., Stewart, J., & Centeno, C. (2015). Information and Communication Technologies for Informal Carers and Paid Assistants: Benefits from Micro-, Meso-, and Macro-Levels. *European Journal of Ageing*, 12(2), 163-173.
- Casado-Marín, D. (2006). Long-Term Care Services in Spain: An Overview. *Gaceta Sanitaria*, 20(SUPPL. 1), 135-142.
- Casado-Marín, D., García-Gómez, P., & López-Nicolás, Á. (2011). Informal Care and Labour Force Participation among Middle-Aged Women in Spain. *SERIEs*, 2(1), 1-29.
- Cascioli, T. R., & Al-Madfai, H. (2008). An Evaluation of the Needs and Service Usage of Family Carers of People with Dementia. *Quality in Ageing*, 9(2), 18-27.
- Casey, J. (2014). Carers Assistive Technology Service. *International Journal of Integrated Care (IJIC)*, 14, 44-45.
- Cash, B., Hodgkin, S., & Warburton, J. (2016). Practitioners' Perspectives on Choice for Older Spousal Caregivers in Rural Areas. *Australian Social Work*, 69(3), 283-296.
- Cass, B. (2007). Exploring Social Care: Applying a New Construct to Young Carers and Grandparent Carers. *Australian Journal of Social Issues (Australian Council of Social Service)*, 42(2), 241-254.
- Cass, B. (2007). Using the Social Care Framework to Analyse Research on Young Carers. *Youth Studies Australia*, 26(2), 44-49.
- Cassidy, T., Curran, E., & Neill, S. (2010). The Impact of Context and Focus of Care on Health and Wellbeing. *Psychology & Health*, 25, 175-175.
- Cassidy, T., & Giles, M. (2013). Further Exploration of the Young Carers Perceived Stress Scale: Identifying a Benefit-Finding Dimension. *Br J Health Psychol*, 18(3), 642-655.
- Castan, C., Arino, B., & Tazon, A. (2006). Support and Guidance to Informal Carers: Family Schools and Self-Help Groups (Prospect Project). *Acta Psychiatrica Scandinavica*, 114, 36-36.
- Cecil, R., Parahoo, K., Thompson, K., McCaughan, E., Power, M., & Campbell, Y. (2011). The Hard Work Starts Now: A Glimpse into the Lives of Carers of Community-Dwelling Stroke Survivors. *Journal of Clinical Nursing*, 20(11-12), 1723.
- Ceilleachair, A. O., Costello, L., Finn, C., Timmons, A., Fitzpatrick, P., Kapur, K., Staines, A., & Sharp, L. (2012). Inter-Relationships between the Economic and Emotional Consequences of Colorectal Cancer for Patients and Their Families: A Qualitative Study. *Bmc Gastroenterology*, 12.
- Chadwick, D. D., Mannan, H., Garcia, I. E., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A., & Harrington, G. (2013). Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 119-132.
- Challis, D., von Abendorff, R., Brown, P., Chesterman, J., & Hughes, J. (2002). Care Management, Dementia Care and Specialist Mental Health Services: And Evaluation. *International Journal of Geriatric Psychiatry*, 17(4), 315-325.

- Chalmers, H., & Lucyk, L. (2012). The Impact of Caregiving: Is It Who I Am or What I Do? *Relational Child & Youth Care Practice*, 25(2), 37-46.
- Chambers, E., & Coleman, K. (2016). Enablers and Barriers for Engaged, Informed Individuals and Carers: Left Wall of the House of Care Framework. *Br J Gen Pract*, 66(643), 108-109.
- Chambers, M. (2001). User Acceptance of a Multi-Media Software Application to Increase Preparedness for Caring Problems. *Health Informatics Journal*, 7(3/4), 152-157.
- Chan, C., & Chui, E. (2011). Association between Cultural Factors and the Caregiving Burden for Chinese Spousal Caregivers of Frail Elderly in Hong Kong. *Aging and Mental Health*, 15(4), 500-509.
- Chan, S. M., & O'Connor, D. L. (2008). Finding a Voice: The Experiences of Chinese Family Members Participating in Family Support Groups. *Social Work with Groups*, 31(2), 117-135.
- Chang, E. (2012). Community Palliative Care Nurse Experiences and Perceptions of Follow-up Bereavement Support Visits to Carers. *Int J Nurs Pract*, 18(4), 332-339.
- Chantal, S., & Kendrick, T. (2001). Informal Carers: The Role of General Practitioners and District Nurses. *British Journal of General Practice*, 655-657.
- Chapman, B., & Koskelainen, M. (2003). Survey Addresses Improving Support for Family Carers. *Journal of Dementia Care*, 36-37.
- Charles, G. (2011). Bringing Young Carers out of the Shadows. *Reclaiming Children & Youth*, 20(3), 26-30.
- Charles, G., Marshall, S., & Stainton, T. (2010). An Overview of the Demographics Profiles and Initial Results from the British Columbia Young Carers Study. *Relational Child & Youth Care Practice*, 23(4), 65-68.
- Charles, G., Stainton, T., & Marshall, S. (2008). Young Carers in Canada: An Invisible Population. *Relational Child & Youth Care Practice*, 21(4), 5-12.
- Charles, G., Stainton, T., & Marshall, S. (2009). Young Carers: Mature before Their Time. *Reclaiming Children & Youth*, 18(2), 38-41.
- Charlesworth, G., Shepstone, L., Wilson, E., Reynolds, S., Mugford, M., Price, D., Harvey, I., & Poland, F. (2008). Befriending Carers of People with Dementia: Randomised Controlled Trial. *British Medical Journal*, 336(7656), 1295-1297.
- Charlesworth, G., Shepstone, L., Wilson, E., Thalanany, M., Mugford, M., & Poland, F. (2008). Does Befriending by Trained Lay Workers Improve Psychological Well-Being and Quality of Life for Carers of People with Dementia, and at What Cost? A Randomised Controlled Trial. *Health Technology Assessment*, 12(4).
- Charlesworth, G., Tzimoula, X., Higgs, P., & Poland, F. (2007). Social Networks, Befriending and Support for Family Carers of People with Dementia. *Quality in Ageing*, 8(2), 37-44.
- Charlesworth, G. M., Tzimoula, X. M., & Newman, S. P. (2007). Carers Assessment of Difficulties Index (Cadi): Psychometric Properties for Use with Carers of People with Dementia. *Aging & Mental Health*, 11(2), 218-225.
- Cheater, F. M. (2008). Carers Living with Stroke Survivors Who Were Incontinent Had Minimal Social Interaction and Felt Socially Isolated. *Evidence Based Nursing*, 11(2), 64-64 61p.
- Cheng, H., Chair, S., & Chau, J. (2014). The Effectiveness of Psychosocial Interventions for Stroke Family Caregivers and Stroke Survivors: A Systematic Review and Meta-Analysis. *Patient Education and Counselling*, 95, 30-44.
- Chepngeno-Langat, G. (2014). Entry and Re-Entry into Informal Care-Giving over a 3-Year Prospective Study among Older People in Nairobi Slums, Kenya. *Health & Social Care in The Community*, 22(5), 533-544.



- Chepngeno-Langat, G., Madise, N., Evandrou, M., & Falkingham, J. (2011). Gender Differentials on the Health Consequences of Care-Giving to People with Aids-Related Illness among Older Informal Carers in Two Slums in Nairobi, Kenya. *Aids Care-Psychological and Socio-Medical Aspects of AIDS/HIV*, 23(12), 1586-1594.
- Chernesky, R. H., & Gutheil, I. A. (2008). Rethinking Needs Assessment in Planning Services for Older Adults. *Journal of Gerontological Social Work*, 51(1/2), 109-125.
- Chesterman, J., Bauld, L., & Judge, K. (2001). Satisfaction with the Care-Managed Support of Older People: An Empirical Analysis. *Health and Social Care in the Community*, 9(1), 31-42.
- Cheung, J., & Hocking, P. (2004). Caring as Worrying: The Experience of Spousal Carers. *Journal of Advanced Nursing*, 47(5), 475.
- Chi, N.-C., & Demiris, G. (2015). A Systematic Review of Telehealth Tools and Interventions to Support Family Caregivers. *J Telemed Telecare*, 21(1), 37-44.
- Chien, L., Chu, H., Guo, J., Liao, Y., Chang, L., Chen, C., & Chou, K. (2011). Caregiver Support Grups in Patients with Dementia: A Meta-Analysis. *Int J Geriatr Psychiatry*, 26, 1089-1098.
- Chimwaza, A. F., & Watkins, S. C. (2004). Giving Care to People with Symptoms of Aids in Sub-Saharan Africa. *AIDS Care*, 16(7), 795-807.
- Chiou, C.-J., Chen, I. P., & Wang, H.-H. (2005). The Health Status of Family Caregivers in Taiwan: An Analysis of Gender Differences. *International Journal of Geriatric Psychiatry*, 20(9), 821-826.
- Chi-pun, L., Leung, C.-t. A., Sau-yee, L., Chi, I., & Chow, W.-s. N. (2004). An Experience of Social Work Case Management for Frail Elders in Hong Kong. *Geriatrics & Gerontology International*, 4, S173-S177.
- Chiu, M., Pauley, T., Wesson, V., Pushpakumar, D., & Sadavoy, J. (2015). Evaluation of a Problem-Solving (Ps) Techniques-Based Intervention for Informal Carers of Patients with Dementia Receiving in-home Care. *International Psychogeriatrics*, 27(6), 937-948.
- Chiu, M., Wesson, V., & Sadavoy, J. (2013). Improving Caregiving Competence, Stress Coping, and Mental Well-Being in Informal Dementia Carers. *World Journal of Psychiatry*, 3(3), 65-73.
- Cho, E., Lee, N., & Kim, E. (2011). The Impact of Informal Caregivers on Depressive Symptoms among Older Adults Receiving Formal Home Health Care. *Geriatric Nursing*, 32(1), 18-20.
- Choi, G., Tirrito, T., & Mills, F. (2008). Caregiver's Spirituality and Its Influence on Maintaining the Elderly and Disabled in a Home Environment. *Journal of Gerontological Social Work*, 51(3-4), 247-259.
- Chon, Y. (2015). An Exploratory Qualitative Study on Relationships between Older People and Home Care Workers in South Korea: The View from Family Carers and Service Providers. *Ageing and Society*, 35(3), 629-652.
- Chou, Y. C., Pu, C. Y., Fu, L. Y., & Kroger, T. (2010). Depressive Symptoms in Older Female Carers of Adults with Intellectual Disabilities. *Journal of Intellectual Disability Research*, 54(12), 1031-1044.
- Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L. C., & Kroger, T. (2009). Effect of Perceived Stigmatisation on the Quality of Life among Ageing Female Family Carers: A Comparison of Carers of Adults with Intellectual Disability and Carers of Adults with Mental Illness. *Journal of Intellectual Disability Research*, 53(7), 654-664.

- Chou, Y. C., Tzou, P., PU, C. Y., Kroger, T., & Lee, W. P. (2008). Respite Care as a Community Care Service: Factors Associated with the Effects on Family Carers of Adults with Intellectual Disability in Taiwan. *Journal of Intellectual and Developmental Disability*, 33(1), 12-21.
- Chou, Y.-C., Fu, L.-Y., Kröger, T., & Ru-Yan, C. (2011). Job Satisfaction and Quality of Life among Home Care Workers: A Comparison of Home Care Workers Who Are and Who Are Not Informal Carers. *International Psychogeriatrics / IPA*, 23(5), 814-825.
- Chou, Y.-C., Kröger, T., Chiao, C., & Pu, C.-y. (2013). Well-Being among Employed and Non-Employed Caregiving Women in Taiwan. *International Journal of Social Welfare*, 22(2), 164-174.
- Chou, Y.-C., Pu, C.-Y., Kroger, T., & Fu, L.-y. (2010). Caring, Employment, and Quality of Life: Comparison of Employed and Non-employed Mothers of Adults with Intellectual Disability. *American Journal on Intellectual and Developmental Disabilities*, 115(5), 406-420.
- Chou, Y.-C., Wang, S.-C., Chang, H.-H., & Fu, L.-Y. (2014). Working but Not Employed: Mothers of Adults with Intellectual Disability as Hidden Workers. *Journal of Intellectual & Developmental Disability*, 39(4), 353-362.
- Chow, S., Wong, F., & Poon, C. (2007). Coping and Caring: Support for Family Caregivers of Stroke Survivors. *Journal of Clinical Nursing*, 16(7B), 133-143.
- Chow, W. H. (2001). An Investigation of Carers' Burden: Before and after a Total Hip Replacement. *British Journal of Occupational Therapy*, 64(10), 503-508.
- Chung, P. Y., Ellis-Hill, C., & Coleman, P. G. (2008). Carers Perspectives on the Activity Patterns of People with Dementia. *Dementia: The International Journal of Social Research and Practice*, 7(3), 359-381.
- Ciani, E. (2012). Informal Adult Care and Caregivers' Employment in Europe. *Labour Economics*, 19(2), 155-164.
- Clabburn, O., & O'Brien, M. R. (2015). Exploring the Impact on Young People Who Are Caring and Grieving for a Parent with Motor Neurone Disease. *British Journal of Neuroscience Nursing*, 11(5).
- Clare, L., Woods, R. T., Nelis, S. M., Martyr, A., Markova, I. S., Roth, I., Whitaker, C. J., & Morris, R. G. (2014). Trajectories of Quality of Life in Early-Stage Dementia: Individual Variations and Predictors of Change. *International Journal of Geriatric Psychiatry*, 29(6), 616-623.
- Clark, A. M., Reid, M. E., Morrison, C. E., Capewell, S., Murdoch, D. L., & McMurray, J. J. (2008). The Complex Nature of Informal Care in Home-Based Heart Failure Management. *Journal of Advanced Nursing*, 61(4), 373.
- Clark, D., Ferguson, C., & Nelson, C. (2000). Macmillan Carers Schemes in England: Results of a Multicentre Evaluation. *Palliative Medicine*, 14(2), 129-139.
- Clark, J., & McGee-Lennon, M. (2011). A Stakeholder-Centred Exploration of the Current Barriers to the Uptake of Home Care Technology in the UK. *Journal of Assistive Technologies*, 5(1), 12-25.
- Clark, J. S., & Turner, K. J. (2016). Evaluating Automated Goals for Home Care Support. *Journal of Assistive Technologies*, 10(2), 79-91.
- Clarke, A., & Seymour, J. (2010). 'At the Foot of a Very Long Ladder': Discussing the End of Life with Older People and Informal Caregivers. *Journal of Pain and Symptom Management*, 40(6), 857-869.

- Clarke, C. L., Lhussier, M., Minto, C., Gibb, C. E., & Perini, T. (2005). Paradoxes, Locations and the Need for Social Coherence: A Qualitative Study of Living with a Learning Difficulty. *Disability and Society*, 20(4), 405-419.
- Clarke, D. J., Tyson, S., Rodgers, H., Drummond, A., Palmer, R., Prescott, M., Tyrrell, P., Burton, L., Grenfell, K., Brkic, L., & Forster, A. (2015). Why Do Patients with Stroke Not Receive the Recommended Amount of Active Therapy (React)? Study Protocol for a Multisite Case Study Investigation. *BMJ Open*, 5(8), e008443-e008443.
- Clarke, H. (2006). Carers. *Research Matters*, 19-24.
- Clarke, H., & Cropley, M. (2010). The Birds and the Bees. *Learning Disability Today*, 10(2), 18-20.
- Clarke, N. (2001). Training as a Vehicle to Empower Carers in the Community: More Than a Question of Information Sharing. *Health Soc Care Community*, 9(2), 79-88.
- Clausen, H., Kendall, M., Murray, S., Worth, A., Boyd, K., & Benton, F. (2005). Would Palliative Care Patients Benefit from Social Workers' Retaining the Traditional 'Casework' Role Rather Than Working as Care Managers? A Prospective Serial Qualitative Interview Study. *British Journal of Social Work*, 35(2), 277-285.
- Clayton, J., Butow, P., & Tattersall, M. (2005). When and How to Initiate Discussion About Prognosis and End-of-Life Issues with Terminally Ill Patients. *Journal of Pain and Symptom Management*, 30(2), 132-144.
- Cleary, M. (2006). Carer Participation in Mental Health Service Delivery. *Int J Mental Health Nurs*, 15(3), 189-194.
- Cleary, M., Freeman, A., Hunt, G. E., & Walter, G. (2005). What Patients and Carers Want to Know: An Exploration of Information and Resource Needs in Adult Mental Health Services. *Aust N Z J Psychiatry*, 39(6), 507-513.
- Cleary, M., Hunt, G., & Matheson, S. (2008). The Association between Substance Use and the Needs of Patients with Psychiatric Disorder, Levels of Anxiety, and Caregiving Burden. *Archives of Psychiatric Nursing*, 22(6), 375-385.
- Clegg, A., & Bee, A. (2008). Community Matrons: Patients' and Carers' Views of a New Service. *Nurs Stand*, 5(22), 35-39.
- Clements, L. (2004). Carers - the Sympathy and Services Stereotype. *British Journal of Learning Disabilities*, 32(1), 6-8.
- Cline, T., Crafter, S., de Abreu, G., & O'Dell, L. (2009). Changing Families, Changing Childhoods: Changing Schools? *Pastoral Care in Education*, 27(1), 29-39.
- Closs, S., Cash, K., & Barr, B. (2005). Cues for the Identification of Pain in Nursing Home Residents. *International Journal of Nursing Studies*, 42(1), 3-12.
- Clukey, L. (2007). 'Just Be There': Hospice Caregivers' Anticipatory Mourning Experience. *Journal of Hospice and Palliative Nursing*, 9(3), 150-158.
- Cluver, L., Operario, D., Lane, T., & Kganakga, M. (2012). "I Can't Go to School and Leave Her in So Much Pain": Educational Shortfalls among Adolescent 'Young Carers' in the South African Aids Epidemic. *Journal of Adolescent Research*, 27(5), 581-605.
- Cockerill, R., Jaglal, S., Lemieux-Charles, L., Chambers, L., Brazil, K., & Cohen, C. (2006). Components of Coordinated Care: A New Instrument to Assess Caregivers' and Care Recipients' Experiences with Networks of Dementia Care. *Dementia: The International Journal of Social Research and Practice*, 5(1), 51-66.
- Coe, N. B., & van Houtven, C. H. (2009). Caring for Mom and Neglecting Yourself? The Health Effects of Caring for an Elderly Parent. *Health Economics*, 18(9), 991-1010.

- Coetzee, S. J., Leask, S. J., & Jones, R. G. (2003). The Attitudes of Carers and Old Age Psychiatrists Towards the Treatment of Potentially Fatal Events in End-Stage Dementia. *International Journal of Geriatric Psychiatry*, 18(2), 169-173.
- Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive Aspects of Caregiving: Rounding out the Caregiver Experience. *International Journal of Geriatric Psychiatry*, 17(2), 184-188.
- Cohen, L., Ferguson, C., Harms, C., A., P. J., & Tomlinson, S. (2011). Family Systems and Mental Health Issues: A Resilience Approach. *Journal of Social Work Practice: Psychotherapeutic Approaches in Health*, 25(1), 109-125.
- Cohen-Mansfield, J., & Biddison, J. (2007). The Scope and Future Trends of Gerontechnology: Consumers' Opinions and Literature Survey. *Journal of Technology in Human Services*, 25(3), 1-19.
- Collins, F. (2004). An Evaluation of Palliative Care Services in the Community. *Nursing Times*, 34-37.
- Collins, J., & Bayless, S. (2013). How Caring for a Parent Affects the Psychosocial Development of the Young. *Nursing Children & Young People*, 25(10), 16-21.
- Collins, K., McClimens, A., Mekonnen, S., & Wyld, L. (2014). Breast Cancer Information and Support Needs for Women with Intellectual Disabilities: A Scoping Study. *Psycho-Oncology*, 23(8), 892-897.
- Colombo, A., Bendelow, G., Fulford, B., & Williams, S. (2003). Evaluating the Influence of Implicit Models of Mental Disorder on Processes of Shared Decision Making within Community-Based Multi-Disciplinary Teams. *Social Science and Medicine*, 56(7), 1557-1570.
- Colvez, A., Joel, M. E., Ponton-Sanchez, A., & Rover, A. C. (2002). Health Status and Work Burden of Alzheimer Patients' Informal Caregivers: Comparisons of Five Different Care Programs in the European Union. *Health Policy*, 60(3), 219-233.
- Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Lopez-Pousa, S., & Vilalta-Franch, J. (2009). Factors Related to Perceived Quality of Life in Patients with Alzheimer's Disease: The Patient's Perception Compared with That of Caregivers. *International Journal of Geriatric Psychiatry*, 24(6), 585-594.
- Connolly, A., Illife, S., Gaehl, E., Campbell, S., Drake, R., Morris, J., Martin, H., & Purandare, N. (2012). Quality of Care Provided to People with Dementia: Utilisation and Quality of the Annual Dementia Review in General Practice. *British Journal of General Practice*, 62(595), 78-79.
- Connor, A. (2002). Broadening the Definition of Leadership: Active Citizens as Leaders of Change. *Mental Health Review*, 7(4), 15-17.
- Convey, V., Ede, J., & Sealey, T. (2008). How Are the Carers Being Cared For? A Review of the Literature. *European Journal of Palliative Care*, 15(4), 182-185.
- Cook, M. (2016). How Woodlands and Forests Enhance Mental Well-Being. *Journal of Dementia Care*, 24(3), 20-23.
- Coolbrandt, A., De Casterle, B. D., Wildiers, H., Aertgeerts, B., van der Elst, E., van Achterberg, T., & Milisen, K. (2016). Dealing with Chemotherapy-Related Symptoms at Home: A Qualitative Study in Adult Patients with Cancer. *European Journal of Cancer Care*, 25(1), 79-92.
- Coombes, E., Colligan, J., & Keenan, H. (2004). Evaluation of an Early Onset Dementia Service. *Journal of Dementia Care*, 12(1), 35.
- Coombes, R. (2001). On the Shoulders of Children...Young Carers. *Nursing Times*, 97(28), 10-11.

- Cooney, C., Howard, R., & Lawlor, B. (2006). Abuse of Vulnerable People with Dementia by Their Carers: Can We Identify Those Most at Risk? *International Journal of Geriatric Psychiatry*, 21(6), 564-571.
- Cooper, C., Blanchard, M., Selwood, A., Walker, Z., & Livingston, G. (2010). Family Carers' Distress and Abusive Behaviour: Longitudinal Study. *British Journal of Psychiatry*, 196(6), 480-485.
- Cooper, C., Manela, M., Katona, C., & Livingston, G. (2008). Screening for Elder Abuse in Dementia in the Laser-Ad Study: Prevalence, Correlates and Validation of Instruments. *International Journal of Geriatric Psychiatry*, 23(3), 283-288.
- Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R., & Livingston, G. (2009). Abuse of People with Dementia by Family Carers: Representative Cross-Sectional Survey. *British Medical Journal* (7.3.09), 583-586.
- Cooper, V., & Ward, C. (2011). Valuing People: Family Matters Ten Years On. *Tizard Learning Disability Review*, 16(2), 44-48.
- Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., Brooker, D., & Ballard, C. (2012). Systematic Review of Services Providing Information and/or Advice to People with Dementia and/or Their Caregivers. *International Journal of Geriatric Psychiatry*, 27(6), 628-636.
- Corden, A., & Hirst, M. (2011). Partner Care at the End-of-Life: Identity, Language and Characteristics. *Ageing & Society*, 31(2), 217-242.
- Cormac, I., Lindon, D., Jones, H., Gedeon, T., & Ferriter, M. (2010). Facilities for Carers of in-Patients in Forensic Psychiatric Services in England and Wales. *Psychiatrist (The)*, 34(9), 381-384.
- Corry, M., & While, A. (2009). The Needs of Carers of People with Multiple Sclerosis: A Literature Review. *Scandinavian Journal of Caring Sciences*, 23(3), 569.
- Costantini, M., Beccaro, M., Merlo, F., Sormani, M. P., Bruzzi, P., Morasso, G., Di Leo, S., Rosi, P. G., Borgia, P., Montella, M., Grimaldi, M., Paci, E., Susini, N., Cecioni, R., Miccinesi, G., & Pisanti, R. (2005). The Last Three Months of Life of Italian Cancer Patients. Methods, Sample Characteristics and Response Rate of the Italian Survey of the Dying of Cancer (Isdoc). *Palliative Medicine*, 19(8), 628-638.
- Costantini, M., Pellegrini, F., di Leo, S., Beccaro, M., Rossi, C., Flego, G., Romoli, V., Giannotti, M., Morone, P., Ivaldi, G. P., Cavallo, L., Fusco, F., & Higginson, I. J. (2014). The Liverpool Care Pathway for Cancer Patients Dying in Hospital Medical Wards: A before-after Cluster Phase II Trial of Outcomes Reported by Family Members. *Palliative Medicine*, 28(1), 10-17.
- Costello, J., & Thorne, A. (2007). Nightmare or Needed Strategy? *Therapy Today*, 18(1), 32-34.
- Cotterill, N., Fowler, S., Avery, M., Cottenden, A. M., Wilde, M., Long, A., & Fader, M. J. (2016). Development and Psychometric Evaluation of the Icq-Ltcqol: A Self-Report Quality of Life Questionnaire for Long-Term Indwelling Catheter Users. *Neurology And Urodynamics*, 35(3), 423-428.
- Courtin, E., Jemai, N., & Mossialos, E. (2014). Mapping Support Policies for Informal Carers across the European Union. *Health Policy*, 118(1), 84-94.
- Cox, S. D., & Pakenham, K. I. (2014). Confirmatory Factor Analysis and Invariance Testing of the Young Carer of Parents Inventory (Ycopi). *Rehabilitation Psychology*, 59(4), 439-452.
- Coyle, C. E., Kramer, J., & Mutchler, J. E. (2014). Aging Together: Sibling Carers of Adults with Intellectual and Developmental Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4), 302-312.

- Craddock, E. (2013). Supporting Mental Health Carers' Role in Recovery. *Nursing Times*, 109(47), 22-24.
- Craig, J. E., & Cartwright, C. (2015). A 10-Year Plan for Quality Living for People with Disabilities and Their Carers. *British Journal of Learning Disabilities*, 43(4), 302-309.
- Crawford, K. (2002). Research into Practice. *Community Care* (1449), 45.
- Crawford, P., Lewis, L., Brown, B., & Manning, N. (2013). Creative Practice as Mutual Recovery in Mental Health. *Mental Health Review Journal*, 18(2), 55-64.
- Cree, L., Brooks, H. L., Berzins, K., Fraser, C., Lovell, K., & Bee, P. (2015). Carers' Experiences of Involvement in Care Planning: A Qualitative Exploration of the Facilitators and Barriers to Engagement with Mental Health Services. *BMC Psychiatry*, 15, 208.
- Cree, V. E. (2003). Worries and Problems of Young Carers: Issues for Mental Health. *Child & Family Social Work*, 8(4), 301-309.
- Crellin, N. E., Orrell, M., McDermott, O., & Charlesworth, G. (2014). Self-Efficacy and Health-Related Quality of Life in Family Carers of People with Dementia: A Systematic Review. *Aging and Mental Health*, 18(8), 954-969.
- Crettenden, A., Wright, A., & Skinner, N. (2014). Mothers Caring for Children and Young People with Developmental Disabilities: Intent to Work, Patterns of Participation in Paid Employment and the Experience of Workplace Flexibility. *Community, Work & Family*, 17(3), 244-267.
- Criel, B., Vanlerberghe, V., De Koker, B., Decraene, B., Engels, E., & Waltens, R. (2014). Informal Home Care for Elderly in Belgium: A Study on the Features and Challenges of Informal Care at Local Level. *Community Mental Health Journal*, 50(7), 848-853.
- Crompton, R. (2001). Gender Restructuring, Employment, and Caring. *Social Politics*, 8(3), X.
- Crompton, R. (2002). Employment, Flexible Working and the Family. *British Journal of Sociology*, 53(4), 537-558.
- Crompton, R., & Birkelund, G. E. (2000). Employment and Caring in British and Norwegian Banking: An Exploration through Individual Careers. *Work, Employment and Society*, 14(2), 331-352.
- Cronin, A., Ward, R., Pugh, S., King, A., & Price, E. (2011). Categories and Their Consequences: Understanding and Supporting the Caring Relationships of Older Lesbian, Gay and Bisexual People. *International Social Work*, 54(3), 421-435.
- Cronin, P., Hynes, G., Breen, M., McCarron, M., McCallion, P., & O'Sullivan, L. (2015). Between Worlds: The Experiences and Needs of Former Family Carers. *Health Soc Care Community*, 23(1), 88-96.
- Crossley, D., & Rockett, K. (2005). The Experience of Shame in Older Psychiatric Patients: A Preliminary Enquiry. *Aging and Mental Health*, 9(4), 368-373.
- Crowther, J., Wilson, K. C. M., Horton, S., & Lloyd-Williams, M. (2013). Compassion in Healthcare - Lessons from a Qualitative Study of the End of Life Care of People with Dementia. *Journal of The Royal Society of Medicine*, 106(12), 492-497.
- Crowther, J., Wilson, K. C. M., Horton, S., & Lloyd-Williams, M. (2013). Palliative Care for Dementia-Time to Think Again? *Qjm-an International Journal of Medicine*, 106(6), 491-494.
- Cuesta-Benjumea, C. d. I. (2010). The Legitimacy of Rest: Conditions for the Relief of Burden in Advanced Dementia Care-Giving. *J Adv Nurs*, 66(5), 988-998.
- Cuesta-Benjumea, C. d. I. (2011). Strategies for the Relief of Burden in Advanced Dementia Care-Giving. *J Adv Nurs*, 67(8), 1790-1799.

- Cumella, S., & Heslam, S. (2014). Supported Housing for People with Down's Syndrome. *British Journal of Learning Disabilities*, 42(4), 251-256.
- Cummings, S. M., & MacNeil, G. (2008). Caregivers of Older Clients with Severe Mental Illness: Perceptions of Burdens and Rewards. *Families in Society*, 89(1), 51-59.
- Currie, C., Di Mambro, P., Joice, A., McGilp, R., O'Neill, M., Ralston, G. E., Davidson, R., & Scott, J. (2002). Evaluating the Quality of Educational Materials About Schizophrenia. *Psychiatric Bulletin*, 26(3), 96-98.
- Curtice, L. (2003). Developing Local Area Co-Ordination in Scotland: Supporting Individuals and Families in Their Own Communities. *Tizard Learning Disability Review*, 8(1), 38-44.
- Cuthill, F. M., Espie, C. A., & Cooper, S.-A. (2003). Development and Psychometric Properties of the Glasgow Depression Scale for People with a Learning Disability. *British Journal of Psychiatry*, 182(4), 347-353.
- Da Roit, B. (2007). Changing Intergenerational Solidarities within Families in a Mediterranean Welfare State - Elderly Care in Italy. *Current Sociology*, 55(2), 251-269.
- Da Roit, B., Hoogenboom, M., & Weicht, B. (2015). The Gender Informal Care Gap a Fuzzy-Set Analysis of Cross-Country Variations. *European Societies*, 17(2), 199-218.
- Da Roit, B., & Le Bihan, B. (2010). Similar and yet So Different: Cash for Care in Six European Countries' Long-Term Care Policies. *The Milbank Quarterly*, 88(3), 286-309.
- Da Roit, B., & Naldini, M. (2010). Should I Stay or Should I Go? Combining Work and Care for an Older Parent in Italy. *South European Society and Politics*, 15(4), 531-551.
- Da Roit, B., & Sabatinelli, S. (2013). Nothing on the Move or Just Going Private? Understanding the Freeze on Child- and Eldercare Policies and the Development of Care Markets in Italy. *Social Politics*, 20(3), 430-453.
- Da Silva, R. D. M., Da Silva, D. M. G. V., Poletto, D., Martins, T., & Fangier, A. (2011). Social Network of Informal Carers for People with Stoma Intestinal. *Journal of Wound, Ostomy & Continence Nursing*, 38, S87-S87 81p.
- Dahlberg, L., Demack, S., & Bambra, C. (2007). Age and Gender of Informal Carers: A Population-Based Study in the UK. *Health and Social Care in the Community (Print edition)*, 15(5), 439-445.
- Dahlrup, B., Ekstrom, H., Nordell, E., & Elmstahl, S. (2015). Coping as a Caregiver: A Question of Strain and Its Consequences on Life Satisfaction and Health-Related Quality of Life. *Archives of Gerontology and Geriatrics*, 61(2), 261-270.
- Dale, J., Tadros, G., Adams, S., & Deshpande, N. (2004). Do Patients Really Want Copies of Their GP Letters? A Questionnaire Survey of Older Adults and Their Carers. *Psychiatric Bulletin*, 28(6), 199-200.
- Dale, M., Freire-Patino, D., & Matthews, H. (2014). Caring with Confidence for Huntington's Disease. *Social Care and Neurodisability*, 5(4), 191-200.
- Dallinger, T. (2015). The Choices Method: Helping People Take Control of Their Mental Health. *Mental Health Today*, 18-19.
- Dal-Santo, T. S., Scharlach, A. E., Nielsen, J., & Fox, P. J. (2007). A Stress Process Model of Family Caregiver Service Utilization: Factors Associated with Respite and Counselling Service Use. *Journal of Gerontological Social Work*, 49(4), 29-49.
- Daly, L., McCarron, M., Higgins, A., & McCallion, P. (2013). 'Sustaining Place' - a Grounded Theory of How Informal Carers of People with Dementia Manage Alterations to Relationships within Their Social Worlds. *Journal of Clinical Nursing*, 22(3/4), 501-512.

- Dam, A. E. H., de Vugt, M. E., Klinkenberg, I. P. M., Verhey, F. R. J., & van Boxtel, M. P. J. (2016). A Systematic Review of Social Support Interventions for Caregivers of People with Dementia: Are They Doing What They Promise? *Maturitas*, 85, 117-130.
- Damodaran, L., & Olphert, W. (2010). User Responses to Assisted Living Technologies (Alts) -- a Review of the Literature. *Journal of Integrated Care*, 18(2), 25-32 28p.
- Dang, S. (2008). Care Coordination Assisted by Technology for Multi-ethnic Caregivers of Persons with Dementia: A Pilot Clinical Demonstration Project on Caregiver Burden and Depression. *J Telemed Telecare*, 14(8), 443-447.
- Danoff-Burg, S., & Mosner, C. E. (2004). Effects of Gender and Employment Status on Support Provided to Caregivers. *Sex Roles: A Journal of Research*, 51(9/10), 589-595.
- Danucalov, M. A. D., Kozasa, E. H., Ribas, K. T., Galduroz, J. C. F., Garcia, M. C., Verreschi, I. T. N., Oliveira, K. C., de Oliveira, L. R., & Leite, J. R. (2013). A Yoga and Compassion Meditation Program Reduces Stress in Familial Caregivers of Alzheimer's Disease Patients. *Evidence-Based Complementary and Alternative Medicine*.
- Darby, J., Williamson, T., Logan, P., & Gladman, J. (2016). Comprehensive Geriatric Assessment on an Acute Medical Unit: A Qualitative Study of Older People's and Informal Carer's Perspectives of the Care and Treatment Received. *Clinical Rehabilitation*.
- Davey, C. (2004). Falling in Parkinson's Disease: The Impact on Informal Caregivers. *Disability & Rehabilitation*, 26(23), 1360-1366.
- Davies, A., & Newman, S. (2011). A Systematic Review to Examine the Effect of Telecare for People with Social Care Needs on Outcomes for Their Informal Carers. *International Journal of Integrated Care*, 11.
- Davies, A., Rixon, L., & Newman, S. (2013). Systematic Review of the Effects of Telecare Provided for a Person with Social Care Needs on Outcomes (F)or Their Informal Carers. *Health Soc Care Community*, 21, 582-597.
- Davies, N. (2000). Patients' and Carers' Perceptions of Factors Influencing Recovery after Cardiac Surgery. *Journal of Advanced Nursing*, 32(2), 318-326.
- Davies, R. (2010). Supporting Carers to Care in a Crisis: An Analysis of Additional Service Provision Essential to Carers of People with Learning Disabilities. *Llais* (98), 14-17.
- Davies, S. (2011). Research Focus. *Primary Health Care*, 21(8), 14-14.
- Davies, S., Clarkson, P., Hughes, J., Stewart, K., Xie, C., Saunders, R., & Challis, D. (2015). Resource Allocation Priorities in Social Care for Adults with a Learning Disability: An Analysis and Comparison of Different Stakeholder Perspectives. *Tizard Learning Disability Review*, 20(4), 199-206.
- Davies, S., & Nolan, M. (2004). 'Making the Move': Relatives' Experiences of the Transition to a Care Home. *Health and Social Care in the Community*, 12(6), 517-526.
- Davis, J. C., Robertson, M. C., Comans, T., & Scuffham, P. A. (2011). Guidelines for Conducting and Reporting Economic Evaluation of Fall Prevention Strategies. *Osteoporosis International*, 22(9), 2449-2459.
- Davis, L. L. (2011). The Nature and Scope of Stressful Spousal Caregiving Relationships. *J Fam Nurs*, 17(2).
- Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward, R. (2015). Evidence of What Works to Support and Sustain Care at Home for People with Dementia: A Literature Review with a Systematic Approach. *BMC Geriatrics*, 15(59).
- Dawson, F., Shanahan, S., Fitzsimons, E., Malley, G., Mac Giollabhui, N., & Bramham, J. (2016). The Impact of Caring for an Adult with Intellectual Disability and Psychiatric



- Comorbidity on Carer Stress and Psychological Distress. *Journal of Intellectual Disability Research: JIDR*, 60(6), 553.
- Dawson, S., Gerace, A., Muir-Cochrane, E., O'Kane, D., Henderson, J., Lawn, S., & Fuller, J. (2015). Carers' Experiences of Accessing and Navigating Mental Health Care for Older People in a Rural Area in Australia. *Aging and Mental Health*.
- Dawson, S., Gerace, A., Muir-Cochrane, E., O'Kane, D., Henderson, J., Lawn, S., & Fuller, J. (2016). Accessing Mental Health Services for Older People in Rural South Australia. *Australian Nursing and Midwifery Journal*, 23(7), 50.
- Day, C. (2015). Young Adult Carers: A Literature Review Informing the Re-Conceptualisation of Young Adult Caregiving in Australia. *Journal of Youth Studies*, 18(7), 855-866.
- Day, K., Kenealy, T. W., & Sheridan, N. F. (2016). Should We Embed Randomized Controlled Trials within Action Research: Arguing from a Case Study of Telemonitoring. *Bmc Medical Research Methodology*, 16.
- Day, M. (2006). Caring for the Carers. *Nursing in the Community*, 7(3), 18-19.
- De Boer, A. H., Oudijk, D., Timmermans, J. M., & Pot, A. M. (2012). Self-Perceived Burden from Informal Care: Construction of the Ediz-Plus. *Tijdschrift Voor Gerontologie En Geriatrie*, 43(2), 77-88.
- De Graaff, F. M., & Francke, A. L. (2009). Barriers to Home Care for Terminally Ill Turkish and Moroccan Migrants, Perceived by GPs and Nurses: A Survey. *BMC Palliative Care*, 8(1).
- De Judicibus, M. A., & McCabe, M. P. (2005). Economic Deprivation and Its Effects on Subjective Wellbeing in Families of People with Multiple Sclerosis. *Journal of Mental Health*, 14(1), 49-59.
- de la Cuesta, C. (2005). The Craft of Care: Family Care of Relatives with Advanced Dementia. *Qual Health Res*, 15(7), 881-896.
- De Meijer, C., Brouwer, W., & Koopmanschap, M. (2010). The Value of Informal Care: A Further Investigation of the Feasibility of Contingent Valuation in Informal Caregivers. *Health Economics*, 19(7), 755-771.
- De Oliveira, D. C., & Hlebec, V. (2016). Predictors of Satisfaction with Life in Family Carers: Evidence from the Third European Quality of Life Survey. *Teorija in Praksa*, 53(2), 503-523.
- de Rotrou, J., Cantegreil, I., Faucounau, V., Wenisch, E., Chausson, C., Jejou, D., Grabar, S., & Rigaud, A. S. (2011). Do Patients Diagnosed with Alzheimer's Disease Benefit from a Psycho-Educational Programme for Family Caregivers? A Randomised Controlled Study. *International Journal of Geriatric Psychiatry*, 26(8), 833-842.
- Dean, J., Todd, G., Morrow, H., & Sheldon, K. (2001). 'Mum I Used to Be Good Looking... Look at Me Now': The Physical Health Needs of Adults with Mental Health Problems: The Perspectives of Users, Carers and Front-Line Staff. *International Journal of Mental Health Promotion*, 3(4), 16-24.
- Deb, S., Hare, M., & Prior, L. (2007). Symptoms of Dementia among Adults with Down's Syndrome: A Qualitative Study. *Journal of Intellectual Disability Research*, 51(9), 726-739.
- Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K., & Ingham, J. M. (2003). Care for the Caregivers: A Review of Self-Report Instruments Developed to Measure the Burden, Needs, and Quality of Life of Informal Caregivers. *Journal of Pain and Symptom Management*, 26(4), 922-953.
- Del Bono, E., Sala, E., & Hancock, R. (2009). Older Carers in the UK: Are There Really Gender Differences? New Analysis of the Individual Sample of Anonymised Records from the 2001 UK Census. *Health and Social Care in the Community*, 17(3), 267-273.

- del Mar García-Calvente, M., Mateo-Rodríguez, I., & Maroto-Navarro, G. (2004). Impact of Caregiving on Women's Health and Quality of Life. *Gaceta sanitaria / S.E.S.P.A.S*, 18 Suppl 2, 83-92.
- Del Piccolo, L., Goss, C., Bottacini, A., Rigoni, V., Mazzi, M. A., Deledda, G., Ballarin, M., Molino, A., Fiorio, E., & Zimmermann, C. (2014). Asking Questions During Breast Cancer Consultations: Does Being Alone or Being Accompanied Make a Difference? *European Journal of Oncology Nursing*, 18(3), 299-304.
- Delaney, S., Meyer, I., & Muller, S. (2013). The Ecare Client Impact Survey (Eccis) - Developing a New Tool for Assessing Client Impacts of Telehealthcare. *International Journal of Integrated Care (IJIC)*, 13, 1-1.
- Delicado Useros, M. V., Candel Parra, E., Alfaro Espín, A., López Máñez, M., & García Borge, C. (2004). Interaction of Nurses and Women Caring Informally for Dependent Persons. *Atencion Primaria*, 33(4), 193-199.
- del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Pancorbo-Hidalgo, P. L. (2011). Coping and Subjective Burden in Caregivers of Older Relatives: A Quantitative Systematic Review. *Journal of Advanced Nursing*, 67(11), 2311-2322.
- Dementia Research Group. (2004). Care Arrangements for People with Dementia in Developing Countries. *International Journal of Geriatric Psychiatry*, 19(2), 170-177.
- Demiris, G., Oliver, D. R. P., Courtney, K. L., & Porock, D. (2005). Use of Technology as a Support Mechanism for Caregivers of Hospice Patients. *Journal of Palliative Care*, 21(4), 303-309.
- Denham, M., Francis, S.-A., Graffy, J., Gray, N., & Smith, F. (2003). A Multi-Centre Survey among Informal Carers Who Manage Medication for Older Care Recipients: Problems Experienced and Development of Services. *Health and Social Care in the Community*, 11(2), 138-145.
- Dentinger, E., & Clarkberg, M. (2002). Informal Caregiving and Retirement Timing among Men and Women: Gender and Caregiving Relationships in Late Midlife. *Journal of Family Issues*, 23(7), 857-879.
- Denvir, M. A., Highet, G., Robertson, S., Cudmore, S., Reid, J., Ness, A., Hogg, K., Weir, C., Murray, S., & Boyd, K. (2014). Future Care Planning for Patients Approaching End-of-Life with Advanced Heart Disease: An Interview Study with Patients, Carers and Healthcare Professionals Exploring the Content, Rationale and Design of a Randomised Clinical Trial. *BMJ Open*, 4(7), e005021-e005021.
- Devapriam, J., Thorp, C., Tyrer, F., Gangadharan, S., Raju, L., & Bhaumik, S. (2008). A Comparative Study of Stress and Unmet Needs in Carers of South Asian and White Adults with Learning Disabilities. *Ethnicity and Inequalities in Health and Social Care*, 1(2), 35-43.
- Devlin, M., & McIlfratrick, S. (2009). The Role of the Home-Care Worker in Palliative and End-of-Life Care in the Community Setting: A Literature Review. *International Journal of Palliative Nursing*, 15(11), 526-532 525p.
- Dewar, B. (2002). The Carer's Role in Planning Care for People with Dementia. *Professional Nurse*, 17(5), 318-321.
- Dewar, B., Tocher, R., & Watson, W. (2003). Enhancing Partnerships with Relatives in Care Settings. *Nurs Stand*, 17(40), 33-39.
- Dibsdall, L., & Rugg, S. (2008). Carers' Perspectives on Their Needs and Local Authority Occupational Therapy Practice. *British Journal of Occupational Therapy*, 71(7), 277-285.
- Dickens, A., Miles, A., & Watkins, M. (2006). Improving User/Carer Involvement in Commissioning and Reviewing Mental Health Services. *Mental Health Review Journal*, 11(1), 16-20.

- Diehl, J. T., Mayer, H., & Forstl, A. K. (2003). A Support Group for Caregivers of Patients with Frontotemporal Dementia. *Dementia: The International Journal of Social Research and Practice*, 2(2), 151-161.
- Dimakopoukou, E., Sakka, P., Efthymiou, A., Karpathiou, N., & Karydaki, M. (2015). Evaluating the Needs of Dementia Patients' Caregivers in Greece: A Questionnaire Survey. *International Journal of Caring Sciences*, 8(2), 274-280.
- Do, E. K., Cohen, S. A., & Brown, M. J. (2014). Socioeconomic and Demographic Factors Modify the Association between Informal Caregiving and Health in the Sandwich Generation. *BMC Public Health*, 14(1), 1-14.
- Do, Y. K., Norton, E., Sterans, S., & Van Houtven, C. H. (2015). Informal Care and Caregiver's Health. *Health Economics*, 24(2), 224-237.
- Dobiášová, K., Kotrusová, M., & Hošyálková, J. (2015). General Practitioners (GPs) and Their Role in Supporting Informal Carers for Elderly and Disabled People from the Informal Carers' Perspective. *Prakticky Lekar*, 95(4), 161-166.
- Dobrof, J., & Ebenstein, H. (2003). Family Caregiver Self-Identification: Implications for Healthcare and Social Services Professionals. *Generations*, 27(4), 33-38.
- Docherty, A., Owens, A., Asadi-Lari, M., Petchey, R., Williams, J., & Carter, Y. H. (2008). Knowledge and Information Needs of Informal Caregivers in Palliative Care: A Qualitative Systematic Review. *Palliative Medicine*, 22(2), 153-171.
- Doel, M., & Marsh, P. (2006). Across the Divide. *Community Care* (8.06.06), 30-31.
- Doka, K. (2003). The Spiritual Gifts and Burdens of Family Caregiving. *Generations*, 27(4), 45-48.
- Donath, C., Winkler, A., & Grassel, E. (2009). Short-Term Residential Care for Dementia Patients: Predictors for Utilization and Expected Quality from a Family Caregiver's Point of View. *International Psychogeriatrics*, 21(4), 703-710.
- Done, D. J., & Thomas, J. A. (2001). Training in Communication Skills for Informal Carers of People Suffering from Dementia: A Cluster Randomised Clinical Trial Comparing a Therapist Led Workshop and a Booklet. *International Journal of Geriatric Psychiatry*, 16(8), 816-821.
- Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What Are the Factors That Facilitate or Hinder Resilience in Older Spousal Dementia Carers? A Qualitative Study. *Aging and Mental Health*, 19(10), 932-939.
- Donnelly, N.-A., Hickey, A., Burns, A., Murphy, P., & Doyle, F. (2015). Systematic Review and Meta-Analysis of the Impact of Carer Stress on Subsequent Institutionalisation of Community-Dwelling Older People. *PLoS ONE*, 10(6).
- Donner, B., Mutter, R., & Scior, K. (2010). Mainstream in-Patient Mental Health Care for People with Intellectual Disabilities: Service User, Carer and Provider Experiences. *Journal of Applied Research in Intellectual Disabilities*, 23(3), 214-225.
- Donovan, R., & Williams, A. M. (2015). Care-Giving as a Canadian-Vietnamese Tradition: 'It's Like Eating, You Just Do It'. *Health Soc Care Community*, 23(1), 79-87.
- Doorenbos, A. Z., Given, B., Given, C. W., Wyatt, G., Gift, A., Rahbar, M., & Jeon, S. (2007). The Influence of End-of-Life Cancer Care on Caregivers. *Res Nurs Health*, 30(3), 270-281.
- Doran, T., Drever, F., & Whitehead, M. (2003). Health of Young and Elderly Informal Carers: Analysis of UK Census Data. *BMJ*, 327(1388).
- Doughty, K., Godfrey, D., & Mulvihill, B. (2012). Self-Care, Plesio-Care, Telecare and M-Care: A New Assisted Living Model. *Journal of Assistive Technologies*, 6(4), 292-301.

- Douglas-Dunbar, M., & Gardiner, P. (2007). Support for Carers of People with Dementia During Hospital Admission. *Nursing Older People*, 19(8), 27-30 24p.
- Doutre, G., Green, R., & Knight-Elliott, A. (2013). Listening to the Voices of Young Carers Using Interpretative Phenomenological Analysis and a Strengths-Based Perspective. *Educational & Child Psychology*, 30(4), 30-43.
- Dow, B., & McDonald, J. (2007). The Invisible Contract: Shifting Care from the Hospital to the Home. *Australian Health Review: A Publication of The Australian Hospital Association*, 31(2), 193-202.
- Dow, B., & Meyer, C. (2010). Caring and Retirement: Crossroads and Consequences. *International Journal of Health Services*, 40(4), 645-665 621p.
- Dow, B., Moore, K., Scott, P., Ratnayake, A., Wise, K., & Sims, J. (2008). Rural Carers Online: A Feasibility Study. *Aus J Rural Health*, 16(4), 221-225.
- Dow, J. (2005). The Carers (Equal Opportunities) Act 2004. *Journal of Integrated Care*, 13(4), 24-25.
- Downs, M., Ariss, S. M. B., Grant, E., Keady, J., Turner, S., Bryans, M., Wilcock, J., Levin, E., O'Carroll, R., & Illife, S. (2006). Family Carers' Accounts of General Practice Contacts for Their Relatives with Early Signs of Dementia. *Dementia: The International Journal of Social Research and Practice*, 5(3), 353-373.
- Drake, R. F. (2002). Disabled People Voluntary Organisations and Participation in Policy Making. *Policy and Politics*, 30(3), 373-385.
- Draper, H., Sorell, T., Bedaf, S., Syrdal, D. S., Gutierrez-Ruiz, C., Duclos, A., & Amirabdollahian, F. (2014). Ethical Dimensions of Human-Robot Interactions in the Care of Older People: Insights from 21 Focus Groups Convened in the UK, France and the Netherlands. *Social Robotics*, 8755, 135-145.
- Draper, H., & Sorell, T. O. M. (2013). Telecare. Remote Monitoring and Care *Bioethics*, 27(7), 365-372.
- Draper, P., & Brocklehurst, H. (2007). The Impact of Stroke on the Well-Being of the Patient's Spouse: An Exploratory Study. *Journal of Clinical Nursing*, 16(2), 264-271.
- Dreßke, S. (2001). Cooperation and Negotiations in the Home-Healthcare Sector. *Zeitschrift für Gesundheitswissenschaften*, 9(1), 68-84.
- Drinkwater, S. (2015). Informal Caring and Labour Market Outcomes within England and Wales. *Regional Studies*, 49(2), 273-286.
- Dröes, R., Meiland, F. J. M., Schmitz, M. J., & van Tilburg, W. (2006). Effect of the Meeting Centres Support Program on Informal Carers of People with Dementia: Results from a Multi-Centre Study. *Aging & Mental Health*, 10(2), 112-124 113p.
- Droes, R.-M., Boelens-van der knoop, E., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., Hoogeveen, F., De Lange, J., & Scholzel-Dorenbos, J. L. (2006). Quality of Life in Dementia in Perspective; an Explorative Study of Variations in Opinions among People with Dementia and Their Professional Caregivers, and in Literature. *Dementia: The International Journal of Social Research and Practice*, 5(4), 533-558.
- Droes, R.-M., Meiland, F., Schmitz, M., & van Tilburg, W. (2004). Effect of Combined Support for People with Dementia and Carers Versus Regular Day Care on Behaviour and Mood of Persons with Dementia: Results from a Multi-Centre Implementation Study. *International Journal of Geriatric Psychiatry*, 19(7), 673-684.
- Ducharme, J. K., & Geldmacher, D. S. (2011). Family Quality of Life in Dementia: A Qualitative Approach to Family-Identified Care Priorities. *Quality of life Research: an international journal of quality of life aspects of treatment, care and rehabilitation*, 20(8), 1331.

- Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. L. (2015). Perceptions, Experiences and Needs of Patients with Idiopathic Pulmonary Fibrosis. *Journal of Advanced Nursing*, 71(5), 1055-1065.
- Duffy, J., Das, C., & Davidson, G. (2013). Service User and Carer Involvement in Role-Plays to Assess Readiness for Practice. *Social Work Education (The International Journal)*, 32(1), 39-54.
- Dujardin, C., Farfan-Portet, M., Mitchell, R., Popham, F., Thomas, I., & Lorant, V. (2011). Does Country Influence the Health Burden of Informal Care? An International Comparison between Belgium and Great Britain. *Soc Sci Med*, 73(8), 1123-1132.
- Dumaret, A.-C., Donati, P., & Crost, M. (2011). After a Long-Term Placement: Investigating Educational Achievement, Behaviour, and Transition to Independent Living. *Children & Society*, 25(3), 215-227.
- Dunk, B., Longman, B., & Newton, L. (2010). GPs Technologies in Managing the Risks Associated with Safer Walking in People with Dementia - a Practical Perspective. *Journal of Assistive Technologies*, 4(3), 4-8.
- Dunne, E., & Rogers, B. (2013). "It's Us That Have to Deal with It Seven Days a Week": Carers and Borderline Personality Disorder. *Community Mental Health Journal*, 49(6), 643-648.
- Dury, R. (2014). Older Carers in the UK: Who Cares? *British Journal of Community Nursing*, 19(11), 556-558.
- Dwason, S., Kristjanson, L., Toye, C. M., & Flett, P. (2004). Living with Huntington's Disease: Need for Supportive Care. *Nursing and Health Sciences*, 6(2), 123-130.
- Earle, A., & Heymann, J. (2011). Protecting the Health of Employees Caring for Family Members with Special Health Care Needs. *Soc Sci Med*, 73(1), 68-78.
- Earley, L., Cushway, D., & Cassidy, T. (2007). Children's Perceptions and Experiences of Care Giving: A Focus Group Study. *Counselling Psychology Quarterly*, 20(1), 69-80.
- Earley, L., & Cushway, D. J. (2002). The Parentified Child. *Clinical Child Psychology & Psychiatry*, 7(2), 163.
- Edge, P. (2007). Carers' Needs When Relatives Go into a Care Home. *Nursing Times*, 103(47), 32-33.
- Edmonds, P., Karlsen, S., Khan, S., & Addington-Hall, J. (2001). A Comparison of the Palliative Care Needs of Patients Dying from Chronic Respiratory Diseases and Lung Cancer. *Palliative Medicine*, 15(4), 287-295.
- Edmonds, P., Vivat, B., Burman, R., Silber, E., & Higginson, I. J. (2007). 'Fighting for Everything': Service Experiences of People Severely Affected by Multiple Sclerosis. *Multiple Sclerosis (13524585)*, 13(5), 660-667.
- Edmonds, P., Vivat, B., Burman, R., Silber, E., & Higginson, I. J. (2007). Loss and Change: Experiences of People Severely Affected by Multiple Sclerosis. *Palliative Medicine*, 21(2), 101-107.
- Edwards, B., & Higgins, D. J. (2009). Is Caring a Health Hazard? The Mental Health and Vitality of Carers of a Person with a Disability in Australia. *Med J Aust*, 190(7), 61.
- Edwards, C. A., McDonnell, C., & Merl, H. (2013). An Evaluation of a Therapeutic Garden's Influence on the Quality of Life of Aged Care Residents with Dementia. *Dementia (London, England)*, 12(4), 494-510.
- Edwards, G. (2003). Good Practice for Keeping Stroke Patients and Carers Informed. *Prof Nurse*, 18(9), 529-532.

- Egan, P. (2004). Working with Families in Mental Health: Some Pointers from Research. *Irish Social Worker*, 22(1), 29-30.
- Egdell, V. (2013). Who Cares? Managing Obligation and Responsibility across the Changing Landscapes of Informal Dementia Care. *Ageing & Society*, 33, 888-907.
- Egdell, V., Bond, J., Brittain, K., & Jarvis, H. (2010). Disparate Routes through Support: Negotiating the Sites, Stages and Support of Informal Dementia Care. *Health & Place*, 16(1), 101-107 107p.
- Ekwall, A., Sivberg, B., & Hallberg, I. (2007). Older Caregivers' Coping Strategies and Sense of Coherence in Relation to Quality of Life. *Journal of Advanced Nursing*, 57(6), 584-596.
- Ekwall, A. K., & R., H. I. (2007). The Association between Caregiving Satisfaction, Difficulties and Coping among Older Family Caregivers. *J Clin Nurs*, 16(5), 832-844.
- Eldh, A. C., & Carlsson, E. (2011). Seeking a Balance between Employment and the Care of an Ageing Parent. *Scandinavian Journal of Caring Sciences*, 25(2), 285-293.
- Eldred, C., & Sykes, C. (2008). Psychosocial Interventions for Carers of Survivors of Stroke: A Systematic Review of Interventions Based on Psychological Principles and Theoretical Frameworks. *British Journal of Health Psychology*, 13, 563-581.
- Eley, S. (2004). 'If They Don't Recognize It, You've Got to Deal with It Yourself': Gender, Young Caring and Educational Support. *Gender and Education*, 16(1), 65-75.
- Elf, M., Rystedt, H., Lundin, J., & Krevers, B. (2012). Young Carers as Co-Designers of a Web-Based Support System: The Views of Two Publics. *Informatics for Health & Social Care*, 37(4), 203-216.
- Elf, M., Skärsäter, I., & Krevers, B. (2011). 'The Web Is Not Enough, It's a Base' An Explorative Study of What Needs a Web-Based Support System for Young Carers Must Meet. *Informatics for Health & Social Care*, 36(4), 206-219.
- Elia, M., Russell, C. A., & Stratton, R. J. (2010). Malnutrition in the UK: Policies to Address the Problem. *Proceedings of the Nutrition Society*, 69(4), 470-476.
- Ellins, J., & Glasby, J. (2016). You Don't Know What You Are Saying 'Yes' and What You Are Saying 'No' To: Hospital Experiences of Older People from Minority Ethnic Communities. *Ageing and Society*, 36(1), 42-63.
- Elliott, T. R., & Shewchuk, R. M. (2003). Social Problem-Solving Abilities and Distress among Family Members Assuming a Caregiving Role. *British Journal of Health Psychology*, 8(2), 149-163.
- Ellis, J. (2012). The Impact of Lung Cancer on Patients and Carers. *Chronic Respiratory Disease*, 9(1), 39-47.
- Ellis, J., Williams, M. L., Wagland, R., Bailey, C., & Molassiotis, A. (2013). Coping with and Factors Impacting Upon the Experience of Lung Cancer in Patients and Primary Carers. *European Journal of Cancer Care*, 22(1), 97-106.
- Ellis-Hill, C., Robison, J., Wiles, R., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Going Home to Get on with Life: Patients and Carers Experiences of Being Discharged from Hospital Following a Stroke. *Disability & Rehabilitation*, 31(2), 61-72.
- El-Nimr, G., & Tams, S. (2010). J15 a Care Model in Huntington's Disease: Delivering Care with Carers. *Journal of Neurology, Neurosurgery & Psychiatry*, 81, A44-A44.
- Elsom, S., Sands, N., Roper, C., Hoppner, C., & Gerdtz, M. (2013). Telephone Survey of Service-User Experiences of a Telephone-Based Mental Health Triage Service. *International Journal of Mental Health Nursing*, 22(5), 437-443.

- Elvish, R., Lever, S. J., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological Interventions for Carers of People with Dementia: A Systematic Review of Quantitative and Qualitative Evidence. *Counselling and Psychotherapy Research*, 13(2), 106-125.
- Emery, D. (2001). Telecare in Practice: A Telecare Initiative Focusing on Carers of Older People Based on Action. *Health Informatics Journal*, 7(1).
- Emery, H., Jones, B., & Chaplin, E. (2013). A Comparison of Carers Needs for Service Users Cared for Both in and out of Area. *Advances in Mental Health and Intellectual Disabilities*, 7(3), 143-151.
- Empeno, J., Raming, N. T. J., Irwin, S. A., Nelesen, R. A., & Lloyd, L. S. (2011). The Hospice Caregiver Support Project: Providing Support to Reduce Caregiver Stress. *J Palliat Med*, 14(5), 593-597.
- England, K., & Dyck, I. (2011). Managing the Body Work of Home Care. *Sociology of Health & Illness*, 33(2), 206-219.
- Epelde, G., Valencia, X., Ardanza, A., Fanchon, E., De Mauro, A., Rueda, F. M., Carrasco, E., & Rajasekharan, S. (2013). Virtual Arm Representation and Multimodal Monitoring for the Upper Limb Robot Assisted Teletherapy. *Neurotechnix: Proceedings of the International Congress on Neurotechnology, Electronics and Informatics*, 69-80.
- Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., Rob, G., Beynon, T., Higginson, I., & Harding, R. (2012). Adjusting to the Caregiving Role: The Importance of Coping and Support. *International Journal of Palliative Nursing*, 18(11), 541-545.
- Eriksson, H., & Sandberg, J. (2008). Transitions in Men's Caring Identities: Experiences from Home-Based Care to Nursing Home Placement. *International Journal Of Older People Nursing*, 3(2), 131-137.
- Eriksson, H., Sandberg, J., Holmgren, J., & Pringle, K. (2013). His Helping Hands -Adult Daughter's Perceptions' of Fathers with Caregiving Responsibility. *European Journal of Social Work*, 16(2), 235-248.
- Ervin, K., Pallant, J., & Reid, C. (2015). Caregiver Distress in Dementia in Rural Victoria. *Australasian Journal on Ageing*, 34(4), 235-240.
- Ervin, K., & Reid, C. (2015). Service Utilisation by Carers of People with Dementia in Rural Victoria. *Australasian Journal on Ageing*, 34(4), E1-E6.
- Escobar Pinzon, L. C., Claus, M., Zepf, K. I., Letzel, S., Fischbeck, S., & Weber, M. (2011). Preference for Place of Death in Germany. *Journal of Palliative Medicine*, 14(10), 1097-1103.
- Espejo, J. L. M., Segura, F. C., & Neyra, M. R. (2008). Training Provided to Home Peritoneal Dialysis Patients in Spain. *Revista de la Sociedad Espanola de Enfermeria Nefrologica*, 11(1), 13-19.
- Evandrou, M., & Glaser, K. (2003). Combining Work and Family Life: The Pension Penalty of Caring. *Ageing and Society*, 23(5), 583-601.
- Evandrou, M., & Glaser, K. (2004). Family, Work and Quality of Life: Changing Economic and Social Roles through the Lifecourse. *Ageing and Society*, 24(5), 771-791.
- Evandrou, M., & Glass, K. (2002). Changing Economic and Social Roles: The Experience of Four Cohorts of Mid-Life Individuals in Britain, 1985-2000. *Population Trends*, 110, 19-30.
- Evans, S. A., Airey, M. C., Chell, S. M., Connelly, J. B., Rigby, A. S., & Tennant, A. (2003). Disability in Young Adults Following Major Trauma: 5 Year Follow up of Survivors. *BMC Public Health*, 3.
- Evans, S. C., & Bray, J. (2016). Best Practice for Providing Social Care and Support to People Living with Concurrent Sight Loss and Dementia: Professional Perspectives. *Working with Older People*, 20(2), 86-93.

- Ewing, G., Brundle, C., Payne, S., & Grande, G. (2013). The Carer Support Needs Assessment Tool (Csnat) for Use in Palliative and End-of-Life Care at Home: A Validation Study. *Journal of Pain and Symptom Management*, 46(3), 395-405.
- Ewing, G., & Grande, G. (2013). Development of a Carer Support Needs Assessment Tool (Csnat) for End-of-Life Care Practice at Home: A Qualitative Study. *Palliative Medicine*, 27(3), 244-256.
- Exel van, J., Brouwer, W., & de Graaf, G. (2008). Give Me a Break! Informal Caregiver Attitudes Towards Respite Care. *Health Policy*, 88(1), 73-87.
- Eyre, S. (2010). Supporting Informal Carers of Dying Patients: The District Nurse's Role. *Nurs Stand*, 24(22), 43-48.
- Fadden, G., Shooter, M., & Holsgrove, G. (2005). Involving Carers and Service Users in the Training of Psychiatrists. *Psychiatric Bulletin*, 29(7), 270-274.
- Falco, J. L., Vaquerizo, E., Lain, L., Artigas, J. I., & Ibarz, A. (2013). Ami and Deployment Considerations in Aal Services Provision for Elderly Independent Living: The Monami Project. *Sensors*, 13(7), 8950-8976.
- Falls, D., Stevens, J., Andersen, M., Collin, S., Dodd, N., Fitzgerald, E., Mitchell, G., Ramsay, A., Sheriden, J., Weaver, A., & Wilson, V. (2004). Carers' Perceptions of Pain in People with Dementia: A Grounded Theory Approach. *The Australian Journal of Holistic Nursing*, 11(2), 4-11.
- Farfan-Portet, M., Popham, F., Mitchell, R., Swine, C., & Lorant, V. (2010). Caring, Employment and Health among Adults of Working Age: Evidence from Britain and Belgium. *European Journal of Public Health*, 20(1), 52-57.
- Farquhar, M., Penfold, C., Walter, F. M., Kuhn, I., & Benson, J. (2016). What Are the Key Elements of Educational Interventions for Lay Carers of Patients with Advanced Disease? A Systematic Literature Search and Narrative Review of Structural Components, Processes and Modes of Delivery. *Journal of Pain and Symptom Management*.
- Farquhar, M. C., Prevost, A. T., McCrone, P., Brafman-Price, B., Bentley, A., Higginson, I. J., Todd, C. J., & Booth, S. (2016). The Clinical and Cost Effectiveness of a Breathlessness Intervention Service for Patients with Advanced Non-Malignant Disease and Their Informal Carers: Mixed Findings of a Mixed Method Randomised Controlled Trial. *Trials*, 17.
- Farzanegan, D., Hadi, S., & Anderson, S. (2014). Future of Social Media in Health and Care with Co-Production. *International Journal of Integrated Care (IJIC)*, 14, 72-73.
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tshanz, J. (2012). Caregivers' Relationship Closeness with the Person with Dementia Predicts Both Positive and Negative Outcomes for Caregivers' Physical Health and Psychological Well-Being. *Aging and Mental Health*, 16(6), 699-711.
- Fear, T. (2000). Male and Female Care: A Different Experience? *Journal of Dementia Care*, 8(4), 28-29.
- Feinberg, L. F. (2003). The State of the Art of Caregiver Assessment. *Generations*, 27(4), 24-32.
- Feinberg, L. F., & Whitlatch, C. J. (2001). Are Persons with Cognitive Impairment Able to State Consistent Choices? *Gerontologist*, 41(3), 374-382.
- Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L., & Bauco, C. (2008). Prevalence of Stress, Anxiety and Depression in with Alzheimer Caregivers. *Health Qual Life Outcomes*, 6(93).



- Ferrario, S. R., Zotti, A. M., Baroni, A., Cavagnino, A., & Fornara, R. (2002). Emotional Reactions and Practical Problems of the Caregivers of Hemodialysed Patients. *Journal of Nephrology*, 15(1), 54-60.
- Ferrario, S. R., Zotti, A. M., Ippoliti, M., & Zotti, P. (2003). Caregiving-Related Needs Analysis: A Proposed Model Reflecting Current Research and Socio-Political Developments. *Health and Social Care in the Community*, 11(2), 103-110.
- Fine, M. (2012). Employment and Informal Care: Sustaining Paid Work and Caregiving in Community and Home-Based Care. *Ageing International*, 37(1), 57-68.
- Fine, M., & Glendinning, C. (2005). Dependence, Independence or Inter-Dependence? Revisiting the Concepts of 'Care' and 'Dependency'. *Ageing and Society*, 25(4), 601-621.
- Finlayson, M., & Cho, C. (2008). A Descriptive Profile of Caregivers of Older Adults with Ms and the Assistance They Provide. *Disability & Rehabilitation*, 30(24), 1848-1857.
- Fisher, K. R., Parker, S., & Purcal, C. (2009). Measuring the Effectiveness of New Approaches to Housing Support Policy for Persons with Disabilities. *Australian Journal of Public Administration*, 68(3), 319-332.
- Fleming, D. A., Sheppard, V. B., Mangan, P. A., Taylor, K. L., Tallarico, M., Adams, I., & Ingham, J. (2006). Caregiving at the End of Life: Perceptions of Health Care Quality and Quality of Life among Patients and Caregivers. *Journal of Pain and Symptom Management*, 31(5), 407-420.
- Foley, R. (2002). Assessing the Applicability of GIS in a Health and Social Care Setting: Planning Services for Informal Carers in East Sussex, England. *Social Science & Medicine*, 55(1), 79-96.
- Fonseca, A. M., Gonçalves, D. C., & Pereira, S. M. (2010). Working Family Carers in Portugal: Between the Duty and the Burden of Caring for Old Vulnerable People. *International Journal of Palliative Nursing*, 16(10), 476-480.
- Fontaine, R., Gramain, A., & Wittwer, J. (2009). Providing Care for an Elderly Parent: Interactions among Siblings? *Health Economics*, 18(9), 1011-1029.
- Forbat, L. (2002). 'Tinged with Bitterness': Re-Presenting Stress in Family Care. *Disability and Society*, 17(7), 759-768.
- Forbat, L. (2004). The Care and Abuse of Minoritized Ethnic Groups: The Role of Statutory Services. *Critical Social Policy*, 24(3), 312-331.
- Forbat, L. (2005). Matter of Discourse. *Community Care* (24.03.05), 38-39.
- Forbat, L., & Nar, S. (2003). Dementia's Cultural Challenge. *Community Care* (25.9.03), 38-39.
- Ford, R. (2001). Carers at the Centre. *Nursing Management*, 8(1), 8-10.
- Foreva, G., & R., A. (2014). Hidden Patients: The Relatives of Patients in Need of Palliative Care. *J Palliat Med*, 17(1), 56-61.
- Forster, A., Dickerson, J., Young, J., Patel, A., Kalra, L., Nixon, J., Smithard, D., Knapp, M., Holloway, I., Anwar, S., & Farrin, A. (2013). A Structured Training Programme for Caregivers of Inpatients after Stroke (Tracs): A Cluster Randomised Controlled Trial and Cost-Effectiveness Analysis. *The Lancet*, 382(9910), 2069-2076.
- Fortune, D. G., Rogan, C. R., & Richards, H. L. (2016). A Structured Multicomponent Group Programme for Carers of People with Acquired Brain Injury: Effects on Perceived Criticism, Strain, and Psychological Distress. *British Journal of Health Psychology*, 21(1), 224-243.
- Fortune, D. G., Smith, J. V., & Garvey, K. (2005). Perceptions of Psychosis, Coping, Appraisals, and Psychological Distress in the Relatives of Patients with Schizophrenia: An

- Exploration Using Self-Regulation Theory. *British Journal of Clinical Psychology*, 44(3), 319-331.
- Foster, K. (2011). "I Wanted to Learn How to Heal My Heart": Family Carer Experiences of Receiving an Emotional Support Service in the Well Ways Programme. *Int J Mental Health Nurs*, 20(1), 56-62.
- Fox, A. (2010). From Independence to Interdependence: Integration Means 'Think Family'. *Journal of Integrated Care*, 18(2), 41-48.
- Fox, A., & Conochie, G. (2010). Unpaid Carers Hold the Key to Sustainable Social Care: Is It Time They Got the Credit? *Journal of Care Services Management*, 4(4), 270-279.
- Fox, A., Sparrow, N., & Webber, J. (2010). Carers and the NHS. *British Journal of General Practice*, 60(575), 462-463.
- Fox, C., Maidment, I., Moniz-Cook, E., White, J., Thyrian, R. J., Young, J., Katona, C., & Chew-Graham, C. A. (2013). Optimising Primary Care for People with Dementia. *Mental Health in Family Medicine*, 10(3), 143-151.
- Fox, J. (2007). Experience of Mental Health Recovery and the Service User Researcher. *Ethics and Social Welfare*, 1(2), 219-223.
- Fox, J. (2009). A Participatory Action Research Project Evaluating a Carers' Representation Group: Carers against Stigma. *Mental Health Review*, 14(4), 25-35.
- Fox, J., Ramon, S., & Morant, N. (2015). Exploring the Meaning of Recovery for Carers: Implications for Social Work Practice. *British Journal of Social Work*, 45(S1), i117-i134.
- Fox, M. (2002). A Question of Survival: Who Cares for Carers? *Journal of Social Work Practice*, 16(2).
- Francis, B., Harman, J. C., McIlmurray, M. B., Morris, S. M., Soothill, K., & Thomas, C. (2002). Cancer and Faith. Having Faith - Does It Make a Difference among Patients and Their Informal Carers. *Scandinavian Journal of Caring Sciences*, 16(3), 256-263.
- Francis, J., Greenwell, K., James, P., Robinson, L., Rodgers, H., & Tindle, N. (2005). Caring for Carers of People with Stroke: Developing a Complex Intervention Following the Medical Research Council Framework. *Clinical Rehabilitation*, 19(5), 560-571.
- Francis, S., Smith, F., & Gray, N. (2006). Partnerships between Older People and Their Carers in the Management of Medication. *International Journal of Older People Nursing*, 1(4), 201-207.
- Francis, S. A., Smith, F., Gray, N., & Graffy, J. (2002). The Roles of Informal Carers in the Management of Medication for Older Care-Recipients. *International Journal of Pharmacy Practice*, 10(1), 1-9.
- Francke, A. L., Verkaik, R., Peeters, J. M., Spreeuwenberg, P., de Lange, J., & Pot, A. M. (2015). Dementia Case Management through the Eyes of Informal Carers. A National Evaluation Study. *Dementia (London, England)*.
- Frank, A. O., Ward, J., Orwell, N. J., McCullagh, C., & Belcher, M. (2000). Introduction of a New NHS Electric-Powered Indoor/Outdoor Chair (Epioc) Service: Benefits, Risks and Implications for Prescribers. *Clinical Rehabilitation*, 14(6), 665-673.
- Frank, J., & Slatcher, C. (2009). Supporting Young Carers and Their Families Using a Whole Family Approach. *Journal of Family Health Care*, 19(3), 86-89.
- Fraser, E., & Pakenham, K. I. (2008). Evaluation of a Resilience-Based Intervention for Children of Parents with Mental Illness. *Australian & New Zealand Journal of Psychiatry*, 42(12), 1041-1050.

- Fraser, E., & Pakenham, K. I. (2009). Resilience in Children of Parents with Mental Illness: Relations between Mental Health Literacy, Social Connectedness and Coping, and Both Adjustment and Caregiving. *Psychology, Health & Medicine*, 14(5), 573-584.
- Free, T. (2002). Counsel of Success. *Journal of Dementia Care*, 10(6), 18.
- Frey, R., Williams, L., Trussardi, G., Black, S., Robinson, J., Moeke-Maxwell, T., & Gott, M. (2016). The Views of Informal Carers' Evaluation of Services (Voices): Toward an Adaptation for the New Zealand Bicultural Context. *Palliative and Supportive Care*, 1-10.
- Friedemann-Sanchez, G. (2012). Caregiving Patterns in Rural Andean Colombia. *Feminist Economics*, 18(3), 55-80.
- Friedemann-Sanchez, G., & Griffin, J. M. (2011). Defining the Boundaries between Unpaid Labor and Unpaid Caregiving: Review of the Social and Health Sciences Literature. *Journal of Human Development and Capabilities*, 12(4), 511-534.
- Friedman, S. M., Steinwachs, D. M., Temkin-Greener, H., & Mukamel, D. B. (2006). Informal Caregivers and the Risk of Nursing Home Admission among Individuals Enrolled in the Program of All-Inclusive Care for the Elderly. *Gerontologist*, 46(4), 456-463.
- Fujinami, R., Sun, V., Zachariah, F., Uman, G., Grant, M., & Ferrell, B. (2015). Family Caregivers' Distress Levels Related to Quality of Life, Burden, and Preparedness. *Psycho-Oncology*, 24(1), 54-62.
- Fukahori, R., Sakai, T., & Sato, K. (2015). The Effects of Incidence of Care Needs in Households on Employment, Subjective Health, and Life Satisfaction among Middle-Aged Family Members. *Scottish Journal of Political Economy*, 62(5), 518-545.
- Fukui, S., Fukui, N., & Kawagoe, H. (2004). Predictors of Place of Death for Japanese Patients with Advanced-Stage Malignant Disease in Home Care Settings: A Nationwide Survey. *Cancer*, 101(2), 421-429.
- Fulford, M., & Farhall, J. (2001). Hospital Versus Home Care for the Acutely Mentally Ill? Preferences of Caregivers Who Have Experienced Both Forms of Service. *Aust N Z J Psychiatry*, 35(5), 619-625.
- Funk, L., Staiduhar, K., Tove, C., Aoun, S., Grande, G., & Todd, C. (2010). Part 2: Home-Based Family Caregiving at the End of Life: A Comprehensive Review of Published Quantitative Research (1998-2008). *Palliat Med*, 24(6), 594-607.
- Furness, L., Simpson, R., Chakrabarti, S., & Dennis, M. S. (2000). A Comparison of Elderly Day Care and Day Hospital Attenders in Leicestershire: Client Profile Carer Stress and Unmet Need. *Aging and Mental Health*, 4(4), 324-329.
- Galfin, J. M., Watkins, E. R., & Harlow, T. (2010). Psychological Distress and Rumination in Palliative Care Patients and Their Caregivers. *J Palliat Med*, 13(11), 1345-1348.
- Gall, S. H., Atkinson, J., Elliott, L., & Johansen, R. (2003). Supporting Carers of People Diagnosed with Schizophrenia: Evaluating Change in Nursing Practice Following Training. *Journal of Advanced Nursing*, 41(3), 295-305.
- Gall, S. H., Elliott, L., Atkinson, J. M., & Johansen, R. (2001). Training Nurses to Support Carers of Relatives with Schizophrenia. *B J Nurs*, 10(4), 238-241.
- Gandy, R., Wilford, S., & Alexander, A. (2012). Young Carers and End of Life Services. *British Journal of Healthcare Management*, 18(6), 298-306.
- Gans, D., Lowenstein, A., Katz, R., & Zissimopoulos, J. (2013). Is There a Trade-Off between Caring for Children and Caring for Parents? *Journal of Comparative Family Studies*, 44(4), 455-471.
- Ganyo, M., Dunn, M., & Hope, T. (2011). Ethical Issues in the Use of Fall Detectors. *Ageing & Society*, 31(8), 1350-1367.

- García Alcaraz, F., Delicado Useros, V., Alfaro Espín, A., & López-Torres Hidalgo, J. (2015). The Use of Social Healthcare Resources and Informal Care Characteristics Care of Immobilised Homecare Patients. *Atencion Primaria / Sociedad Española De Medicina De Familia Y Comunitaria*, 47(4), 195-204.
- García-Calvente, M. D. M., Castaño-López, E., Mateo-Rodríguez, I., Maroto-Navarro, G., & Ruiz-Cantero, M. T. (2007). A Tool to Analyse Gender Mainstreaming and Care-Giving Models in Support Plans for Informal Care: Case Studies in Andalusia and the United Kingdom. *Journal of Epidemiology and Community Health*, 61(SUPPL. 2).
- Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L., & Gott, M. (2014). Exploring the Financial Impact of Caring for Family Members Receiving Palliative and End-of-Life Care: A Systematic Review of the Literature. *Palliative Medicine*, 28(5), 375-390.
- Garrido-Garcia, S., Sanchez-Martinez, F. I., Abellan-Perpinan, J. M., & van Exel, J. (2015). Monetary Valuation of Informal Care Based on Carers' and Noncarers' Preferences. *Value in Health*, 18(6), 832-840.
- Garter, P. (2003). Sexual Health. *Research Matters*, 29.
- Garvelink, M. M., Ngangue, P. A. G., & Adejpedjou, R. (2016). A Synthesis of Knowledge About Caregiver Decision Making Finds Gaps in Support for Those Who Care for Aging Loved Ones. *Health Aff*, 35(4), 619-626.
- Gates, L., & Akabas, S. (2012). Meeting the Demands of Work and Responsibilities of Caring for a Child with Asthma: Consequences for Caregiver Well-Being. *Journal of Social Service Research*, 38(5), 656-671.
- Gau, Y. M., Buettner, P., Usher, K., & Stewart, L. (2014). Development and Validation of an Instrument to Measure the Burden Experienced by Community Health Volunteers. *Journal of Clinical Nursing*, 23(19-20), 2740-2747.
- Gaugler, J., & Kane, R. (2005). The Effects of Duration of Caregiving on Institutionalization. *Gerontologist*, 45(1), 78-89.
- Gaugler, J. E. (2010). The Longitudinal Ramifications of Stroke Caregiving: A Systematic Review. *Rehabilitation Psychology*, 55(2), 108-125.
- Gaugler, J. E., Given, W. C., Linder, J., Kataria, R., Tucker, G., & Regine, W. F. (2008). Work, Gender, and Stress in Family Cancer Caregiving. *Supportive Care in Cancer*, 16(4), 347-357.
- Gaugler, J. E., Zarit, S. H., Townsend, A., Stephens, M. A. P., & Greene, R. (2003). Evaluating Community-Based Programs for Dementia Caregivers: The Cost Implications of Adult Day Services. *Journal of Applied Gerontology*, 22(1), 118-133.
- Gault, I. (2009). Service-User and Carer Perspectives on Compliance and Compulsory Treatment in Community Mental Health Services. *Health Soc Care Community*, 17(5), 504-513.
- Gavrilova, S. I., Ferri, C. P., Mikhaylova, N., Sokolova, O., Banerjee, S., & Prince, M. (2009). Helping Carers to Care - the 10/66 Dementia Research Group's Randomized Control Trial of a Caregiver Intervention in Russia. *International Journal of Geriatric Psychiatry*, 24(4), 347-354.
- Gee, A., McGarty, C., & Banfield, M. (2016). Barriers to Genuine Consumer and Carer Participation from the Perspectives of Australian Systemic Mental Health Advocates. *Journal of Mental Health*, 25(3), 231-237.
- Gee, M., Ager, W., & Haddow, A. (2009). The Caring Experience: Learning About Community Care through Spending 24 Hours with People Who Use Services and Family Carers. *Social Work Education (The International Journal)*, 28(7), 691-706.

- Genaamd Kolmer, B., Bongers, I. M. B., Garretsen, H. F. L., & Tellings, A. E. J. M. (2004). Family Care: A Conceptual Clarification: Challenges for Future Health Policy and Practice. *Eurohealth*, 10(3-4), 44-47.
- Gené Badia, J., Contel Segura, J. C., Hidalgo García, A., Borràs Santos, A., Porta Borges, M., Oliver Olius, A., Saus Arus, M., Ascaso Terren, C., Piñeiro González, M., Cegri Lombardo, F., Limón Ramírez, E., Aranzana Martínez, A., Heras Tebar, A., Noguera Rodríguez, R., Pedret Llaberia, R., Borrell Muñoz, M., Camprubí Casellas, M. D., Ortiz Molina, J., Martín Royo, J., & Gonzalez Martinez, S. (2009). Health Problems Also Explain Social Services Use in Home Care. *Atencion Primaria*, 41(2), 91-101.
- Genet, N., Boerma, W. G. W., Kringos, D. S., Bouman, A., Francke, A. L., Fagerstrom, C., Melchiorre, M. G., Greco, C., & Deville, W. (2011). Home Care in Europe: A Systematic Literature Review. *BMC Health Services Research*, 11.
- George, S., Boulay, S., Jones, H., Bartlett, C., Farley, T., & Clarke, C. (2009). Carers' Clinics: Support Group for Carers of Heroin Addicts. *Psychiatric Bulletin*, 33(11), 426-428.
- Georges, J., & Gove, D. (2007). Disclosing a Diagnosis: The Alzheimer Europe Position. *Journal of Dementia Care*, 15(6), 28-30.
- Georges, J., Jansen, S., Jackson, J., Meyrieux, A., Sadowska, A., & Selmes, M. (2008). Alzheimer's Disease in Real Life - the Dementia Carer's Survey. *International Journal Of Geriatric Psychiatry*, 23(5), 546-551.
- Gerdner, L., Buckwalter, K., & Reed, D. (2002). Impact of a Psychoeducational Intervention on Caregiver Response to Behavioral Problems. *Nursing Research*, 51(6), 363-374.
- Gerrish, K. (2008). Caring for the Carers: The Characteristics of District Nursing Support for Family Carers. *Primary Health Care Research & Development*, 9(1), 14-24.
- Gettings, S., Franco, F., & Santosh, P. J. (2015). Facilitating Support Groups for Siblings of Children with Neurodevelopmental Disorders Using Audio-Conferencing: A Longitudinal Feasibility Study. *Child and Adolescent Psychiatry and Mental Health*, 9, 8-8.
- Geyer, J., & Korfhage, T. (2015). Long-Term Care Insurance and Carers' Labor Supply - a Structural Model. *Health Economics*, 24(9), 1178-1191.
- Ghosh, S., Ha, J.-H., Pai, M., Essenfeld, H., & Park, S. M. (2016). Impact of Mid-Life Symptoms of Alcoholism on the Health and Wellbeing of Aging Parents of Adults with Disabilities. *Journal of Gerontological Social Work*, 59(1), 56-72.
- Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2007). The Impact of Location on Satisfaction with Dementia Services Amongst People with Dementia and Their Informal Carers: A Comparative Evaluation of a Community-Based and a Clinic-Based Memory Service. *International Psychogeriatrics / IPA*, 19(2), 267-277.
- Giebel, C., Sutcliffe, C., Verbeek, H., Zabalegui, A., Soto, M., Hallberg, I. R., Saks, K., Renom-Guiteras, A., Suhonen, R., & Challis, D. (2016). Depressive Symptomatology and Associated Factors in Dementia in Europe: Home Care Versus Long-Term Care. *International Psychogeriatrics*, 28(4), 621-630.
- Giebel, C. M., Sutcliffe, C., & Challis, D. (2014). Activities of Daily Living and Quality of Life across Different Stages of Dementia: A UK Study. *Aging and Mental Health*, 19(1), 63-71.
- Giebel, C. M., Sutcliffe, C., Stolt, M., Karlsson, S., Renom-Guiteras, A., Soto, M., Verbeek, H., Zabalegui, A., & Challis, D. (2014). Deterioration of Basic Activities of Daily Living and Their Impact on Quality of Life across Different Cognitive Stages of Dementia: A European Study. *International Psychogeriatrics*, 26(8), 1283-1293.
- Giesbrecht, M., Crooks, V. A., & Williams, A. (2010). Perspectives from the Frontlines: Palliative Care Providers' Expectations of Canada's Compassionate Care Benefit Programme. *Health & Social Care in The Community*, 18(6), 643-652.

- Gilbert, E., Ussher, J. M., & Hawkins, Y. (2009). Accounts of Disruptions to Sexuality Following Cancer: The Perspective of Informal Carers Who Are Partners of a Person with Cancer. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine*, 13(5), 523-541 519p.
- Gilbert, E., Ussher, J. M., & Perz, J. (2014). 'Not That I Want to Be Thought of as a Hero': Narrative Analysis of Performative Masculinities and the Experience of Informal Cancer Caring. *Psychology & Health*, 29(12), 1442-1457.
- Gilbert, E., Ussher, J. M., Perz, J., Hobbs, K., & Kirsten, L. (2010). Positive and Negative Interactions with Health Professionals. *Cancer Nursing*, 33(6), E1-E9.
- Gilbertson, L., Ainge, S., Dyer, R., & Platts, G. (2003). Consulting Service Users: The Stroke Association Home Therapy Project. *British Journal of Occupational Therapy*, 66(6), 255-262.
- Gill, L., McCaffrey, N., Cameron, I. D., Ratcliffe, J., Kaambwa, B., Corlis, M., Fiebig, J., & Gresham, M. (2016). Consumer Directed Care in Australia: Early Perceptions and Experiences of Staff, Clients and Carers. *Health and Social Care in the Community*.
- Gillespie, D., & Campbell, F. (2011). Effect of Stroke on Family Carers and Family Relationships. *Nursing Standard*, 26(2), 39-46.
- Gilley, D. W. (2006). Commentary. *Evidence Based Mental Health*, 9(1), 19-19.
- Gilliard, J., Means, R., Beattie, A., & Daker-White, G. (2005). Dementia Care in England and the Social Model of Disability. *Dementia: The International Journal of Social Research and Practice*, 4(4), 571-586.
- Gillies, B. (2000). Acting Up: Role Ambiguity and the Legal Recognition of Carers. *Ageing & Society*, 20(4), 429-444.
- Gillies, B. (2012). Continuity and Loss: The Carer's Journey through Dementia. *Dementia: the International Journal of Social Research and Practice*, 11(5), 657-676.
- Gillings-Taylor, S. (2004). Why the Difference? Advice on Breast Examination Given to Carers of Women Who Have Learning Disability and to Women Who Do Not. *Journal of Learning Disabilities*, 8(2), 175-189.
- Gillman, M., Heyman, B., & Swain, J. (2000). What's in a Name? The Implications of Diagnosis for People with Learning Difficulties and Their Family Carers. *Disability and Society*, 15(3), 389-409.
- Ginn, J., & Arber, S. (2000). The Pensions Cost of Caring. *Benefits* (28), 13-18.
- Giordano, A., Cimino, V., Campanella, A., Morone, G., Fusco, A., Farinotti, M., Palmisano, L., Confalonieri, P., Lugaresi, A., Grasso, M. G., Ponzio, M., Veronese, S., Patti, F., & Solari, A. (2016). Low Quality of Life and Psychological Wellbeing Contrast with Moderate Perceived Burden in Carers of People with Severe Multiple Sclerosis. *Journal of the Neurological Sciences*, 366, 139-145.
- Giovannetti, E. R., Reider, L., Wolff, J. L., Frick, K. D., Boulton, C., Steinwachs, D., & Boyd, C. M. (2013). Do Older Patients and Their Family Caregivers Agree About the Quality of Chronic Illness Care? *Int J Qual Health Care*, 25(5), 515-524.
- Girgis, A., Lambert, S., Johnson, C., Waller, A., & Currow, D. (2013). Physical, Psychosocial, Relationship, and Economic Burden of Caring for People with Cancer: A Review. *Journal of oncology practice / American Society of Clinical Oncology*, 9(4), 197.
- Gitlin, L. N., & Rose, K. (2014). Factors Associated with Caregiver Readiness to Use Nonpharmacologic Strategies to Manage Dementia-Related Behavioral Symptoms. *International Journal of Geriatric Psychiatry*, 29(1), 93-102.
- Given, B., Sherwood, P., & Given, C. (2008). What Knowledge and Skills Do Caregivers Need? *American Journal of Nursing*, 108(9), 28-29, 31-24.

- Glaser, K., & Grundy, E. (2002). Class, Caring and Disability: Evidence from the British Retirement Survey. *Ageing & Society*, 22(3), 325-342.
- Glaser, K., Stuchbury, R., Tomassini, C., & Askham, J. (2008). The Long-Term Consequences of Partnership Dissolution for Support in Later Life in the United Kingdom. *Ageing & Society*, 28(3), 329-351.
- Glasper, A. (2010). Patient and Carer Input and the NHS: A Vital Tool in Improving Care. *B J Nurs*, 19(2), 76-77.
- Glaser, K., Evandrou, M., & Tomassini, C. (2005). The Health Consequences of Multiple Roles at Older Ages in the UK. *Health Soc Care Community*, 13(5), 470-477.
- Glendinning, C., Mitchell, W., & Brooks, J. (2015). Ambiguity in Practice? Carers' Roles in Personalised Social Care in England. *Health and Social Care in the Community*, 23, 23-32.
- Glucksmann, M., & Lyon, D. (2006). Configurations of Care Work: Paid and Unpaid Elder Care in Italy and the Netherlands. *Sociological Research Online*, 11(2).
- Godwin, B. (2012). The Ethical Evaluation of Assistive Technology for Practitioners: A Checklist Arising from a Participatory Study with People with Dementia, Family and Professionals. *Journal of Assistive Technologies*, 6(2), 123-135.
- Goldschmidt, D., Schmidt, L., Krasnik, A., Christensen, U., & Groenvold, M. (2006). Expectations to and Evaluation of a Palliative Home-Care Team as Seen by Patients and Carers. *Supportive Care in Cancer: Official Journal of The Multinational Association Of Supportive Care In Cancer*, 14(12), 1232-1240.
- Golynger, O. (2015). Family-Friendly Reform of Employment Law in the UK: An Overstretched Flexibility. *Journal of Social Welfare & Family Law*, 37(3), 378-392.
- Gómez, A. G., Pfeiffer, C. C., Ugalde, P. C., & Revilla, P. G. (2005). Group of Support and Mutual Help for Informal Carers of Dependent Elderly People. *Gerokomos*, 16(2), 74-79 76p.
- Gomez-Gallego, M., Gomez-Amor, J., & Ato, M. (2010). Assessing Quality of Life in Alzheimer's Disease: Agreement between Patients, Informal Carers and Professional Carers. *Journal of Neurology*, 257, S165-S165.
- Gomez-Gallego, M., Gomez-Amor, J., & Gomez-Garcia, J. (2010). Determinants of the Quality of Life in Alzheimer's Disease: Perspective of Patients, Informal Carers and Professional Carers. *Journal of Neurology*, 257, S164-S164.
- Gonçalves-Pereira, M., & Sampaio, D. (2011). Family Psychoeducation in Dementia: From Clinical Practice to Public Health. *Revista Portuguesa de Saude Publica*, 29(1), 3-10.
- Goodwin, V., & Happell, B. (2006). Conflicting Agendas between Consumers and Carers: The Perspectives of Carers and Nurses. *International Journal of Mental Health Nursing*, 15(2), 135-143.
- Goodwin, V., & Happell, B. (2007). Psychiatric Nurses Enhancing Consumer and Caregiver Participation in the State of Victoria: The Impact of History and Policy. *Policy, Politics & Nursing Practice*, 8(1), 55-63 59p.
- Gopinath, B., Kifley, A., Cummins, R., Heraghty, J., & Mitchell, P. (2015). Predictors of Psychological Distress in Caregivers of Older Persons with Wet Age-Related Macular Degeneration. *Aging & Mental Health*, 19(3), 239-246.
- Gorfin, L., & McGlaughlin, A. (2004). Planning for the Future with Adults with a Learning Disability Living with Older Carers. *Housing Care and Support*, 7(3), 2-24.
- Gori, C. (2012). Home Care in Italy: A System on the Move, in the Opposite Direction to What We Expect. *Health Soc Care Community*, 20(3), 255-264.

- Gormley, N. (2000). The Role of Dementia Training Programmes in Reducing Care-Giver Burden. *Psychiatric Bulletin*, 24(2), 41-42.
- Gosman-Hedstrom, G., & Dahlin-Ivanoff, S. (2012). 'Mastering an Unpredictable Everyday Life after Stroke' - Older Women's Experiences of Caring and Living with Their Partners. *Scandinavian Journal of Caring Sciences*, 26(3), 587-597.
- Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older People's Views About Home as a Place of Care at the End of Life. *Palliative Medicine*, 18(5), 460-467.
- Graessel, E., Trilling, A., Donath, C., & Luttenberger, K. (2010). Support Groups for Dementia Caregivers Predictors for Utilisation and Expected Quality from a Family Caregiver's Point of View: A Questionnaire Survey Part I. *BMC Health Services Research*, 10(219).
- Graff, M. J. L., Vernooij-Dassen, M., Thissen, M., Dekker, J., Hoefnagels, W. H., & Rikkert, M. G. (2006). Community Based Occupational Therapy for Patients with Dementia and Their Care Givers: Randomised Controlled Trial. *BMJ*, 333(7580), 1196.
- Graham, C. R., Banerjee, S., & Gill, R. S. (2009). Using Postal Questionnaires to Identify Carer Depression Prior to Initial Patient Contact. *Psychiatric Bulletin*, 33(5), 169-171.
- Grande, G., Stajduhar, K., & Aoun, S. (2009). Supporting Lay Carers in End of Life Care: Current Gaps and Future Priorities. *Palliative Medicine*, 23(4), 339-344.
- Grande, G., Todd, C., Barclay, S., & Farquhar, M. (2000). A Randomized Controlled Trial of a Hospital at Home Service for the Terminally Ill. *Palliative Medicine*, 14(5), 375-385.
- Grande, G. E., & Ewing, G. (2009). Informal Carer Bereavement Outcome: Relation to Quality of End of Life Support and Achievement of Preferred Place of Death. *Palliative Medicine*, 23(3), 248-256.
- Grande, G. E., Farquhar, M. C., Barclay, S. I., & Todd, C. J. (2004). Caregiver Bereavement Outcome: Relationship with Hospice at Home, Satisfaction with Care, and Home Death. *Journal of Palliative Care*, 20(2), 69.
- Grande, G. E., Farquhar, M. C., Barclay, S. I., & Todd, C. J. (2004). Valued Aspects of Primary Palliative Care: Content Analysis of Bereaved Carers' Descriptions. *The British Journal of General Practice: The Journal of The Royal College of General Practitioners*, 54(507), 772-778.
- Grande, G. E., Farquhar, M. C., Barclay, S. I., & Todd, C. J. (2006). The Influence of Patient and Carer Age in Access to Palliative Care Services. *Age & Ageing*, 35(3), 267-273.
- Grande, G. E., McKerral, A., & Todd, C. J. (2002). Which Cancer Patients Are Referred to Hospital at Home for Palliative Care? *Palliative Medicine*, 16(2), 115-123.
- Graneheim, U. H., Johansson, A., & Lindgren, B.-M. (2014). Family Caregivers' Experiences of Relinquishing the Care of a Person with Dementia to a Nursing Home: Insights from a Meta-Ethnographic Study. *Scandinavian Journal of Caring Sciences*, 28(2), 215-224.
- Grant, G., Repper, J., & Nolan, M. (2008). Young People Supporting Parents with Mental Health Problems: Experiences of Assessment and Support. *Health & Social Care in The Community*, 16(3), 271-281.
- Grant, G., & Whittel, B. (2000). Differentiated Coping Strategies in Families with Children or Adults with Intellectual Disabilities: The Relevance of Gender, Family Composition and the Life Span. *Journal of Applied Research in Intellectual Disabilities*, 13(4), 256-275.
- Grant, J. S., Elliott, T. R., Giger, J. N., & Bartolucci, A. A. (2001). Social Problem-Solving Telephone Partnerships with Family Caregivers of Persons with Stroke. *International Journal of Rehabilitation Research*, 24(3), 181-189.



- Grant, M., Cavanagh, A., & Yorke, J. (2012). The Impact of Caring for Those with Chronic Obstructive Pulmonary Disease (COPD) on Carers' Psychological Well-Being: A Narrative Review. *Int J Nurs Stud*, 49(11), 1459-1471.
- Graven, C., Sansonetti, D., Moloczij, N., Cadilhac, D., & Joubert, L. (2013). Stroke Survivor and Carer Perspectives of the Concept of Recovery: A Qualitative Study. *Disability and Rehabilitation*, 35(7), 578-585.
- Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Third-Party Disability in Family Members of People with Aphasia: A Systematic Review. *Disability and Rehabilitation*, 35(16), 1324-1341.
- Gray, B., & Robinson, C. (2009). Hidden Children: Perspectives of Professionals on Young Carers of People with Mental Health Problems. *Child Care in Practice*, 15(2), 95-108.
- Gray, B., Robinson, C., & Seddon, D. (2008). Invisible Children: Young Carers of Parents with Mental Health Problems - the Perspectives of Professionals. *Child & Adolescent Mental Health*, 13(4), 169-172.
- Gray, B., Robinson, C., Seddon, D., & Roberts, A. (2010). Patterns of Exclusion of Carers for People with Mental Health Problems - the Perspectives of Professionals. *Journal of Social Work Practice*, 24(4), 475-492.
- Gray, B., Robinson, C. A., Seddon, D., & Roberts, A. (2008). 'Confidentiality Smokescreens' and Carers for People with Mental Health Problems: The Perspectives of Professionals. *Health and Social Care in The Community*, 16(4), 376-387.
- Gray, B., Robinson, C. A., Seddon, D., & Roberts, A. (2009). An Emotive Subject: Insights from Social, Voluntary and Healthcare Professionals into the Feelings of Family Carers for People with Mental Health Problems. *Health & Social Care in The Community*, 17(2), 125-132.
- Gray, M., Edwards, B. E. N., & Zmijewski, N. (2008). Caring and Women's Labour Market Participation. *Family Matters* (78), 28-35.
- Gray, M., & Heinsch, M. (2009). Ageing in Australia and the Increased Need for Care. *Ageing International*, 34(3), 102-118.
- Gray, R. J., Myint, P. K., Elender, F., Barton, G., Pfeil, M., Price, G., Wyatt, N., Ravenhill, G., Thomas, E., Jagger, J., Hursey, A., Waterfield, K., & Hardy, S. (2011). A Depression Recognition and Treatment Package for Families Living with Stroke (Depret-Stroke): Study Protocol for a Randomised Controlled Trial. *Trials*, 12.
- Grbich, C. F., Maddocks, I., & Parker, D. (2001). Family Caregivers, Their Needs, and Home-Based Palliative Cancer Services. *Journal of Family Studies*, 7(2), 171-188.
- Greenwood, N., & Habibi, R. (2014). Carer Mentoring: A Mixed Methods Investigation of a Carer Mentoring Service. *International Journal of Nursing Studies*, 51(3), 359-369.
- Greenwood, N., Habibi, R., & Mackenzie, A. (2012). Respite: Carers' Experiences and Perceptions of Respite at Home. *BMC Geriatrics*, 12, 42-42.
- Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to Access and Minority Ethnic Carers' Satisfaction with Social Care Services in the Community: A Systematic Review of Qualitative and Quantitative Literature. *Health Soc Care Community*, 23(1), 64-78.
- Greenwood, N., Holley, J., Ellmers, T., Bowling, A., & Cloud, G. (2015). Assessing Satisfaction with Social Care Services among Black and Minority Ethnic and White British Carers of Stroke Survivors in England. *Health and Social Care in the Community*.
- Greenwood, N., Holley, J., Ellmers, T., Mein, G., & Cloud, G. (2016). Qualitative Focus Group Study Investigating Experiences of Accessing and Engaging with Social Care Services:

- Perspectives of Carers from Diverse Ethnic Groups Caring for Stroke Survivors. *BMJ Open*, 6(1), e009498-e009498.
- Greenwood, N., & Mackenzie, A. (2010). An Exploratory Study of Anxiety in Carers of Stroke Survivors. *Journal of Clinical Nursing*, 19(13/14), 2032-2038 2037p.
- Greenwood, N., & Mackenzie, A. (2010). Informal Caring for Stroke Survivors: Meta-Ethnographic Review of Qualitative Literature. *Maturitas*, 66(3), 268-276.
- Greenwood, N., Mackenzie, A., Cloud, G., & Wilson, N. (2010). Loss of Autonomy, Control and Independence When Caring: A Qualitative Study of Informal Carers of Stroke Survivors in the First Three Months after Discharge. *Disability & Rehabilitation*, 32(2), 125-133 129p.
- Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2008). Informal Carers of Stroke Survivors-Factors Influencing Carers: A Systematic Review of Quantitative Studies. *Disability & Rehabilitation*, 30(18), 1329-1349 1321p.
- Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2009). Informal Primary Carers of Stroke Survivors Living at Home-Challenges, Satisfactions and Coping: A Systematic Review of Qualitative Studies. *Disability & Rehabilitation*, 31(5), 337-351.
- Greenwood, N., Mackenzie, A., Habibi, R., Atkins, C., & Jones, R. (2010). General Practitioners and Carers: A Questionnaire Survey of Attitudes, Awareness of Issues, Barriers and Enablers to Provision of Services. *BMC Family Practice*, 11, 100-107.
- Greenwood, N., Mackenzie, A., & Harris, R. (2008). New Deal for Carers or Unfair Deal: What Is in It for Informal Carers of Stroke Survivors? *Policy and Politics*, 36(2), 299-303.
- Greenwood, N., Mackenzie, A., Harris, R., Fenton, W., & Cloud, G. (2011). Perceptions of the Role of General Practice and Practical Support Measures for Carers of Stroke Survivors: A Qualitative Study. *BMC Family Practice*, 12.
- Greenwood, N., Mackenzie, A., Wilson, N., & Cloud, G. (2009). Managing Uncertainty in Life after Stroke: A Qualitative Study of the Experiences of Established and New Informal Carers in the First 3 Months after Discharge. *International Journal of Nursing Studies*, 46(8), 1122-1133 1112p.
- Greenwood, N., Pelone, F., & Hassenkamp, A. M. (2016). General Practice Based Psychosocial Interventions for Supporting Carers of People with Dementia or Stroke: A Systematic Review. *BMC Family Practice*, 17.
- Greenwood, N., & Smith, R. (2015). Barriers and Facilitators for Male Carers in Accessing Formal and Informal Support: A Systematic Review. *Maturitas*, 82(2), 162-169.
- Greenwood, N., & Smith, R. (2016). The Oldest Carers: A Narrative Review and Synthesis of the Experiences of Carers Aged over 75 Years. *Maturitas*, 94, 161-172.
- Gregory, N., Collins-Atkins, C., & Macpherson, R. (2006). Identifying the Needs of Carers in Mental Health Services. *Nursing Times*, 102(17), 32-35.
- Gregory, N., & Macpherson, R. (2010). Assertive Outreach Handbook Will Aid Mental Health Staff in Maintaining Client Engagement. *Nursing Times* (23.2.10), 16-17.
- Griffiths, P., Bridges, J., Sheldon, H., & Thompson, R. (2015). The Role of the Dementia Specialist Nurse in Acute Care: A Scoping Review. *J Clin Nurs*, 24(9-10), 1394-1405.
- Grimshaw, J. M., Eccles, M. P., Lavis, J. N., & Hill, J. & Squires., J. E. (2012). Knowledge Translation of Research Findings. *Implementation Science*, 7.
- Grinyer, A. (2006). Caring for a Young Adult with Cancer: The Impact on Mothers' Health. *Health & Social Care in The Community*, 14(4), 311-318.
- Grootegeod, E., Knijn, T., & Roit, B. D. (2010). Relatives as Paid Care-Givers: How Family Carers Experience Payments for Care. *Ageing and Society*, 30(3), 467-489.

- Grose, J., Frost, J., Richardson, J., & Skirton, H. (2013). Using Meta-Ethnography to Understand the Emotional Impact of Caring for People with Increasing Cognitive Impairment. *Nurs Health Sci*, 15(1), 113-123.
- Gross, R., Brammli-Greenberg, S., & Bentur, N. (2003). Women Caring for Disabled Parents and Other Relatives: Implications for Social Workers in the Health Services. *Social Work in Health Care*, 37(4), 19-37.
- Grov, E. K., Fossa, S. D., Sorebo, O., & Dahl, A. A. (2006). Primary Caregivers of Cancer Patients in the Palliative Phase: A Path Analysis of Variables Influencing Their Burden. *Soc Sci Med*, 63(9), 2429-2439.
- Grover, C. (2005). Living Wages and the 'Making Work Pay' Strategy. *Critical Social Policy*, 25(1), 5-27.
- Gruffydd, E., & Randle, J. (2006). Alzheimer's Disease and the Psychosocial Burden for Caregivers. *Community Practitioner*, 79(1), 15-18.
- Grundy, E., & Henretta, J. C. (2006). Between Elderly Parents and Adult Children: A New Look at the Intergenerational Care Provided by the 'Sandwich Generation'. *Ageing & Society*, 26(5), 705-722.
- Guberman, N., Keefe, J., Fancey, P., & Barylak, L. (2007). 'Not Another Form!': Lessons for Implementing Carer Assessment in Health and Social Service Agencies. *Health and Social Care in the Community*, 15(6), 577-587.
- Guberman, N., Lavoie, J.-P., & Olazabal, I. (2011). Baby-Boomers and the 'Denaturalisation' of Care-Giving in Quebec. *Ageing and Society*, 31(7), 1141-1158.
- Guberman, N., Nicholas, E., Nolan, M., Rembicki, D., Lundh, U., & Keefe, J. (2003). Impacts on Practitioners of Using Research-Based Carer Assessment Tools: Experiences from the UK, Canada and Sweden, with Insights from Australia. *Health and Social Care in The Community*, 11(4), 345-355.
- Guise, J., McKinlay, A., & Widdicombe, S. (2010). The Impact of Early Stroke on Identity: A Discourse Analytic Study. *Health*, 14(1), 75-90.
- Gullick, J. G., & Stainton, C. M. (2012). The Ties That Bind Us: How Existing Relationships, Health and Gender Shape Family Care in Chronic Obstructive Pulmonary Disease. *Nursing Reports*, 2(1), e6-e6.
- Gupta, D., Smith, F., & Francis, S. A. (2002). Investigating Medicines-Related Roles and Problems Experienced by Informal Carers of Older Patients. *Hospital Pharmacist*, 9(2), 55-58.
- Gustavsson, A., Jonsson, L., & McShane, R. (2010). Willingness-to-Pay for Reductions in Care Need: Estimating the Value of Informal Care in Alzheimer's Disease. *International Journal of Geriatric Psychiatry*, 25(6), 622-632.
- Gysels, M., Bausewein, C., & Higginson, I. J. (2007). Experiences of Breathlessness: A Systematic Review of the Qualitative Literature. *Palliative and Supportive Care*, 5(3), 281-302.
- Gysels, M., & Higginson, I. J. (2009). Reconciling Employment with Caring for a Husband with an Advanced Illness. *BMC Health Services Research*, 9.
- Gysels, M., Pell, C., Straus, L., & Pool, R. (2011). End of Life Care in Sub-Saharan Africa: A Systematic Review of the Qualitative Literature. *BMC Palliative Care*, 10.
- Gysels, M. H., & Higginson, I. J. (2009). Caring for a Person in Advanced Illness and Suffering from Breathlessness at Home: Threats and Resources. *Palliative & Supportive Care*, 7(2), 153-162.
- Gzil, F. (2008). Ethical Issues in Informal Care for Alzheimer Patients. *NPG Neurologie - Psychiatrie - Geriatrie*, 8(48), 8-21.

- Ha Trong, N., & Connelly, L. B. (2014). The Effect of Unpaid Caregiving Intensity on Labour Force Participation: Results from a Multinomial Endogenous Treatment Model. *Social Science & Medicine*, 100, 115-122.
- Haberkern, K., Schmid, T., & Szydlik, M. (2015). Gender Differences in Intergenerational Care in European Welfare States. *Ageing & Society*, 35(2), 298-320.
- Habermann, S., Cooper, C., Katona, C., & Livingston, G. (2009). Predictors of Entering 24-H Care for People with Alzheimer's Disease: Results from the Laser-Ad Study. *International Journal of Geriatric Psychiatry*, 24(11), 1291-1298.
- Haddock, G., Barrowclough, C., Tarrier, N., Moring, J., O'Brien, R., Schofield, N., Quinn, J., Palmer, S., Davies, L., Lowens, I., McGovern, J., & Lewis, S. (2003). Cognitive-Behavioural Therapy and Motivational Intervention for Schizophrenia and Substance Misuse: 18-Month Outcomes of a Randomised Controlled Trial. *British Journal of Psychiatry*, 183(11), 418-426.
- Hafsteinsdottir, T. B., Verqunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational Needs of Patients with a Stroke and Their Caregivers: A Systematic Review of the Literature. *Patient Education and Counselling*, 85(1), 14-25.
- Hägglund, M., Scandurra, I., & Koch, S. (2009). Studying Intersection Points - an Analysis of Information Needs for Shared Homecare of Elderly Patients. *Journal on Information Technology in Healthcare*, 7(1), 23-42.
- Haigler, D. H., Bauer, L. J., & Travis, S. S. (2006). "Caring for You, Caring for Me": A Ten-Year Caregiver Educational Initiative of the Rosalynn Carter Institute for Human Development. *Health and Social Work*, 31(2), 149-152.
- Hailey, E., Hodge, S., Burns, A., & Orrell, M. (2016). Patients' and Carers' Experiences of UK Memory Services. *International Journal of Geriatric Psychiatry*, 31(6), 676-680.
- Haley, W. E., Bergman, E. J., Roth, D. L., McVie, T., Gaugler, J. E., & Mittelman, M. S. (2008). Long-Term Effects of Bereavement and Caregiver Intervention on Dementia Caregiver Depressive Symptoms. *Gerontologist*, 48(6), 732-740.
- Hall, J. (2002). Assessing the Health Promotion Needs of Informal Carers. *Nursing Older People*, 14(2), 14-18.
- Hall, J., & Callaghan, P. (2011). Focus Group Study of Service User and Carer Experience of an Integrated Care Pathway. *International Journal of Care Coordination*, 15(2).
- Hall, J., Kenny, P., Hossain, I., Street, D. J., & Knox, S. A. (2014). Providing Informal Care in Terminal Illness: An Analysis of Preferences for Support Using a Discrete Choice Experiment. *Medical Decision Making: An International Journal of The Society for Medical Decision Making*, 34(6), 731-745.
- Hall, L., & Skelton, D. A. (2012). Occupational Therapy for Caregivers of People with Dementia: A Review of the United Kingdom Literature. *British Journal of Occupational Therapy*, 75(6).
- Hallam, L. (2007). How Involuntary Commitment Impacts on the Burden of Care of the Family. *Int J Mental Health Nurs*, 16(4), 247-256.
- Halley, E., Mulligan, E., Pratt, E., Taylor, E., & Tilki, M. (2010). Older Irish People with Dementia in England. *Advances in Mental Health*, 9(3), 221-232.
- Hamill, M., Smith, L., & Rohricht, F. (2012). 'Dancing Down Memory Lane': Circle Dancing as a Psychotherapeutic Intervention in Dementia: A Pilot Study. *Dementia: The International Journal of Social Research and Practice*, 11(6), 709-724.
- Hamilton, M. G., & Adamson, E. (2013). Bounded Agency in Young Carers' Lifecourse-Stage Domains and Transitions. *Journal of Youth Studies*, 16(1), 101-117.

- Hammer, E., & Österle, A. (2003). Welfare State Policy and Informal Long-Term Care Giving in Austria: Old Gender Divisions and New Stratification Processes among Women. *Journal of Social Policy*, 32(1), 37-53.
- Hammond, T., Weinberg, M., & Cummins, R. (2014). The Dyadic Interaction of Relationships and Disability Type on Informal Carer Subjective Well-Being. *Quality of Life Research*, 23(5), 1535-1542.
- Hampson, C., & Smith, S. J. (2015). Helping Occupational Performance through Engagement: A Service Evaluation of a Programme for Informal Carers of People with Dementia. *British Journal of Occupational Therapy*, 78(3), 200-204.
- Hancock, G. A., Reynolds, T., Woods, B., Thornicroft, G., & Orrell, M. (2003). The Needs of Older People with Mental Health Problems According to the User, the Carer, and the Staff. *International Journal of Geriatric Psychiatry*, 18(9), 803-811.
- Handley, E., & Hutchinson, N. (2013). The Experience of Carers in Supporting People with Intellectual Disabilities through the Process of Bereavement: An Interpretative Phenomenological Analysis. *Journal of Applied Research in Intellectual Disabilities*, 26(3), 186-194.
- Hanly, P., Céilleachair, A. Ó., Skally, M., O'Leary, E., Staines, A., Kapur, K., Fitzpatrick, P., & Sharp, L. (2013). Time Costs Associated with Informal Care for Colorectal Cancer: An Investigation of the Impact of Alternative Valuation Methods. *Applied Health Economics and Health Policy*, 11(3), 193-203.
- Hanly, P., Maguire, R., Balfe, M., Hyland, P., Timmons, A., O'Sullivan, E., Butow, P., & Sharp, L. (2016). Burden and Happiness in Head and Neck Cancer Carers: The Role of Supportive Care Needs. *Supportive Care in Cancer: Official Journal of The Multinational Association Of Supportive Care In Cancer*.
- Hanly, P., Maguire, R., Hyland, P., & Sharp, L. (2015). Examining the Role of Subjective and Objective Burden in Carer Health-Related Quality of Life: The Case of Colorectal Cancer. *Supportive Care in Cancer*, 23(7), 1941-1949.
- Hannan, R. (2013). The Triangle of Care: Carers Included. *Journal of Public Mental Health*, 12(3), 171-172.
- Hannon, L. (2004). Better Preadmission Assessment Improves Learning Disability Care. *Nursing Times* (22.6.04), 44-47.
- Hanratty, B. (2000). Palliative Care Provided by GPs: The Carer's Viewpoint. *British Journal of General Practice*, 457(50), 653-654.
- Hanratty, B., Lowson, E., Grande, G., Payne, S., Addington Hall, J. M., Valtorta, N., & Seymour, J. (2014). Transitions at the End of Life for Older Adults: Patient, Carer and Professional Perspectives: A Mixed-Methods Study. *Health Services and Delivery Research*, 2(17).
- Hanson, E. J., & Clarke, A. (2000). The Role of Telematics in Assisting Family Carers and Frail Older People at Home. *Health Soc Care Community*, 8(2), 129-137.
- Hanson, J., Percival, J., Aldred, H., Brownsell, S., & Hawley, M. (2007). Attitudes to Telecare among Older People, Professional Care Workers and Informal Carers: A Preventative Strategy or Crisis Management? *Universal Access in the Information Society*, 6(2), 193-205.
- Hanson, K., & Hamilton, T. (2006). Private Family Arrangements and the Welfare of Adults Who Lack Capacity: An Analysis of the Safeguarding Vulnerable Groups Bill. *Journal of Adult Protection*, 8(3), 16-27.
- Hanssen, H., Norheim, A., & Hanson, E. (2016). How Can Web-Based Training Facilitate a More Carer Friendly Practice in Community-Based Health and Social Care Services in

Norway? Staff Experiences and Implementation Challenges. *Health and Social Care in the Community*.

Harding, C., & Wright, J. (2010). Dysphagia: The Challenge of Managing Eating and Drinking Difficulties in Children and Adults Who Have Learning Disabilities. *Tizard Learning Disability Review*, 15(1), 4-13.

Harding, R., & Higginson, I. (2000). Working with Ambivalence: A Qualitative Study of Informal Carers of Patients with Advanced Illness. *Psycho-Oncology*, 9(4), 357-357.

Harding, R., & Higginson, I. (2001). Working with Ambivalence: Informal Caregivers of Patients at the End of Life. *Supportive Care in Cancer*, 9(8), 642.

Harding, R., Higginson, I., & Leam, C. (2004). Evaluation of a Short-Term Group Intervention for Informal Carers of Patients Attending a Home Palliative Care Service. *Journal of Pain and Symptom Management*, 27(5), 396-408.

Harding, R., & Higginson, I. J. (2003). What Is the Best Way to Help Caregivers in Cancer and Palliative Care? A Systematic Literature Review of Interventions and Their Effectiveness. *Palliative Medicine*, 17(1), 63-74.

Harding, R., Higginson, I. J., & Donaldson, N. (2003). The Relationship between Patient Characteristics and Carer Psychological Status in Home Palliative Cancer Care. *Supportive Care in Cancer: Official Journal of The Multinational Association of Supportive Care in Cancer*, 11(10), 638-643.

Harding, R., & Leam, C. (2005). Clinical Notes for Informal Carers in Palliative Care: Recommendations from a Random Patient File Audit. *Palliative Medicine*, 19(8), 639-642.

Harding, R., Leam, C., Pearce, A., Taylor, E., & Higginson, I. J. (2002). A Multi-Professional Short-Term Group Intervention for Informal Caregivers of Patients Using a Home Palliative Care Service. *Journal of Palliative Care*, 18(4), 275-281.

Harding, R., List, S., Epiphaniou, E., & Jones, H. (2012). How Can Informal Caregivers in Cancer and Palliative Care Be Supported? An Updated Systematic Literature Review of Interventions and Their Effectiveness. *Palliat Med*, 28(1), 7-22.

Harding, R., Smith, P., & Pahl, N. (2004). Informal Carers in Palliative Care: Underserved and Overlooked. *Journal of Palliative Care*, 20(3), 243-243.

Hardy, B., Young, R., & Wistow, G. (2000). Dimensions of Choice in the Assessment and Care Management Process: The Views of Older People, Carers and Care Managers. *Health and Social Care in the Community*, 8(1), 483-491.

Hardy, J., Baynham, J., Brooker, S., Macaulay, P., Vaz, H., & Wiley, S. (2005). Informing and Communicating with Informal Carers of Palliative Care Patients (and Patients without Carers): The Challenges of Undertaking Research. *Journal of Palliative Care*, 21(3), 226-227.

Hare, P., & Newbronner, E. (2002). Supporting the Supporters. *Mental Health Today*, 27-29.

Hare, R., Rogers, H., Lester, H., McManus, R., & Mant, J. (2006). What Do Stroke Patients and Their Carers Want from Community Services? *Fam Pract*, 23(1), 131-136.

Haritou, M., Glickman, Y., Androulidakis, A., Xeferis, S., Anastasiou, A., Baboshin, A., Cuno, S., & Koutsouris, D. (2012). A Technology Platform for a Novel Home Care Delivery Service to Patients with Dementia. *Journal of Medical Imaging and Health Informatics*, 2(1), 49-55.

Harland, J. A., & Bath, P. A. (2008). Understanding the Information Behaviours of Carers of People with Dementia: A Critical Review of Models from Information Science. *Aging and Mental Health*, 12(4), 467-477.

Haro, J. M., Kahle-Wroblewski, K., Bruno, G., Belger, M., Dell'Agnello, G., Dodel, R., Jones, R. W., Reed, C. C., Vellas, B., Wimo, A., & Argimon, J. M. (2014). Analysis of Burden in

- Caregivers of People with Alzheimer's Disease Using Self-Report and Supervision Hours. *Journal of Nutrition, Health and Aging*, 18(7), 677-684.
- Harris, J. (2002). Caring for Citizenship. *British Journal of Social Work*, 32(3), 267-281.
- Harris, M., Diminic, S., Marshall, C., Stockings, E., & Degenhardt, L. (2015). Estimating Service Demand for Respite Care among Informal Carers of People with Psychological Disabilities in Australia. *Australian and New Zealand Journal of Public Health*, 39(3), 284-292.
- Harris, P. B., & Keady, J. (2009). Selfhood in Younger Onset Dementia: Transitions and Testimonies. *Aging and Mental Health*, 13(3), 437-444.
- Harrison, M., Ryan, T., Gardiner, C., & Jones, A. (2013). Patients' and Carers' Experiences of Gaining Access to Acute Stroke Care: A Qualitative Study. *Emergency Medicine Journal*, 30(12), 1033-1037.
- Harriss, K. (2008). Ill Health in the Family: The Intersection of Employment and Caring across Households from Four Ethnic Groups. *Benefits*, 16(1), 33-45.
- Harstone, A., Bergen, S. J. R., & Sweetgrass, M. (2010). Young Carers: Children Caring for Family Members Living with an Illness or Disability. *Relational Child & Youth Care Practice*, 23(1), 39-45.
- Hart, D. J., Craig, D., Compton, S. A., Critchlow, S., Kerrigan, B. M., Mcilroy, S. P., & Passmore, A. P. (2003). A Retrospective Study of the Behavioural and Psychological Symptoms of Mid and Late Phase Alzheimer's Disease. *International Journal of Geriatric Psychiatry*, 18(11), 1037-1042.
- Hart, E. (2001). System Induced Setbacks in Stroke Recovery. *Sociology of Health & Illness*, 23(1), 101-123.
- Hassan, H., & Das, S. (2012). Innovative Approaches for Training Young Carers: Nurses Cannot Be Left Behind. *International Journal of Mental Health Nursing*, 21(5), 492-492.
- Hassink, W. H. J., & van den Berg, B. (2011). Time-Bound Opportunity Costs of Informal Care: Consequences for Access to Professional Care, Caregiver Support, and Labour Supply Estimates. *Social Science & Medicine*, 73(10), 1508-1516.
- Hasson, F., Kernohan, W. G., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H., & Cochrane, B. (2010). An Exploration into the Palliative and End-of-Life Experiences of Carers of People with Parkinson's Disease. *Palliat Med*, 24(7), 731-736.
- Hassouneh-Phillips, D. (2005). Understanding Abuse of Women with Physical Disabilities: An Overview of the Abuse Pathways Model. *Advances in Nursing Science*, 28(1), 70-80.
- Hastall, M. R., Eiermann, N. D., & Ritterfeld, U. (2014). Formal and Informal Carers' Views on ICT in Dementia Care: Insights from Two Qualitative Studies. *Gerontechnology*, 13(1), 53-58.
- Hattink, B. J. J., Meiland, F. J. M., Campman, C. A. M., Rietsema, J., Sitskoorn, M., & Dröes, R.-M. (2015). Experiencing Dementia: Evaluation of into Dementia. *Tijdschrift Voor Gerontologie En Geriatrie*, 46(5), 262-281.
- Hattink, B. J. J., Meiland, F. J. M., Overmars-Marx, T., de Boer, M., Ebben, P. W. G., van Blanken, M., Verhaeghe, S., Stalpers-Croeze, I., Jedlitschka, A., Flick, S. E., van der Leeuw, J., Karkowski, I., & Dröes, R. M. (2016). The Electronic, Personalizable Rosetta System for Dementia Care: Exploring the User-Friendliness, Usefulness and Impact. *Disability and Rehabilitation. Assistive Technology*, 11(1), 61-71.
- Hatzidimitriadou, E., & Milne, A. (2005). Planning Ahead: Meeting the Needs of Older People with Intellectual Disabilities in the United Kingdom. *Dementia: The International Journal of Social Research and Practice*, 4(3), 341-359.

- Hatzmann, J., Peek, N., Heymans, H., Maurice-Stam, H., & Grootenhuis, M. (2014). Consequences of Caring for a Child with a Chronic Disease: Employment and Leisure Time of Parents. *Journal of Child Health Care*, 18(4), 346-357.
- Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M., & Sundquist, K. (2009). Changes in Sexuality and Intimacy after the Diagnosis and Treatment of Cancer: The Experience of Partners in a Sexual Relationship with a Person with Cancer. *Cancer Nursing*, 32(4), 271-280.
- Hawranik, P., & Strain, L. (2007). Giving Voice to Informal Caregivers of Older Adults. *Canadian Journal of Nursing Research*, 39(1), 156-172.
- Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (2015). Quality of Life and Social Isolation among Caregivers of Adults with Schizophrenia: Policy and Outcomes. *Community Mental Health Journal*, 51(5), 591-597.
- Hayman, F. (2005). Helping Carers Care: An Education Programme for Rural Carers of People with a Mental Illness. *Australas Psychiatry*, 13(2), 148-153.
- Hayman, J., & Rasmussen, E. (2013). Gender, Caring, Part Time Employment and Work/Life Balance. *Employment Relations Record*, 13(1), 45.
- Hayslip, B., Han, G., & Anderson, C. I. (2008). Predictors of Alzheimers Disease Caregiver Depression and Burden: What Non-caregiving Adults Can Learn from Active Caregivers. *Educational Gerontology*, 34(11), 945-969.
- Hayward, M., Ockwell, C., Bird, T., Pearce, H., Parfoot, S., & Bates, T. (2005). Making It Work: Service Users and Professionals as Research Partners. *A Life in the Day*, 9(3), 13-17.
- Hazif-Thomas, C., David, P., & Thomas, P. (2013). The Care of Frail Persons: From the Professionals Skills to the Laymen Ones, What Remains of the Medical Act? *Annales Medico-Psychologiques*, 171(8), 574-578.
- He, D., & McHenry, P. (2016). Does Formal Employment Reduce Informal Caregiving? *Health Economics*, 25(7), 829-843.
- Heaton, J. (2001). Hospital Discharge and the Temporal Regulation of Bodies. *Time and Society*, 10(1), 93-111.
- Heaton, J., & Bamford, C. (2001). Assessing the Outcomes of Equipment and Adaptations: Issues and Approaches. *British Journal of Occupational Therapy*, 64(7), 346-356.
- Hecht, M. J., Graesel, E., Tigges, S., Hillemacher, T., Winterholler, M., Hilz, M. J., Heuss, D., & Neundorfer, B. (2003). Burden of Care in Amyotrophic Lateral Sclerosis. *Palliative Medicine*, 17(4), 327-333.
- Heckel, L., Fennell, K. M., Reynolds, J., Osborne, R. H., Chirgwin, J., Botti, M., Ashley, D. M., & Livingston, P. M. (2015). Unmet Needs and Depression among Carers of People Newly Diagnosed with Cancer. *European Journal of Cancer*, 51(14), 2049-2057.
- Hedman, A. M. R., Stromberg, L., Grafstrom, M., & Heikkila, K. (2011). Hip Fracture Patients' Cognitive State Affects Family Members' Experiences - a Diary Study of the Hip Fracture Recovery. *Scandinavian Journal of Caring Sciences*, 25(3), 451-458.
- Heenan, D. (2000). Expectations and Attitudes Affecting Patterns of Informal Care in Farming Families in Northern Ireland. *Ageing and Society*, 20, 203-216.
- Heenan, D. (2000). Informal Care in Farming Families in Northern Ireland: Some Considerations for Social Work. *British Journal of Social Work*, 30(6), 855-866.
- Hegarty, M. M., Abernethy, A. P., Olver, I., & Currow, D. C. (2011). Former Palliative Caregivers Who Identify That Additional Spiritual Support Would Have Been Helpful in a Population Survey. *Palliat Med*, 25(3), 266-277.



- Heitmueller, A. (2007). The Chicken or the Egg? Endogeneity in Labour Market Participation of Informal Carers in England. *Journal of Health Economics*, 26(3), 536-559.
- Heitmueller, A., & Inglis, K. (2007). The Earnings of Informal Carers: Wage Differentials and Opportunity Costs. *Journal of Health Economics*, 26(4), 821-841.
- Heller, T., Gibbons, H. M., & Fisher, D. (2015). Caregiving and Family Support Interventions: Crossing Networks of Aging and Developmental Disabilities. *Les interventions de prestation de soins et de soutien familial: à la croisée des réseaux en matière de vieillissement et de troubles du développement.*, 53(5), 329-345.
- Heller, T., Hsieh, K., & Rimmer, J. (2002). Barriers and Supports for Exercise Participation among Adults with Down Syndrome. *Journal of Gerontological Social Work*, 38(1/2), 161-177.
- Helleso, R., Eines, J., & Fagermoen, M. S. (2012). The Significance of Informal Caregivers in Information Management from the Perspective of Heart Failure Patients. *Journal of Clinical Nursing*, 21(3-4), 495-503.
- Hellstrom, Y., Andersson, M., & Hallberg, I. (2004). Quality of Life among Older People in Sweden Receiving Help from Informal and/or Formal Helpers at Home or in Special Accommodation. *Health and Social Care in the Community (Print edition)*, 12(6), 504-516.
- Hellstrom, Y., & Hallberg, I. R. (2001). Perspectives of Elderly People Receiving Home Help on Health, Care and Quality of Life. *Health & Social Care in The Community*, 9(2), 61-71.
- Hempel, S., Norman, G., Golder, S., Aqiar-Ibanez, R., & Eastwood, A. (2007). Psychosocial Interventions for Non-Professional Carers of People with Parkinson's Disease: A Scoping Review. *J Adv Nurs*, 64(3), 214-228.
- Hempton, C., Dow, B., Cortes-Simonet, E. N., Ellis, K., Koch, S., LoGiudice, D., Mastwyk, M., Livingston, G., Cooper, C., & Ames, D. (2011). Contrasting Perceptions of Health Professionals and Older People in Australia: What Constitutes Elder Abuse? *International Journal of Geriatric Psychiatry*, 26(5), 466-472.
- Hemsley, B., Balandin, S., & Togher, L. (2008). Professionals' Views on the Roles and Needs of Family Carers of Adults with Cerebral Palsy and Complex Communication Needs in Hospital. *Journal of Intellectual & Developmental Disability*, 33(2), 127-136.
- Henderson, J. (2001). 'He Stopped Being My Husband and Became My Carer', *Open Mind*, 109(12-13).
- Henderson, J. (2002). Experiences of 'Care' in Mental Health. *Journal of Adult Protection*, 4(3), 34-45.
- Henderson, J., & Forbat, L. (2002). Relationship-Based Social Policy: Personal and Policy Constructions of 'Care'. *Critical Social Policy*, 22(4), 669-687.
- Hendriks, A. A. J., Smith, S. C., Chrysanthaki, T., & Black, N. (2016). Reliability and Validity of a Self-Administration Version of Demqol-Proxy. *International Journal of Geriatric Psychiatry*.
- Hendriksen, E., Williams, E., Sporn, N., Greer, J., DeGrange, A., & Koopman, C. (2015). Worried Together: A Qualitative Study of Shared Anxiety in Patients with Metastatic Non-Small Cell Lung Cancer and Their Family Caregivers. *Supportive Care in Cancer*, 23(4), 1035-1041.
- Henley, C. (2006). The Day-Care We Can't Desert. *Professional Social Work*, 18-19.
- Henriksson, A., & Arestedt, K. (2013). Exploring Factors and Caregiver Outcomes Associated with Feelings of Preparedness for Caregiving in Family Caregivers in Palliative Care: A Correlational, Cross-Sectional Study. *Palliative Medicine*, 27(7), 639-646.
- Henriksson, A., Carlander, I., & Arestedt, K. (2015). Feelings of Rewards among Family Caregivers During Ongoing Palliative Care. *Palliative & Supportive Care*, 13(6), 1509-1517.
- Hensman, S. (2001). Equal but Different. *Community Care* (16.8.01), 22-23.

- Henz, U. (2004). The Effects of Informal Care on Paid-Work Participation in Great Britain: A Lifecourse Perspective. *Ageing & Society*, 24(6), 851-880.
- Henz, U. (2006). Informal Caregiving at Working Age: Effects of Job Characteristics and Family Configuration. *Journal of Marriage and Family*, 68(2), 411-429.
- Henz, U. (2009). Couples' Provision of Informal Care for Parents and Parents-in-Law: Far from Sharing Equally? *Ageing & Society*, 29(3), 369-395.
- Heppenstall, C. P., Keeling, S., Hanger, H. C., & Wilkinson, T. J. (2014). Perceived Factors Which Shape Decision-Making around the Time of Residential Care Admission in Older Adults: A Qualitative Study. *Australasian Journal on Ageing*, 33(1), 9-13.
- Hepworth, D. (2005). Asian Carers' Perceptions of Care Assessment and Support in the Community. *British Journal of Social Work*, 35(3), 337-353.
- Hepworth, M. (2004). A Framework for Understanding User Requirements for an Information Service: Defining the Needs of Informal Carers. *Journal of the American Society for Information Science & Technology*, 55(8), 695-708 614p.
- Herrera-Espiñeira, C., Del Aguila, M. D. M. R., Del Castillo, M. R., De Hoyos, E. A., Rufián, A. Q., Cirre, C. M., Santos, D. C., García, P. A., & Sánchez, I. R. (2008). Evaluation of a Health Care Programme with Nursing Tutor in a Hospital Traumatological Facility in a Hospital. Granada, Spain, 2004. *Revista Espanola de Salud Publica*, 82(1), 69-80.
- Herron-Foster, B. J., & Bustos, J. J. (2014). Special Needs: Caring for the Older Adult with Down Syndrome. *MEDSURG Nursing*, 23(4), 225-237.
- Heslin, M., Forster, A., Healey, A., & Patel, A. (2016). A Systematic Review of the Economic Evidence for Interventions for Family Carers of Stroke Patients. *Clinical Rehabilitation*, 30(2), 119-133.
- Heslop, P., Folkes, L., & Rodgers, J. (2005). The Knowledge People with Learning Disabilities and Their Carers Have About Psychotropic Medication. *Tizard Learning Disability Review*, 10(4), 10-18.
- Heward, K., Gough, B., & Molineux, M. (2011). Change of Identity: The Psychological and Emotional Impact of Caring for Someone with Multiple Sclerosis. *Social Care and Neurodisability*, 2(1), 21-32.
- Hewitt, G., Sims, S., Greenwood, N., Jones, F., Ross, F., & Harris, R. (2015). Interprofessional Teamwork in Stroke Care: Is It Visible or Important to Patients and Carers? *Journal of Interprofessional Care*, 29(4), 331-339.
- Heyman, A., & Heyman, B. (2013). 'The Sooner You Can Change Their Life Course the Better': The Time-Framing of Risks in Relationship to Being a Young Carer. *Health, Risk & Society*, 15(6/7), 561-579.
- Higginbottom, G. M. A., Rivers, K., & Story, R. (2014). Health and Social Care Needs of Somali Refugees with Visual Impairment (VIP) Living in the United Kingdom: A Focused Ethnography with Somali People with VIP, Their Caregivers, Service Providers, and Members of the Horn of Africa Blind Society. *Journal of Transcultural Nursing*, 25(2), 192-201.
- Higgins, I., Joyce, T., Parker, V., Fitzgerald, M., & McMillan, M. (2007). The Immediate Needs of Relatives During Hospitalisation of Acutely Ill Older Relatives. *Contemporary Nurse*, 26(2), 208-220.
- Hill, K. (2001). Developing a Joint Mental Health Strategy for Elders. *Mental Health Review*, 6(2), 14-17.
- Hill, S. R., Mason, H., Poole, M., Vale, L., & Robinson, L. (2016). What Is Important at the End of Life for People with Dementia? The Views of People with Dementia and Their Carers: End-of- Life Care for People with Dementia. *Int J Geriatr Psychiatry*.

- Hill, T., Thomson, C., Bittman, M., & Griffiths, M. (2008). What Kinds of Jobs Help Carers Combine Care and Employment? *Family Matters* (80), 27-32.
- Himes, C. L., & Reidy, E. B. (2000). The Role of Friends in Caregiving. *Research on Aging*, 22(4), 315-336.
- Hinojosa, M. S., & Rittman, M. (2009). Association between Health Education Needs and Stroke Caregiver Injury. *Journal of Aging and Health*, 21(7), 1040-1058.
- Hirst, M. (2001). Trends in Informal Care in Great Britain During the 1990s. *Health and Social Care in the Community*, 9(6), 348-357.
- Hirst, M. (2002). Transitions to Informal Care in Great Britain During the 1990s. *Journal of Epidemiology and Community Health*, 56, 579-587.
- Hirst, M. (2003). Caring-Related Inequalities in Psychological Distress in Britain During the 1990s. *Journal of Public Health Medicine*, 25(4), 336-343.
- Hirst, M. (2005). Carer Distress: A Prospective, Population-Based Study. *Social Science & Medicine*, 61(3), 697-708.
- Hirst, M. (2005). Distress Relief. *Care and Health Magazine* (5.04.05), 26-27.
- Hirst, M. (2005). Estimating the Prevalence of Unpaid Adult Care over Time. *Research Policy and Planning*, 23(1), 1-15.
- Hirst, M., & Arksey, H. (2000). Informal Carers Count. *Nursing Standard*, 14(42), 33-34.
- Hirst, M., & Hutton, S. (2000). Informal Care over Time. *Benefits* (28), 9-12.
- Hjortsberg, C., Helldin, L., Hjaerthag, F., & Loethgren, M. (2011). Costs for Patients with Psychotic Illness: Differences Depending Upon State of Remission. *The Journal of Mental Health Policy and Economics*, 14(2), 87-93.
- Hlebec, V., Srakar, A., & Majcen, B. (2016). Determinants of Unmet Needs among Slovenian Old Population. *Zdravstveno Varstvo*, 55(1), 78-85.
- Hoad, P. (2002). Drawing the Line: The Boundaries of Volunteering in the Community Care of Older People. *Health Soc Care Community*, 10(4), 239-246.
- Hobson, P., Leeds, L., & Meara, J. (2001). The Coping Methods of Patients with Parkinson's Disease Their Carers and the Associations between Health-Related Quality of Life and Depression. *Quality in Ageing*, 2(4), 12-19.
- Hoefman, R. J., van Exel, J., & Brouwer, W. B. F. (2013). Measuring the Impact of Caregiving on Informal Carers: A Construct Validation Study of the Carerqol Instrument. (Research) (Report). *Health and Quality of Life Outcomes*, 11, 173.
- Hoefman, R. J., Van Exel, N. J., Foets, M., & Brouwer, W. B. (2011). Sustained Informal Care: The Feasibility, Construct Validity and Test-Retest Reliability of the Carerqol-Instrument to Measure the Impact of Informal Care in Long-Term Care. *Ageing and Mental Health*, 15(8), 1018-1027.
- Hogstel, M. O., Curry, L. C., & Walker, C. (2005). Caring for Older Adults: The Benefits of Informal Family Caregiving. *Journal of Theory Construction & Testing*, 9(2), 55-60.
- Hollins, S. (2000). Developmental Psychiatry - Insights from Learning Disability. *British Journal of Psychiatry* (177), 201-206.
- Holman, A. (2010). Where Carers Become the Cared For. *Community Living*, 23(4), 16-18.
- Holst, G., & Edberg, A. (2011). Wellbeing among People with Dementia and Their Next of Kin over a Period of 3 Years. *Scandinavian Journal of Caring Sciences*, 25(3), 549-557.

- Holtum, S., Lea, L., Morris, D., Riley, L., & Byrne, D. (2011). Now I Have a Voice: Service User and Carer Involvement in Clinical Psychology Training. *Mental Health and Social Inclusion*, 15(4), 190-197.
- Holzhausen, E., & Perlman, V. (2000). Carers' Policies in the UK. *Benefits* (28), 5-8.
- Hong, S.-I., Hasche, L., & Lee, M. J. (2011). Service Use Barriers Differentiating Care-Givers' Service Use Patterns. *Ageing and Society*, 31(8), 1307-1329.
- Hooper, H., & Ong, B. N. (2005). When Harry Met Barry, and Other Stories: A Partner's Influence on Relationships in Back Pain Care. *Anthropology & Medicine*, 12(1), 47-60 14p.
- Höppner, C., Schneemilch, M., & Lichte, T. (2015). Identifying Informal Carers and Their Burden in Family Practices - Barriers and Recommendations. *Zeitschrift für Allgemeinmedizin*, 91(7-8), 310-314.
- Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to Care: Supporting the Health of Informal Caregivers for Older People. *Health Psychology*, 34(4), 339-348.
- Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. (2013). Working Together-Apart: Exploring the Relationships between Formal and Informal Care Networks for People Dying at Home. *Progress in Palliative Care*, 21(6), 331-336.
- Horton, K. (2008). The Use of Telecare for People with Chronic Obstructive Pulmonary Disease: Implications for Management. *Journal of Nursing Management*, 16(2), 173-180 178p.
- Horton, R. (2015). Caring for Adults in the Eu: Work-Life Balance and Challenges for Eu Law. *Journal of Social Welfare and Family Law*, 37(3), 356-367.
- Hoskins, S., Coleman, M., & McNeely, D. (2005). Stress in Carers of Individuals with Dementia and Community Mental Health Teams: An Uncontrolled Evaluation Study. *J Adv Nurs*, 50(3), 325-333.
- Houngaard, L., Pedersen, B., & Wagner, L. (2011). The Daily Living for Informal Caregivers with a Partner with Parkinson's Disease - an Interview Study of Women's Experiences of Care Decisions and Self-Management. *Journal of Nursing and Healthcare of Chronic Illness*, 3(4), 504-512.
- Houtjes, W., Van Meijel, B., Deeg, D. J. H., & Beekman, A. T. F. (2011). Unmet Needs of Outpatients with Late-Life Depression; a Comparison of Patient, Staff and Carer Perceptions. *Journal of Affective Disorders*, 134(1-3), 242-248.
- Hovey, T., & Cheswick, C. (2009). Copying Letters to Service Users with Learning Disabilities: Opinions of Service Users, Carers and Professionals Working within Learning Disability Services. *British Journal of Learning Disabilities*, 37(1), 50-55.
- Howard, R., Avery, A., & Bissell, P. (2008). Causes of Preventable Drug-Related Hospital Admissions: A Qualitative Study. *Quality & Safety in Health Care*, 17(2), 109-116 108p.
- Howells, A., Morris, F. R., & Darwin, C. (2012). A Questionnaire to Assess Carers' Experience of Stroke Rehabilitation. *Topics in Stroke Rehabilitation (Thomas Land Publishers Incorporated)*, 19(3), 256-267 212p.
- Hu, C. L., Kung, S., Rummans, T. A., Clark, M. M., & Lapid, M. I. (2015). Reducing Caregiver Stress with Internet-Based Interventions: A Systematic Review of Open-Label and Randomized Controlled Trials. *Journal of the American Medical Informatics Association*, 22(E1), E194-E209.
- Hubbard, G., Downs, M., & Tester, S. (2003). Including Older People with Dementia in Research: Challenges and Strategies. *Ageing & Mental Health*, 7(5), 351-351 351p.
- Hubbard, G., Illingworth, N., Rowa-Dewar, N., Forbat, L., & Kearney, N. (2010). Treatment Decision-Making in Cancer Care: The Role of the Carer. *J Clin Nurs*, 19(13-14), 2023-2031.

- Hudson, P., & Payne, S. (2011). Family Caregivers and Palliative Care: Current Status and Agenda for the Future. *J Palliat Med*, 14(7), 864-869.
- Hudson, P. L., Trauer, T., Graham, S., Grande, G., & Ewing, G. (2010). A Systematic Review of Instruments Related to Family Caregivers of Palliative Care Patients. *Palliat Med*, 24(7), 656-668.
- Hudson, V. (2005). Plan with Care. *Community Care*.
- Hughes, H., Meddings, S., Vandrevalla, T., Holmes, S., & Hayward, M. (2011). Carers' Experiences of Assertive Outreach Services: An Exploratory Study. *J Ment Health*, 20(1), 70-78.
- Hughes, J. C., Hope, T., Reader, S., & Rice, D. (2002). Dementia and Ethics: The Views of Informal Carers. *Journal of The Royal Society of Medicine*, 95(5), 242-246.
- Hughes, J. C., Hope, T., Savulescu, J., & Ziebland, S. (2002). Carers, Ethics and Dementia: A Survey and Review of the Literature. *International Journal of Geriatric Psychiatry*, 17(1), 35-40.
- Hughes, J. C., & Louw, S. J. (2002). Electronic Tagging of People with Dementia Who Wander. *British Medical Journal* (19.10.02), 847-848.
- Hughes, J. C., Robinson, L., & Volicer, L. (2005). Specialist Palliative Care in Dementia. *British Medical Journal*, 330(7482), 57-58.
- Hughes, M. (2012). End-of-Life Care in the Setting of the Home: The Practices and Strengths of Informal Carers. *Journal of Palliative Care*, 28(3), 203-204.
- Hughes, M., & Kentlyn, S. (2011). Older LGBT People's Care Networks and Communities of Practice: A Brief Note. *International Social Work*, 54(3), 436-444.
- Hughes, M. E. (2013). Decriminalising an Expected Death in the Home: A Social Work Response. *British Journal of Social Work*, 43(2), 282-297.
- Hughes, M. E. (2015). A Strengths Perspective on Caregiving at the End-of-Life. *Australian Social Work*, 68(2), 156-168.
- Hughes, R., Saleem, T., & Addington-Hall, J. (2005). Towards a Culturally Acceptable End-of-Life Survey Questionnaire: A Bengali Translation of Voices. *International Journal of Palliative Nursing*, 11(3), 116-123.
- Huis in het Veld, J., Verkaik, R., van Meijel, B., Verkade, P. J., Werkman, W., Hertogh, C., & Francke, A. (2016). Self-Management by Family Caregivers to Manage Changes in the Behavior and Mood of Their Relative with Dementia: An Online Focus Group Study. *BMC Geriatrics*, 16(95).
- Huis in het Veld, J. G., Verkaik, R., & Mistiaen, P. (2015). The Effectiveness of Interventions in Supporting Self-Management of Informal Caregivers of People with Dementia; a Systematic Meta Review. *BMC Geriatrics*, 11(15), 147.
- Hulme, C., Wright, J., Crocker, T., Oluboyede, Y., & House, A. (2010). Non-Pharmacological Approaches for Dementia That Informal Carers Might Try or Access: A Systematic Review. *International Journal of Geriatric Psychiatry*, 25(7), 756-763 758p.
- Hunt, K. J., Shlomo, N., & Addington-Hall, J. (2014). End-of-Life Care and Preferences for Place of Death among the Oldest Old: Results of a Population-Based Survey Using Voices-Short Form. *Journal of Palliative Medicine*, 17(2), 176-182.
- Hurley, R., Patterson, T., & Cooley, S. (2014). Meditation-Based Interventions for Family Caregivers of People with Dementia: A Review of the Empirical Literature. *Aging & Mental Health*, 18(3), 281-288.

- Hussein, S., & Ismail, M. (2016). Ageing and Elderly Care in the Arab Region: Policy Challenges and Opportunities. *Ageing International*, 1-16.
- Hussein, S., & Manthorpe, J. (2012). The Diversity of Staff Supporting Family Carers in England: Findings from an Analysis of a National Data Set. *Diversity and Equality in Health and Care*, 9(2), 101-111.
- Hutchings, D., Vanoli, A., McKeith, I., Brotherton, S., Mcnamee, P., & Bond, J. (2010). Good Days and Bad Days: The Lived Experience and Perceived Impact of Treatment with Cholinesterase Inhibitors for Alzheimer's Disease in the United Kingdom. *Dementia*, 9(3).
- Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A Systematic Review of Hospital Experiences of People with Intellectual Disability. *BMC Health Services Research*, 14(505).
- Ibarz, A., Falco, J. L., Vaquerizo, E., Lain, L., Artigas, J. I., & Roy, A. (2013). Monami: Mainstream on Ambient Intelligence. E-Inclusion Living Scaled Field Trial Experience in Spain. *Journal of Research and Practice in Information Technology*, 45(2), 133-149.
- Idstad, M. (2011). The Effect of Change in Mental Disorder Status on Change in Spousal Mental Health: The Hunt Study. *Soc Sci Med*, 73(9), 1408-1415.
- Iecovich, E. (2011). Quality of Relationships between Care Recipients and Their Primary Caregivers and Its Effect on Caregivers' Burden and Satisfaction in Israel. *Journal of Gerontological Social Work*, 54(6), 570-591.
- Iliffe, S., Levin, E., Kharicha, K., & Davey, B. (2005). Health-Related Quality of Life and Attitudes to Long-Term Care among Carers of Older People Using Social Services. *Research Policy and Planning*, 23(3), 165-173.
- Iliffe, S., & Manthorpe, J. (2004). The Recognition of and Response to Dementia in the Community: Lessons for Professional Development. *Learning in Health and Social Care*, 3(1), 5-16.
- Ilse, L. B., Feys, H., de Wit, L., Putman, K., & Weerdt, W. (2008). Stroke Caregivers' Strain Prevalence and Determinants in the First Six Months after Stroke. *Disability & Rehabilitation*, 30(7), 523-530.
- Imaiso, J. (2015). Negative/Positive Home-Based Caregiving Appraisals by Informal Carers of the Elderly in Japan. *Primary Health Care Research and Development*, 16(2), 167-178.
- Ingleton, C., Morgan, J., Hughes, P., Noble, B., Evans, A., & Clark, D. (2004). Carer Satisfaction with End-of-Life in Powys, Wales: A Cross-Sectional Survey. *Health & Social Care in The Community*, 12(1), 43-52 10p.
- Ingleton, C., Payne, S., Nolan, M., & Carey, I. (2003). Respite in Palliative Care: A Review and Discussion of the Literature. *Palliative Medicine*, 17(7), 567-575.
- Innes, A. (2005). Dementia Care Provision in Rural Scotland: Service Users' and Carers' Experiences. *Health and Social Care in The Community*, 13(4), 354-365.
- Innes, A., Abela, S., & Scerri, C. (2011). The Organisation of Dementia Care by Families in Malta: The Experiences of Family Caregivers. *Dementia: The International Journal of Social Research and Practice*, 10(2), 165-184.
- Innes, A., Kelly, F., & Dincarslan, O. (2011). Care Home Design for People with Dementia: What Do People with Dementia and Their Family Carers Value? *Aging and Mental Health*, 15(5), 548-556.
- Innes, S., & Scott, G. (2003). 'After I've Done the Mum Things': Women, Care and Transitions. *Sociological Research Online*, 8(4).
- Inoue, M., Pickard, J., & Welch-Saleeby, P. (2009). African-American Caregivers' Breast Health Behavior. *Health Education Research*, 24(5), 735-747.

- Iqbal, J., Francis, L., Reid, J., Murray, S., & Denvir, M. (2010). Quality of Life in Patients with Chronic Heart Failure and Their Carers: A 3-Year Follow-up Study Assessing Hospitalization and Mortality. *European Journal of Heart Failure*, 12(9), 1002-1008.
- Ireland, M. J., & Pakenham, K. I. (2010). The Nature of Youth Care Tasks in Families Experiencing Chronic Illness/Disability: Development of the Youth Activities of Caregiving Scale (YACS). *Psychology & Health*, 25(6), 713-731.
- Ireland, M. J., & Pakenham, K. I. (2010). Youth Adjustment to Parental Illness or Disability: The Role of Illness Characteristics, Caregiving, and Attachment. *Psychology, Health & Medicine*, 15(6), 632-645.
- Ishii, Y., Miyashita, M., Sato, K., & Ozawa, T. (2012). Family's Difficulty Scale in End-of-Life Home Care: A New Measure of the Family's Difficulties in Caring for Patients with Cancer at the End of Life at Home from Bereaved Family's Perspective. *J Palliat Med*, 15(2), 2010-2015.
- Iskrov, G. G., Stefanov, R. S., López-Bastida, J., Linertová, R., Oliva-Moreno, J., & Serrano-Aguilar, P. (2015). Economic Burden and Health-Related Quality of Life of Patients with Cystic Fibrosis in Bulgaria. *Folia medica*, 57(1), 56-64.
- Ismail, Y., McNeill, E., Townsend, M., & MacConnell, T. (2006). Short Report. Palliative Care in Heart Failure - a Neglected Area in Specialist Training? *British Journal of Cardiology*, 13(4), 283-283 281p.
- Jack, B., & O'Brien, M. (2010). Dying at Home: Community Nurses' Views on the Impact of Informal Carers on Cancer Patients' Place of Death. *European Journal of Cancer Care*, 19(5), 636-642.
- Jack, B. A., O'Brien, M. R., Scrutton, J., Baldry, C. R., & Groves, K. E. (2015). Supporting Family Carers Providing End-of-Life Home Care: A Qualitative Study on the Impact of a Hospice at Home Service. *Journal of Clinical Nursing*, 24(1-2), 131-140.
- Jackson, D., Turner-Stokes, L., Murray, J., Leese, M., & McPherson, K. M. (2009). Acquired Brain Injury and Dementia: A Comparison of Carer Experiences. *Brain Injury*, 23(5), 433-444.
- Jacobs, J. C., Laporte, A., van Houtven, C. H., & Coyte, P. C. (2014). Caregiving Intensity and Retirement Status in Canada. *Social Science & Medicine*, 102, 74-82.
- Jacobs, J. C., Lilly, M. B., Ng, C., & Coyte, P. C. (2013). The Fiscal Impact of Informal Caregiving to Home Care Recipients in Canada: How the Intensity of Care Influences Costs and Benefits to Government. *Social Science & Medicine*, 81, 102-109.
- Jacobs, T. (2003). Paying for Informal Care: A Contradiction in Terms? *European Societies*, 5(4), 397-417.
- Jacobs, T., Lodewijckx, E., Craeynest, K., de Koker, B., & Vanbrabant, A. (2005). Measuring Informal Care: A Synthesis of European Practices and a New Proposal. *Retraite et Societe*, 46(3), 59-87.
- Jacobson, J., Gomersall, J. S., Campbell, J., & Hughes, M. (2015). Carers' Experiences When the Person for Whom They Have Been Caring Enters a Residential Aged Care Facility Permanently: A Systematic Review. *JBI Database of Systematic Reviews and Implementation Reports*, 13(7).
- Jaffray, L., Bridgman, H., Stephens, M., & Skinner, T. (2016). Evaluating the Effects of Mindfulness-Based Interventions for Informal Palliative Caregivers: A Systematic Literature Review. *Palliative Medicine*, 30(2), 117-131.
- James, A. N. (2008). A Critical Consideration of the Cash for Care Agenda and Its Implications for Social Services in Wales. *Journal of Adult Protection*, 10(3), 23-34.

- James, N. (2013). The Formal Support Experiences of Family Carers of People with an Intellectual Disability Who Also Display Challenging Behaviour and/or Mental Health Issues: What Do Carers Say? *Journal of Intellectual Disabilities*, 17(1), 6-23.
- James, N. (2016). Family Carers' Experience of the Need for Admission of Their Relative with an Intellectual Disability to an Assessment and Treatment Unit. *Journal of Intellectual Disabilities*, 20(1), 34-54.
- James, N. (2016). Supporting Carers During Assessment and Treatment Unit Admissions. *Advances in Mental Health and Intellectual Disabilities*, 10(2), 116-127.
- Jamieson-Craig, R., Scior, K., Chan, T., Fenton, C., & Strydom, A. (2010). Reliance on Carer Reports of Early Symptoms of Dementia among Adults with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 34-41.
- Janice, C. (2014). Integrating People with Dementia and Their Carers into Service Design. *Journal of Integrated Care*, 22(3), 91-98.
- Janicki, M. P., Zendell, A., & Dehaven, K. (2010). Coping with Dementia and Older Families of Adults with Down Syndrome. *Dementia: The International Journal of Social Research and Practice*, 9(3), 391-407.
- Jankey, O., & Modie-Moroka, T. (2011). The Daily Grind of the Forgotten Heroines: Experiences of HIV/AIDS Informal Caregivers in Botswana. *Ethics and Social Welfare*, 5(2), 217-224.
- Janse, B., Huijsman, R., & de Kuyper, R. (2014). The Effects of an Integrated Care Intervention for the Frail Elderly on Informal Caregivers: A Quasi-Experimental Study. *BMC Geriatrics*, 14(58).
- Jansen, A., van Hout, H., & Nijpels, G. (2011). Effectiveness of Case Management among Older Adults with Early Symptoms of Dementia and Their Primary Informal Caregivers: A Randomized Clinical Trial. *International Journal of Nursing Studies*, 48(8), 933-943.
- Jansen, A. P., van Hout, H. P., van Marwijk, H. W., Nijpels, G., de Bruijne, M. C., Bosmans, J. E., Pot, A. M., & Stalman, W. A. (2005). (Cost)-Effectiveness of Case-Management by District Nurses among Primary Informal Caregivers of Older Adults with Dementia Symptoms and the Older Adults Who Receive Informal Care: Design of a Randomized Controlled Trial. *BMC Public Health*, 12(5), 133.
- Janssen, B., Abma, T. A., & van Regenmortel, T. (2014). Paradoxes in the Care of Older People in the Community: Walking a Tightrope. *Ethics & Social Welfare*, 8(1), 39-56.
- Jardim, C., & Pakenham, K. I. (2009). Pilot Investigation of the Effectiveness of Respite Care for Carers of an Adult with Mental Illness. *Clinical Psychologist*, 13(3), 87-93 87p.
- Jarvis, A. (2010). Working with Carers in the Next Decade: The Challenge. *British Journal of Community Nursing*, 15(3), 125-128.
- Jarvis, A., & McIntosh, G. (2004). Recognition and Support of Carers. *Professional Nurse*, 20(4), 24-26.
- Jarvis, A., & Worth, A. (2005). The Development of a Screening Tool to Identify Carers in a General Practice by a Large-Scale Mailed Survey: The Experience in One Scottish General Practice. *Journal Of Clinical Nursing*, 14(3), 363-372.
- Jarvis, A., & Worth, A. (2005). Meeting Carers' Information Needs. *Community Practitioner*, 78(9), 322-326.
- Jarvis, A., Worth, A., & Porter, M. (2006). The Experience of Caring for Someone over 75 Years of Age: Results from a Scottish General Practice Population. *Journal of Clinical Nursing*, 15(11), 1450-1459.



- Jegermalm, M. (2002). Direct and Indirect Support for Carers: Patterns of Support for Informal Caregivers to Elderly People in Sweden. *Journal of Gerontological Social Work*, 38(4), 67-83.
- Jegermalm, M. (2004). Informal Care and Support for Carers in Sweden: Patterns of Service Receipt among Informal Caregivers and Care Recipients. *European Journal of Social Work*, 7(1), 7-24 18p.
- Jegermalm, M., & Sundstrom, G. (2015). Stereotypes About Caregiving and Lessons from the Swedish Panorama of Care. *European Journal of Social Work*, 18(2), 185-197.
- Jegermalm, M., & SundstrÖM, G. (2013). Carers in Sweden: The Public Support They Receive, and the Support They Desire. *Journal of Care Services Management*, 7(1), 17-25.
- Jeggels, J. D. (2009). A Reflection on the Application of Grounded Theory in the Exploration of the Experiences of Informal Carers. *Curationis*, 32(2), 21-30 10p.
- Jenkins, K. R., Kabeto, M. U., & Langa, K. M. (2009). Does Caring for Your Spouse Harm One's Health? Evidence from a United States Nationally-Representative Sample of Older Adults. *Ageing & Society*, 29(2), 277-293.
- Jenkins, S., & Draper, H. (2015). Care, Monitoring, and Companionship: Views on Care Robots from Older People and Their Carers. *International Journal of Social Robotics*, 7(5), 673-683.
- Jenkinson, C., Dummett, S., Kelly, L., Peters, M., Dawson, J., Morley, D., & Fitzpatrick, R. (2012). The Development and Validation of a Quality of Life Measure for the Carers of People with Parkinson's Disease (the Pdq-Carer). *Parkinsonism & Related Disorders*, 18(5), 483-487.
- Jensen, C. J., Ferrari, M., & Cavanaugh, J. C. (2004). Building on the Benefits: Assessing Satisfaction and Well-Being in Elder Care. *Ageing International*, 29(1), 88-110.
- Jeon, Y. H., Chenoweth, L., & McIntosh, H. (2007). Factors Influencing the Use and Provision of Respite Care Services for Older Families of People with a Severe Mental Illness. *Int J Mental Health Nurs*, 16(2), 96-107.
- Jeon, Y.-H., Brodaty, H., & Chesterson, J. (2005). Respite Care for Caregivers and People with Severe Mental Illness: Literature Review. *J Adv Nurs*, 49(3), 297-306.
- Jessie, R., Hannah, Y., Ken, A., Anne, M., & James, H. (2012). The Needs of Carers Who Push Wheelchairs. *Journal of Integrated Care*, 20(1), 23-34.
- Jester, R. (2003). Early Discharge to Hospital at Home: Should It Be a Matter of Choice? *Journal of Orthopaedic Nursing*, 7(2), 64-69.
- Jester, R., & Hicks, C. (2003). Using Cost-Effectiveness Analysis to Compare Hospital at Home and in-Patient Interventions, Part 1. *Journal of Clinical Nursing*, 12(1), 13-19.
- Jiwa, M., Mitchell, G., Sibbrit, D., Girgis, A., & Burridge, L. (2010). Addressing the Needs of Caregivers of Cancer Patients in General Practice: A Complex Intervention. *Qual Prim Care*, 18(1), 9-16.
- Johannesen, M., & Logiudice, D. (2013). Elder Abuse: A Systematic Review of Risk Factors in Community-Dwelling Elders. *Age & Ageing*, 42(3), 292-298.
- Johansson, M. B., Carlsson, M., Ostberg, P., & Sonnander, K. (2012). Communication Changes and Slp Services According to Significant Others of Persons with Aphasia. *Aphasiology*, 26(8), 1005-1028.
- Jolanki, O. (2015). To Work or to Care? Working Women's Decision-Making. *Community, Work & Family*, 18(3), 268-283.
- Joling, K. J., Schöpe, J., van Hout, H. P. J., van Marwijk, H. W. J., van Der Horst, H. E., & Bosmans, J. E. (2015). Predictors of Societal Costs in Dementia Patients and Their Informal

- Caregivers: A Two-Year Prospective Cohort Study. *American Journal of Geriatric Psychiatry*, 23(11), 1193-1203.
- Joling, K. J., Smit, F., van Marwijk, H. W., van der Horst, H. E., Scheltens, P., Schulz, R., & van Hout, H. P. (2012). Identifying Target Groups for the Prevention of Depression among Caregivers of Dementia Patients. *International Psychogeriatrics*, 24(2), 298-306.
- Jones, A., Jeyasingham, D., & Rajasooriya, S. (2002). Invisible Families: The Strengths and Needs of Black Families in Which Young People Have Caring Responsibilities.
- Jones, C., Edwards, R. T., & Hounscome, B. (2012). Health Economics Research into Supporting Carers of People with Dementia: A Systematic Review of Outcome Measures.
- Jones, E., & Betts, T. (2016). Poetry, Philosophy and Dementia. *Journal of Mental Health Training Education and Practice*, 11(2), 75-80.
- Jones, I. R., Ahmed, N., Catty, J., McLaren, S., Rose, D., Wykes, T., & Burns, T. (2009). Illness Careers and Continuity of Care in Mental Health Services: A Qualitative Study of Service Users and Carers. *Social Science & Medicine*, 69(4), 632-639.
- Jones, K. (2006). Informal Care as Relationship: The Case of the Magnificent Seven. *Journal of Psychiatric and Mental Health Nursing*, 13(2), 214-220.
- Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H., & Moran, N. (2012). Can Individual Budgets Have an Impact on Carers and the Caring Role? *Ageing and Society*, 34(01), 157-175.
- Jones, L., Candy, B., Davis, S., Elliott, M., Gola, A., Harrington, J., Kupeli, N., Lord, K., Moore, K., Scott, S., Vickerstaff, V., Omar, R. Z., King, M., Leavey, G., Nazareth, I., & Sampson, E. L. (2016). Development of a Model for Integrated Care at the End of Life in Advanced Dementia: A Whole Systems UK-Wide Approach. *Palliative Medicine*, 30(3), 279-295.
- Jones, L., & Morris, R. (2013). Experiences of Adult Stroke Survivors and Their Parent Carers: A Qualitative Study. *Clinical Rehabilitation*, 27(3), 272-280.
- Jones, L., & Watson, B. M. (2012). Developments in Health Communication in the 21st Century. *Journal of Language and Social Psychology*, 31(4), 415-436.
- Jones, P. S., Lee, J. W., & Zhang, X. E. (2011). Clarifying and Measuring Filial Concepts across Five Cultural Groups. *Res Nurs Health*, 34(4), 310-326.
- Jones, R., Mackenzie, A., Greenwood, N., Atkins, C., & Habibi, R. (2012). General Practitioners, Primary Care and Support for Carers in England: Can Training Make a Difference? *Health & Social Care in The Community*, 20(2), 128-136.
- Jordan, J., & Linden, M. A. (2013). It's Like a Problem That Doesn't Exist: The Emotional Well-Being of Mothers Caring for a Child with Brain Injury. *Brain Injury*, 27(9), 1063-1072.
- Jorgensen, D., Arksey, H., Parsons, M., & Jacobs, S. (2009). Caregiver Assessment of Support Need, Reaction to Care, and Assessment of Depression. *Home Health Care Services Quarterly*, 28(4), 130-150.
- Jorgensen, D., Arksey, H., Parsons, M., Senior, H., & Thomas, D. (2009). Why Do Older People in New Zealand Enter Residential Care Rather Than Choosing to Remain at Home, and Who Makes That Decision? *Ageing Int*, 34(1-2), 15-32.
- Joseph, S., Becker, S., Becker, F., & Regal, S. (2009). Assessment of Caring and Its Effects in Young People: Development of the Multidimensional Assessment of Caring Activities Checklist (Maca-Yc18) and the Positive and Negative Outcomes of Caring Questionnaire (Panoc-Yc20) for Young Carers. *Child: Care, Health & Development*, 35(4), 510-520.
- Joseph, S., Becker, S., Elwick, H., & Silburn, R. (2012). Adult Carers Quality of Life Questionnaire (Ac-QoL): Development of an Evidence-Based Tool. *Mental Health Review Journal*, 17(2), 57-69.

- Jowsey, T., McRae, I., Gillespie, J., Banfield, M., & Yen, L. R. (2013). Time to Care? Health of Informal Older Carers and Time Spent on Health-Related Activities: An Australian Survey. *BMC Public Health*, 13.
- Jowsey, T., Strazdins, L., & Yen, L. (2016). Worry and Time: The Unseen Costs of Informal Care. *Chronic Illness*.
- Jowsey, T., Yen, L., & Mathews, W. P. (2012). Time Spent on Health-Related Activities Associated with Chronic Illness: A Scoping Literature Review. *BMC Public Health*, 12.
- Juaristi, G.-E. A., & Dening, K. H. (2016). Promoting Participation of People with Dementia in Research. *Nursing Standard*, 30(39), 38-43.
- Jullamate, P., de Azeredo, Z., Paul, C., & Subgranon, R. (2006). Thai Stroke Patient Caregivers: Who They Are and What They Need. *Cerebrovascular Diseases*, 21(1-2), 128-133.
- Jumisko, E., Lexell, J., & Soderberg, S. (2007). Living with Moderate or Severe Traumatic Brain Injury: The Meaning of Family Members' Experiences. *J Fam Nurs*, 13(3), 353-369.
- Jung-won, L., & Zebrack, B. (2004). Caring for Family Members with Chronic Physical Illness: A Critical Review of Caregiver Literature. *Health Qual Life Outcomes*, 2(50).
- Kaambwa, B., Lancsar, E., McCaffrey, N., Chen, G., Gill, L., Cameron, I. D., Crotty, M., & Ratcliffe, J. (2015). Investigating Consumers' and Informal Carers' Views and Preferences for Consumer Directed Care: A Discrete Choice Experiment. *Social Science & Medicine*, 140, 81-94.
- Kaehne, A., & Beyer, S. (2011). 'Stroppy' or 'Confident'? Do Carers and Professionals View the Impact of Transition Support on Young People Differently? *British Journal of Learning Disabilities*, 39(2), 154-160.
- Kalawsky, K., Munir, F., Wallis, D., & Donaldson-Feilder, E. (2013). Work It out for Carers: The Development of a Work-Focused Self-Management Tool for Informal Carers of People Affected by Cancer. *Psycho-Oncology*, 22, 65-66.
- Kallert, T. W., & Nitsche, I. (2010). Direct Health-Related Costs of Severely Mentally Ill Patients and Their Informal Carers in Community Care. *Neuropsychiatrie*, 24(1), 42-55.
- Kanters, T. A., van Der Ploeg, A. T., Brouwer, W. B. F., & Hakkaart, L. (2013). The Impact of Informal Care for Patients with Pompe Disease: An Application of the Carerqol Instrument. *Molecular Genetics and Metabolism*, 110(3), 281-286.
- Kara, H. (2016). The Value of Carers in Mental Health Research. *Journal of Public Mental Health*, 15(2), 83-92.
- Karagiozi, K., Papaliagkas, V., Giaglis, G., Papastavrou, E., Pattakou, V., & Tsolaki, M. (2014). Combined Intervention for Caregivers of Patients with Dementia: A Randomized Controlled Trial. *International Journal of Academic Research in Psychology*, 1(2).
- Karban, K. (2003). Social Work Education and Mental Health in a Changing World. *Social Work Education (The International Journal)*, 22(2), 191-202.
- Karlsson, M., Mayhew, L., Plumb, R., & Rickayzen, B. (2006). Future Costs for Long-Term Care: Cost Projections for Long-Term Care for Older People in the United Kingdom. *Health Policy*, 75(2), 187-213.
- Karnieli-Miller, O., Perlick, D. A., Nelson, A., Mattias, K., Corrigan, P., & Roe, D. (2013). Family Members' of Persons Living with a Serious Mental Illness: Experiences and Efforts to Cope with Stigma. *J Ment Health*, 22(3), 254-262.
- Katbamna, S., Ahmad, W., & Bhakta, P. (2004). Do They Look after Their Own? Informal Support for South Asian Carers. *Health and Social Care in the Community (Print edition)*, 12(5), 398-406.

- Katbamna, S., Bhakta, P., Ahmad, W., Baker, R., & Parker, G. (2002). Supporting South Asian Carers and Those They Care For: The Role of the Primary Health Care Team. *British Journal of General Practice*, 52(477).
- Katbamna, S., Johnson, M., Robinson, T., & Manning, L. (2014). Ethnic Differences in Caring for Stroke Survivors: Observations from Study of White British and British Indian Informal Carers. *International Journal of Stroke*, 9, 16-16.
- Katz, R., Lowenstein, A., Prilutzky, D., & Halperin, D. (2011). Employers' Knowledge and Attitudes Regarding Organizational Policy toward Workers Caring for Aging Family Members. *Journal of Aging and Social Policy*, 23(2), 159-181.
- Kaufer, D. I., Borson, S., Kershaw, P., & Sadik, K. (2005). Reduction of Caregiver Burden in Alzheimer's Disease by Treatment with Galantamine. *Cns Spectrums*, 10(6), 481-488.
- Kavanaugh, M. (2014). Children and Adolescents Providing Care to a Parent with Huntington's Disease: Disease Symptoms, Caregiving Tasks and Young Carer Well-Being. *Child & Youth Care Forum*, 43(6), 675-690.
- Kealey, P., & McIntyre, I. (2005). An Evaluation of the Domiciliary Occupational Therapy Service in Palliative Cancer Care in a Community Trust: A Patient and Carers Perspective. *European Journal of Cancer Care*, 14(3), 232-243.
- Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the Caring Capacity of Informal Networks of Frail Seniors: A Case for Care Networks. *Ageing & Society*, 23(1), 115-127.
- Keesing, S., Rosenwax, L., & McNamara, B. (2011). Doubly Deprived: A Post-Death Qualitative Study of Primary Carers of People Who Died in Western Australia. (Report). *Health and Social Care in the Community*, 19(6), 636.
- Kempenaar, L., McNamara, C., & Creaney, W. J. (2002). An Investigation of a Group Education Programme for the Informal Carers of People with Dementia. *Neurobiology of Aging*, 23(1), S45-S45.
- Kendall, M., Boyd, K., Campbell, C., Cormie, P., Fife, S., Thomas, K., Weller, D., & Murray, S. A. (2006). How Do People with Cancer Wish to Be Cared for in Primary Care? Serial Discussion Groups of Patients and Carers. *Fam Pract*, 23(6), 644-650.
- Kendall, S., Thompson, D., & Couldridge, L. (2004). The Information Needs of Carers of Adults Diagnosed with Epilepsy. *Seizure*, 13(7), 499-508.
- Kenealy, T. W., Parsons, M. J. G., Rouse, A. P. B., Doughty, R. N., Sheridan, N. F., Hindmarsh, J. K. H., Masson, S. C., & Rea, H. H. (2015). Telecare for Diabetes, Chf or Copd: Effect on Quality of Life, Hospital Use and Costs. A Randomised Controlled Trial and Qualitative Evaluation. *PLoS ONE*, 10(3).
- Kennan, D., Fives, A., & Canavan, J. (2012). Accessing a Hard to Reach Population: Reflections on Research with Young Carers in Ireland. *Child & Family Social Work*, 17(3), 275-283.
- Kenneson, A., & Bobo, J. K. (2010). The Effect of Caregiving on Women in Families with Duchenne/Becker Muscular Dystrophy. *Health and Social Care in the Community*, 18(5), 520-528.
- Kenny, C., Sarma, K., & Egan, J. (2012). An Interpretive Phenomenological Account of the Experiences of Family Carers of the Elderly. *The Irish Journal of Psychology*, 33(4), 199-214.
- Kenny, K., & McGilloway, S. (2007). Caring for Children with Learning Disabilities: An Exploratory Study of Parental Strain and Coping. *British Journal of Learning Disabilities*, 35(4), 221-228 228p.

- Kenny, P., King, M. T., & Hall, J. (2014). The Physical Functioning and Mental Health of Informal Carers: Evidence of Care-Giving Impacts from an Australian Population-Based Cohort. *Health & Social Care in The Community*, 22(6), 646-659.
- Kenny, P. M., Hall, J. P., Zapart, S., & Davis, P. R. (2010). Informal Care and Home-Based Palliative Care: The Health-Related Quality of Life of Carers. *Journal of Pain & Symptom Management*, 40(1), 35-48 14p.
- Kerkhof, Y. J. F., Rabiee, F., & Willems, C. G. (2015). Experiences of Using a Memory Aid to Structure and Support Daily Activities in a Small-Scale Group Accommodation for People with Dementia. *Dementia (London, England)*, 14(5), 633-649.
- Kerr, C., Murray, E., Stevenson, F., Gore, C., & Nazareth, I. (2005). Interactive Health Communication Applications for Chronic Disease: Patient and Carer Perspectives. *Journal of Telemedicine & Telecare*, 11(5), 32-34.
- Kerr, S. M., Langhorne, P., Lawrence, M., Lees, K. R., & Smith, L. N. (2004). Informal Carers' Experience of Caring for Stroke Survivors. *Journal of Advanced Nursing*, 46(3), 235-244.
- Kerr, S. M., & Smith, L. N. (2001). Stroke: An Exploration of the Experience of Informal Caregiving. *Clinical Rehabilitation*, 15(4), 428-436.
- Kersten, P., McLellan, L., George, S., Mullee, M. A., & Smith, J. A. E. (2001). Needs of Carers of Severely Disabled People: Are They Identified and Met Adequately? *Health & Social Care in the Community*, 9(4), 235-243.
- Keywood, K. (2003). Gatekeepers, Proxies, Advocates? The Evolving Role of Carers under Mental Health and Mental Incapacity Law Reforms. *Journal of Social Welfare and Family Law*, 25(4), 355-368.
- Khalaila, R. (2014). Meeting the Needs of Patients' Families in Intensive Care Units. *Nursing Standard*, 28(43), 37-44.
- Khan, F., Pallant, J., & Brand, C. (2007). Caregiver Strain and Factors Associated with Caregiver Self-Efficacy and Quality of Life in a Community Cohort with Multiple Sclerosis. *Disability & Rehabilitation*, 29(16), 1241-1250.
- Killaspy, H., King, M., Wright, C., White, S., McCrone, P., Kallert, T., Cervilla, J., Raboch, J., Onchev, G., Mezzina, R., Wiersma, D., Kiejna, A., Ploumpidis, D., & de Almeida, J. M. C. (2009). Study Protocol for the Development of a European Measure of Best Practice for People with Long Term Mental Health Problems in Institutional Care (Demobinc). *BMC Psychiatry*, 9.
- Kim, E. Y., Cho, E., & Lee, N. J. (2013). Effects of Family Caregivers on the Use of Formal Long-Term Care in South Korea. *International Nursing Review*, 60(4), 520-527.
- Kim, H., & Choi, W.-Y. (2008). Willingness to Use Formal Long-Term Care Services by Korean Elders and Their Primary Caregivers. *Journal of Aging and Social Policy*, 20(4), 474-492.
- Kim, Y. (2009). Korean-American Family Post-caregivers on Dementia Caregiving: A Phenomenological Inquiry. *Journal of Gerontological Social Work*, 52(6), 600-617.
- King, D., & Pickard, L. (2013). When Is a Carer's Employment at Risk? Longitudinal Analysis of Unpaid Care and Employment in Midlife in England. *Health & Social Care in The Community*, 21(3), 303-314.
- King, G., Mackenzie, J., Smith, H., & Clark, D. (2000). Dying at Home: Evaluation of a Hospice Rapid-Response Service. *Int J Palliat Nurs*, 6(6), 280.
- King, M., & Wagner, L. C. (2005). Existential Needs of People with Psychotic Disorders in Porto Alegre, Brazil. *British Journal of Psychiatry*, 186, 141-145.

- King, M. T., Hall, J., Caleo, S., Gurney, H. P., & Harnett, P. R. (2000). Home or Hospital? An Evaluation of the Costs, Preferences, and Outcomes of Domiciliary Chemotherapy. *International Journal of Health Services*, 30(3), 557-579.
- Kinnear, H., Connolly, S., Rosato, M., Hall, C., Mairs, A., & O'Reilly, D. (2010). Are Caregiving Responsibilities Associated with Non-Attendance at Breast Screening? *BMC Public Health*, 10(749).
- Kinney, J. M., & Kart, C. S. (2006). Not Quite a Panacea: Technology to Facilitate Family Caregivers for Elders with Dementia. *Generations*, 30(2), 64-66.
- Kirk, S. (2001). Negotiating Lay and Professional Roles in the Care of Children with Complex Health Care Needs. *Journal of Advanced Nursing*, 34(5), 593-602.
- Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J., & Bond, J. (2011). The Impact of Organisational Culture on the Delivery of Person-Centred Care in Services Providing Respite Care and Short Breaks for People with Dementia. *Health and Social Care in the Community*, 19(4), 438-448.
- Kirton, J. A., Richardson, K., Jack, B. A., & Jinks, A. M. (2012). A Study Identifying the Difficulties Healthcare Students Have in Their Role as a Healthcare Student When They Are Also an Informal Carer. *Nurse Education Today*, 32(6), 641-646.
- Klemm, P., & Wheeler, E. (2005). Cancer Caregivers Online - Hope, Emotional Roller Coaster, and Physical/Emotional/Psychological Responses. *Cin-Computers Informatics Nursing*, 23(1), 38-45.
- Klevan, T., Davidson, L., Ruud, T., & Karlsson, B. (2016). "We Are Different People": A Narrative Analysis of Carers' Experiences with Mental Health Crisis and Support from Crisis Resolution Teams. *Social Work in Mental Health*, 1-18.
- Klindtworth, K., Geiger, K., Pleschberger, S., Bleidorn, J., Schneider, N., & Müller-Mundt, G. (2016). Living and Dying with Frailty: Qualitative Interviews with Elderly People in the Domestic Environment. *Zeitschrift für Gerontologie und Geriatrie*, 1-8.
- Knapp, M., Lemmi, V., & Romeo, R. (2013). Dementia Care Costs and Outcomes: A Systematic Review. *International Journal of Geriatric Psychiatry*, 28(6), 551-561.
- Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., How, J., L., S. E., Cooper, C., & Livingston, G. (2013). Cost Effectiveness of a Manual Based Coping Strategy Programme in Promoting the Mental Health of Family Carers of People with Dementia (the Start (Strategies for Relatives) Study): A Pragmatic Randomised Controlled Trial. *BMJ*, 347(f6342), 1-12.
- Kniepmann, K. (2012). Female Family Carers for Survivors of Stroke: Occupational Loss and Quality of Life. *British Journal of Occupational Therapy*, 75(5), 208-216.
- Kniepmann, K., & Cupler, M. H. (2014). Occupational Changes in Caregivers for Spouses with Stroke and Aphasia. *British Journal of Occupational Therapy*, 77(1), 10-18.
- Knighting, K., Brien, M. R., Roe, B., Gandy, R., Lloyd-Williams, M., Nolan, M., & Jack, B. A. (2015). Development of the Carers' Alert Thermometer (Cat) to Identify Family Carers Struggling with Caring for Someone Dying at Home: A Mixed Method Consensus Study. *BMC Palliative Care*, 14, 22.
- Knowles, J. (2010). Cognitive Stimulation Therapy. *Working with Older People*, 14(1), 22-25.
- Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden Caring, Hidden Carers? Exploring the Experience of Carers for People with Long-Term Conditions. *Health & Social Care in The Community*, 24(2), 203-213.
- Ko, J. Y., Aycock, D. M., & Clark, P. C. (2007). A Comparison of Working Versus Nonworking Family Caregivers of Stroke Survivors. *Journal of Neuroscience Nursing*, 39(4), 217-225.

- Koch, A., Vogel, A., Holzmann, M., Pfennig, A., Salize, H. J., Puschner, B., & Schutzwahl, M. (2014). Memento-'Mental Healthcare Provision for Adults with Intellectual Disability and a Mental Disorder'. A Cross-Sectional Epidemiological Multisite Study Assessing Prevalence of Psychiatric Symptomatology, Needs for Care and Quality of Healthcare Provision for Adults with Intellectual Disability in Germany: A Study Protocol. *BMJ Open*, 4(5).
- Kodwo-Nyameazea, Y., & Nguyen, P. V. (2008). Immigrants and Long-Distance Elder Care: An Exploratory Study. *Ageing International*, 32(4), 279-297.
- Koerin, B. B., Harrigan, M. P., & Secret, M. (2008). Eldercare and Employed Caregivers: A Public/Private Responsibility? *Journal of Gerontological Social Work*, 51(1/2), 143-161.
- Koeva, S., & Bould, S. (2007). Women as Workers and as Carers under Communism and After: The Case of Bulgaria. *International Review of Sociology*, 17(2), 303-318.
- Koffman, J. S., & Higginson, I. J. (2003). Fit to Care? A Comparison of Informal Caregivers of First -Generation Black Caribbeans and White Dependents with Advanced Progressive Disease in the UK. *Health and Social Care in the Community*, 11(6), 528-536.
- Koo, K. (2012). Carers' Representations of Affective Mental Disorders in British Chinese Communities. *Sociology of Health & Illness*, 34(8), 1140-1155.
- Kotronoulas, G., Wengström, Y., & Kearney, N. (2012). Informal Carers: A Focus on the Real Caregivers of People with Cancer. *Forum of Clinical Oncology*, 3(3), 58-65.
- Kotronoulas, G., Wengström, Y., & Kearney, N. (2012). Sleep-Wake Disturbances in Patients with Cancer and Their Informal Caregivers: A Matter of Dyads. *Forum of Clinical Oncology*, 3(1), 32-40.
- Kotsadam, A. (2011). Does Informal Eldercare Impede Women's Employment? The Case of European Welfare States. *Feminist Economics*, 17(2), 121-144.
- Kotsadam, A. (2012). The Employment Costs of Caregiving in Norway. *International Journal of Health Care Finance & Economics*, 12(4), 269-283.
- Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., & van Exel, J. (2014). The Perseverance Time of Informal Carers of Dementia Patients: Validation of a New Measure to Initiate Transition of Care at Home to Nursing Home Care. *Journal of Alzheimers Disease*, 40(3), 631-642.
- Kraijo, H., de Leeuw, R., & Schrijvers, G. (2015). How Spouses Evaluate Nursing Home Placement of Their Demented Partner: A Study About the End of Perseverance Time. *Scandinavian Journal of Caring Sciences*, 29(1), 101-109.
- Kraijo, H., van Exel, J., & Brouwer, W. (2015). The Perseverance Time of Informal Carers for People with Dementia: Results of a Two-Year Longitudinal Follow-up Study. *BMC Nursing*, 14(1).
- Kraijo, H., W., B., De Leeuw, R., Schrijvers, G., & van Exel, J. (2012). Coping with Caring: Profiles of Caregiving by Informal Carers Living with a Loved One Who Has Dementia. *Dementia: The International Journal of Social Research and Practice*, 11(1), 113-130.
- Kremer, M. (2006). Consumers in Charge of Care: The Dutch Personal Budget and Its Impact on the Market, Professionals and the Family. *European Societies*, 8(3), 385-401.
- Krevers, B., & Oberg, B. (2011). Support Services and Family Carers of Persons with Stroke Impairment: Perceived Importance and Services Received. *Journal of Rehabilitation Medicine*, 43(3), 204-209.
- Kriegel, J., & Auinger, K. (2015). Aal Service Development Loom--from the Idea to a Marketable Business Model. *Studies in Health Technology and Informatics*, 212, 125-133.

- Krishnasamy, M., Wilkie, E., & Haviland, J. (2001). Lung Cancer Health Care Needs Assessment: Patients' and Informal Carers' Responses to a National Mail Questionnaire Survey. *Palliative Medicine*, 15(3), 213-227.
- Kruijswijk, W., da Roit, B., & Hoogenboom, M. (2015). Elasticity of Care Networks and the Gendered Division of Care. *Ageing & Society*, 35(4), 675-703.
- Krupnik, Y., Pilling, S., Killaspy, H., & Dalton, J. (2005). A Study of Family Contact with Clients and Staff of Community Mental Health Teams. *Psychiatric Bulletin*, 29(5), 174-176.
- Kshetri, D. B. B., Smith, C. S., & Khadka, M. (2012). Social Care and Support for Elderly Men and Women in an Urban and a Rural Area of Nepal. *Aging Male*, 15(3), 148-152.
- Kuipers, E., Bebbington, P., Dunn, G., Fowler, D., Freeman, D., Watson, P., Hardy, A., & Garety, P. (2006). Influence of Carer Expressed Emotion and Affect on Relapse in Non-Affective Psychosis. *British Journal of Psychiatry*, 188(2), 173-179.
- Kuipers, E., Onwumere, J., & Bebbington, P. (2010). Cognitive Model of Caregiving in Psychosis. *British Journal of Psychiatry*, 196(4), 259-265.
- Kunkel, S. R., Applebaum, R. A., & Nelson, I. M. (2003). For Love and Money: Paying Family Caregivers. *Generations*, 27(4), 74-80.
- Kurlus, F. (2012). Developing and Implementing Telecare Enhanced Services in Scotland. *Assistive Technology Research Series*, 30, 187-193.
- Kurz, A., Wagenpfeil, S., Hallauer, J., Schneider-Schelte, H., & Jansen, S. (2010). Evaluation of a Brief Educational Program for Dementia Carers: The Aeneas Study. *International Journal of Geriatric Psychiatry*, 25(8), 861-869 869p.
- Kuzuya, M., Hasegawa, J., Hirakawa, Y., Enoki, H., Izawa, S., Hirose, T., & Iguchi, A. (2011). Impact of Informal Care Levels on Discontinuation of Living at Home in Community-Dwelling Dependent Elderly Using Various Community-Based Services. *Archives of Gerontology & Geriatrics*, 52(2), 127-132.
- Kwak, J., Montgomery, R. J. V., Kosloski, K., & Lang, J. (2011). The Impact of Tcare® on Service Recommendation, Use, and Caregiver Well-Being. *Gerontologist*, 51(5), 704-713.
- Laakkonen, M.-L., & Pitkaka, K. (2013). Supporting People Who Care for Adults with Dementia. *BMJ*, 347(f6691).
- Labiano-Fontcuberta, A., Mitchell, A. J., Moreno-García, S., & Benito-León, J. (2015). Anxiety and Depressive Symptoms in Caregivers of Multiple Sclerosis Patients: The Role of Information Processing Speed Impairment. *Journal of the Neurological Sciences*, 349(1-2), 220-225.
- Lach, H. W., Krampe, J., & Phongphanngam, S. (2011). Best Practice in Fall Prevention: Roles of Informal Caregivers, Health Care Providers and the Community. *International Journal of Older People Nursing*, 6(4), 299-306.
- Lafortune, C., Huson, K., Santi, S., & Stolee, P. (2015). Community-Based Primary Health Care for Older Adults: A Qualitative Study of the Perceptions of Clients, Caregivers and Health Care Providers.
- Lai, D. W. L. (2008). Intention and Use of Long-Term Care Facilities and Home Support Services by Chinese-Canadian Family Caregivers. *Social Work in Health Care*, 47(3), 259-276.
- Lai, D. W. L., & Surwood, S. (2008). Service Barriers of Chinese Family Caregivers in Canada. *Journal of Gerontological Social Work*, 51(3-4), 315-336.
- Lakeman, R. (2008). Practice Standards to Improve the Quality of Family and Carer Participation in Adult Mental Health Care: An Overview and Evaluation. *Int J Mental Health Nurs*, 17(1), 44-56.



- Lambert, S., Pallant, J., & Girgis, A. (2011). Rasch Analysis of the Hospital Anxiety and Depression Scale among Caregivers of Cancer Survivors: Implications for Its Use in Psycho-Oncology. *Psycho-Oncology*, 20(9), 919-925.
- Lamore, K. W. (2011). Use of Alzheimer Family Support Group by Community-Residing Caregivers. *Groupwork*, 21(2), 84-98.
- Lamura, G., Mnich, E., Nolan, M., Wojszel, B., Krevers, B., Mestheneos, L., & Dohner, H. (2008). Family Carers' Experiences Using Support Services in Europe: Empirical Evidence from the Eurofamcare Study. *Gerontologist*, 48(6), 752-771.
- Landau, R., Auslander, G. K., Werner, S., Shoval, N., & Heinik, J. (2011). Who Should Make the Decision on the Use of GPS for People with Dementia? *Aging and Mental Health*, 15(1), 78-84.
- Landau, R., Werner, S., Auslander, G. K., Shoval, N., & Heinik, J. (2009). Attitudes of Family and Professional Care-Givers Towards the Use of GPS for Tracking Patients with Dementia: An Exploratory Study. *British Journal of Social Work*, 39(4), 670-692.
- Lane, P., McKenna, H., & Ryan, A. (2001). Focus Group Methodology. *Nurse Researcher*, 8(3).
- Lapierre, T. A., & Keating, N. (2013). Characteristics and Contributions of Non-Kin Carers of Older People: A Closer Look at Friends and Neighbours. *Ageing and Society*, 33(8), 1442-1468.
- Larizza, M., Zukerman, I., Bohnert, F., Russell, R. A., Busija, L., Albrecht, D. W., & Rees, G. (2012). Studies to Determine User Requirements Regarding in-Home Monitoring Systems. *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)*, 7379 LNCS, 139-150.
- Larkin, M. (2007). Group Support During Caring and Post-Caring: The Role of Carers Groups. *Groupwork*, 17(2), 28-51.
- Larkin, M. (2008). Life after Caring: The Post-Caring Experiences of Former Carers. *Br J Soc Work*, 39(6), 1026-1042.
- Larkin, M. (2015). Developing the Knowledge Base About Carers and Personalisation: Contributions Made by an Exploration of Carers' Perspectives on Personal Budgets and the Carer-Service User Relationship. *Health and Social Care in the Community*, 23(1), 33-41.
- Larkin, M., & Milne, A. (2013). Carers and Empowerment in the Uk: A Critical Reflection. *Social Policy and Society*, 13(1), 25-38.
- Larkin, M., & Mitchell, W. (2016). Carers, Choice and Personalisation: What Do We Know? *Social Policy and Society*, 15(2), 189-205.
- Larson, J., Franzen-Dahlin, A., & Billing, E. (2005). Predictors of Quality of Life among Spouses of Stroke Patients During the First Year after the Stroke Event. *Scandinavian Journal of Caring Sciences*, 19(4), 439-445.
- Latham, D. (2001). How the District Nurse Cares for the Terminally Ill Patient with Cachexia. *British Journal of Community Nursing*, 6(1), 5-10.
- Lathlean, J., Burgess, A., Coldham, T., Gibson, C., Herbert, L., Levett-Jones, T., Simons, L., & Tee, S. (2006). Experiences of Service User and Carer Participation in Health Care Education. *Nurse Educ Today*, 26(8), 732-737.
- Lau, D. T., Berman, R., Halpern, L., Pickard, A. S., Schrauf, R., & Witt, W. (2010). Exploring Factors That Influence Informal Caregiving in Medication Management for Home Hospice Patients. *J Palliat Med*, 13(9), 1085-1090.
- Laudenslager, M. L. (2014). Anatomy of an Illness: Control from a Caregiver's Perspective. *Brain Behavior and Immunity*, 36, 1-8.

- Lauriks, S., Reinersmann, A., van der Roest, H. G., Meiland, F. J. M., Davies, R. J., Moelaert, F., Mulvenna, M. D., Nugent, C. D., & Droes, R. M. (2007). Review of Ict-Based Services for Identified Unmet Needs in People with Dementia. *Ageing Research Reviews*, 6(3), 223-246.
- Lavdaniti, M., Raftopoulos, V., Sgantzios, M., Psychogiou, M., Areti, T., Georgiadou, C., Serpanou, I., & Sapountzi-Krepia, D. (2011). In-Hospital Informal Caregivers' Needs as Perceived by Themselves and by the Nursing Staff in Northern Greece: A Descriptive Study. *BMC Nursing*, 10(19).
- Law, E., Starr, J. M., & Connelly, P. J. (2013). Dementia Research – What Do Different Public Groups Want? A Survey by the Scottish Dementia Clinical Research Network. *Dementia: The International Journal of Social Research and Practice*, 12(1), 23-28.
- Lawlor, B. (2002). Managing Behavioural and Psychological Symptoms in Dementia. *British Journal of Psychiatry*, 181(12), 463-465.
- Lawn, S., McNaughton, D., & Fuller, L. (2015). What Carers of Family Members with Mental Illness Say, Think and Do About Their Relative's Smoking and the Implications for Health Promotion and Service Delivery: A Qualitative Study. *International Journal of Mental Health Promotion*, 17(5), 261-277.
- Lawrence, V., & Murray, J. (2009). Understanding the Experiences and Needs of People with Dementia and Sight Loss. *Working with Older People*, 13(3), 29-33.
- Lawrence, V., Murray, J., Samsi, K., & Bannerjee, S. (2008). Attitudes and Support Needs of Black Caribbean, South Asian and White British Carers of People with Dementia in the UK. *Br J Psychiatry*, 193(3), 240-246.
- Lawrence, V., Samsi, K., Murray, J., Harari, D., & Bannerjee, S. (2011). Dying Well with Dementia: Qualitative Examination of End-of-Life Care. *British Journal of Psychiatry*, 199(5), 417-422.
- Lázaro, N., Moltó, M. L., & Sanchez, R. (2004). Paid Employment and Unpaid Caring Work in Spain. *Applied Economics*, 36(9), 977-986.
- Le Bihan, B. (2012). The Redefinition of the Familialist Home Care Model in France: The Complex Formalization of Care through Cash Payment. *Health & Social Care in the Community*, 20(3), 238-246.
- Le Dorze, G., & Signori, F. H. (2010). Needs, Barriers and Facilitators Experienced by Spouses of People with Aphasia. *Disability and Rehabilitation*, 32(13), 1073-1087.
- Leckie, F. (2015). The Care Act 2014: How Is It Changing Social Care Provision? *Equipment Services*, 74-75.
- Lecouturier, J., Bamford, C., Hughes, J. C., Francis, J. J., Foy, R., Johnston, M., & Eccles, M. P. (2008). Appropriate Disclosure of a Diagnosis of Dementia: Identifying the Key Behaviours of 'Best Practice'. *BMC Health Services Research*, 8.
- Lee, J., Soeken, K., & Picot, S. J. (2007). A Meta-Analysis of Interventions for Informal Stroke Caregivers. *Western Journal of Nursing Research*, 29(3), 357-364.
- Lee, Y., Tang, F. Y., Kim, K. H., & Albert, S. M. (2015). The Vicious Cycle of Parental Caregiving and Financial Well-Being: A Longitudinal Study of Women. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences*, 70(3), 425-431.
- Lee, Y. J., & Zurlo, K. A. (2014). Spousal Caregiving and Financial Strain among Middle-Aged and Older Adults. *International Journal of Aging & Human Development*, 79(4), 302-321.
- Lefaiver, C., Keough, V., & Letizia, M. (2007). Using the Roy Adaptation Model to Explore the Dynamics of Quality of Life and the Relationship between Lung Transplant Candidates and Their Caregivers. *Advances in Nursing Science*, 30(3), 266-274.

- LeFrancois, B. A. (2012). Distressed Fathers and Their Children: A Review of the Literature. *International Journal of Social Psychiatry*, 58(2), 123-130.
- Légaré, F., Stacey, D., Brière, N., Robitaille, H., Lord, M.-C., Desroches, S., & Drolet, R. (2014). An Interprofessional Approach to Shared Decision Making: An Exploratory Case Study with Family Caregivers of One IP Home Care Team. *BMC Geriatrics*, 14(83).
- Legault, A., & Ducharme, F. (2009). Advocating for a Parent with Dementia in a Long-Term Care Facility: The Process Experienced by Daughters. *J Fam Nurs*, 15(2), 198-219.
- Leinonen, A. (2011). Masters of Their Own Time? Working Carers' Visions of Retirement. *European Journal of Ageing*, 8(4), 243-253.
- Leinonen, A. M. (2011). Adult Children and Parental Care-Giving: Making Sense of Participation Patterns among Siblings. *Ageing and Society*, 31(2), 308-327.
- Lelliott, P. (2003). Carers' and Users' Expectations of Services - Carer Version (Cues-C): A New Instrument to Support the Assessment of Carers of People with a Severe Mental Illness. *Journal of Mental Health*, 12(2), 143-152.
- León-Salas, B., Olazarán, J., Muñiz, R., González-Salvador, T., & Martínez-Martín, P. (2011). Caregivers' Estimation of Patients' Quality of Life (QoL) in Alzheimer's Disease (Ad): An Approach Using the Adrql. *Archives of Gerontology & Geriatrics*, 53(1), 13-18.
- Leroi, I., Baker, P., Kehoe, P., Daniel, E., & Byrne, E. J. (2010). A Pilot Randomized Controlled Trial of Sleep Therapy in Parkinson's Disease: Effect on Patients and Caregivers. *International Journal of Geriatric Psychiatry*, 25(10), 1073-1079.
- Leroi, I., Harbissettar, V., Andrews, M., McDonald, K., Byrne, E. J., & Burns, A. (2012). Carer Burden in Apathy and Impulse Control Disorders in Parkinson's Disease. *International Journal of Geriatric Psychiatry*, 27(2), 160-166.
- Lethin, C., Leino-Kilpi, H., Roe, B., Soto, M., Saks, K., Stephan, A., Zwakhalen, S., Zabalegui, A., & Karlsson, S. (2013). Formal Support for Informal Caregivers to Older Persons with Dementia through the Course of the Disease: An Exploratory, Cross-Sectional Study. *BMC Geriatrics*, 16(32).
- Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., Hum, S., Garcia, L., Dalziel, W., Emerson, D. F., Pimlott, M. J., Persaud, M., Kozak, J., & Drummond, N. (2011). Pathways to Diagnosis: Exploring the Experiences of Problem Recognition and Obtaining a Dementia Diagnosis among Anglo-Canadians. *Health and Social Care in the Community*, 19(4), 372-381.
- Levine, C. (2000). Family Caregivers in the USA. *Benefits* (28), 18-21.
- Levine, C. (2004). The Good Doctor: The Carer's Perspective. *Clin Med*, 4, 244-245.
- Levine, C. (2011). Supporting Family Caregivers: The Hospital Nurse's Assessment of Family Caregiver Needs: A Smooth Transition for the Patient Is the Ultimate Goal, *American Journal of Nursing*, 111(10), 47-51.
- Levine, C., Halper, D., Peist, A., & Gould, D. A. (2010). Bridging Troubled Waters: Family Caregivers, Transitions and Long Term Care. *Health Aff*, 29(1), 116-124.
- Lewis, J., & West, A. (2014). Re-Shaping Social Care Services for Older People in England: Policy Development and the Problem of Achieving 'Good Care'. *Journal of Social Policy*, 43, 1-18.
- Lewis, J. M., Digiacomo, M., Currow, D. C., & Davidson, P. M. (2014). Social Capital in a Lower Socioeconomic Palliative Care Population: A Qualitative Investigation of Individual, Community and Civic Networks and Relations. *BMC Palliative Care*, 13.
- Lewis, S., Miner-Williams, D., & Novian, A. (2009). A Stress-Busting Program for Family Caregivers. *Rehabilitation Nursing*, 34(4), 151-159.

- Li, C. Y., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moinpour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., & Ramsey, S. D. (2013). Burden among Partner Caregivers of Patients Diagnosed with Localized Prostate Cancer within 1 Year after Diagnosis: An Economic Perspective. *Supportive Care in Cancer*, 21(12), 3461-3469.
- Li, G., Yuan, H., & Zhang, W. (2016). The Effects of Mindfulness-Based Stress Reduction for Family Caregivers: Systematic Review. *Archives of Psychiatric Nursing*, 30(2), 292.
- Li, H., Chadiha, L., & Morrow-Howell, N. (2005). Association between Unmet Needs for Community Services and Caregiving Strain. *Families in Society*, 86(1), 55-62.
- Li, L. W. (2005). Longitudinal Changes in the Amount of Informal Care among Publicly Paid Home Care Recipients. *Gerontologist*, 45(4), 465-473.
- Liegeois, A., & van Audenhove, C. (2005). Ethical Dilemmas in Community Mental Health Care. *Journal of Medical Ethics*, 31(8), 452-456.
- Liljeroos, M., Agren, S., Jaarsma, T., & Stromberg, A. (2014). Perceived Caring Needs in Patient-Partner Dyads Affected by Heart Failure: A Qualitative Study. *Journal of Clinical Nursing*, 23(19-20), 2928-2938.
- Lilley, S. A., Lincoln, N. B., & Francis, V. M. (2003). A Qualitative Study of Stroke Patients' and Carers' Perceptions of the Stroke Family Support Organizer Service. *CLINICAL REHABILITATION*, 17(5), 540-547.
- Lilly, M. B., Coyte, P. C., & Laporte, A. (2007). Labor Market Work and Home Care's Unpaid Caregivers: A Systematic Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work. *Milbank Quarterly*, 85(4), 641-690.
- Lilly, M. B., Laporte, A., & Coyte, P. C. (2010). Do They Care Too Much to Work? The Influence of Caregiving Intensity on the Labour Force Participation of Unpaid Caregivers in Canada. *Journal of Health Economics*, 29(6), 895-903.
- Lin, M.-C., Macmillan, M., & Brown, N. (2012). A Grounded Theory Longitudinal Study of Carers' Experiences of Caring for People with Dementia. *Dementia: The International Journal of Social Research and Practice*, 11(2), 181-197.
- Lin, P., & Lu, C. (2007). Psychosocial Factors Affecting Hip Fracture Elder's Burden of Care in Taiwan. *Orthopaedic Nursing*, 26(3), 155-161.
- Linacre, S., Heywood-Everett, S., Sharma, V., & Hill, A. J. (2015). Comparing Carer Wellbeing: Implications for Eating Disorders. *Mental Health Review Journal*, 20(2), 105-118.
- Lincoln, N. B., Walker, M. F., Dixon, A., & Knights, P. (2004). Evaluation of a Multiprofessional Community Stroke Team: A Randomized Controlled Trial. *Clinical Rehabilitation*, 18(1), 40-47.
- Linderholm, M., & Friedrichsen, M. (2010). A Desire to Be Seen Family Caregivers' Experiences of Their Caring Role in Palliative Home Care. *Cancer Nursing*, 33(1), 28-36.
- Lindqvist, G., Albin, B., Heikkilä, K., & Hjelm, K. (2013). Conceptions of Daily Life in Women Living with a Man Suffering from Chronic Obstructive Pulmonary Disease. *Primary Health Care Research & Development*, 14(1), 40-51.
- Lindsay, S., & Vrijhoef, H. J. (2009). Introduction -- a Sociological Focus on 'Expert Patients'. *Health Sociology Review*, 18(2), 139-144 136p.
- Lindsay, S., & Vrijhoef, H. J. M. (2009). A Sociological Focus on 'Expert Patients'. *Health Sociology Review*, 18(2), 139-144.
- Lingler, J. H., Martire, L. M., & Schulz, R. (2006). Review: Cholinesterase Inhibitors Reduce Burden and Care Time for Informal Carers of People with Alzheimer's Disease. *Evidence Based Mental Health*, 9(1), 19-19.

- Linnarsson, J. R., Bubini, J., & Perseus, K. I. (2010). Review: A Meta Synthesis of Qualitative Research into Needs and Experiences of Significant Others to Critically Ill or Injured Patients. *Journal of Clinical Nursing*, 19(21-22), 3102-3111.
- Lins, S., Hayder-Beichel, D., Rucker, G., Motschall, E., Antes, G., Meyer, G., & Langer, G. (2014). Efficacy and Experiences of Telephone Counselling for Informal Carers of People with Dementia. *Cochrane Database of Systematic Reviews* (9).
- Litwin, H., & Attias-Donfut, C. (2009). The Inter-Relationship between Formal and Informal Care: A Study in France and Israel. *Ageing & Society*, 29, 71-91.
- Litzelman, K., Witt, W. P., Gangnon, R. E., Nieto, F. J., Engelman, C. D., Mallick, M. R., & Skinner, H. G. (2014). Association between Informal Caregiving and Cellular Aging in the Survey of the Health of Wisconsin: The Role of Caregiving Characteristics, Stress, and Strain. *Am J Epidemiol*, 179(11), 1340-1352.
- Liu, L.-F., & Tinker, A. (2001). Factors Associated with Nursing Home Entry for Older People in Taiwan Republic of China. *Journal of Interprofessional Care*, 15(3), 245-255.
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., & Cooper, C. (2013). Clinical Effectiveness of a Manual Based Coping Strategy Programme (Start, Strategies for Relatives) in Promoting the Mental Health of Carers of Family Members with Dementia: Pragmatic Randomised Controlled Trial. *BMJ*, 347(f6276).
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Romeo, R., Livingston, D., Mummery, C., Walker, Z., Hoe, J., & Cooper, C. (2014). Long-Term Clinical and Cost-Effectiveness of Psychological Intervention for Family Carers of People with Dementia: A Single-Blind, Randomised, Controlled Trial. *The Lancet Psychiatry*, 1(7), 539-548.
- Livingston, G., Leavey, G., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K., & Cooper, C. (2010). Making Decisions for People with Dementia Who Lack Capacity: Qualitative Study of Family Carers in the Uk. *BMJ*, 341(c4184).
- Lloyd, B., & Stirling, C. (2011). Ambiguous Gain: Uncertain Benefits of Service Use for Dementia Carers. *Sociology of Health & Illness*, 33(6), 899-913.
- Lloyd, K. (2013). Happiness and Well-Being of Young Carers: Extent, Nature and Correlates of Caring among 10 and 11 Year Old School Children. *Journal of Happiness Studies*, 14(1), 67-80.
- Lloyd, L. (2000). Caring About Carers: Only Half the Picture. *Critical Social Policy* (62), 136-150.
- Lloyd, L. (2006). Call Us Carers: Limitations and Risks in Campaigning for Recognition and Exclusivity. *Critical Social Policy*, 26(4), 945-960.
- Lloyd, M., & Carson, A. (2005). Culture Shift: Carer Empowerment and Cooperative Inquiry. *Journal of Psychiatric & Mental Health Nursing*, 12(2), 187-191.
- Lloyd, M., Lefroy, F., Yorke, S., & Mottershead, R. (2011). Working with Carers in Educational Settings: Developing Innovations in Practice. *Journal of Mental Health Training Education and Practice*, 6(3), 135-141.
- Lobban, F., Glentworth, D., Haddock, G., Wainwright, L., Clancy, A., & Bentley, R. (2011). The Views of Relatives of Young People with Psychosis on How to Design a Relatives Education and Coping Toolkit (React). *J Ment Health*, 20(6), 567-579.
- Lobchuk, M., & Bokhari, S. (2008). Linkages among Empathic Behaviors, Physical Symptoms, and Psychological Distress in Patients with Ovarian Cancer: A Pilot Study. *Oncology Nursing Forum*, 35(5), 808-814.

- Lobchuk, M., McClement, S., & McPherson, C. (2008). Does Blaming the Patient with Lung Cancer Affect the Helping Behavior of Primary Caregivers? *Oncology Nursing Forum*, 35(4), 681-689.
- Lockeridge, S., & Simpson, J. (2013). The Experience of Caring for a Partner with Young Onset Dementia: How Younger Carers Cope. *Dementia: The International Journal of Social Research and Practice*, 12(5), 635-651.
- Loi, S. M., Lautenschlager, N., Dow, B., Moore, K., Cyarto, E., Ames, D., Malta, S., Hill, K., & Russell, M. (2016). Factors Associated with Depression in Older Carers. *International Journal of Geriatric Psychiatry*, 31(3), 294-301.
- Long, A., Hesketh, A., & Bowen, A. (2009). Communication Outcome after Stroke: A New Measure of the Carer's Perspective. *Clinical Rehabilitation*, 23(9), 846-856.
- Longo, S., & Scior, K. (2004). In-Patient Psychiatric Care for Individuals with Intellectual Disabilities: The Service Users' and Carers' Perspectives. *Journal of Mental Health*, 13(2), 211-221.
- Lopez-Hartmann, M., Wens, J., & Verhoeven, V. (2012). The Effect of Caregiver Support Interventions for Informal Caregivers of Community-Dwelling Frail Elderly: A Systematic Review. *Int J Integr Care* (12).
- Lou, S., Carstensen, K., Jørgensen, C. R., & Nielsen, C. P. (2016). Stroke Patients' and Informal Carers' Experiences with Life after Stroke: An Overview of Qualitative Systematic Reviews. *Disability and Rehabilitation*, 1-13.
- Loughland, C. M., Lawrence, G., Allen, G., Hunter, M., Lewin, T. J., Oud, N. E., & Carr, V. J. (2009). Aggression and Trauma Experiences among Carer-Relatives of People with Psychosis. *Soc Psychiatry Psychiatr Epidemiol*, 44(12), 1031-1040.
- Louie, S. W. S., Liu, P. K. K., & Man, D. W. K. (2009). Stress of Caregivers in Caring for People with Stroke Implications for Rehabilitation. *Topics in Geriatric Rehabilitation*, 25(3), 191-197.
- Lovatt, M., Nanton, V., Roberts, J., Ingleton, C., Noble, B., Pitt, E., Seers, K., & Munday, D. (2015). The Provision of Emotional Labour by Health Care Assistants Caring for Dying Cancer Patients in the Community: A Qualitative Study into the Experiences of Health Care Assistants and Bereaved Family Carers. *International Journal of Nursing Studies*, 52(1), 271-279.
- Lovell, H., & Cleaver, K. (2015). The Needs of Young Carers and the Role of the School Nurse. *British Journal of School Nursing*, 10(9), 441-445.
- Low, J., Perry, R., & Wilkinson, S. (2005). A Qualitative Evaluation of the Impact of Palliative Care Day Services: The Experiences of Patients, Informal Carers, Day Unit Managers and Volunteer Staff. *Palliative Medicine*, 19(1), 65-70.
- Low, J. T. S., Roderick, P., & Payne, S. (2004). An Exploration Looking at the Impact of Domiciliary and Day Hospital Delivery of Stroke Rehabilitation on Informal Carers. *Clinical Rehabilitation*, 18(7), 776-784 779p.
- Lowson, E., Hanratty, B., Holmes, L., Addington-Hall, J., Grande, G., Payne, S., & Seymour, J. (2013). From 'Conductor' to 'Second Fiddle': Older Adult Care Recipients' Perspectives on Transitions in Family Caring at Hospital Admission. *Int J Nurs Stud*, 50(9), 1197-1205.
- Lowton, K. (2002). Parents and Partners: Lay Carers' Perceptions of Their Role in the Treatment and Care of Adults with Cystic Fibrosis. *J Adv Nurs*, 39(2), 174-181.
- Lowton, K., Laybourne, A. H., Whiting, D. G., & Martin, F. C. (2010). Can Fire and Rescue Services and the National Health Service Work Together to Improve the Safety and Wellbeing of Vulnerable Older People? Design of a Proof of Concept Study. *BMC Health Services Research*, 10.

- Luengo-Fernandez, R., Leal, J., Gray, A., & Sullivan, R. (2013). Economic Burden of Cancer across the European Union: A Population-Based Cost Analysis. *Lancet Oncology*, 14(12), 1165-1174.
- Lui, M. H., Lee, D. T. F., Greenwood, N., & Ross, F. M. (2012). Informal Stroke Caregivers' Self-Appraised Problem-Solving Abilities as a Predictor of Well-Being and Perceived Social Support. *Journal of Clinical Nursing*, 21(1-2), 232-242.
- Luker, K. A., Wilson, K., Pateman, B., & Beaver, K. (2003). The Role of District Nursing: Perspectives of Cancer Patients and Their Carers before and after Hospital Discharge. *European Journal of Cancer Care*, 12(4), 308-316.
- Lundsgard, J. (2006). Choice and Long-Term Care in OECD Countries: Care Outcomes, Employment and Fiscal Sustainability. *European Societies*, 8(3), 361-383.
- Lunsky, Y., Tint, A., Robinson, S., Gordeyko, M., & Ouellette-Kuntz, H. (2014). System-Wide Information About Family Carers of Adults with Intellectual/Developmental Disabilities: Scoping Review of the Literature. *Journal of Policy and Practice in Intellectual Disabilities*, 11(1), 8-18.
- Lutz, B. J., Chumbler, N. R., & Roland, K. (2007). Care Coordination/Home-Telehealth for Veterans with Stroke and Their Caregivers: Addressing an Unmet Need. *Topics in Stroke Rehabilitation*, 14(2), 32-42.
- Lutz, B. J., & Young, M. E. (2010). Rethinking Intervention Strategies in Stroke Family Caregiving. *Rehabilitation Nursing*, 35(4), 152-160.
- Lyonette, C., & Yardley, L. (2003). The Influence on Carer Wellbeing of Motivations to Care for Older People and the Relationship with the Care Recipient. *Ageing & Society*, 23(4), 487-506.
- Lyonette, C., & Yardley, L. (2006). Predicting Mental Health Outcomes in Female Working Carers: A Longitudinal Analysis. *Aging and Mental Health*, 10(4), 368-377.
- Macdonald, M., & Lang, A. (2014). Applying Risk Society Theory to Findings of a Scoping Review on Caregiver Safety. *Health Soc Care Community*, 22(2), 124-133.
- Macdonald, M. T., Lang, A., McKenna, P., Blanchard, N., & Edwards, E. (2011). Safety in Home Care for Unpaid Caregivers. Healthcare Systems Ergonomics and Patient Safety 2011: An Alliance between Professionals and Citizens for Patient Safety and Quality of Life, 269-272.
- Macdonald, P., Rhind, C., Hibbs, R., Goddard, E., Raenker, S., Todd, G., Schmidt, U., & Treasure, J. (2014). Carers' Assessment, Skills and Information Sharing (Casis) Trial: A Qualitative Study of the Experiential Perspective of Caregivers and Patients. *European Eating Disorders Review*, 22(6), 430-438.
- MacInnes, D. L., & Watson, J. P. (2002). The Differences in Perceived Burdens between Forensic and Non-Forensic Caregivers of Individuals Suffering from Schizophrenia. *Journal of Mental Health*, 11(4), 375-388.
- Mackenzie, A., & Greenwood, N. (2008). Assessment of Informal Carers: What Implications Will the New Strategy for Carers Have? *Policy and Politics*, 36(4), 601-604.
- Mackenzie, C., & Poulin, P. (2006). Living with the Dying: Using the Wisdom of Mindfulness to Support Caregivers of Older Adults with Dementia. *International Journal of Health Promotion and Education*, 44(1), 43-47.
- Mackenzie, J. (2006). Stigma and Dementia: East European and South Asian Family Carers Negotiating Stigma in the UK. *Dementia*, 5(2), 233-247.
- Mackenzie, R., & Watts, J. (2011). Can Clinicians and Carers Make Valid Decisions About Others' Decision-Making Capacities Unless Tests of Decision-Making Competence and

- Capacity Include Emotionality and Neurodiversity? *Tizard Learning Disability Review*, 16(3), 43-51.
- MacKereth, P., Sylt, P., & Weinberg, A. (2005). Chair Massage for Carers in an Acute Cancer Hospital. *European Journal of Oncology Nursing*, 9(2), 167-179.
- Mafullul, Y. M. (2002). Burden of Informal Carers of Mentally Infirm Elderly in Lancashire. *East African Medical Journal*, 79(6), 291-298.
- Mafullul, Y. M. (2002). Informal Carers of Mentally Infirm Elderly in Lancashire. *East African Medical Journal*, 79(6), 284-290.
- Mafullul, Y. M., & Morriss, R. K. (2000). Determinants of Satisfaction with Care and Emotional Distress among Informal Carers of Demented and Non-Demented Elderly Patients. *International Journal of Geriatric Psychiatry*, 15(7), 594-599 596p.
- Magnusson, L., & Hanson, E. (2005). Supporting Frail Older People and Their Family Carers at Home Using Information and Communication Technology: Cost Analysis. *J Adv Nurs*, 51(6), 645-657.
- Magnusson, L., Hanson, E., & Nolan, M. (2005). The Impact of Information and Communication Technology on Family Carers of Older People and Professionals in Sweden. *Ageing & Society*, 25(5), 693-713.
- Magnusson, L., & Hanson, E. J. (2003). Ethical Issues Arising from a Research, Technology and Development Project to Support Frail Older People and Their Family Carers at Home. *Health Soc Care Community*, 11(5), 431-439.
- Magnusson, L., Sandman, L., Gustav-Rosén, K., & Hanson, E. (2014). Extended Safety and Support Systems for People with Dementia Living at Home. *Journal of Assistive Technologies*, 8(4), 188-206.
- Magorrian, K. (2001). Responding to the Needs of Carers of People with Schizophrenia. *Professional Nurse*, 17(4), 225-229.
- Maguire, R., Forbat, L., Kearney, N., & Rowa-Dewar, N. (2009). 'Quite an Awkward Situation to Be In': Perceptions of Patients, Carers and Health and Social Care Professionals of the Supportive Cancer Care in British Military Personnel Stationed in Germany. *Supportive Care in Cancer*, 17(10), 1269-1276.
- Majeed, T., Forder, P., Mishra, G., Kendig, H., & Byles, J. (2015). A Gendered Approach to Workforce Participation Patterns over the Life Course for an Australian Baby Boom Cohort. *Journal of Vocational Behavior*, 87, 108-122.
- Mak, A. K. M., Mackenzie, A., & Lui, M. H. L. (2007). Changing Needs of Chinese Family Caregivers of Stroke Survivors. *Journal of Clinical Nursing*, 16(5), 971-979.
- Mak, W. W., & Cheung, R. Y. (2012). Psychological Distress and Subjective Burden of Caregivers of People with Mental Illness: The Role of Affiliate Stigma and Face Concern. *Community Mental Health Journal*, 48(3), 270-274.
- Maketlow, R., Hughes, P., Britton, F., Campbell, J., Hamilton, B., & Wilson, G. (2002). The Experience and Practice of Approved Social Workers in Northern Ireland. *British Journal of Social Work*, 32(4), 443-461.
- Malihi-Shoja, L., Catherall, D., Titherington, J., Mallen, E., & Hough, G. (2013). We Aren't All Winners: A Discussion Piece on 'Failure to Fail' from a Service User and Carer Perspective. *Journal of Practice Teaching and Learning*, 11(3), 8-16.
- Mancini, J., Baumstarck-Barrau, K., Simeoni, M. C., Grob, J. J., Michel, G., Tarpin, C., Loundou, A. D., Lambert, A., Clement, A., & Auquier, P. (2011). Quality of Life in a Heterogeneous Sample of Caregivers of Cancer Patients: An in-depth Interview Study. *European Journal of Cancer Care*, 20(4), 483-492.



- Mannell, R. C., Salmoni, A. W., & Martin, L. (2002). Older Adults Caring for Older Adults: Physically Active Leisure Lifestyles as a Coping Resource for the Health of Caregivers. *Loisir & Societe-Society and Leisure*, 25(2), 397-420.
- Manning, L., Katbamna, S., Johnson, M. R. D., Mistri, A., & Robinson, T. (2014). British Indian Carers of Stroke Survivors Experience Higher Levels of Anxiety and Depression Than White British Carers: Findings of a Prospective Observational Study. *Diversity and Equality in Health and Care*, 11(3-4), 187-200.
- Mannion, E. (2008). Alzheimer's Disease: The Psychological and Physical Effects of the Caregiver's Role, Part 2. *Nursing Older People*, 20(4), 33-39.
- Mansell, I., & Wilson, C. (2009). Current Perceptions of Respite Care: Experiences of Family and Informal Carers of People with a Learning Disability. *Journal of Intellectual Disabilities*, 13(4), 255-267.
- Mansell, I. A. N., & Wilson, C. (2010). 'It Terrifies Me, the Thought of the Future': Listening to the Current Concerns of Informal Carers of People with a Learning Disability. *Journal of Intellectual Disabilities*, 14(1), 21-31.
- Mant, J., Carter, J., Wade, D. T., & Winner, S. (2000). Family Support for Stroke: A Randomised Controlled Trial. *Lancet*, 356(9232), 808-813.
- Manthorpe, J. (2000). Developing Carers' Contributions to Social Work Training. *Social Work Education*, 19(1), 19-27.
- Manthorpe, J. (2000). Older People. *Research Matters*, 14-16.
- Manthorpe, J. (2001). Caring at a Distance: Learning and Practice Issues. *Social Work Education*, 20(5), 593-602.
- Manthorpe, J. (2003). Nearest and Dearest? The Neglect of Lesbians in Caring Relationships. *British Journal of Social Work*, 33(6), 753-768.
- Manthorpe, J. (2009). Carers and Individual Budgets. *Community Care* (1769), 30-32.
- Manthorpe, J., Alaszewski, A., Gates, B., Ayer, S., & Motherby, E. (2003). Learning Disability Nursing: User and Carer Perceptions. *Journal of Learning Disabilities*, 7(2), 119-135.
- Manthorpe, J., & Bowling, A. (2008). Quality of Life Measures for Carers for People with Dementia: Measurement Issues, Gaps in Research and Promising Paths. *Research, Policy & Planning*, 31(3), 163-178.
- Manthorpe, J., Illife, S., & Alison, E. (2003). Testing Twigg and Atkin's Typology of Caring: A Study of Primary Care Professionals' Perceptions of Dementia Care Using a Modified Focus Group Method. *Health and Social Care in the Community*, 11(6), 477-485.
- Manthorpe, J., Moriarty, J., & Cornes, M. (2015). Parent? Carer? Mid-Lifer? Older Person? Similarities and Diversities across Different Experiences of Caring and Their Implications for Practice. *Working with Older People*, 19(2), 94-103.
- Manthorpe, J., Moriarty, J., & Cornes, M. (2015). Supportive Practice with Carers of People with Substance Misuse Problems. *Practice: Social Work in Action*, 27(1), 51-65.
- Manthorpe, J., Moriarty, J., Cornes, M., Hussein, S., & Lombard, D. (2013). On-Line Information and Registration with Services: Patterns of Support for Carers in England. *Working with Older People*, 17(3), 117-124.
- Manthorpe, J., Rapaport, J., & Stanley, N. (2009). Expertise and Experience: People with Experiences of Using Services and Carers' Views of the Mental Capacity Act 2005. *British Journal of Social Work*, 39(5), 884-900.

- Manthorpe, J., S., I., Goodman, C., Drennan, V., & Warner, J. (2013). Working Together in Dementia Research: Reflections on the Evidem Programme. *Working with Older People*, 17(4), 138-145.
- Marais, S., Conradie, G., & Kritzinger, A. (2006). Risk Factors for Elder Abuse and Neglect: Brief Descriptions of Different Scenarios in South Africa. *International Journal of Older People Nursing*, 1(3), 186-189.
- Marco, E., Duarte, E., Santos, J. F., Aguirrezabal, A., Morales, A., Belmonte, R., Muniesa, J. M., Tejero, M., & Escalada, F. (2010). Loss of Quality of Life in Family Caregivers of Stroke Patients: An Entity to Be Considered. *Revista de Calidad Asistencial*, 25(6), 356-364.
- Marim, C., Silva, V., Taminato, M., & Barbosa, D. (2013). Effectiveness of Educational Programs on Reducing the Burden of Caregivers of Elderly Individuals with Dementia: A Systematic Review. *Rev. Latino-Am Enfermagem*, 21, 267-275.
- Markle-Reid, M., & Browne, G. (2002). Explaining the Use and Non-Use of Community-Based Long-Term Care Services by Caregivers of Persons with Dementia. *Journal of evaluation in Clinical Practice*, 7(3), 271-287.
- Marriott, A., Donaldson, C., Tarrier, N., & Burns, A. (2000). Effectiveness of Cognitive-Behavioural Family Intervention in Reducing the Burden of Care in Carers of Patients with Alzheimer's Disease. *British Journal of Psychiatry*, 176, 557-562.
- Marriott, S., Audini, B., Lelliott, P., Webb, Y., & Duffett, R. (2001). Research into the Mental Health Act: A Qualitative Study of the Views of Those Using or Affected by It. *Journal of Mental Health*, 10(1), 33-39.
- Marrugat, M. L. (2005). Family Care and Their Incidence in the Quality of Life of Dependent Elderly People. *Revista Multidisciplinar de Gerontologia*, 15(3), 171-177.
- Marshall, S., Bauer, J., Capra, S., & Isenring, E. (2013). Are Informal Carers and Community Care Workers Effective in Managing Malnutrition in the Older Adult Community? A Systematic Review of Current Evidence. *Journal of Nutrition Health & Aging*, 17(8), 645-651.
- Martin, G. P., Nancarrow, S. A., Parker, H., Phelps, K., & Regen, E. L. (2005). Place, Policy and Practitioners: On Rehabilitation, Independence and the Therapeutic Landscape in the Changing Geography of Care Provision to Older People in the Uk. *Social Science and Medicine*, 61(9), 1893.
- Martin, R., Williams, J., & Hadjistavropoulos, T. (2005). A Qualitative Investigation of Seniors' and Caregivers' Views on Pain Assessment and Management. *Canadian Journal of Nursing Research*, 37(2), 142-164.
- Martin, Y., Gilbert, P., McEwan, K., & Irons, C. (2006). The Relation of Entrapment, Shame and Guilt to Depression, in Carers of People with Dementia. *Aging and Mental Health*, 10(2), 101-106.
- Martin-Carrasco, M., Martin, M. F., Valero, C. P., Millan, P. R., Garcia, C. I., Montalban, S. R., Vazquez, A. L., Piris, S. P., & Vilanova, M. B. (2009). Effectiveness of a Psychoeducational Intervention Program in the Reduction of Caregiver Burden in Alzheimers Disease Patients and Caregivers. *International Journal of Geriatric Psychiatry*, 24(5), 489-499.
- Martinez-Martin, P., Rodriguez-Blazquez, C., & Forjaz, M. J. (2012). Quality of Life and Burden in Caregivers for Patients with Parkinson's Disease: Concepts, Assessment and Related Factors. *Expert Reviews*, 12, 221-230.
- Martins, M., & Couto, A. P. (2014). Everyday Experiences of Parents with Disabled Children. *Revista de Enfermagem Referência*, 4(1), 113-120.
- Maruf, F. A., Muonwe, C., & Odetunde, M. (2016). Social Risk Factors for Falls among Rural Nigerian Community-Dwelling Older Adults. *Geriatrics and Gerontology International*, 16(6), 747-753.

- Marziali, E., Donahue, P., & Crossin, G. (2005). Caring for Others: Internet Health Care Support Intervention for Family Caregivers of Persons with Alzheimer's, Stroke, or Parkinson's Disease. *Families in Society*, 86(3), 375-383.
- Maskell, P., Somerville, M., & Mathews, A. (2015). Supporting Carers: A Learning Resource for Community Nurses. *British Journal of Community Nursing*, 20(7), 335-337.
- Maskill, V., Crowe, M., & Luty, S. (2010). Two Sides of the Same Coin: Caring for a Person with Bipolar Disorder. *Journal of Psychiatric and Mental Health Nursing*, 17(6), 535-542.
- Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamsom, J., Drummond, M., & Glendinning, C. (2007). A Systematic Review of the Effectiveness and Cost-Effectiveness of Different Models of Community-Based Respite Care for Frail Older People and Their Carers. *Health Technology Assessment*, 11(15), 1-157.
- Mason, L., & Cunningham, C. (2009). Pre-Menstrual Syndrome in Women with Down Syndrome. *Journal of Applied Research in Intellectual Disabilities*, 22(3), 287-297.
- Masters, S., Gordon, J., Whitehead, C., Davies, O., Giles, L. C., & Ratcliffe, J. (2012). Coaching Older Adults and Carers to Have Their Preferences Heard (Coach): A Randomised Controlled Trial in an Intermediate Care Setting (Study Protocol). *Australasian Medical Journal*, 5(8), 444-454.
- Masuy Amandine, J. (2009). Effect of Caring for an Older Person on Women's Lifetime Participation in Work. *Ageing and Society*, 29(5), 745-763.
- Matthews, T., Weston, N., Baxter, H., Felce, D., & Kerr, M. (2008). A General Practice-Based Prevalence Study of Epilepsy among Adults with Intellectual Disabilities and of Its Association with Psychiatric Disorder, Behaviour Disturbance and Carer Stress. *Journal of Intellectual Disability Research*, 52(2), 163-173.
- Mavall, L., & Malmberg, B. (2007). Day Care for Persons with Dementia: An Alternative for Whom? *Dementia*, 8(1), 27-43.
- May, C. R., Masters, J., Welch, L., Hunt, K., Pope, C., Myall, M., Griffiths, P., Roderick, P., Glanville, J., & Richardson, A. (2015). Experts 1 - Experiences of Long-Term Life-Limiting Conditions among Patients and Carers: Protocol for a Qualitative Meta-Synthesis and Conceptual Modelling Study. *BMJ Open*, 5(4).
- May, J., Ellis-Hill, C., & Payne, S. (2001). Gatekeeping and Legitimization: How Informal Carers' Relationship with Health Care Workers Is Revealed in Their Everyday Interactions. *Journal Of Advanced Nursing*, 36(3), 364-375.
- Maybin, M. (2003). New Group with Old Issues. *Community Care* (6.11.03), 40-41.
- Mazanec, S., Daly, B., Douglas, S., & Lipson, A. (2011). Work Productivity and Health of Informal Caregivers of Persons with Advanced Cancer. *Research in Nursing and Health*, 34(6), 483-495.
- McAndrew, S., Warne, T., Fallon, D., & Moran, P. (2012). Young, Gifted, and Caring: A Project Narrative of Young Carers, Their Mental Health, and Getting Them Involved in Education, Research and Practice. *International Journal of Mental Health Nursing*, 21(1), 12-19.
- McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). 'What I Want to Do Is Get Half a Dozen of Them and Go and See Simon Cowell': Reflecting on Participation and Outcomes for People with Dementia Taking Part in a Creative Musical Project. *Dementia: The International Journal of Social Research and Practice*, 14(6), 734-750.
- McCabe, M. P., Roberts, C., & Firth, L. (2008). Satisfaction with Services among People with Progressive Neurological Illnesses and Their Carers in Australia. *Nursing & Health Sciences*, 10(3), 209-215.

- McCabe, R., Heath, C., Burns, T., & Priebe, S. (2002). Engagement of Patients with Psychosis in the Consultation: Conversation Analytic Study. *British Medical Journal*, 325(7373), 1148-1151.
- McCaffrey, N., Gill, L., Kaambwa, B., Cameron, I. D., Patterson, J., Crotty, M., & Ratcliffe, J. (2015). Important Features of Home-Based Support Services for Older Australians and Their Informal Carers. *Health & Social Care in The Community*, 23(6), 654-664.
- McCann, S., & Evans, D. S. (2002). Informal Care: The Views of People Receiving Care. *Health and Social Care in the Community*, 10(4), 221-228.
- McCann, S., McKenna, H., & Ryan, A. A. (2005). The Challenges Associated with Providing Community Care for People with Complex Needs in Rural Areas: A Qualitative Investigation. *Health & Social Care in the Community*, 13(5), 462-469.
- McCann, T. V., & Bamberg, J. (2016). Carers of Older Adults' Satisfaction with Public Mental Health Service Clinicians: A Qualitative Study. *Journal of Clinical Nursing*, 25(11/12), 1634-1643.
- McCann, T. V., Lubman, D. I., & Clark, E. (2012). Primary Caregivers' Satisfaction with Clinicians' Response to Them as Informal Carers of Young People with First-Episode Psychosis: A Qualitative Study. *Journal of Clinical Nursing*, 21(1-2), 224-231.
- McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). Alzheimer's Dementia in Persons with Down's Syndrome: Predicting Time Spent on Day-to-Day Caregiving. *Dementia: The International Journal of Social Research and Practice*, 4(4), 521-538.
- McCarthy, G., Gresswell, I., & Adamis, D. (2016). Burden of Informal Carers in Northwest Ireland: A Pilot Study of Factors That Influence Burden. *European Psychiatry*, 33, S219-S219.
- McCarthy, S. A., Jenn, N. C., Leng, C. C. K., & Hamzah, E. (2016). What Are the Experiences and Needs of Patients and Carers Receiving Community Palliative Care in Malaysia? A Qualitative Study. *Progress in Palliative Care*, 24(2), 73-83.
- McClendon, M. J., Smyth, A., K., & Neudorfer, M. M. (2004). Survival of Persons with Alzheimer's Disease: Caregiver Coping Matters. *Gerontologist*, 44(4), 508-519.
- McConaghy, R., & Caltabiano, M. L. (2005). Caring for a Person with Dementia: Exploring Relationships between Perceived Burden, Depression, Coping and Well-Being. *Nursing & Health Sciences*, 7(2), 81-91.
- McConkey, R., Kelly, F., & Craig, S. (2011). Access to Respite Breaks for Families Who Have a Relative with Intellectual Disabilities: A National Survey. *Journal of Advanced Nursing*, 67(6), 1349-1357.
- McConkey, R., McConaghie, J., Roberts, P., & King, D. (2004). Family Placement Schemes for Adult Persons with Intellectual Disabilities Living with Elderly Carers. *Journal of Learning Disabilities*, 8(3), 267-282.
- McConkey, R., & McCullough, J. (2006). Holiday Breaks for Adults with Intellectual Disabilities Living with Older Carers. *Journal of Social Work*, 6(1), 65-79.
- McCormack, B., Borg, M., Cardiff, S., Dewing, J., Jacobs, G., Titchen, A., van Lieshout, F., & Wilson, V. (2016). A Kaleidoscope of Hope: Exploring Experiences of Hope among Service Users and Informal Carers in Health Care Contexts. *Journal of Holistic Nursing: Official Journal of The American Holistic Nurses' Association*.
- McCoulough, S. (2016). Adapting a Skin Bundle for Carers to Aid Identification of Pressure Damage and Ulcer Risks in the Community. *British Journal of Community Nursing*, 21(Sup6), S19-S25.

- McCrae, J. (2010). Physical Health Concerns of the Patient, the Family and the Carer. *European Psychiatry: The Journal Of The Association Of European Psychiatrists*, 25 Suppl 2, S34-S36.
- McCreadie, C. (2002). A Review of Research Outcomes in Elder Abuse. *Journal of Adult Protection*, 4(2), 3-8.
- McCrone, P., Kuipers, E., & Szmukler, G. (2005). Service Use and Cost Associated with Caring for People with Serious Mental Illness. *Journal of Mental Health*, 14(1), 37-47.
- McCusker, J., Latimer, E., & Cole, M. (2007). Major Depression among Medically Ill Elders Contributes to Sustained Poor Mental Health in Their Informal Caregivers. *Age and Ageing*, 36(4), 400-406.
- McCusker, P., Macintyre, G., Stewart, A., & Jackson, J. (2012). Evaluating the Effectiveness of Service User and Carer Involvement in Post Qualifying Mental Health Social Work Education in Scotland: Challenges and Opportunities. *The Journal of Mental Health Training, Education and Practice*, 7(3), 143-153.
- McDaid, D. (2001). Estimating the Costs of Informal Care for People with Alzheimer's Disease: Methodological and Practical Challenges. *International Journal of Geriatric Psychiatry*, 16(4), 400-405.
- McDonald, J., Dew, K., & Cumming, J. (2010). Change and Adaptation in Families with Young Carers. *Australian Journal of Social Issues (Australian Council of Social Service)*, 45(4), 459-475.
- McEvoy, C., & Nosowska, G. (2012). Working Together - Learning through Sharing. *Journal of Integrated Care*, 20(1), 62-67.
- McFarlane, L. (2001). Managing a Dual Role: Working Carers in Social Services. *Journal of Integrated Care*, 9(4), 26-31.
- McGarrigle, C., Cronin, H., & Kenny, R. (2014). The Impact of Being the Intermediate Caring Generation and Intergenerational Transfers on Self-Reported Health of Women in Ireland. *Int J Public Health*, 59(2), 301-308.
- McGarrigle, C. A., McCrory, C., & Kenny, R. A. (2014). PI01 the Impact of Caring for Spouses on Mental Health and Health Behaviours in over 50s in Ireland, the Irish Longitudinal Study on Ageing. *J Epidemiol Community Health*, 68(Suppl 1), A3.
- McGarry, J., & Arthur, A. (2001). Informal Caring in Later Life: A Qualitative Study of the Experiences of Older Carers. *Journal of Advanced Nursing*, 33(2), 182-189.
- McGarry, J., & Thom, N. (2004). How Users and Carers View Their Involvement in Nurse Education. *Nursing Times* (4.05.04), 36-37.
- McGee, H. M., Molloy, G., O'Hanlon, A., Layte, R., & Hickey, A. (2008). Older People: Recipients but Also Providers of Informal Care: An Analysis among Community Samples in the Republic of Ireland and Northern Ireland. *Health Soc Care Community*, 16(5), 548-553.
- McGrother, C., Thorp, C., Taub, N., & Machado, O. (2001). Prevalence, Disability and Need in Adults with Severe Learning Disability. *Tizard Learning Disability Review*, 6(3), 4-13 10p.
- McGuigan, K., McDermott, L., Magowan, C., McCorkell, G., Witherow, A., & Coates, V. (2016). The Impact of Direct Payments on Service Users Requiring Care and Support at Home. *Practice*, 28(1), 37-54.
- McGurk, R., Kneebone, I. I., Ineke, M., & Pit-Ten Cate, I. (2011). "Sometimes We Get It Wrong but We Keep on Trying": A Cross-Sectional Study of Coping with Communication Problems by Informal Carers of Stroke Survivors with Aphasia. *Aphasiology*, 25(12), 1507-1522.
- McGurk, R., & Kneebone, I. I. (2013). The Problems Faced by Informal Carers to People with Aphasia after Stroke: A Literature Review. *Aphasiology*, 27(7), 765-783.

- McIlfatrick, S. (2007). Assessing Palliative Care Needs: Views of Patients, Informal Carers and Healthcare Professionals. *Journal of Advanced Nursing*, 57(1), 77-86.
- McIlfatrick, S., Sullivan, K., & McKenna, H. (2006). What About the Carers? Exploring the Experience of Caregivers in a Chemotherapy Day Hospital Setting. *European Journal of Oncology Nursing*, 10(4), 294-303.
- McIlrae, S., Wilkes, E., Downey, M., & Colley, M. (2010). A Cognitive Behavioural Approach for Carers of Significant Others with Depression: A Pilot Study. *Journal of Mental Health Training Education and Practice*, 5(1), 28-34.
- McIntyre, A. (2012). There's No Apprenticeship for Alzheimer's: The Caring Relationship When an Older Person Experiencing Dementia Falls. *Ageing and Society*, 32(5), 873-896.
- McKechnie, R., MacLeod, R., & Jaye, C. (2010). Palliative Care for People with Non-Malignant Conditions in a New Zealand Community. *Progress in Palliative Care*, 18(5), 275-280.
- McKechnie, V., Barker, C., & Stott, J. (2014). The Effectiveness of an Internet Support Forum for Carers of People with Dementia: A Pre-Post Cohort Study. *Journal of Medical Internet Research*, 16(2), e68-e68.
- McKechnie, V., Barker, C., & Stott, J. (2014). Effectiveness of Computer-Mediated Interventions for Informal Carers of People with Dementia-a Systematic Review. *International Psychogeriatrics*, 26(10), 1619-1637.
- McKee, K., Brown, J., & Nolan, M. (2006). Determinants of Quality of Life in Informal Carers of Older People. *Psychology & Health*, 21, 101-101.
- McKee, K., Spazzafumo, L., Nolan, M., Wojszel, B., Lamura, G., & Bien, B. (2009). Components of the Difficulties, Satisfaction and Management Strategies of Carers of Older People: A Principal Component Analysis of Cadi-Casi-Cami. *Aging & Mental Health*, 13(2), 255-264 210p.
- McKee, K. J., Bien, B., Wojszel, B., Kofahl, C., Krevers, B., Melchiorre, M. G., Mnich, E., & Prouskis, C. (2010). The Willingness of Informal Carers of Older People to Continue Caring: Results of the Eurofamcare Study. *Psychology & Health*, 25, 59-59.
- McKee, K. J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., Spazzafumo, L., Bien, B., Parker, C., Nolan, M. R., & Szczerbinska, K. (2003). The Cope Index -- a First Stage Assessment of Negative Impact, Positive Value and Quality of Support of Caregiving in Informal Carers of Older People. *Aging & Mental Health*, 7(1), 39-52 14p.
- McKenzie, H., Boughton, M., Hayes, L., Forsyth, S., Davies, M., Underwood, E., & McVey, P. (2007). A Sense of Security for Cancer Patients at Home: The Role of Community Nurses. *Health and Social Care in the Community*, 15(4), 352-359.
- McKenzie, S. J., Lucke, J. C., Hockey, R. L., Dobson, A. J., & Tooth, L. R. (2014). Is Use of Formal Community Services by Older Women Related to Changes in Their Informal Care Arrangements? *Ageing & Society*, 34(2), 310-329.
- McKenzie, S. J., McLaughlin, D., Dobson, A. J., & Byles, J. E. (2010). Urban-Rural Comparisons of Outcomes for Informal Carers of Elderly People in the Community: A Systematic Review. *Maturitas*, 67(2), 139-143.
- McKenzie, T., Quig, M. E., Tyry, T., Marrie, R. A., Cutter, G., Shearin, E., Johnson, K., & Simsarian, J. (2015). Care Partners and Multiple Sclerosis: Differential Effect on Men and Women. *International journal of MS care*, 17(6), 253.
- McKeown, P., Piggot, M., Burghri, S., & McConkey, R. (2001). An Evaluation of the Mencap Family Adviser Service in Northern Ireland. *Child Care in Practice*, 7(4), 273-287.

- McKevitt, C. J., Beech, R., Pound, P., Rudd, A. G., & Wolfe, C. D. A. (2000). Putting Stroke Outcomes into Context - Assessment of Variations in the Processes of Care. *European Journal of Public Health*, 10(2), 120-126.
- McKie, L., Bowlby, S., & Gregory, S. (2001). Gender, Caring and Employment in Britain. *Journal of Social Policy*, 30(2), 233-258.
- McKie, L., Gregory, S., & Bowlby, S. (2002). Shadow Times: The Temporal and Spatial Frameworks and Experiences of Caring and Working. *Sociology*, 36(4), 897-924.
- McLaughlin, C., McGowan, I., Kernohan, G., & O'Neill, S. (2016). The Unmet Support Needs of Family Members Caring for a Suicidal Person. *Journal of Mental Health*, 25(3), 212-216.
- McLaughlin, C., McGowan, I., O'Neill, S., & Kernohan, G. (2014). The Burden of Living with and Caring for a Suicidal Family Member. *Journal of Mental Health*, 23(5), 236-240.
- McLaughlin, D., Barr, O., McIlpatrick, S., & McConkey, R. (2015). Service User Perspectives on Palliative Care Education for Health and Social Care Professionals Supporting People with Learning Disabilities. *BMJ Supportive & Palliative Care*, 5(5), 531-537.
- McLaughlin, D., Hasson, F., & Kernohan, W. (2011). Living and Coping with Parkinson's Disease: Perceptions of Informal Carers. *Palliative Medicine*, 25(2), 177-182.
- McLaughlin, K. (2011). 'It's All Changed:' Carers' Experiences of Caring for Adults Who Have Down's Syndrome and Dementia. *British Journal of Learning Disabilities*, 39(1), 57-63.
- McLellan, D. L., & Pain, H. (2003). The Relative Importance of Factors Affecting the Choice of Bathing Devices. *British Journal of Occupational Therapy*, 66(9), 396-401.
- McManus, R. J., Bray, E. P., Mant, J., Holder, R., Greenfield, S., Bryan, S., Jones, M. I., Little, P., Williams, B., & Richard, F. D. R. (2009). Protocol for a Randomised Controlled Trial of Telemonitoring and Self-Management in the Control of Hypertension: Telemonitoring and Self-Management in Hypertension. [Isrctn17585681]. *BMC Cardiovascular Disorders*, 9.
- McMunn, A., Nazroo, J., Wahrendorf, M., Breeze, E., & Zaninotto, P. (2009). Participation in Socially-Productive Activities, Reciprocity and Wellbeing in Later Life: Baseline Results in England. *Ageing & Society*, 29(5), 765-782.
- McNamara, B., & Rosenwax, L. (2010). Which Carers of Family Members at the End of Life Need More Support from Health Services and Why? *Social Science and Medicine*, 70(7), 1035-1041.
- McNamara, R., & Shaw, C. (2007). Older People and Respite Care. *Reviewing Research Evidence for Nursing Practice: Systematic Reviews*, 210-225.
- McPherson, C. J., & Addington-Hall, J. M. (2004). How Do Proxies' Perceptions of Patients' Pain, Anxiety, and Depression Change During the Bereavement Period? *Journal of Palliative Care*, 20(1), 12-19.
- McPherson, C. J., Wilson, K. G., Chyurlia, L., & Leclerc, C. (2011). The Caregiving Relationship and Quality of Life among Partners of Stroke Survivors: A Cross-Sectional Study. *Health and Quality of Life Outcomes*, 9.
- McPherson, K. M., Kayes, N. K., Molocziej, N., & Cummins, C. (2014). Improving the Interface between Informal Carers and Formal Health and Social Services: A Qualitative Study. *International Journal of Nursing Studies*, 51(3), 418-429.
- McPherson, K. M., McNaughton, H., & Pentland, B. (2000). Information Needs of Families When One Member Has a Severe Brain Injury. *International Journal of Rehabilitation Research*, 23(4), 295.
- McSherry, R., & Duggan, S. (2016). Involving Carers in the Teaching, Learning and Assessment of Masters Students. *Nurse Education in Practice*, 16(1), 156-159.

- Mechling, B. M. (2011). The Experiences of Youth Serving as Caregivers for Mentally Ill Parents. *J Psychosoc Nurs Mental Health Serv*, 49(3), 28-33.
- Meijer, K., Schene, A., Koeter, M., Knudsen, H. C., Becker, T., Thornicroft, G., Vazquez-Barquero, J. L., & Tansella, M. (2004). Needs for Care of Patients with Schizophrenia and the Consequences for Their Informal Caregivers. *Soc Psychiatry Psychiatr Epidemiol*, 39(251).
- Meiland, F. J. M., Hattink, B. J. J., Overmars-Marx, T., de Boer, M. E., Jedlitschka, A., Ebben, P. W. G., Stalpers-Croeze, I., Flick, S., van der Leeuw, J., Karkowski, I. P., & Droes, R. M. (2014). Participation of End Users in the Design of Assistive Technology for People with Mild to Severe Cognitive Problems; the European Rosetta Project. *International Psychogeriatrics*, 26(5), 769-779.
- Melis, R. J., van Eijken, M. I., Van Achterberg, T., Teerenstra, S., Vernooij-Dassen, M., van de Lisdonk, E. H., & Rikkert, M. G. (2009). The Effect on Caregiver Burden of a Problem-Based Home Visiting Programme for Frail Older People. *Age & Ageing*, 38(5), 542-547.
- Melunsky, N., Crellin, N., Dudzinski, E., Orrell, M., Wenborn, J., Poland, F., Woods, B., & Charlesworth, G. (2015). The Experience of Family Carers Attending a Joint Reminiscence Group with People with Dementia: A Thematic Analysis. *Dementia: The International Journal of Social Research and Practice*, 14(6), 842-859.
- Melville, C. A., Hamilton, S., Miller, S., Boyle, S., Robinson, N., Pert, C., & Hankey, C. R. (2009). Carer Knowledge and Perception of Healthy Lifestyles for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(3), 298-306.
- Meng, A. (2013). Informal Home Care and Labor-Force Participation of Household Members (Report). *Empirical Economics*, 44(2), 959.
- Mentzakis, E., McNamee, P., & Ryan, M. (2009). Who Cares and How Much: Exploring the Determinants of Co-Residential Informal Care. *Review of Economics of the Household*, 7(3), 283-303.
- Merrell, J., Kinsella, F., & Murphy, F. (2006). Accessibility and Equity of Health and Social Care Services: Exploring the Views and Experiences of Bangladeshi Carers in South Wales, UK. *Health and Social Care in the Community (Print edition)*, 14(3), 197-205.
- Merrell, J., Kinsella, F., Murphy, F., Philpin, S., & Ali, A. (2005). Support Needs of Carers of Dependent Adults from a Bangladeshi Community. *Journal of Advanced Nursing*, 51(6), 549.
- Metzger, M., Norton, S. A., Quinn, J. R., & Gramling, R. (2013). "That Don't Work for Me" Patients' and Family Members' Perspectives on Palliative Care and Hospice in Late-Stage Heart Failure. *Journal of Hospice & Palliative Nursing*, 15(3), 177-182.
- Metzing, S., & Schnepf, W. (2007). Children and Adolescents as Caregivers: Who They Are and What They Do. An International Literature Review (1990-2006). *Pflege*, 20(6), 323-330 328p.
- Metzing-Blau, S., & Schnepf, W. (2008). Young Carers in Germany: To Live on as Normal as Possible - a Grounded Theory Study. *BMC Nursing*, 7, 15-15.
- Mezue, W., Draper, P., Watson, R., & Mathew, B. (2011). Caring for Patients with Brain Tumour: The Patient and Care Giver Perspectives. *Nigerian Journal of Clinical Practice*, 14(3), 368-372.
- Michalowsky, B., Thyrian, J. R., Eichler, T., Hertel, J., Wucherer, D., Flessa, S., & Hoffmann, W. (2015). Economic Analysis of Formal Care, Informal Care, and Productivity Losses in Primary Care Patients Who Screened Positive for Dementia in Germany. *Journal of Alzheimer's Disease, JAD*, 50(1), 47.
- Michaud, P.-C., Heitmueller, A., & Nazarov, Z. (2010). A Dynamic Analysis of Informal Care and Employment in England. *Labour Economics*, 17(3), 455-465.



- Michels, C. T. J., Boulton, M., Adams, A., Wee, B., & Peters, M. (2016). Psychometric Properties of Carer-Reported Outcome Measures in Palliative Care: A Systematic Review. *Palliative Medicine*, 30(1), 23-44.
- Michelson, W., & Tepperman, L. (2003). Focus on Home: What Time-Use Data Can Tell About Caregiving to Adults. *Journal of Social Issues*, 59(3), 591-610.
- Middleton, T. (2001). Mental Health Services for Older People Towards an Integrates Approach. *Mental Health Review*, 6(2), 22-24.
- Milberg, A., & Strang, P. (2004). Exploring Comprehensibility and Manageability in Palliative Home Care: An Interview Study of Dying Cancer Patients' Informal Carers. *Psycho-Oncology*, 13(9), 605-618.
- Milberg, A., & Strang, P. (2007). What to Do When 'There Is Nothing More to Do'? A Study within a Salutogenic Framework of Family Members' Experience of Palliative Home Care Staff. *Psycho-Oncology*, 16(8), 741-751.
- Miller, C., & Kapp, S. (2015). Informal Carers and Wound Management: An Integrative Literature Review. *Journal of Wound Care*, 24(11), 489-497.
- Miller, E., Cook, A., & Whoriskey, M. (2008). Outcomes for Users and Carers in the Context of Health and Social Care Partnership Working: From Research to Practice. *Journal of Integrated Care*, 16(2), 21-28.
- Miller, J., & Timson, D. (2004). Exploring the Experiences of Partners Who Live with a Chronic Low Back Pain Sufferer. *Health and Social Care in the Community*, 12(1), 34-42.
- Milligan, C. (2005). From Home to 'Home': Situating Emotions within the Caregiving Experience. *Environment and Planning A*, 37(12), 2105-2120.
- Milligan, C. (2005). Placing Narrative Correspondence in the Geographer's Toolbox: Insights from Care Research in New Zealand. *New Zealand Geographer*, 61(3), 213-224.
- Milligan, C. (2006). Caring for Older People in the 21st Century: 'Notes from a Small Island'. *Health & Place*, 12(3), 320-331.
- Mills, J., & Aubeeluck, A. (2006). Nurses' Experiences of Caring for Their Own Family Members. *Br J Nurs*, 15(3), 160-165.
- Milne, A. (2002). Developing a Profile of Older Carers. *Generations Review*, 12(2), 17-19.
- Milne, A., Brigden, C., Palmer, A., & Konta, E. (2013). The Intersection of Employment and Care: Evidence from a UK Case Study. *European Journal of Social Work*, 16(5), 651-670.
- Milne, A., & Hatzidimitriadou, E. (2003). The 'Caring in Later Life' Report: A Secondary Analysis of the 1995 General Household Survey. *Quality in Ageing*, 3(3), 3-15.
- Milne, A., & Hatzidimitriadou, E. (2003). "Isn't He Wonderful?" Exploring the Contribution and Conceptualisation of Older Husbands as Carers. *Ageing Int*, 28(389).
- Milne, A., Hatzidimitriadou, E., & Chryssanthopoulou, C. (2004). Carers of Older Relatives in Long Term Care: Support Needs and Services. *Generations Review*, 14(3), 4-9.
- Milne, A., & Larkin, M. (2015). Knowledge Generation About Care-Giving in the UK: A Critical Review of Research Paradigms. *Health Soc Care Community*, 23(1), 4-13.
- Minogue, V. (2015). "Let Me Back into the World": Compassionate Care in Practice: A Carer and Patient's View. *Quality in Ageing and Older Adults*, 16(2), 75-82.
- Minogue, V., Holt, B., Karban, K., Gelsthorpe, S., Firth, S., & Ramsay, T. (2009). Service User and Carer Involvement in Mental Health Education, Training and Research - a Literature Review. *Mental Health and Learning Disabilities Research and Practice*, 6(2), 211-227.

- Mir, G. (2003). Asian Carers' Experiences of Medical and Social Care: The Case of Cerebral Palsy. *British Journal of Social Work*, 33(4), 465-479.
- Mir, G., & Tovey, P. (2002). Cultural Competency: Professional Action and South Asian Carers. *Journal of Management in Medicine*, 16(1), 7-19.
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2010). People with Dementia Living Alone: What Are Their Needs and What Kind of Support Are They Receiving? *International Psychogeriatrics / IPA*, 22(4), 607-617.
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2013). The Needs of People with Dementia Living at Home from User, Caregiver and Professional Perspectives: A Cross-Sectional Survey. *BMC Health Services Research*, 13(43).
- Misplon, S., Pacolet, J., & Hedeboew, G. (2004). Care Time and Costs of Care for Elderly Persons with Dementia. *Archives of Public Health*, 62(3-4), 143-156.
- Mitchell, E. (2000). Managing Carer Stress: An Evaluation of a Stress Management Programme for Carers of People with Dementia. *British Journal of Occupational Therapy*, 63(4), 179-184.
- Mitchell, G., Porter, S., & Manias, E. (2015). A Critical Ethnography of Communication Processes Involving the Management of Oral Chemotherapeutic Agents by Patients with a Primary Diagnosis of Colorectal Cancer: Study Protocol., 71(4), 922-932. *Journal of Advanced Nursing*
- Mitchell, S., Lucas, C., Norton, M., & Phipps, L. (2016). Dementia Risk Reduction: It's Never Too Early, It's Never Too Late. *Perspectives in Public Health*, 136(2), 79-80.
- Mitchell, W., Brooks, J and Glendinning, C. (2015). Carers' Roles in Personal Budgets: Tensions and Dilemmas in Front Line Practice. *British Journal of Social Work*, 45(5), 1433-1450.
- Mitchell, W., & Glendinning, C. (2008). Risk and Adult Social Care: Identification, Management and New Policies. What Does Uk Research Evidence Tell Us? *Health, Risk & Society*, 10(3), 297-315 219p.
- Mitseva, A., Kyriazakos, S., Litke, A., Papadakis, N., & Prasad, N. (2009). Isisemd: Intelligent System for Independent Living and Self-Care of Seniors with Mild Cognitive Impairment or Mild Dementia. *Journal on Information Technology in Healthcare*, 7(6), 383-399.
- Mittelman, M. S. (2002). Family Caregiving for People with Alzheimer's Disease: Results of the Nyu Spouse Caregiver Intervention Study. *Generations (San Francisco, California)*, 26(1), 104.
- Mockford, C., Jenkinson, C., & Fitzpatrick, R. (2009). Development of the Motor Neuron Disease Carer Questionnaire. *Amyotrophic Lateral Sclerosis*, 10(5/6), 463-469.
- Mogar, M., & von Kutzleben, M. (2014). Dementia in Families with a Turkish Migration Background: Organization and Characteristics of Domestic Care Arrangements. *Zeitschrift fur Gerontologie und Geriatrie*, 48(5), 465-472.
- Molassiotis, A., Coventry, P. A., Stricker, C. T., Clements, C., Eaby, B., Velders, L., Rittenberg, C., & Gralla, R. J. (2007). Validation and Psychometric Assessment of a Short Clinical Scale to Measure Chemotherapy-Induced Nausea and Vomiting: The Mascc Antiemesis Tool. *Journal of Pain and Symptom Management*, 34(2), 148-159.
- Mold, F., McKevitt, C., & Wolfe, C. (2003). A Review and Commentary of the Social Factors Which Influence Stroke Care: Issues of Inequality in Qualitative Literature. *Health & Social Care in the Community*, 11(5), 405-414.
- Molewyk Doornbos, M. (2001). The 24-7-52 Job: Family Caregiving for Young Adults with Serious and Persistent Mental Illness. *Journal of Family Nursing*, 7(4), 328-344.

- Molinuevo, J. L., & Hernández, B. (2011). Profile of the Informal Carer Associated with the Clinical Management of the Alzheimer's Disease Patient Refractory to Symptomatic Treatment of the Disease. *Neurologia*, 26(9), 518-527.
- Molloy, G. J., Johnston, D. W., & Witham, M. D. (2005). Family Caregiving and Congestive Heart Failure. Review and Analysis. *European Journal of Heart Failure*, 7(4), 592-603.
- Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the Term 'Carer': A Critique of the Universal Adoption of the Term 'Carer'. *Ageing & Society*, 31, 422-437.
- Molyneux, G. J., McCarthy, G. M., McEniff, S., Cryan, M., & Conroy, R. M. (2008). Prevalence and Predictors of Carer Burden and Depression in Carers of Patients Referred to an Old Age Psychiatric Service. *International Psychogeriatrics / IPA*, 20(6), 1193-1202.
- Montero, I., Masanet, M. J., Lacruz, M., Bellver, F., Asencio, A., & García, E. (2006). Family Intervention in Schizophrenia: Long-Term Effect on Main Caregivers. *Actas Espanolas de Psiquiatria*, 34(3), 169-174.
- Mooney, L. R., & Lashewicz, B. (2014). Voices of Care for Adults with Disabilities and/or Mental Health Issues in Western Canada: What Do Families and Agencies Need from Each Other? *Health and Social Care in the Community*, 22(2), 178-186.
- Moore, A. (2007). Older People. We Can Work It Out. *The Health Service Journal*, 117(6038), 24-26.
- Moore, A. R., & Henry, D. (2005). Experiences of Older Informal Caregivers to People with HIV/AIDS in Lome, Togo. *Ageing International*, 30(2), 147 - 166.
- Moore, S. (2004). Shifting the Balance of Power? Short Breaks for Carers in Wolverhampton. *Management Issues in Social Care*, 9(3), 34-40.
- Moore, T. (2005). Young Carers and Education. *Youth Studies Australia*, 24(4), 50-55.
- Moore, T., & McArthur, M. (2007). We're All in It Together: Supporting Young Carers and Their Families in Australia. *Health & Social Care In The Community*, 15(6), 561-568.
- Moore, T., McArthur, M., & Morrow, R. (2009). Attendance, Achievement and Participation: Young Carers' Experiences of School in Australia. *Australian Journal of Education (ACER Press)*, 53(1), 5-18.
- Moore, T., McArthur, M., & Noble-Carr, D. (2011). Different but the Same? Exploring the Experiences of Young People Caring for a Parent with an Alcohol or Other Drug Issue. *Journal of Youth Studies*, 14(2), 161-177.
- Moorhouse, C., George, M., & Smith, B. (2000). Palliative Care in Rural Australia: Involving the Community in Multidisciplinary Coordinated Care. *Australian Journal of Primary Health - Interchange*, 6(3-4), 141-146.
- Moradi, A. R., Miraghaei, M. A., Parhon, H., Jabbari, H., & Jobson, L. (2013). Posttraumatic Stress Disorder, Depression, Executive Functioning, and Autobiographical Remembering in Individuals with HIV and in Carers of Those with HIV in Iran. *AIDS Care*, 25(3), 281-288.
- Moran, N., Arksey, H., Glendinning, C., Jones, K., Netten, A., & Rabiee, P. (2012). Personalisation and Carers: Whose Rights? Whose Benefits? *British Journal of Social Work*, 42(3), 461-479.
- Morano, C., & King, D. (2010). Lessons Learned from Implementing a Psycho-Educational Intervention for African American Dementia Caregivers. *Dementia*, 9(4), 558-568.
- Morano, C. L., & King, D. (2005). Religiosity as a Mediator of Caregiver Well-Being: Does Ethnicity Make a Difference? *Journal of Gerontological Social Work*, 45(1/2), 69-84.

- Morano, C. L., & Sanders, S. (2005). Exploring Differences in Depression, Role Captivity, and Self-Acceptance in Hispanic and Non-Hispanic Adult Children Caregivers. *Journal of Ethnic and Cultural Diversity in Social Work*, 14(1/2), 27-46.
- Moreno, P. A., Garcia-Pacheco, J. L., Charvill, J., Lofti, A., Langensiepen, C., Saunders, A., Berckmans, K., Gaspersic, J., Walton, L., Carmona, M., Perez de la Camara, S., Sanchez-de-Madariaga, R., Pozo, J., Muñoz, A., Pascual, M., & Gomez, E. J. (2015). Icarer: Aal for the Informal Carers of the Elderly. *Studies in Health Technology and Informatics*, 210, 678-680.
- Morgan, A. (2001). Protective Coping: A Grounded Theory of Educative Interactions in Palliative Care Nursing. *International Journal of Palliative Nursing*, 7(2), 91-99.
- Moriarty, J. (2001). Planning Care for People with Dementia. *Working with Older People*, 5(1), 16-20.
- Moriarty, J., & Manthorpe, J. (2014). Fragmentation and Competition: Voluntary Organisations' Experiences of Support for Family Carers. *Voluntary Sector Review*, 5(2), 249-257.
- Moriarty, J., Manthorpe, J., & Cornes, M. (2014). Skills Social Care Workers Need to Support Personalisation. *Social Care and Neurodisability*, 5(2), 83-90.
- Moriarty, J., Manthorpe, J., & Cornes, M. (2015). Reaching out or Missing Out: Approaches to Outreach with Family Carers in Social Care Organisations. *Health and Social Care in the Community*, 23(1), 42-50.
- Morita, T., Chihara, S., & Kashiwagi, T. (2002). A Scale to Measure Satisfaction of Bereaved Family Receiving Inpatient Palliative Care. *Palliative Medicine*, 16(2), 141-150.
- Morris, G., Prankard, S., & Lefroy, L. (2013). Animating Experience: Bringing Student Learning to Life through Animation and Service User and Carer Experience. *Journal of Practice Teaching and Learning*, 12(1), 22-33.
- Morris, R., & Morris, P. (2012). Participants' Experiences of Hospital-Based Peer Support Groups for Stroke Patients and Carers. *Disability & Rehabilitation*, 34(4), 347-354.
- Morris, S., & Thomas, C. (2002). The Need to Know: Informal Carers and Information. *European Journal of Cancer Care*, 11(3), 183-187.
- Morris, S. M., & Thomas, C. (2001). The Carer's Place in the Cancer Situation: Where Does the Carer Stand in the Medical Setting? *European Journal of Cancer Care*, 10(2), 87-95.
- Mosquera, I., Vergara, I., Larranaga, I., Machon, M., del Rio, M., & Calderon, C. (2016). Measuring the Impact of Informal Elderly Caregiving: A Systematic Review of Tools. *Quality of Life Research*, 25(5), 1059-1092.
- Moss, B., Boath, L., Buckley, S., & Colgan, A. (2009). The Fount of All Knowledge: Training Required to Involve Service Users and Carers in Health and Social Care Education and Training. *Social Work Education (The International Journal)*, 28(5), 562-572.
- Motiejunaite, A., & Kravchenko, Z. (2008). Family Policy, Employment and Gender-Role Attitudes: A Comparative Analysis of Russia and Sweden. *Journal of European Social Policy*, 18(1), 38-49.
- Moule, P., Pollard, K., & Clarke, J. (2014). An Integrated Approach for Individualised Support: Carers' Views. *Journal of Integrated Care*, 22(5/6), 253-262.
- Moyon, M., Hertzog, M., Vogel, T., & Lang, P. O. (2015). Place of Volunteers in Home Care Setting for Taking Care of Individuals with Alzheimer's Disease and Related Dementia: Qualitative Survey in a Specialized Unit. *NPG Neurologie - Psychiatrie - Geriatrie*, 15(87), 147-157.
- Mudzi, W., Stewart, A., & Musenge, E. (2012). Effect of Carer Education on Functional Abilities of Patients with Stroke. *Int J Ther Rehabil*, 19(7), 380.

- Mullan, F., Acheson, K., & Coates, V. (2011). Assessing Multiple Sclerosis Patients' and Carers' Views of Respite Care. *British Journal of Neuroscience Nursing*, 7(3), 547-552 546p.
- Mullin, A. (2011). Gratitude and Caring Labor. *Ethics and Social Welfare*, 5(2), 110-122.
- Munck, B., Fridlund, B., & Martensson, J. (2008). Next-of-Kin Caregivers in Palliative Home Care - from Control to Loss of Control. *Journal of Advanced Nursing*, 64(6), 578-586.
- Munn-Giddings, C. (2007). Self-Help Groups as Mutual Support: What Do Carers Value? *Health and Social Care in the Community*, 15(1), 26-34.
- Munoz, C., Juarez, G., Munoz, M. L., Portnow, J., Fineman, I., Badie, B., Mamelak, A., & Ferrell, B. (2008). The Quality of Life of Patients with Malignant Gliomas. *Social Work in Health Care*, 47(4), 455-478.
- Munro, F., & Muirhead, S. (2015). Homeward Bound: Co-Designing the Pathway from Hospital to Home for Older People. *International Journal of Integrated Care (IJIC)*, 15, 1-2.
- Murphy, J., & Oliver, T. (2013). The Use of Talking Mats to Support People with Dementia and Their Carers to Make Decisions Together. *Health and Social Care in the Community*, 21(2), 171-180.
- Murray, A. (2014). The Effect of Dementia on Patients, Informal Carers and Nurses. *Nursing Older People*, 26(5), 27-31.
- Murray, E., Kerr, C., Stevenson, F., Gore, C., & Nazareth, I. (2007). Internet Interventions Can Meet the Emotional Needs of Patients and Carers Managing Long-Term Conditions. *Journal of Telemedicine & Telecare*, 13(supp 1), 42-44.
- Murray, J., Ashworth, R., Forster, A., & Young, J. (2003). Developing a Primary Care-Based Stroke Service: A Review of the Qualitative Literature. *The British Journal of General Practice: The Journal of The Royal College Of General Practitioners*, 53(487), 137-142.
- Murray, S. A., Kendall, M., Boyd, K., Worth, A., & Benton, T. F. (2003). Patient and Carer Perspectives: A Man with Inoperable Lung Cancer. *Progress in Palliative Care*, 11(6), 321.
- Murray, S. A., Kendall, M., Grant, E., & Grant, A. (2003). Dying from Cancer in Developed and Developing Countries: Lessons from Two Qualitative Interview Studies of Patients and Their Carers. *BMJ: British Medical Journal (International Edition)*, 326(7385), 368.
- Murray, S. A., Manktelow, K., & Clifford, C. (2000). The Interplay between Social and Cultural Context and Perceptions of Cardiovascular Disease. *Journal of Advanced Nursing*, 32(5), 1224-1233 1210p.
- Musil, C. M., Gordon, N. L., Warner, C. B., Zauszniewski, J. A., Standing, T., & Wykle, M. (2011). Grandmothers and Caregiving to Grandchildren: Continuity, Change, and Outcomes over 24 Months. *Gerontologist*, 51(1), 86-100.
- Mutch, K. (2010). In Sicknes and in Health: Experience of Caring for a Spouse with Ms. *British Journal of Nursing*, 19(4).
- Myles, S., Douglas, M. J., Ward, H. J., Campbell, H., & Will, R. G. (2002). Variant Creutzfeldt-Jakob Disease: Cost Borne by Families. *Health and Social Care in the Community*, 10(2), 91-98.
- Mystakidou, K., Parpa, E., Panagiotou, I., Tsilika, E., Galanos, A., & Gouliamos, A. (2013). Caregivers' Anxiety and Self-Efficacy in Palliative Care. *European Journal of Cancer Care*, 22(2), 188-195.
- Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and Effects of Caregiving on Children. *Journal of Advanced Nursing*, 70(10), 2314-2325.
- Naiditch, M. (2016). Carers and the Policy for Autonomy. *Soins; la revue de référence infirmière* (803), 30-33.

- Naiditch, M., Triantafillou, J., di Santo, P., Carretero, S., & Durrett, E. H. (2013). User Perspectives in Long-Term Care and the Role of Informal Carers. *Long-Term Care in Europe: Improving Policy and Practice*, 45-80.
- Nankervis, K., Rosewarne, A., & Vassos, M. (2011). Why Do Families Relinquish Care? An Investigation of the Factors That Lead to Relinquishment into out-of-Home Respite Care. *Journal of Intellectual Disability Research*, 55(4), 422-433.
- Nanton, V., Osborne, D., & Dale, J. (2010). Maintaining Control over Illness: A Model of Partner Activity in Prostate Cancer. *European Journal of Cancer Care*, 19(3), 329-339.
- Navaie-Waliser, M., Spriggs, A., & Feldman, P. H. (2002). Informal Caregiving - Differential Experiences by Gender. *Medical Care*, 40(12), 1249-1259.
- Nay, R., Bauer, M., Fetherstonhaugh, D., Moyle, W., Tarzia, L., & McAuliffe, L. (2015). Social Participation and Family Carers of People Living with Dementia in Australia. *Health & Social Care In The Community*, 23(5), 550-558.
- Nazarko, L. (2014). Urostomy Management in the Community. *British Journal of Community Nursing*, 19(9), 448-452.
- Negi, R., Seymour, J., Flemons, C., Impey, M., Thomas, N., & Witrylak, R. (2009). Psychiatric out-Patient Clinics for Older Adults: Highly Regarded by Users and Carers, but Irreplaceable? *Psychiatric Bulletin*, <http://www.thehealthwell.info/node/9207>.
- Negus, J. (2004). Improving Care of Older People through Intermediate Services. *Nursing Times*, 100(28), 34-36.
- Nehra, R., Chakrabarti, S., Kulhara, P., & Sharma, R. (2005). Caregiver-Coping in Bipolar Disorder and Schizophrenia: A Re-Examination. *Soc Psychiatry Psychiatr Epidemiol*, 40(4), 329-336.
- Neil, W., & Bowie, P. (2008). Carer Burden in Dementia - Assessing the Impact of Behavioural and Psychological Symptoms Via Self-Report Questionnaire. *International Journal of Geriatric Psychiatry*, 23(1), 60-64.
- Nelis, S. M., Clare, L., Martyr, A., Markova, I., Roth, I., Woods, R. T., Whitaker, C. J., & Morriss, R. G. (2011). Awareness of Social and Emotional Functioning in People with Early-Stage Dementia and Implications for Carers. *Aging and Mental Health*, 15(8), 961-969.
- Nelis, S. M., Clare, L., & Whitaker, C. J. (2012). Attachment Representations in People with Dementia and Their Carers: Implications for Well-Being within the Dyad. *Aging and Mental Health*, 16(7), 845-854.
- Nelson, S., & Macdonald, A. (2010). Time to Care. *Mental Health Today*, 30-31.
- Nepal, B., Brown, L., Ranmuthugala, G., & Percival, R. (2011). A Comparison of the Lifetime Economic Prospects of Women Informal Carers and Non-Carers, Australia, 2007. *Australian Journal of Social Issues*, 46(1), 91-108.
- Netten, A., Burge, P., Malley, J., Potoglou, D., Towers, A. M., Brazier, J., Flynn, T., Forder, J., & Wall, B. (2012). Outcomes of Social Care for Adults: Developing a Preference-Weighted Measure. *Health Technology Assessment*, 16(50), 1-166 166p.
- Netto, N. R., Jenny, G. Y. N., & Philip, Y. L. K. (2009). Growing and Gaining through Caring for a Loved One with Dementia. *Dementia (14713012)*, 8(2), 245-261.
- Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015). Literature Review: Use of Respite by Carers of People with Dementia. *Health and Social Care in the Community*, 23(1), 51-63.
- Newbury, J. (2011). The Drama of End of Life Care at Home. *Nursing Times*, 107(11), 20-23.

- Newell, J. M., Lyons, R., Martin-Misener, R., & Shearer, C. L. (2009). Creating a Supportive Environment for Living with Stroke in Rural Areas: Two Low-Cost Community-Based Interventions. *Topics in Stroke Rehabilitation*, 16(2), 147-156.
- Newman, R. (2005). Partners in Care: Being Equally Different: Lesbian and Gay Carers. *Psychiatric Bulletin*, 29(7), 266-267.
- Newman, T. (2002). 'Young Carers' and Disabled Parents: Time for a Change of Direction? *Disability & Society*, 17(6), 613-625.
- Nicholas, E. (2003). How to Stay Afloat. *Community Care*, 40-41.
- Nicholas, E. (2003). An Outcomes Focus in Carer Assessment and Review: Value and Challenge. *British Journal of Social Work*, 33(1), 31-47.
- Nichols, K. R., Fam, D., Cook, C., Pearce, M., Elliot, G., Baago, S., Rockwood, K., & Chow, T. W. (2013). When Dementia Is in the House: Needs Assessment Survey for Young Caregivers. *The Canadian Journal Of Neurological Sciences. Le Journal Canadien Des Sciences Neurologiques*, 40(1), 21-28.
- Nicholson, J., & Friesen, B. J. (2014). Developing the Evidence Base for Families Living with Parental Psychiatric Disabilities: Crossing the Bridge While We're Building It. *Psychiatric Rehabilitation Journal*, 37(3), 157-161.
- Nickel, W., Hanns, S., Brähler, E., & Born, A. (2012). Care Counselling - the Client's Expectations. *Gesundheitswesen*, 74(12), 795-805.
- Nicolaou, P. L., Egan, S. J., Gasson, N., & Kane, R. T. (2010). Identifying Needs, Burden, and Distress of Carers of People with Frontotemporal Dementia Compared to Alzheimer's Disease. *Dementia*, 9(2), 215-235.
- Nicoll, M., Ashworth, M., McNally, L., & Newman, S. (2002). Satisfaction with Respite Care: A Pilot Study. *Health and Social Care in the Community*, 10(6), 479-484.
- Nies, H. (2014). Communities as Co-Producers in Integrated Care. *International Journal of Integrated Care*, 14, e022-e022.
- Noble, A. J., & Marson, A. G. (2016). Which Outcomes Should We Measure in Adult Epilepsy Trials? The Views of People with Epilepsy and Informal Carers. *Epilepsy & Behavior*, 59, 105-110.
- Noble, H., Price, J. E., & Porter, S. (2015). The Challenge to Health Professionals When Carers Resist Truth Telling at the End of Life: A Qualitative Secondary Analysis. *Journal of Clinical Nursing*, 24(7-8), 927-936.
- Noble, H. R., Agus, A., Brazil, K., Burns, A., Goodfellow, N. A., Guiney, M., McCourt, F., McDowell, C., Normand, C., Roderick, P., Thompson, C., Maxwell, A. P., & Yaqoob, M. M. (2015). Palliative Care in Chronic Kidney Disease: The Packs Study - Quality of Life, Decision Making, Costs and Impact on Carers in People Managed without Dialysis. *BMC Nephrology*, 16, 104-104.
- Nocon, A., & Pearson, M. (2000). The Roles of Friends and Neighbours in Providing Support for Older People. *Ageing & Society*, 20(3), 341-367.
- Nolan, M. (2001). Supporting Family Carers in the Uk: Overview of Issues and Challenges. *British Journal of Nursing*, 10(9), 608-613.
- Nolan, M., Ingram, P., & Watson, R. (2002). Working with Family Carers of People with Dementia: 'Negotiated' Coping as an Essential Outcome. *Dementia: The International Journal of Social Research and Practice*, 1(1), 75-93.
- Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a More Inclusive Vision of Dementia Care Practice and Research. *Dementia: The International Journal of Social Research and Practice*, 1(2), 193-211.

- Nordberg, G., von Strauss, E., Kareholt, I., Johansson, L., & Wimo, A. (2005). The Amount of Informal and Formal Care among Non-Demented and Demented Elderly Persons - Results from a Swedish Population-Based Study. *International Journal of Geriatric Psychiatry*, 20(9), 862-871.
- Norman, I., Redfern, S., Briggs, K., & Askham, J. (2004). Perceptions and Management of Change by People with Dementia and Their Carers Living at Home. *Dementia: The International Journal of Social Research and Practice*, 3(1), 19-44.
- Northcott, N. (2000). Nurses' Experiences as Patients' Relatives. *Nursing Times*, 96(16), 46.
- Northfield, S., & Nebauer, M. (2010). The Caregiving Journey for Family Members of Relatives with Cancer: How Do They Cope? *Clinical journal of oncology nursing*, 14(5), 567.
- Nowotny, M., Dachenhausen, A., Stastny, P., Zidek, T., & Brainin, M. (2004). Empowerment, Quality of Life and Participation in Neurological Rehabilitation. Empirical Study with Stroke Patients and Their Relatives. *Wiener Medizinische Wochenschrift*, 154(23-24), 577-583.
- Obadina, S. (2010). Parental Mental Illness: Effects on Young Carers. *British Journal of School Nursing*, 5(3), 135-139.
- O'Brien, C. (2012). Confronting the Care Penalty: The Case for Extending Reasonable Adjustment Rights Along the Disability/Care Continuum. *Journal of Social Welfare & Family Law*, 34(1), 5-30.
- O'Brien, M. R., Whitehead, B., Jack, B. A., & Mitchell, J. D. (2012). The Need for Support Services for Family Carers of People with Motor Neurone Disease (MND): Views of Current and Former Family Caregivers a Qualitative Study. *Disability and Rehabilitation*, 34(3), 247-256.
- Ochoa, S., Salvador-Carulla, L., Villalta-Gil, V., Gibert, K., & Hero, J. M. (2012). Use of Functioning-Disability and Dependency for Case-Mix and Subtyping of Schizophrenia. *European Journal of Psychiatry*, 26(1), 5-20.
- O'Connor, L., Gardner, A., Millar, L., & Bennett, P. (2009). Absolutely Fabulous-but Are We? Carers' Perspectives on Satisfaction with a Palliative Homecare Service. *Collegian*, 16(4), 201-209.
- O'Dell, L., Crafter, S., de Abreu, G., & Cline, T. (2010). Constructing 'Normal Childhoods': Young People Talk About Young Carers. *Disability & Society*, 25(6), 643-655.
- O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & de Leo, D. (2013). Suicidal Ideation in Family Carers of People with Dementia: A Pilot Study. *International Journal of Geriatric Psychiatry*, 28(11), 1182-1188.
- Ogg, J., & Renault, S. (2006). The Support of Parents in Old Age by Those Born During 1945-1954: A European Perspective. *Ageing and Society*, 26(723), 1-21.
- Oh, K. M., & Warnes, A. M. (2001). Care Services for Frail Older People in South Korea. *Ageing and Society*, 21, 701-720.
- O'Halloran, S., & Cornes, M. (2009). Supporting Rural Carers: Understanding the Role of the Voluntary Sector. *Research, Policy & Planning*, 27(1), 17-24.
- Ohlen, J., Andershed, B., Berg, C., Frid, I., Palm, C. A., Ternstedt, B. M., & Segesten, K. (2007). Relatives in End-of-Life Care - Part 2: A Theory for Enabling Safety. *Journal of Clinical Nursing*, 16(2), 382-390.
- Ohlsson-Nevo, E., Andershed, B., Nilsson, U. G., & Anderzen-Carlsson, A. (2013). Finding a Wider Horizon: Experiences of Being a Next-of-Kin of a Person Suffering from Colorectal Cancer as Told after Having Participated in a Psychoeducational Program. *European Journal of Oncology Nursing*, 17(3), 324-330.



- Ohnishi, M., Nakamura, K., & Kizuki, M. (2008). Caregivers' and Non-Caregivers' Knowledge Regarding HIV/AIDS and Attitude Towards HIV/AIDS and Orphans in Nigeria. *Health and Social Care in the Community (Print edition)*, 16(5), 483-492.
- Oishi, A., & Murtagh, F. E. M. (2014). The Challenges of Uncertainty and Interprofessional Collaboration in Palliative Care for Non-Cancer Patients in the Community: A Systematic Review of Views from Patients, Carers and Health-Care Professionals. *Palliative Medicine*, 28(9), 1081-1098.
- Oktaý, J. S., & Tompkins, C. J. (2004). Personal Assistance Providers' Mistreatment of Disabled Adults. *Health and Social Work*, 29(3), 177-188.
- Olasoji, M., Maude, P., & McCauley, K. (2016). A Journey of Discovery: Experiences of Carers of People with Mental Illness Seeking Diagnosis and Treatment for Their Relative. *Issues in Mental Health Nursing*, 37(4), 219-228.
- Oldenkamp, M., Wittek, R. P., Hagedoorn, M., Stolk, R. P., & Smidt, N. (2016). Survey Nonresponse among Informal Caregivers: Effects on the Presence and Magnitude of Associations with Caregiver Burden and Satisfaction. *BMC Public Health*, 16, 480.
- Olson, R. E. (2012). Is Cancer Care Dependent on Informal Carers? *Australian Health Review*, 36(3), 254-257.
- Olson, R. E. (2014). A Time-Sovereignty Approach to Understanding Carers of Cancer Patients' Experiences and Support Preferences. *European Journal of Cancer Care*, 23(2), 239-248.
- Olson, R. E. (2015). Exploring Identity in the 'Figured Worlds' of Cancer Care-Giving and Marriage in Australia. *Health & Social Care in the Community*, 23(2), 171-179.
- Olson, R. E., & Connor, J. (2015). When They Don't Die: Prognosis Ambiguity, Role Conflict and Emotion Work in Cancer Caregiving. *Journal of Sociology*, 51(4), 857-871.
- O'Neill, J. (2008). Preparing Carers to Look after Palliative Care Patients at Home. *End of Life Care*, 2(3), 14-24.
- O'Neill, S., & Evans, D. S. (2001). Carers in the Community: The Nature, Extent and Needs of Informal Care Provision within the Western Health Board. *All Ireland Journal of Nursing & Midwifery*, 1(6), 201-205 205p.
- O'Neill, T., Lynch, C., & Brewin, L. (2004). It's a Different Thing. *Mental Health Today*, 30-32.
- Onwumere, J., Learmonth, S., & Kuipers, E. (2016). Caring for a Relative with Delusional Beliefs: A Qualitative Exploration. *Journal of Psychiatric and Mental Health Nursing*, 23(3-4), 145-155.
- Opara, J., Jaracz, K., & Broła, W. (2012). Burden and Quality of Life in Caregivers of Persons with Multiple Sclerosis. *Neurologia / Neurochirurgia Polska*, 46(5), 472-479.
- O'Reilly, D. (2008). Is Caring Associated with an Increased Risk of Mortality? A Longitudinal Study. *Soc Sci Med*, 67(8), 1282-1290.
- Orgeta, V., & Miranda-Castillo, C. (2014). Does Physical Activity Reduce Burden in Carers of People with Dementia? A Literature Review. *International Journal of Geriatric Psychiatry*, 29(8), 771-783.
- Orgeta, V., Orrel, M., Hounscome, B., & Woods, B. (2015). Self and Carer Perspectives of Quality of Life in Dementia Using the QoL-Ad. *International Journal of Geriatric Psychiatry*, 30(1), 97-104.
- Orpin, P., Stirling, C., Hetherington, S., & Robinson, A. (2014). Rural Dementia Carers: Formal and Informal Sources of Support. *Ageing & Society*, 34(2), 185-208.

- Orr, L. C., Barbour, R. S., & Elliott, L. (2013). Carer Involvement with Drug Services: A Qualitative Study. *Health Expectations*, 16(3), E60-E72.
- Orr, L. C., Barbour, R. S., & Elliott, L. (2014). Involving Families and Carers in Drug Services: Are Families 'Part of the Problem'? *Families, Relationships and Societies*, 3(3), 405-424.
- O'Shea, E. (2003). Costs and Consequences for the Carers of People with Dementia in Ireland. *Dementia: The International Journal of Social Research and Practice*, 2(2), 201-219.
- O'Shea, E., & O'Reilly, S. (2000). The Economic and Social Cost of Dementia in Ireland. *International Journal of Geriatric Psychiatry*, 15(3), 208-218.
- O'Shea, R., & Goode, D. (2013). Effects of Stroke on Informal Carers. *Nurs Stand*, 28(15), 43.
- Ossebaard, H. C., Seydel, E. R., & van Gemert-Pijnen, L. (2012). Online Usability and Patients with Long-Term Conditions: A Mixed-Methods Approach. *International Journal of Medical Informatics*, 81(6), 374-387.
- Osté, J., & Dröes, R. M. (2005). A Meeting Centre for Surinam People with Dementia and Their Informal Carers; Development and Implementation of Culture Specific Combined Support. *Tijdschrift Voor Gerontologie En Geriatrie*, 36(6), 232-242.
- Oudijk, D., Woittiez, I., & de Boer, A. (2011). More Family Responsibility, More Informal Care? The Effect of Motivation on the Giving of Informal Care by People Aged over 50 in the Netherlands Compared to Other European Countries. *Health Policy*, 101(3), 228-235 228p.
- Outshoorn, J. (2002). Gendering the "Graying" of Society: A Discourse Analysis of the Care Gap. *Public Administration Review*, 62(2), 185-196.
- Owens, C., & Cooper, C. (2010). The Relationship between Dementia and Elder Abuse. *Working with Older People*, 14(1), 19-21.
- Owens, C., Ley, A., & Aitken, P. (2008). Do Different Stakeholder Groups Share Mental Health Research Priorities? A Four-Arm Delphi Study. *Health Expectations*, 11(4), 418-431 414p.
- Pahor, M., Domajnko, B., & Hlebec, V. (2011). Social Support in the Case of Illness: Intergenerational Solidarity. *Zdravniški Vestnik-Slovenian Medical Journal*, 80(2), 75-83.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between Social Support, Appraisal and Coping and Both Positive and Negative Outcomes in Young Carers. *Journal of Health Psychology*, 12(1), 89-102.
- Pakenham, K. I., & Cox, S. (2012). The Nature of Caregiving in Children of a Parent with Multiple Sclerosis from Multiple Sources and the Associations between Caregiving Activities and Youth Adjustment Overtime. *Psychology & Health*, 27(3), 324-346.
- Palattiyil, G., & Chakrabarti, M. (2008). Coping Strategies of Families in HIV/AIDS Care: Some Exploratory Data from Two Developmental Contexts. *AIDS Care*, 20(7), 881-885.
- Palm, E. (2013). Who Cares? Moral Obligations in Formal and Informal Care Provision in the Light of Ict-Based Home Care. *Journal of Health, philosophy and policy*, 21(2), 171-188.
- Papachristou, I. (2010). Food and Nutrition in the Care of People with Dementia: A Qualitative Study of Formal and Informal Carers. *Psychology & Health*, 25, 296-296.
- Papadopoulou, C., Johnston, B., & Themessl-Huber, M. (2013). A Life in Limbo: An Ipa Study of Informal Carers' Making Sense Processes of Acute Leukaemia. *International Journal of Qualitative Methods*, 12, 809-810.
- Papastavrou, E., Charalambous, A., & Tsangari, H. (2012). How Do Informal Caregivers of Patients with Cancer Cope: A Descriptive Study of the Coping Strategies Employed, *Eur J Oncol Nurs*, 16(3), 258-263.
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a Relative with Dementia: Family Caregiver Burden. *J Adv Nurs*, 58(5), 446-457.

- Papstavrou, E., Charalambous, A., & Tsangari, H. (2009). Exploring the Other Side of Cancer Care: The Informal Caregiver. *European Journal of Oncology Nursing*, 13(2), 128-136.
- Paquay, L., Wouters, R., Defloor, T., Buntinx, F., Debaille, R., & Geys, L. (2008). Adherence to Pressure Ulcer Prevention Guidelines in Home Care: A Survey of Current Practice. *Journal of Clinical Nursing*, 17(5), 627-636 610p.
- Parish, S. L., Rose, R. A., & Swaine, J. G. (2010). Financial Well-Being of Us Parents Caring for Co-resident Children and Adults with Developmental Disabilities: An Age Cohort Analysis\*. *Journal of Intellectual & Developmental Disability*, 35(4), 235-243.
- Parker, D., Mills, S., & Abbey, J. (2008). Effectiveness of Interventions That Assist Caregivers to Support People with Dementia Living in the Community: A Systematic Review. *International Journal of Evidence-Based Healthcare*, 6(2), 137-172.
- Parker, E. (2011). Up Close and Personal: A Qualitative Study Exploring the Lived Experience of Older Carers. *Mental Health and Learning Disabilities Research and Practice*, 8(1), 15-29.
- Parker, G., & Clarke, H. (2002). Making the Ends Meet: Do Carers and Disabled People Have a Common Agenda? *Policy and Politics*, 30(3), 347-359.
- Parker, J. (2007). Crisis Intervention: A Practice Model for People Who Have Dementia and Their Carers. *Practice: Social Work in Action*, 19(2), 115-126.
- Parker, R., Leggatt, M., & Crowe, J. (2010). Public Interest and Private Concern: The Role of Family Carers for People Suffering Mental Illness in the Twenty First Century. *Australas Psychiatry*, 18(2), 163-166.
- Parker, S., Oliver, P., Pennington, M., Bond, J., Jagger, C., Enderby, P., Curless, R., Chater, T., Vanoli, A., Fryer, K., Cooper, C., Julious, S., Donaldson, C., Dyer, C., Wynn, T., John, A., & Ross, D. (2009). Rehabilitation of Older Patients: Day Hospital Compared with Rehabilitation at Home. A Randomised Controlled Trial. *Health Technology Assessment*, 13(37), 1-168 168p.
- Parsons, M., Senior, H. E. J., Kerse, N., Chen, M. H., Jacobs, S., Vanderhoorn, S., Brown, P. M., & Anderson, C. (2012). The Assessment of Services Promoting Independence and Recovery in Elders Trial (Aspire): A Pre-Planned Meta-Analysis of Three Independent Randomised Controlled Trial Evaluations of Ageing in Place Initiatives in New Zealand. *Age and Ageing*, 41(6), 722-728.
- Pascual, J. C. R. (2005). Geriatric Assessment in Long Term Care Units and Nursing Homes. *Revista Multidisciplinar de Gerontologia*, 15(1), 26-29.
- Patchick, E., Vail, A., Wood, A., & Bowen, A. (2015). Precis (Patient Reported Evaluation of Cognitive State): Psychometric Evaluation of a New Patient Reported Outcome Measure of the Impact of Stroke. *Clinical Rehabilitation*.
- Patel, A., Knapp, M., Evans, A., Perez, I., & Lara, L. (2004). Training Care Givers of Stroke Patients: Economic Evaluation. *BMJ*, 328(7448), 1102.
- Paton, J., Johnston, K., Katona, C., & Livingston, G. (2004). What Causes Problems in Alzheimer's Disease: Attributions by Caregivers. A Qualitative Study. *International Journal of Geriatric Psychiatry*, 19(6), 527-532.
- Patterson, J. M., Rapley, T., Carding, P. N., Wilson, J. A., & McColl, E. (2013). Head and Neck Cancer and Dysphagia; Caring for Carers. *Psycho-Oncology*, 22(8), 1815-1820.
- Paulus, A. T. G., van Raak, A., & Keijzer, F. (2005). Informal and Formal Caregivers' Involvement in Nursing Home Care Activities: Impact of Integrated Care. *Journal of Advanced Nursing*, 49(4), 354-366 313p.

- Pawson, N., Raghavan, R., Small, N., Craig, S., & Spencer, M. (2005). Social Inclusion, Social Networks and Ethnicity: The Development of the Social Inclusion Interview Schedule for Young People with Learning Disabilities. *British Journal of Learning Disabilities*, 33(1), 15-22.
- Payne, F., Jessopp, L., Harvey, K., Plummer, S., Tylee, A., & Thornicroft, G. (2003). Is NHS Direct Meeting the Needs of Mental Health Callers? *Journal of Mental Health*, 12(1), 19-27.
- Payne, S., Burton, C., Addington-Hall, J., & Jones, A. (2010). End-of-Life Issues in Acute Stroke Care: A Qualitative Study of the Experiences and Preferences of Patients and Families. *Palliative Medicine*, 24(2), 146-153.
- Payne, S., Ingleton, C., Scott, G., Steele, K., Nolan, M., & Carey, I. (2004). A Survey of the Perspectives of Specialist Palliative Care Providers in the UK of Inpatient Respite. *Palliative Medicine*, 18(8), 692-697.
- Peck, E. (2002). Integrating Health and Social Care: Commentaries on the Case Studies in MCC 10.2. *MCC Building Knowledge for Integrated Care*, 10(3), 16-22.
- Peck, E., Towell, D., & Guilliver, P. (2001). The Meanings of 'Culture' in Health and Social Care: A Case Study of the Combined Trust in Somerset. *Journal of Interprofessional Care*, 15(4), 319-327.
- Peel, E. (2014). 'The Living Death of Alzheimer's' Versus 'Take a Walk to Keep Dementia at Bay': Representations of Dementia in Print Media and Carer Discourse. *Sociology Of Health & Illness*, 36(6), 885-901.
- Peel, E., & Harding, R. (2014). 'It's a Huge Maze, the System, It's a Terrible Maze': Dementia Carers' Constructions of Navigating Health and Social Care Services. *Dementia (London, England)*, 13(5), 642-661.
- Peeters, J., van Beek, A., & Meerveld, J. (2010). Informal Caregivers of Persons with Dementia, Their Use of and Needs for Specific Professional Support: A Survey of the National Dementia Programme. *BMC Nursing*, 9(9).
- Peeters, J. M., Pot, A. M., de Lange, J., Spreeuwenberg, P. M., & Francke, A. L. (2016). Does the Organisational Model of Dementia Case Management Make a Difference in Satisfaction with Case Management and Caregiver Burden? An Evaluation Study. *BMC Geriatrics*, 16(1), 65-65.
- Peggie, R. S. (2004). Women's Work Is Never Done: Employment, Family and Activism. *University of Cincinnati Law Review*, 73, 399-1767.
- Pejilert, A. (2001). Being a Parent of an Adult Son or Daughter with Severe Mental Illness Receiving Professional Care: Parents' Narratives. *Health and Social Care in the Community*, 9(4), 194-204.
- Pellerin, C., Rochette, A., & Racine, E. (2011). Social Participation of Relatives Post-Stroke: The Role of Rehabilitation and Related Ethical Issues. *Disability & Rehabilitation*, 33(14-14), 1055-1064.
- Péntek, M., Herczegfalvi, Á., Molnár, M. J., Szonyi, L. P., Kosztolányi, G., Pfliegler, G., Meleg, B., Boncz, I., Brodszky, V., Baji, P., Szegedi, M., Pogány, G., & Gulácsi, L. (2016). Disease Burden of Duchenne Muscular Dystrophy Patients and Their Caregivers. *Ideggyógyászati Szemle*, 69(5-6), 183-193.
- Pepin, R., Williams, A. A., Anderson, L. M., & Qualls, S. H. (2013). A Preliminary Typology of Caregivers and Effects on Service Utilization of Caregiver Counseling. *Aging and Mental Health*, 17(4), 495-507.
- Perera, B. D., & Standen, P. J. (2014). Exploring Coping Strategies of Carers Looking after People with Intellectual Disabilities and Dementia. *Advances in Mental Health and Intellectual Disabilities*, 8(5), 292-301.

- Peri, G., Romiti, A., & Rossi, M. (2015). Immigrants, Domestic Labor and Women's Retirement Decisions. *Labour Economics*, 36, 18-34.
- Perkins, E. A., & Haley, W. E. (2013). Emotional and Tangible Reciprocity in Middle- and Older-Aged Carers of Adults with Intellectual Disabilities. *Journal of Policy & Practice in Intellectual Disabilities*, 10(4), 334-344.
- Perkins, E. A., & Lamartin, K. M. (2012). The Internet as Social Support for Older Carers of Adults with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 53-62.
- Perks, A., Nolan, M., Ryan, T., Enderby, P., Hemmings, I., & Robinson, K. (2001). Breaking the Mould: Developing a New Service for People with Dementia and Their Carers. *Quality in Ageing and Older Adults*, 2(1), 3-11.
- Perry, B., Dalton, J. E., & Edwards, M. (2010). Family Caregivers' Compassion Fatigue in Long-Term Facilities. *Nurs Older People*, 22(4), 26-31
- Perry, L., & Middleton, S. (2011). An Investigation of Family Carers' Needs Following Stroke Survivors' Discharge from Acute Hospital Care in Australia. *Disability & Rehabilitation*, 33(19-20), 1890-1900.
- Petch, A. (2009). The Experiences and Needs of Young Adult Carers in the Uk. *Community Care*, 30-31.
- Philip, J., Gold, M., Brand, C., Miller, B., Douglass, J., & Sundararajan, V. (2014). Facilitating Change and Adaptation: The Experiences of Current and Bereaved Carers of Patients with Severe Chronic Obstructive Pulmonary Disease. *J Palliat Med*, 17(4), 421-427.
- Phillips, L. A., Cooper, B., & Reynolds, F. (2012). The Meanings of Art-Making to Informal Carers of Relatives with Dementia. *British Journal of Occupational Therapy*, 75, 28-28.
- Phillips, L. R., de Ardon Torres, E., & Brioonnes, G. S. (2000). Abuse of Female Caregiver by Care Recipients: Another Form of Elder Abuse. *Journal of Elder Abuse and Neglect*, 12(3/4), 123-143.
- Phillipson, L., Jones, S. C., & Magee, C. (2014). A Review of the Factors Associated with the Non-Use of Respite Services by Carers of People with Dementia: Implications for Policy and Practice. *Health & Social Care in The Community*, 22(1), 1-12.
- Phillipson, L., Magee, C., & Jones, S. C. (2013). Why Carers of People with Dementia Do Not Utilise out-of-Home Respite Services. *Health and Social Care in the Community*, 21(4), 411-422.
- Philpin, S., Merrell, J., Warring, J., Gregory, V., & Hobby, D. (2011). Sociocultural Context of Nutrition in Care Homes. *Nursing Older People*, 23(4), 24-30.
- Philpin, S., Merrell, J., Warring, J., Hobby, D., & Gregory, V. (2014). Memories, Identity and Homeliness: The Social Construction of Mealtimes in Residential Care Homes in South Wales. *Ageing & Society*, 34(5), 753-789.
- Pickard, L. (2001). Carer Break or Carer-Blind? Policies for Informal Carers in the Uk. *Social Policy & Administration*, 35(4), 441-458.
- Pickard, L. (2002). The Decline of Intensive Intergenerational Care of Older People in Great Britain, 1985-1995. *Population Trends*, 110, 31-41.
- Pickard, L. (2012). Substitution between Formal and Informal Care: A 'Natural Experiment' in Social Policy in Britain between 1985 and 2000. *Ageing & Society*, 32(7), 1147-1175.
- Pickard, L. (2015). A Growing Care Gap? The Supply of Unpaid Care for Older People by Their Adult Children in England to 2032. *Ageing & Society*, 35(1), 96-123.

- Pickard, L., King, D., Brimblecombe, N., & Knapp, M. (2014). The Effectiveness of Paid Services in Supporting Unpaid Carers' Employment in England. *Journal of Social Policy*, 44(3), 567-590.
- Pickard, L., King, D., & Knapp, M. (2016). The 'Visibility' of Unpaid Care in England. *Journal of Social Work*, 16(3), 263-282.
- Pickard, L., Wittenberg, R., Comas-Herrera, A., & Davies, B. (2000). Relying on Informal Care in the New Century? Informal Care for Elderly People in England to 2031. *Ageing and Society*, 20(6), 745-772.
- Pickard, L., Wittenberg, R., Comas-Herrera, A., King, D., & Malley, J. (2007). Care by Spouses, Care by Children: Projections of Informal Care for Older People in England to 2031. *Social Policy and Society*, 6(3), 353-366.
- Pickard, L., Wittenberg, R., Comas-Herrera, A., King, D., & Malley, J. (2012). Mapping the Future of Family Care: Receipt of Informal Care by Older People with Disabilities in England to 2032. *Social Policy and Society*, 11(4), 533-545.
- Pickard, S. (2010). The 'Good Carer': Moral Practices in Late Modernity. *Sociology - the Journal of the British Sociological Association*, 44(3), 471-487.
- Pickard, S., & Glendinning, C. (2001). Caring for a Relative with Dementia: The Perceptions of Carers and CPNs. *Quality in Ageing and Older Adults*, 2(4), 3-11.
- Pickard, S., & Glendinning, C. (2002). Comparing and Contrasting the Role of Family Carers and Nurses in the Domestic Health Care of Frail Older People. *Health and Social Care in the Community*, 10(3), 144-150.
- Pickard, S., Jacobs, S., & Kirk, S. (2003). Challenging Professional Roles: Lay Carers' Involvement in Health Care in the Community. *Social Policy & Administration*, 37(1), 82-96.
- Pickard, S., Shaw, S., & Glendinning, C. (2000). Health Care Professionals' Support for Older Carers. *Ageing & Society*, 20(6), 725-744.
- Pickup, S. (2012). Improving the Lives of People with Dementia and Their Carers: The Prime Minister's Challenge and a Challenge for Us All. *Journal of Care Services Management*, 6(1), 3-9.
- Pierret, C. R. (2006). The 'Sandwich Generation': Women Caring for Parents and Children. *Monthly Labor Review*(September), 3-9.
- Piette, J., Rosland, A., & Silveira, M. (2010). The Case for Involving Adult Children Outside of the Household in the Self-Management Support of Older Adults with Chronic Illness. *Chronic Illness*, 6(1), 34-45.
- Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just Being Selfish for My Own Sake': Balancing the Views of Young Adults with Intellectual Disabilities and Their Carers in Transition Planning. *Sociological Review*, 59(2), 303-323.
- Pinfold, V., Rapaport, J., & Bellringer, S. (2007). Developing Partnerships with Carers through Good Practice in Information-Sharing. *Mental Health Review Journal*, 12(2), 7-14.
- Pinnock, H., Kendall, M., Murray, S. A., Worth, A., Levack, P., Porter, M., MacNee, W., & Sheikh, A. (2011). Living and Dying with Severe Chronic Obstructive Pulmonary Disease: Multi-Perspective Longitudinal Qualitative Study. *BMJ Supportive & Palliative Care*, 1(2), 174-183.
- Pinquart, M., & Sörensen, S. (2003). Associations of Stressors and Uplifts of Caregiving with Caregiver Burden and Depressive Mood: A Meta- Analysis. *Journals of Gerontology Series B Psychological Sciences and Social Sciences*, 58(2), 112-128.

- Pinto, R. A., Holanda, M. A., Medeiros, M. M., Mota, R. M., & Pereira, E. D. (2007). Assessment of the Burden of Caregiving for Patients with Chronic Obstructive Pulmonary Disease. *Respir Med*, 101(11), 2402-2408.
- Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., & Johnston, A. (2010). Who Cares? A Profile of People Who Care for Relatives with a Mental Disorder. *Aust NZ J Psychiatry*, 44(10), 929-937.
- Pivodic, L., van den Block, L., Pardon, K., Miccinesi, G., Vega Alonso, T., Boffin, N., Donker, G. A., Cancian, M., Lopez-Maside, A., Onwuteaka-Philipsen, B. D., & Deliens, L. (2014). Burden on Family Carers and Care-Related Financial Strain at the End of Life: A Cross-National Population-Based Study. *Eur J Public Health*, 24(5), 819-826.
- Plaisier, I., Broese van Groenou, M. I., & Keuzenkamp, S. (2015). Combining Work and Informal Care: The Importance of Caring Organisations. *Human Resource Management Journal*, 25(2), 267-280.
- Plank, A., Mazzoni, V., & Cavada, L. (2013). Becoming a Caregiver: New Family Carers' Experience During the Transition from Hospital to Home. *J Clin Nurs*, 21(13-14), 2072-2082.
- Plant, H., Moore, S., Richardson, A., Cornwall, A., Medina, J., & Ream, E. (2011). Nurses' Experience of Delivering a Supportive Intervention for Family Members of Patients with Lung Cancer. *European Journal of Cancer Care*, 20(4), 436-444.
- Pleschberger, S. (2013). Family Members in End-of-Life Care - the Diversity of Their Roles and Challenges. *Public Health Forum*, 21(3).
- Ploeg, J., Fear, J., Hutchison, B., Macmillan, H., & Bolan, G. (2009). A Systematic Review of Interventions for Elder Abuse. *Journal of Elder Abuse and Neglect*, 21(3), 187-210.
- Poindexter, C. C. (2002). Meaning from Methods: Re-Presenting Narratives of an HIV-Affected Caregiver. *Qualitative Social Work*, 1(1), 59-78.
- Pointu, A., & Cole, C. (2005). An Education Programme for Social Care Staff: Improving the Health of People Who Have a Learning Disability and Epilepsy. *British Journal of Learning Disabilities*, 33(1), 39-43.
- Ponpaipan, M., Srisuphan, W., Jitapunkul, S., Panuthai, S., Tonmukayakul, O., & While, A. (2011). Multimedia Computer-Assisted Instruction for Carers on Exercise for Older People: Development and Testing. *Journal of Advanced Nursing*, 67(2), 308-316 309p.
- Porock, D., & Oliver, D. P. (2005). Commentary on Schneider Ra (2004) - Assessing the Fatigue Severity Scale for Use among Caregivers of Chronic Renal Failure Patients. *Journal of Clinical Nursing* 13, 219-225. *Journal of Clinical Nursing*, 14(9), 1153-1154.
- Porter, E., Hayward, M., & Frost, M. (2005). Involving NHS Users and Carers in Healthcare Education. *Community Practitioner*, 78(9), 327-330.
- Portrait, F., Deeg, D., & Lindeboom, M. (2000). The Use of Long-Term Care Services by the Dutch Elderly. *Health Economics*, 9(6), 513-531.
- Post, S. G. (2011). Five Sources of Hope for the Deeply Forgetful: Dementia in the Twenty-First Century. *Journal of Care Services Management*, 5(3), 160-167.
- Potgieter, J. C., Heyns, P. M., & Lens, W. (2012). The Time Perspective of the Alzheimer Caregiver. *Dementia: The International Journal of Social Research and Practice*, 11(4), 453-471.
- Potkins, D., Bradley, S., Shrimanker, J., O'Brien, J., Swann, A., & Ballard, C. (2000). End of Life Treatment Decisions in People with Dementia: Carers' Views and the Factors Which Influence Them. *International Journal of Geriatric Psychiatry*, 15(11), 1005-1008.

- Powell, J., Chiu, T., & Eysenbach, G. (2008). A Systematic Review of Networked Technologies Supporting Carers of People with Dementia. *Journal of Telemedicine and Telecare*, 14(3), 154-156.
- Powell, J., Gunn, L., Lowe, P., Sheehan, B., Griffiths, F., & Clarke, A. (2010). New Networked Technologies and Carers of People with Dementia: An Interview Study. *Ageing & Society*, 30(6), 1073-1088.
- Powell, J. L. (2012). Social Work and Elder Abuse: A Foucauldian Analysis. *Social Work and Society: International Online Journal*, 10(1).
- Power, A. (2009). Spatial Perspectives on Voluntarism in Learning Disability Services in Ireland. *Journal of Social Policy*, 38, 299-315.
- Preston-Shoot, M. (2003). Only Connect: Client, Carers and Professional Perspectives on Community Care Assessment Process. *Research Policy and Planning*, 21(3), 23-35.
- Price, E. (2005). All but Invisible: Older Gay Men and Lesbians. *Nurs Older People*, 17(4), 16-18.
- Price, E. (2011). Caring for Mum and Dad: Lesbian Women Negotiating Family and Navigating Care. *British Journal of Social Work*, 41(7), 1288-1303.
- Price, E. (2012). Gay and Lesbian Carers: Ageing in the Shadow of Dementia. *Ageing & Society*, 32(3), 516-532.
- Price, P. E. (2008). Education, Psychology and 'Compliance'. *Diabetes/Metabolism Research & Reviews*, 24(S1), S101-105 101p.
- Priestley, J., & McPherson, S. (2016). Experiences of Adults Providing Care to a Partner or Relative with Depression: A Meta-Ethnographic Synthesis. *Journal of Affective Disorders*, 192, 41-49.
- Prince, M., Brodaty, H., Uwakwe, R., Acosta, D., Ferri, C. P., Guerra, M., Huang, Y., Jacob, K. S., Libre Rodriguez, J. J., Salas, A., Sosa, A. L., Williams, J. D., Jotheeswaran, A. T., & Liu, Z. (2012). Strain and Its Correlates among Carers of People with Dementia in Low-Income and Middle-Income Countries; a 10/66 Dementia Research Group Population-Based Survey. *International Journal of Geriatric Psychiatry*, 27(7), 670-682.
- Principi, A., Lamura, G., Sirolla, C., Mestheneos, L. I. Z., Bien, B., Brown, J., Krevers, B., Melchiorre, M. G., & Dohner, H. (2014). Work Restrictions Experienced by Midlife Family Care-Givers of Older People: Evidence from Six European Countries. *Ageing & Society*, 34(2), 209-231.
- Pringle, J., Hendry, C., & McLafferty, E. (2008). A Review of the Early Discharge Experiences of Stroke Survivors and Their Carers. *Journal of Clinical Nursing*, 17(18), 2384-2397.
- Pritchard, E. J., & Dewing, J. (2001). A Multi-Method Evaluation of an Independent Dementia Care Service and Its Approach. *Aging and Mental Health*, 5(1), 63-72.
- Probst, S., Arber, A., & Faithfull, S. (2013). Malignant Fungating Wounds – the Meaning of Living in an Unbounded Body. *European Journal of Oncology Nursing*, 17(1), 38-45 38p.
- Probst, S., Gerber, V., Gethin, G., Hopkins, A., Rimdeika, R., Seppänen, S., & Mortensen, S. (2014). Development of a Position Document for Home Care - Wound Care. *International Journal of Integrated Care (IJIC)*, 14, 179-180.
- Probst, S., Seppänen, S., Gerber, V., Hopkins, A., Rimdeika, R., & Gethin, G. (2014). Ewma Document: Home Care-Wound Care: Overview, Challenges and Perspectives. *Journal of Wound Care*, 23, S1-S41.
- Procter, R., Greenhalgh, T., Wherton, J., Sugarhood, P., Rouncefield, M., & Dewsbury, G. (2013). The Athene Project: The Importance of Bricolage in Personalising Assisted Living Technologies. *International Journal of Integrated Care (IJIC)*, 13, 1-2.



- Procter, R., Greenhalgh, T., Wherton, J., Sugarhood, P., Rouncefield, M., & Hinder, S. (2014). The Day-to-Day Co-Production of Ageing in Place. *Computer Supported Cooperative Work-the Journal of Collaborative Computing*, 23(3), 245-267.
- Procter, S., Wilcockson, J., Pearson, P., & Allgar, V. (2001). Going Home from Hospital: The Carer/Patient Dyad. *Journal of Advanced Nursing*, 35(2), 206-217 212p.
- Proctor, R., Martin, C., & Hewison, J. (2002). When a Little Knowledge Is a Dangerous Thing: A Study of Carers' Knowledge About Dementia, Preferred Coping Style and Psychological Distress. *International Journal of Geriatric Psychiatry*, 17(12), 1133-1139.
- Proot, I. (2005). Patients Requiring Care and Care Problems: The Outlook for Terminal Patients and Their Carers. *Huisarts en Wetenschap*, 48(10), 494-499.
- Prorok, J. C., Horgan, S., & Seitz, D. P. (2013). Health Care Experiences of People with Dementia and Their Caregivers: A Meta-Ethnographic Analysis of Qualitative Studies. *Canadian Medical Association Journal*, 185(14).
- Proulx, C., & le Bourdais, C. (2014). Impact of Providing Care on the Risk of Leaving Employment in Canada. *Canadian Journal on Aging-Revue Canadienne Du Vieillissement*, 33(4), 488-503.
- Purcal, C., Hamilton, M., Thomson, C., & Cass, B. (2012). From Assistance to Prevention: Categorizing Young Carer Support Services in Australia, and International Implications. *Social Policy & Administration*, 46(7), 788-806.
- Pusey, H. (2000). Dementia Care: Interventions with People with Dementia and Their Informal Carers. *Mental Health & Learning Disabilities Care*, 3(6), 204-207.
- Pusey, H., & Richards, D. (2001). A Systematic Review of the Effectiveness of Psychosocial Interventions for Carers of People with Dementia. *Aging and Mental Health*, 5(2), 107-119.
- Quinn, C., Clare, L., & Woods, B. (2009). The Impact of the Quality of Relationship on the Experiences and Wellbeing of Caregivers of People with Dementia: A Systematic Review. *Aging & Mental Health*, 13(2), 143-154.
- Quinn, C., Clare, L., & Woods, R. T. (2012). What Predicts Whether Caregivers of People with Dementia Find Meaning in Their Role? *International Journal of Geriatric Psychiatry*, 27(11), 1195-1202.
- Quinn, C., Clare, L., & Woods, R. T. (2015). 'You Have to Be Mindful of Whose Story It Is': The Challenges of Undertaking Life Story Work with People with Dementia and Their Family Carers. *Dementia: The International Journal of Social Research and Practice*, 14(2), 238-256.
- Quinn, K., Murray, C., & Malone, C. (2014). Spousal Experiences of Coping with and Adapting to Caregiving for a Partner Who Has a Stroke: A Meta-Synthesis of Qualitative Research. *Disability and Rehabilitation*, 36(3), 185-198.
- Quinn, N., & Evans, T. (2010). Understanding the Carers' Experience: Examples from a Ghanaian Context. *International Social Work*, 53(1), 61-72.
- Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., Pinfold, V., & Andiappan, M. (2012). Development of the Carer Well-Being and Support (CWS) Questionnaire. *Mental Health Review Journal*, 17(3), 128-138.
- Qureshi, H. (2004). Evidence in Policy and Practice: What Kinds of Research Designs? *Journal of Social Work*, 4(1), 7-23.
- Rabow, M. W., Adams, J., & Hauser, J. M. (2004). Supporting Family Caregivers at the End of Life: They Don't Know What They Don't Know. *JAMA*, 291(4), 483-491.
- Radwin, L. E. (2002). Gate Keeping and Legitimation Were Central in the Interactions between Informal Carers of Older People and Healthcare Workers. *Evidence-Based Nursing*, 5(3), 95-95.

- Rafnsson, S. B., Shankar, A., & Steptoe, A. (2015). Informal Caregiving Transitions, Subjective Well-Being and Depressed Mood: Findings from the English Longitudinal Study of Ageing. *Aging & Mental Health*, 1-9.
- Raj, J. T., Manigandan, C., & Jacob, K. S. (2006). Leisure Satisfaction and Psychiatric Morbidity among Informal Carers of People with Spinal Cord Injury. *Spinal Cord*, 44(11), 676-679.
- Ramcharan, P., & Grant, G. (2001). Views and Experiences of People with Intellectual Disabilities and Their Families: (1) the User Perspective. *Journal of Applied Research in Intellectual Disabilities*, 14(4), 348-363.
- Ramsay, S., Grundy, E., & O'Reilly, D. (2013). The Relationship between Informal Caregiving and Mortality: An Analysis Using the ONS Longitudinal Study of England and Wales.
- Ramsden, S., Tickle, S., Dawson, D., & Harris, S. (2016). Perceived Barriers and Facilitators to Positive Therapeutic Change for People with Intellectual Disabilities: Client, Carer and Clinical Psychologist Perspectives. *Journal of Intellectual Disabilities*, 20(3), 241-262.
- Rand, S., & Malley, J. (2014). Carers' Quality of Life and Experiences of Adult Social Care Support in England. *Health Soc Care Community*, 22(4), 375-385.
- Rand, S. E., Malley, J. N., Netten, A. P., & Forder, J. E. (2015). Factor Structure and Construct Validity of the Adult Social Care Outcomes Toolkit for Carers (Ascot-Carer). *Quality of Life Research*, 24(11), 2601-2614.
- Rane, L. J., Fekadu, A., Papadopoulos, A. S., Wooderson, S. C., Poon, L., Markopoulou, K., & Cleare, A. J. (2012). Psychological and Physiological Effects of Caring for Patients with Treatment-Resistant Depression. *Psychological Medicine*, 42(9), 1825-1833.
- Ranmuthugala, G., Nepal, B., Brown, L., & Percival, R. (2009). Impact of Home Based Long Term Care on Informal Carers. *Australian Family Physician*, 38(8), 618-620.
- Rapaport, J. (2004). A Matter of Principle: The Nearest Relative under the Mental Health Act 1983 and Proposals for Legislative Reform. *Journal of Social Welfare and Family Law*, 26(4), 377-396.
- Rapaport, J., Bellringer, S., Pinfold, V., & Huxley, P. (2006). Carers and Confidentiality in Mental Health Care: Considering the Role of the Carer's Assessment: A Study of Service Users', Carers' and Practitioners' Views. *Health Soc Care Community*, 14(4), 357-365.
- Raphael, C., & Cornwell, J. (2008). Influencing Support for Caregivers. *American Journal of Nursing*, 108(9), 78-82.
- Rashid, A. (2015). Informal Carers, Paramedics, Chronic Pain, and Twitter. *British Journal of General Practice*, 65(631), 83.
- Ratcliffe, J., Lancsar, E., Luszcz, M., Crotty, M., Gray, L., Paterson, J., & Cameron, I. D. (2014). A Health Economic Model for the Development and Evaluation of Innovations in Aged Care: An Application to Consumer-Directed Care-Study Protocol. *BMJ Open*, 4(6), e005788-e005788.
- Ratcliffe, J., Lester, L. H., Couzner, L., & Crotty, M. (2013). An Assessment of the Relationship between Informal Caring and Quality of Life in Older Community-Dwelling Adults - More Positives Than Negatives? *Health and Social Care in the Community*, 21(1), 35-46.
- Raune, D., Kuipers, E., & Bebbington, P. E. (2004). Expressed Emotion at First-Episode Psychosis: Investigating a Carer Appraisal Model. *British Journal of Psychiatry*, 184(4), 321-326.
- Ravanera, Z., Beaujot, R., & Liu, J. (2009). Models of Earning and Caring: Determinants of the Division of Work. *Canadian Review of Sociology*, 46(4), 319-337.

- Raver, S. A., Michalek, A. P., & Gillespie, A. M. (2011). Stressors and Life Goals of Caregivers of Individuals with Disabilities. *J Soc Work in Disability and Rehabilitation*, 10(2), 115-128.
- Rawlings, D. (2012). End-of-Life Care Considerations for Gay, Lesbian, Bisexual, and Transgender Individuals. *International Journal of Palliative Nursing*, 18(1), 29-34.
- Rawlinson, S. R. (2001). The Dental and Oral Care Needs of Adults with a Learning Disability Living in a Rural Community: Consideration of the Issues. *Journal of Learning Disabilities*, 5(2), 133-156.
- Ray, R. A., & Street, A. F. (2005). Ecomapping: An Innovative Research Tool for Nurses. *Journal of Advanced Nursing*, 50(5), 545-552 548p.
- Ray, R. A., & Street, A. F. (2005). Who's There and Who Cares: Age as an Indicator of Social Support Networks for Caregivers among People Living with Motor Neurone Disease. *Health & Social Care in The Community*, 13(6), 542-552.
- Raymond, M., Warner, A., Davies, N., Iliffe, S., Manthorpe, J., & Ahmedzhai, S. (2014). Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers. *Dementia: The International Journal of Social Research and Practice*, 13(1), 96-110.
- Read, J., & Blackburn, C. (2005). Carers' Perspectives on the Internet: Implications for Social and Health Care Service Provision. *British Journal of Social Work*, 35(7), 1175-1192.
- Ream, E., Pedersen, V., Oakley, C., Richardson, A., Taylor, C., & Verity, R. (2011). Unrecognised and Underprepared: An Exploratory Mixed Method Study of Informal Carers' Experiences of Supporting Someone through Chemotherapy. *European Journal of Cancer*, 47, 14-15.
- Ream, E., Pedersen, V. H., Oakley, C., Richardson, A., Taylor, C., & Verity, R. (2013). Informal Carers' Experiences and Needs When Supporting Patients through Chemotherapy: A Mixed Method Study. *European Journal of Cancer Care*, 22(6), 797-806.
- Reed, J., Inglis, P., Cook, G., Clarke, C., & Cook, M. (2007). Specialist Nurses for Older People: Implications from Uk Development Sites. *JOURNAL OF ADVANCED NURSING*, 58(4), 368-376 369p.
- Rees, J., MacDonald, R., & O'Boyle, C. (2001). Quality of Life: Impact of Chronic Illness on the Partner. *J R Soc Med*, 94(11), 563-566.
- Regan, T., Lambert, S., Girgis, A., Kelly, B., Kayser, K., & Turner, J. (2012). Do Couple-Based Interventions Make a Difference for Couples Affected by Cancer? A Systematic Review. *BMC Cancer*, 12(279).
- Regan, T., Levesque, J. V., Lambert, S. D., & Kelly, B. (2015). A Qualitative Investigation of Health Care Professionals', Patients' and Partners' Views on Psychosocial Issues and Related Interventions for Couples Coping with Cancer. *PLoS ONE*, 10(7).
- Reichert, M., Hampel, S., & Reuter, V. (2015). Mobile Dementia Counselling: An Instrument to Support Informal Carers in Rural Areas in Germany *Gerontologist*, 55, 799-800.
- Reid, C. M., Gibbins, J., Bloor, S., Burcombe, M., McCoubrie, R., & Forbes, K. (2013). Can the Impact of an Acute Hospital End-of-Life Care Tool on Care and Symptom Burden Be Measured Contemporaneously? *BMJ Supportive and Palliative Care*, 3(2), 161-167.
- Reid, G., & Hulme, C. (2008). The Impact of Intermediate Care: The Carer's Perspective. *International Journal of Therapy and Rehabilitation*, 15(11), 500-507.
- Reid, R. C., Stajduhar, K. I., & Chappell, N. L. (2010). The Impact of Work Interferences on Family Caregiver Outcomes. *Journal of Applied Gerontology*, 29(3), 267-289.
- Relay, A. M. C., & Browne, K. D. (2001). Risk Factor Characteristics in Carers Who Physically Abuse or Neglect Their Elderly Dependents. *Aging and Mental Health*, 5(1), 56-62.

- Remtulla, Y., Charles, G., & Marshall, S. (2012). An Analysis of Responsibility, Attachment Security, and Relationship Efficacy among Young Carers. *Relational Child & Youth Care Practice*, 25(2), 49-57.
- Richardson, A., Plant, H., Moore, S., Medina, J., Cornwall, A., & Ream, E. (2007). Developing Supportive Care for Family Members of People with Lung Cancer: A Feasibility Study. *Supportive Care in Cancer*, 15(11), 1259-1269.
- Richardson, A., Wagland, R., Foster, R., Symons, J., Davis, C., Boyland, L., Foster, C., & Addington-Hall, J. (2015). Uncertainty and Anxiety in the Cancer of Unknown Primary Patient Journey: A Multiperspective Qualitative Study. *BMJ Supportive & Palliative Care*, 5(4), 366-372.
- Richardson, E., & Laird, S. E. (2013). Involving Carers from Minority Ethnic Backgrounds in Carer-Led Research. *Disability & Society*, 28(1), 67-80.
- Richardson, K., Jinks, A., & Roberts, B. (2009). Qualitative Evaluation of a Young Carers' Initiative. *Journal of Child Health Care*, 13(2), 150-160.
- Ridley, J., Hunter, S., & Rosengard, A. (2010). Partners in Care? Views and Experiences of Carers from a Cohort Study of the Early Implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003. *Health and Social Care in the Community*, 18(5), 474-482.
- Riedel, M., & Kraus, M. (2016). Differences and Similarities in Monetary Benefits for Informal Care in Old and New EU Member States. *International Journal of Social Welfare*, 25(1), 7-17.
- Riesner, C., Schnepf, W., & Zegelin, A. (2011). Carenapd -- a Need-Assessment for Families with Dementia; First Use in Germany. *Pflegewissenschaft*, 13(7-8), 389-397 389p.
- Rigaux, N. (2009). Informal Care: Burden or Significant Experience? *Psychologie et NeuroPsychiatrie du Vieillessement*, 7(1), 57-63.
- Rigby, M., Hill, P., Koch, S., & Keeling, D. (2011). Social Care Informatics as an Essential Part of Holistic Health Care: A Call for Action. *International Journal of Medical Informatics*, 80(8), 544-554.
- Riley, J., & Fenton, G. (2007). A Terminal Diagnosis: The Carers' Perspective. *Counselling and Psychotherapy Research*, 7(2), 86-91.
- Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M. C., Cherubini, A., Abate, G., Bartorelli, L., Bonaiuto, S., Capurso, A., Cucinotta, D., Gallucci, M., Giordano, M., Martorelli, M., Masaraki, G., Nieddu, A., Pettenati, C., Putzu, P., Tammaro, V. A., Tomassini, P. F., Vergani, C., Senin, U., & Mecocci, P. (2005). Predictors of High Level of Burden and Distress in Caregivers of Demented Patients: Results of an Italian Multicenter Study. *International Journal of Geriatric Psychiatry*, 20(2), 168-174.
- Ritchie, C. S., Roth, D. L., & Allman, R. M. (2011). Living with an Aging Parent: "It Was a Beautiful Invitation". *JAMA*, 306(7).
- Robards, J., Vlachantoni, A., Evandrou, M., & Falkingham, J. (2015). Informal Caring in England and Wales - Stability and Transition between 2001 and 2011. *Advances in Life Course Research*, 24, 21-33.
- Robben, S., van Kempen, J., Heinen, M., Zuidema, S., Olde Rikkert, M., Schers, H., & Melis, R. (2012). Preferences for Receiving Information among Frail Older Adults and Their Informal Caregivers: A Qualitative Study. *Fam Pract*, 29(6), 742-747.
- Roberto, K. A., & Jarrott, S. E. (2008). Family Caregivers of Older Adults: A Life Span Perspective. *Family Relations*, 57(1), 100-111.
- Robine, J.-M., Michael, J.-P., & Herrmann, F. R. (2007). Who Will Care for the People? *BMJ: British Medical Journal (International Edition)*, 334(7593), 570-571.

- Robinson, A., Elder, J., Emden, C., Lea, E., Turner, P., & Vickers, J. (2009). Information Pathways into Dementia Care Services: Family Carers Have Their Say. *Dementia: The International Journal of Social Research and Practice*, 8(1), 17-37.
- Robinson, A., Lea, E., Hemmings, L., & Vosper, G. (2012). Seeking Respite: Issues around the Use of Day Respite Care for the Carers of People with Dementia. *Ageing & Society*, 32(2), 196-218.
- Robinson, C., & Williams, V. (2002). Carers of People with Learning Disabilities, and Their Experience of the 1995 Carers Act. *British Journal of Social Work*, 32(2), 169-183.
- Robinson, L., Illife, S., Brayne, C., Goodman, C., Rait, G., Manthorpe, J., Ashley, P., & Moniz-Cook, E. (2010). Primary Care and Dementia: 2. Long-Term Care at Home: Psychosocial Interventions, Information Provision, Carer Support and Case Management. *International Journal of Geriatric Psychiatry*, 25(7), 657-664.
- Robison, J., Wiles, R., Ellis-Hill, C., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Resuming Previously Valued Activities Post-Stroke: Who or What Helps. *Disability and Rehabilitation*, 31(19), 1555-1566.
- Robson, E. (2004). Hidden Child Workers: Young Carers in Zimbabwe. *Antipode*, 36(2), 227-248.
- Roca Roger, M., Ubeda Bonet, I., Fuentelsaz Gallego, C., López Pisa, R., Pont Ribas, A., García Viñets, L., & Pedreny Oriol, R. (2000). Impact of Caregiving on the Health of Family Caregivers. *Atencion Primaria*, 26(4), 217-223.
- Roche, J., & Tucker, S. (2003). Extending the Social Exclusion Debate: An Exploration of the Family Lives of Young Carers and Young People with Me. *Childhood*, 10(4), 439-456.
- Rocker, G. M., Young, J., & Simpson, A. C. (2009). Advanced Chronic Obstructive Pulmonary Disease: More Than a Lung Disease. *Progress in Palliative Care*, 17(3), 117-125.
- Roddy, S., Onwumere, J., & Kuipers, E. (2015). A Pilot Investigation of a Brief, Needs-Led Caregiver Focused Intervention in Psychosis. *Journal of Family Therapy*, 37(4), 529-545.
- Rodger, D., Neill, M. O., & Nugent, L. (2015). Informal Carers' Experiences of Caring for Older Adults at Home: A Phenomenological Study. *British Journal of Community Nursing*, 20(6), 280-285.
- Rodger, D., Spencer, A., & Hussey, P. (2016). Using Education Technology as a Proactive Approach to Healthy Ageing. *Studies In Health Technology And Informatics*, 225, 193-197.
- Rodgers, H., Francis, J. J., Brittain, K., & Robinson, A. L. (2007). Who Cares? – caring for the Carers of Stroke Patients. *Disability & Rehabilitation*, 29(5), 425-427.
- Rodgers, J. (2001). The Experience and Management of Menstruation for Women with Learning Disabilities. *Tizard Learning Disability Review*, 6(1), 36-44.
- Rodgers, J., & Lipscombe, J. (2005). The Nature and Extent of Help Given to Women with Intellectual Disabilities to Manage Menstruation. *Journal of Intellectual and Developmental Disability*, 30(1), 45-52.
- Roe, B., Corbett, K., & Byrne, M. (2011). Developments in Mental Health Service Provision: Views of Service Users and Carers. *Research Policy and Planning*, 29(1), 3-19.
- Roe, B., Howell, F., Riniotis, K., Beech, R., Crome, P., & Ong, B. N. (2009). Older People and Falls: Health Status, Quality of Life, Lifestyle, Care Networks, Prevention and Views on Service Use Following a Recent Fall. *Journal of Clinical Nursing*, 18(16), 2261-2272 2212p.
- Roelands, M., Depoorter, A. M., & van Oost, P. (2008). Service Use in Family Caregivers of Persons with Dementia in Belgium: Psychological and Social Factors. *Health Soc Care Community*, 16(1), 42-53.

- Roick, C., Heider, D., Bebbington, P., Angermeyer, M., Azorin, J. M., Brugha, T. S., Kilian, R., Johnson, S., Toumi, M., & Kornfeld, A. (2007). Burden on Caregivers of People with Schizophrenia: Comparison between Germany and Britain. *British Journal of Psychiatry*, 190(4), 333-338.
- Rolley, J., Smith, J., & Di Giacomo, M. (2011). The Caregiving Role Following Percutaneous Coronary Intervention. *Journal of Clinical Nursing*, 20(1-2), 227-235.
- Ron, P. (2006). Care Giving Offspring to Aging Parents: How It Affects Their Marital Relations, Parenthood and Mental Health. *Illness, Crisis & Loss*, 14(1), 1-21.
- Rosanne, C., Thompson, K., Parahoo, K., & McCaughan, E. (2013). Towards an Understanding of the Lives of Families Affected by Stroke: A Qualitative Study of Home Carers. *Journal of Clinical Nursing*, 69(8), 1761-1770.
- Rose, H. D., & Cohen, K. (2010). The Experiences of Young Carers: A Meta-Synthesis of Qualitative Findings. *Journal of Youth Studies*, 13(4), 473-487.
- Rose, K. E. (2000). Gaining Access to Potential Research Participants. *Professional Nurse*, 15(7), 465-467 463p.
- Rosenfeld, P. (2007). Workplace Practices for Retaining Older Hospital Nurses: Implications from a Study of Nurses with Eldercare Responsibilities. *Policy, Politics & Nursing Practice*, 8(2), 120-129.
- Rosenthal, C. J., Matthews, A. M., & Keefe, J. (2007). Care Management and Care Provision for Older Relatives Amongst Employed Informal Care-Givers. *Ageing & Society*, 27(5), 755-778.
- Rosenzweig, M. Q., Wiehagen, T., Brufsky, A., & Arnold, R. (2009). Challenges of Illness in Metastatic Breast Cancer: A Low-Income African American Perspective. *Palliative and Supportive Care*, 7(2), 143-152.
- Rosness, A., Ulstein, I., & Engedal, K. (2009). Stress Affects Carers before Patient's First Visit to a Memory Clinic. *International Journal of Geriatric Psychiatry*, 24(10), 1143-1150.
- Rosness, T. A., Haugen, P. K., & Engedal, K. (2008). Support to Family Carers of Patients with Frontotemporal Dementia. *Aging and Mental Health*, 12(4), 462-466.
- Rosness, T. A., Mjorud, M., & Engedal, K. (2011). Quality of Life and Depression in Carers of Patients with Early Onset Dementia. *Aging and Mental Health*, 15(3), 299-306.
- Rosochacka-Gmitrzak, M., & Raclaw, M. (2014). Caregiving for the Elderly Family Members as a Challenge for Men - the Hidden and Forgotten Carers in Ageing Europe. *International Multidisciplinary Scientific Conference on Social Sciences & Arts SGEM*, 111-118.
- Rossen, C. B., Stenager, E., & Buus, N. (2014). The Experiences of Being Close Relatives and Informal Carers of Mentally Ill Iraqi Refugees: A Qualitative Study. *International Journal of Culture and Mental Health*, 7(4), 452-463.
- Røthing, M., Malterud, K., & Frich, J. C. (2015). Family Caregivers' Views on Coordination of Care in Huntington's Disease: A Qualitative Study. *Scandinavian Journal of Caring Sciences*, 29(4), 803-809.
- Røthing, M., Malterud, K., & Frich, J. C. (2014). Caregiver Roles in Families Affected by Huntington's Disease: A Qualitative Interview Study. *Scandinavian Journal of Caring Sciences*, 28(4), 700-705.
- Roud, H., Keeling, S., & Sainsbury, R. (2006). Using the Cope Assessment Tool with Informal Carers of People with Dementia in New Zealand. *New Zealand Medical Journal*, 119(1237).
- Roure, R. M., Reig, A., & Vidal, J. (2002). Perception of Social Support in Hospitalized Patients. *Revista Multidisciplinar de Gerontologia*, 12(2), 79-85.

- Roustone, A., & Hudson, V. (2007). Carer Participation in England, Wales and Northern Ireland: A Challenge for Interprofessional Working. *Journal of Interprofessional Care*, 21(3), 303-317 315p.
- Rowe, J. (2012). Great Expectations: A Systematic Review of the Literature on the Role of Family Carers in Severe Mental Illness, and Their Relationships and Engagement with Professionals. *J Psychiatr Ment Health Nurs*, 19(1), 70-82.
- Rowe, J. (2013). Enhancing Carers' Experiences of Mental Health Services. *Mental Health Practice*, 17(2), 24-26.
- Roy, N., Shah, H., Patel, V., & Bagalkote, H. (2005). Surgical and Psychosocial Outcomes in the Rural Injured—a Follow-up Study of the 2001 Earthquake Victims. *Injury*, 36(8), 927-934.
- Rusner, M., Carlsson, G., Brunt, D., & Nystrom, M. (2013). Towards a More Liveable Life for Close Relatives of Individuals Diagnosed with Bipolar Disorder. *Int J Mental Health Nurs*, 22(2), 162-169.
- Russell, R. (2006). The Work of Elderly Men Caregivers: From Public Careers to an Unseen World. *Men and Masculinities*, 9(3), 298-314.
- Ruston, A. (2007). Life after Traumatic Brain Injury: The Carer's Trajectory. *International Journal of Interdisciplinary Social Sciences*, 2(3), 159-164.
- Rutherford, A., & Bowes, A. (2014). Networks of Informal Caring: A Mixed-Methods Approach. *Canadian Journal on Aging = La Revue Canadienne Du Vieillissement*, 33(4), 473-487.
- Ryan, A., McKenna, H., & Slevin, O. (2012). Family Care-Giving and Decisions About Entry to Care: A Rural Perspective. *Ageing & Society*, 32(1), 1-18.
- Ryan, C., Harland, N., Drew, B. T., & Martin, D. (2014). Tactile Acuity Training for Patients with Chronic Low Back Pain: A Pilot Randomised Controlled Trial. *Bmc Musculoskeletal Disorders*, 15.
- Ryan, P. J., Howell, V., Jones, J., & Hardy, E. J. (2008). Lung Cancer, Caring for the Caregivers. A Qualitative Study of Providing Pro-Active Social Support Targeted to the Carers of Patients with Lung Cancer. *Palliative Medicine*, 22(3), 233-238.
- Ryan, T. (2002). Exploring the Risk Management Strategies of Informal Carers of Mental Health Service Users. *Journal of Mental Health*, 11(1).
- Ryan, T., & Bamber, C. (2002). A Survey of Policy and Practice on Expenses and Other Payments to Mental Health Service Users and Carers Participating in Service Development. *Journal of Mental Health*, 11(6), 635-644 610p.
- Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the Senses Framework to Achieve Relationship-Centred Dementia Care Services. *Dementia: The International Journal of Social Research and Practice*, 7(1), 71-93.
- Salawu, F. K., Danburam, A., & Olokoba, A. B. (2010). Non-Motor Symptoms of Parkinson's Disease: Diagnosis and Management. *Nigerian Journal of Medicine: Journal of The National Association of Resident Doctors of Nigeria*, 19(2), 126-131.
- Saldivia, S., Torres-Gonzalez, F., Runte-Geidel, A., Xavier, M., Grandon, P., Antonioli, C., Ballester, D., Gibbons, R., Melipillan, R., Caldas, J. M., Vicente, B., Galende, E., & King, M. (2013). Standardization of the Maristán Scale of Informal Care in People with Schizophrenia and Other Psychoses. *Acta Psychiatrica Scandinavica*, 128(6), 468-474.
- Salin, S., Kaunonen, M., & Astedt-Kurki, P. (2009). Informal Carers of Older Family Members: How They Manage and What Support They Receive from Respite Care. *Journal of Clinical Nursing*, 18(4), 492-501.

- Salin, S., Kaunonen, M., & Åstedt-Kurki, P. (2013). Nurses' Perceptions of Their Relationships with Informal Carers in Institutional Respite Care for Older People. *Nursing Research and Practice*.
- Salisbury, L., Wilkie, K., Bulley, C., & Shiels, J. (2010). 'After the Stroke': Patients' and Carers' Experiences of Healthcare after Stroke in Scotland. *Health Soc Care Community*, 18(4), 424-432.
- Salter, K., Zettler, L., Foley, N., & Teasell, R. (2010). Impact of Caring for Individuals with Stroke on Perceived Physical Health of Informal Caregivers. *Disability & Rehabilitation*, 32, 273-281.
- Samitca, S. (2004). The Second Victims: People Living with Patients Suffering from Alzheimer's Disease. *Sciences Sociales et Sante*, 22(2), 73-95.
- Sampson, M. S., & Clark, A. (2015). 'Deferred or Chickened Out?' Decision Making among Male Carers of People with Dementia. *Dementia (London, England)*.
- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., Watts, S., & Bond, J. (2014). Negotiating a Labyrinth: Experiences of Assessment and Diagnostic Journey in Cognitive Impairment and Dementia. *International Journal of Geriatric Psychiatry*, 29(1), 58-67.
- Samuels, S., Hall, I., Parkes, C., & Hassiotis, A. (2007). Professional Staff and Carers' Views of an Integrated Mental Health Service for Adults with Learning Disabilities. *Psychiatric Bulletin*, 31(1), 13-16.
- Sanders, S. (2007). Experiences of Rural Male Caregivers of Older Adults with Their Informal Support Networks. *Journal of Gerontological Social Work*, 49(4), 97-115.
- Sanders, S., & Kathryn, A. B. (2005). Grief Reactions and Depression in Caregivers of Individuals with Alzheimer's Disease: Results from a Pilot Study in an Urban Setting. *Health and Social Work*, 30(4), 287-295.
- Santamaria, N., & McKenzie, M. (2000). The Carers of Hospital in the Home Patients Focus on Clinical Processes, Procedures and the Prediction of Deterioration. *Australian Journal of Advanced Nursing*, 17(4), 16-20.
- Santini, S., Andersson, G., & Lamura, G. (2016). Impact of Incontinence on the Quality of Life of Caregivers of Older Persons with Incontinence: A Qualitative Study in Four European Countries. *Archives of Gerontology & Geriatrics*, 63, 92-101.
- Santini, S., & Miller, R. (2014). Good Practice in European Integration: Lessons from the Aida Project. *International Journal of Integrated Care (IJIC)*, 14, 27-29.
- Sapountzi-Krepia, D., Raftopoulos, V., Sgantzios, M., Dimitriadou, A., Ntourou, I., & Sapkas, G. (2006). Informal in-Hospital Care in a Rehabilitation Setting in Greece: An Estimation of the Nursing Staff Required for Substituting This Care. *Disability & Rehabilitation*, 28(1), 3-11.
- Sargent, P., Pickard, S., Sheaff, R., & Boaden, R. (2007). Patient and Carer Perceptions of Case Management for Long-Term Conditions. *Health and Social Care in the Community*, 15(6), 511-519.
- Saunders, M. M. (2008). Factors Associated with Caregiver Burden in Heart Failure Family Caregivers. *Western Journal of Nursing Research*, 30(8), 943-959.
- Sautter, J. M., Tulskey, J. A., Johnson, K. S., Olsen, M. K., Burton-Chase, A. M., Hoff Lindquist, J., Zimmerman, S., & Steinhauer, K. E. (2014). Caregiver Experience During Advanced Chronic Illness and Last Year of Life. *Journal of the American Geriatrics Society*, 62(6), 1082-1090.
- Savage, S., & Bailey, S. (2004). The Impact of Caring on Caregivers' Mental Health: A Review of the Literature. *Australian Health Review*, 27(1), 111-117.



- Savundranayagam, M. Y., Montgomery, R. J. V., & Kosloski, K. (2011). A Dimensional Analysis of Caregiver Burden among Spouses and Adult Children. *The Gerontologist*, 51(3), 321-331.
- Sawatzky, J., & Fowler-Kerry, S. (2003). Impact of Caregiving: Listening to the Voice of Informal Caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10(3), 277-286.
- Saxena, S., & O'Connell, K. (2003). Initial Steps to Developing the World Health Organization's Quality of Life Instrument (WHOQOL) Module for International Assessment in HIV/AIDS. *AIDS Care-Psychological and Socio-Medical Aspects of AIDS/HIV*, 15(3), 347-357.
- Scazufca, M., Menezes, P. R., & Almeida, O. P. (2002). Caregiver Burden in an Elderly Population with Depression in São Paulo, Brazil. *Social Psychiatry and Psychiatric Epidemiology*, 37(9), 416-422.
- Schaffer, S. K. (2015). The Effect of Free Personal Care for the Elderly on Informal Caregiving. *Health Economics*, 24 Suppl 1, 104-117.
- Schaller, S., Marinova-Schmidt, V., Gobin, J., Criegee-Rieck, M., Griebel, L., Engel, S., Stein, V., Graessel, E., & Kolominsky-Rabas, P. L. (2015). Tailored E-Health Services for the Dementia Care Setting: A Pilot Study of 'E-healthmonitor'. *Bmc Medical Informatics and Decision Making*, 15.
- Scharlach, A. E., Gustavson, K., & Dal Santo, T. S. (2007). Assistance Received by Employed Caregivers and Their Care Recipients: Who Helps Care Recipients When Caregivers Work Full Time? *The Gerontologist*, 47(6), 752-762.
- Schenk, N., Dykstra, P., Maas, I., & van Gaalen, R. (2014). Older Adults' Networks and Public Care Receipt: Do Partners and Adult Children Substitute for Unskilled Public Care? *Ageing & Society*, 34(10).
- Schepers, J., Annemans, L., & Simoens, S. (2015). Hurdles That Impede Economic Evaluations of Welfare Interventions. *Expert Review of Pharmacoeconomics & Outcomes Research*, 15(4), 635-642.
- Schildmann, E. K., & Higginson, I. J. (2011). Evaluating Psycho-Educational Interventions for Informal Carers of Patients Receiving Cancer Care or Palliative Care: Strengths and Limitations of Different Study Designs. *Palliat Med*, 25(4), 345.
- Schlarmann, J. G., Metzing, S., Schoppmann, S., & Schnepf, W. (2011). Germany's First Young Carers Project's Impact on the Children: Relieving the Entire Family. A Qualitative Evaluation. *The Open Nursing Journal*, 5, 86-94.
- Schlarmann, J. g., Metzing-Blau, S., & Schnepf, W. (2008). The Use of Health-Related Quality of Life (HRQOL) in Children and Adolescents as an Outcome Criterion to Evaluate Family Oriented Support for Young Carers in Germany: An Integrative Review of the Lite. *BMC Public Health*, 8, 414-423.
- Schlarmann, J. G., Metzing-Blau, S., & Schnepf, W. (2011). Assessing the Effect of a Complex Psychosocial Intervention: A Methodological Note on Determining Measurement Intervals. *Nurse Researcher*, 18(4), 33-37.
- Schlarmann, J. G., Metzing-Blau, S., & Schnepf, W. (2011). Implementing and Evaluating the First German Young-Carers Project: Intentions, Pitfalls and the Need for Piloting Complex Interventions. *The Open Nursing Journal*, 5, 38-44.
- Schmidt, A. E., Ilinca, S., Schulmann, K., Rodrigues, R., Principi, A., Barbabella, F., Sowa, A., Golinowska, S., Deeg, D., & Galenkamp, H. (2016). Fit for Caring: Factors Associated with Informal Care Provision by Older Caregivers with and without Multimorbidity. *Eur J Ageing* (April 2016).

- Schmidt, A. E., Winkelmann, J., Rodrigues, R., & Leichsenring, K. (2016). Lessons for Regulating Informal Markets and Implications for Quality Assurance - the Case of Migrant Care Workers in Austria. *Ageing & Society*, 36(4), 741-763.
- Schmitz, H., & Stroka, M. A. (2013). Health and the Double Burden of Full-Time Work and Informal Care Provision - Evidence from Administrative Data. *Labour Economics*, 24, 305-322.
- Schmitz, H., & Westphal, M. (2015). Short- and Medium-Term Effects of Informal Care Provision on Female Caregivers' Health. *Journal of Health Economics*, 42, 174-185.
- Schneider, J. (2001). Carers and Community Mental Health Services. *Soc Psychiatry Psychiatr Epidemiol*, 36(12), 604-607.
- Schneider, J., Hallam, A., Murray, J., Foley, B., Atkin, L., Banerjee, S., Islam, M. K., & Mann, A. (2002). Formal and Informal Care for People with Dementia: Factors Associated with Service Receipt. *Aging & Mental Health*, 6(3), 255-265.
- Schneider, U., & Kleindienst, J. (2016). Monetising the Provision of Informal Long-Term Care by Elderly People: Estimates for European out-of-Home Caregivers Based on the Well-Being Valuation Method. *Health and Social Care in the Community*, 24(5), e81-e91.
- Schneider, U., Trukeschitz, B., Mühlmann, R., & Ponocny, I. (2013). 'Do I Stay or Do I Go?'- Job Change and Labor Market Exit Intentions of Employees Providing Informal Care to Older Adults. *Health Economics*, 22(10), 1230-1249.
- Schoenmakers, B., Buntinx, F., & de Lepeleire, J. (2009). Can Pharmacological Treatment of Behavioural Disturbances in Elderly Patients with Dementia Lower the Burden of Their Family Caregiver? *Fam Pract*, 26(4), 279-286.
- Schofield, D., Cunich, M., Shrestha, R., Passey, M., Kelly, S., Tanton, R., & Veerman, L. (2014). The Impact of Chronic Conditions of Care Recipients on the Labour Force Participation of Informal Carers in Australia: Which Conditions Are Associated with Higher Rates of Non-Participation in the Labour Force? *BMC Public Health*, 14.
- Schofield, N., Quinn, J., Haddock, G., & Barrowclough, C. (2001). Schizophrenia and Substance Misuse Problems: A Comparison between Patients with and without Significant Carer Contact. *Social Psychiatry and Psychiatric Epidemiology*, 36(11), 523-528.
- Schook, R. M., Linssen, C., Schramel, F., Festen, J., Lammers, E., Smit, E. F., Postmus, P. E., & Westerman, M. J. (2014). Why Do Patients and Caregivers Seek Answers from the Internet and Online Lung Specialists? A Qualitative Study. *Journal of Medical Internet Research*, 16(2).
- Schrank, B., Ebert-Vogel, A., Amering, M., Masel, E. K., Neubauer, M., Watzke, H., Zehetmayer, S., & Schur, S. (2016). Gender Differences in Caregiver Burden and Its Determinants in Family Members of Terminally Ill Cancer Patients. *Psycho-Oncology*, 25(7), 808-814.
- Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and Consequences of Perceived Lack of Choice in Becoming an Informal Caregiver. *Aging and Mental Health*, 16(6), 712-721.
- Schwartz, C., & Lilit, H. (2007). Parents Caring for Adult Children with Physical Disabilities: The Impact of Hope and Closeness on Caregiving Benefits. *Families in Society*, 88(2), 273-281.
- Scior, K., & Longo, S. (2005). In-Patient Psychiatric Care: What We Can Learn from People with Learning Disabilities and Their Carers. *Tizard Learning Disability Review*, 10(3), 22-33.
- Scourfield, P. (2005). Understanding Why Carers' Assessments Do Not Always Take Place. *Practice: Social Work in Action*, 17(1), 15-28.

- Scuffham, P., Synnott, R., & Turkstra, E. (2010). Present and Past Carers' Health: Some Considerations. *International Journal of Nursing Practice*, 16(6), 609-615.
- Seabrooke, V., & Milne, A. (2004). What Will People Think. *Mental Health Today*, 27-30.
- Seal, K., Murray, C. D., & Seddon, L. (2015). The Experience of Being an Informal "Carer" for a Person with Cancer: A Meta-Synthesis of Qualitative Studies. *Palliative & Supportive Care*, 13(3), 493-504.
- Seal, K., Murray, C. D., & Seddon, L. (2015). Family Stories of End-of-Life Cancer Care When Unable to Fulfil a Loved One's Wish to Die at Home. *Palliative & Supportive Care*, 13(3), 473-483.
- Seamark, D., Blake, S., Brearley, S., Milligan, C., Thomas, C., Turner, M., Wang, X., & Payne, S. (2014). Dying at Home: A Qualitative Study of Family Carers' Views of Support Provided by GPs Community Staff. *Br J Gen Pract*, 64(629), 796-803.
- Searson, R., Hendry, A. M., Ramachandran, R., Burns, A., & Purandare, N. (2008). Activities Enjoyed by Patients with Dementia Together with Their Spouses and Psychological Morbidity in Carers. *Aging and Mental Health*, 12(2), 276-282.
- Sebern, M. D., & Whitlatch, C. J. (2007). Dyadic Relationship Scale: A Measure of the Impact of the Provision and Receipt of Family Care. *The Gerontologist*, 47(6), 741-751.
- Sedden, D., Jones, K., & Boyle, M. (2003). Continuing to Care. *Working with Older People*, 7(2), 35-39.
- Seddon, D., & Harper, G. (2009). What Works Well in Community Care: Supporting Older People in Their Own Homes and Community Networks. *Quality in Ageing*, 10(4), 8-17.
- Seddon, D., Jones, K., & Boyle, M. (2002). Committed to Caring: Carer Experiences after a Relative Goes into Nursing or Residential Care. *Quality in Ageing*, 3(3), 16-26.
- Seddon, D., & Robinson, C. (2004). Supporting Carers in Paid Work. *Working with Older People*, 8(2), 13-18.
- Seddon, D., & Robinson, C. (2015). Carer Assessment: Continuing Tensions and Dilemmas for Social Care Practice. *Health Soc Care Community*, 23(1), 14-22.
- Seddon, D., Robinson, C., Bowen, S., & Boyle, M. (2004). Supporting Carers in Paid Employment: Developing a Needs-Led Approach. *Quality in Ageing and Older Adults*, 5(1), 14-23.
- Seddon, D., Robinson, C., Tommis, Y., Woods, B., Perry, J., & Russell, I. (2010). A Study of the Carers Strategy (2000): Supporting Carers in Wales  
*Br J Soc Work*, 40(5), 1470-1487.
- Seddon, D., & Robinson, C. A. (2001). Carers of Older People with Dementia: Assessment and the Carers Act. *Health Soc Care Community*, 9(3), 151-158.
- Seibaek, C. S., Nexø, M. A., & Borg, V. (2013). Work-Related Factors and Early Retirement Intention: A Study of the Danish Eldercare Sector. *Eur J Public Health*, 23(4), 611-616.
- Selwood, A., Cooper, C., & Livingstone, G. (2007). What Is Elder Abuse - Who Decides? *International Journal of Geriatric Psychiatry*, 22(10), 1009-1012.
- Semiatin, A. M., & O'Connor, M. K. (2012). The Relationship between Self-Efficacy and Positive Aspects of Caregiving in Alzheimer's Disease Caregivers. *Aging and Mental Health*, 16(6), 683-688.
- Sepulveda, A. R., Lopez, C., Todd, G., Whitaker, W., & Treasure, J. (2008). An Examination of the Impact of the Maudsley Eating Disorder Collaborative Care Skills Workshops on the Well Being of Carers; a Pilot Study. *Social Psychiatry and Psychiatric Epidemiology*, 43(7), 584.

- Sequeira, C. (2013). Difficulties, Coping Strategies, Satisfaction and Burden in Informal Portuguese Caregivers. *Journal of Clinical Nursing*, 22(3-4), 491.
- Shah, A., & Jenkins, R. (2003). "Value for Money" in Treating Alzheimer's Disease with the New Cholinesterase Inhibitors. *International Journal of Psychiatry in Clinical Practice*, 7(1), 45-47.
- Shankar, J., & Muthuswamy, S. S. (2007). Support Needs of Family Caregivers of People Who Experience Mental Illness and the Role of Mental Health Services. *Families in Society*, 88(2), 302-310.
- Shanley, C. (2008). Supporting Family Carers through Telephone-Mediated Group Programs: Opportunities for Gerontological Social Workers. *Journal of Gerontological Social Work*, 51(3-4), 199-209.
- Shanley, C., Russell, C., Middleton, H., & Simpson-Young, V. (2011). Living through End-Stage Dementia: The Experiences and Expressed Needs of Family Carers. *Dementia*, 10(3), 325-340.
- Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., Myles, S., O'Mahony, S., Roe, B., & Williams, K. (2009). Systematic Review of Respite Care in the Frail Elderly. *Health Technology Assessment*, 13(37), 1-246 246p.
- Shaw, J., Harrison, J., Young, J., Butow, P., Sandroussi, C., Martin, D., & Solomon, M. (2013). Coping with Newly Diagnosed Upper Gastrointestinal Cancer: A Longitudinal Qualitative Study of Family Caregivers' Role Perception and Supportive Care Needs. *Supportive Care in Cancer*, 21(3), 749-756.
- Shaw, J. M., Young, J. M., Butow, P. N., Badgery-Parker, T., Durcinoska, I., Harrison, J. D., Davidson, P. M., Martin, D., Sandroussi, C., Hollands, M., Joseph, D., Das, A., Lam, V., Johnston, E., & Solomon, M. J. (2016). Improving Psychosocial Outcomes for Caregivers of People with Poor Prognosis Gastrointestinal Cancers: A Randomized Controlled Trial (Family Connect). *Supportive Care in Cancer*, 24(2), 585-595.
- Shaw, M., & Dorling, D. (2004). Who Cares in England and Wales? The Positive Care Law: Cross-Sectional Study. *Br J Gen Pract*, 54(509), 899-903.
- Sheehan, B. D., Lall, R., Stinton, C., Mitchell, K., Gage, H., Holland, C., & Katz, J. (2012). Patient and Proxy Measurement of Quality of Life among General Hospital in-patients with Dementia. *Aging and Mental Health*, 16(5), 603-607.
- Sheets, D. J., Black, K., & Kaye, L. W. (2014). Who Cares for Caregivers? Evidence-Based Approaches to Family Support. *J Gerontol Soc Work*, 57(6-7), 525-530.
- Shergold, I., Lyons, G., & Hubers, C. (2015). Future Mobility in an Ageing Society - Where Are We Heading? *Journal of Transport & Health*, 2(1), 86-94.
- Shim, B., Landerman, L. R., & Davis, L. L. (2011). Correlates of Care Relationship Mutuality among Carers of People with Alzheimer's and Parkinson's Disease. *Journal of Advanced Nursing*, 67(8), 1729-1738.
- Shinya, S., & Nakamura, J. (2014). Can Formal Elderly Care Stimulate Female Labor Supply? The Japanese Experience. *Journal of the Japanese and International Economies*, 34, 98-115.
- Shiue, I. (2015). Assessing Quality of Life in Welsh Carers with and without Back Pain. *British Journal of Community Nursing*, 20(7), 338-343.
- Shulman, S. C. (2005). The Changing Nature of Family Relationships in Middle and Later Life: Parent-Caring and the Mid-Life Developmental Opportunity. *Smith College Studies in Social Work*, 75(2), 103-120.

- Shyu, Y.-I. L., Chen, M.-C., Liang, J., & Tseng, M.-Y. (2012). Trends in Health Outcomes for Family Caregivers of Hip-Fractured Elders During the First 12 Months after Discharge. *Journal of Advanced Nursing*, 68(3), 658-666.
- Sigurdardottir, S. H., Sundstrom, G., Malmberg, B., & Bravell, M. E. (2012). Needs and Care of Older People Living at Home in Iceland. *Scandinavian Journal of Public Health*, 40(1), 1-9.
- Silva-Concha, L., & Goudeau-Radical, D. (2011). Evaluation of Informal Carers of Persons with Dementia. *WFOT Bulletin*, 63, 31-35 35p.
- Silver, H. J. (2004). The Nutrition-Related Needs of Family Caregivers. *Generations*, 28(3), 61-64.
- Sim, D., & Bowes, A. (2005). Youth South Asians with Learning Disabilities: Still Socially Excluded? *Research Policy and Planning*, 23(2), 99-110.
- Simon, C. (2001). Informal Carers and the Primary Care Team. *British Journal of General Practice*, 51(472), 920-923.
- Simon, C., & Kendrick, T. (2001). Informal Carers: The Role of General Practitioners and District Nurses. *British Journal of General Practice*, 51(469), 655-657.
- Simon, C., & Kendrick, T. (2002). Community Provision for Informal Live-in Carers of Stroke Patients. *Br J Community Nurs*, 7(6), 292.
- Simon, C., Kumar, S., & Kendrick, T. (2002). Who Cares for the Carers? The District Nurse Perspective. *Family Practice*, 19(1), 29-35.
- Simon, C., Kumar, S., & Kendrick, T. (2008). Formal Support of Stroke Survivors and Their Informal Carers in the Community: A Cohort Study. *Health & Social Care in The Community*, 16(6), 582-592.
- Simon, C., Kumar, S., & Kendrick, T. (2009). Cohort Study of Informal Carers of First-Time Stroke Survivors: Profile of Health and Social Changes in the First Year of Caregiving. *Social Science & Medicine*, 69(3), 404-410 407p.
- Simon, C., Little, P., Birtwistle, J., & Kendrick, T. (2003). A Questionnaire to Measure Satisfaction with Community Services for Informal Carers of Stroke Patients: Construction and Initial Piloting. *Health & Social Care in the Community*, 11(2), 129-137.i
- Simpson, E. L., Bryant, L. D., Ruddy, R., & Atkin, K. (2006). Developing Partnerships for Research: Training Workshops for Mental Health Service Users, Carers and Workers. *Psychiatric Bulletin*, 30(2), 67-69.
- Simpson, E. L., & House, A. O. (2003). User and Carer Involvement in Mental Health Services: From Rhetoric to Science. *British Journal of Psychiatry*, 183(8), 89-91.
- Simpson, K. (2016). Improving Acute Care for Patients with Dementia. *Nursing Times*, 112(5), 22-24.
- Sims-Gould, J., Byrne, K., & Tong, C. (2015). Home Support Workers Perceptions of Family Members of Their Older Clients: A Qualitative Study. *BMC Geriatrics*, 15(165).
- Sims-Gould, J., & Martin-Matthews, A. (2010). We Share the Care: Family Caregivers' Experiences of Their Older Relative Receiving Home Support Services. *Health Soc Care Community*, 18(4), 415-423.
- Sin, C. H. (2006). Expectations of Support among White British and Asian-Indian Older People in Britain: The Interdependence of Formal and Informal Spheres. *Health Soc Care Community*, 14(3), 215-224.
- Sin, C. H. (2007). Older People from White-British and Asian-Indian Backgrounds and Their Expectations for Support from Their Children. *Quality in Ageing and Older Adults*, 8(1), 31-41.

- Sin, J., Moone, N., & Newell, J. (2007). Developing Services for the Carers of Young Adults with Early-Onset Psychosis – Implementing Evidence-Based Practice on Psycho-Educational Family Intervention. *Journal of Psychiatric & Mental Health Nursing*, 14(3), 282-290.
- Sinclair, A. (2011). Diabetes Care for Older People: A Practical View on Management. *Diabetes & Primary Care*, 13(1), 29-38 10p.
- Sinclair, A. J., Armes, D. G., Randhawa, G., & Bayer, A. J. (2010). Caring for Older Adults with Diabetes Mellitus: Characteristics of Carers and Their Prime Roles and Responsibilities. *Diabetic Medicine: A Journal of The British Diabetic Association*, 27(9), 1055-1059.
- Sinding, C. (2003). "Because You Know There's an End to It": Caring for a Relative or Friend with Advanced Breast Cancer. *Palliative & supportive care.*, 1(2), 153-163.
- Sinfield, P., Baker, R., Ali, S., & Richardson, A. (2012). The Needs of Carers of Men with Prostate Cancer and Barriers and Enablers to Meeting Them: A Qualitative Study in England. *European Journal of Cancer Care*, 21(4), 527-534.
- Singh, P., Hussain, R., Khan, A., Irwin, L., & Foskey, R. (2014). Dementia Care: Intersecting Informal Family Care and Formal Care Systems. *Journal of Aging Research*, 2014(1).
- Singleton, J. (2000). Women Caring for Elderly Family Members: Shaping Non-Traditional Work and Family Initiatives. *Journal of Comparative Family Studies*, 31(3), 367-375.
- Siren, A., & Haustein, S. (2016). How Do Baby Boomers' Mobility Patterns Change with Retirement? *Ageing & Society*, 36(5), 988-1007.
- Ski, C., & O'Connell, B. (2007). Stroke: The Increasing Complexity of Carer Needs. *The Journal of Neuroscience Nursing: Journal of The American Association Of Neuroscience Nurses*, 39(3), 172-179.
- Skilbeck, J. K., Payne, S. A., Ingleton, M. C., Nolan, M., Carey, I., & Hanson, A. (2005). An Exploration of Family Carers' Experience of Respite Services in One Specialist Palliative Care Unit. *PALLIATIVE MEDICINE*, 19(8), 610-618.
- Skira, M. M. (2015). Dynamic Wage and Employment Effects of Elder Parent Care. *International Economic Review*, 56(1), 63-93.
- Skirton, H., Williams, J. K., Jackson-Barnette, J., & Paulsen, J. S. (2010). Huntington Disease: Families' Experiences of Healthcare Services. *J Adv Nurs*, 66(3), 500-510.
- Skovdal, M. (2010). Children Caring for Their "Caregivers": Exploring the Caring Arrangements in Households Affected by Aids in Western Kenya. *AIDS Care*, 22(1), 96-103.
- Skovdal, M. (2010). Community Relations and Child-Led Microfinance: A Case Study of Caregiving Children in Kenya. *AIDS Care*, 22, 1652-1661.
- Skovdal, M. (2011). Examining the Trajectories of Children Providing Care for Adults in Rural Kenya: Implications for Service Delivery. *Children and Youth Services Review*, 33(7), 1262-1269.
- Skovdal, M., Campbell, C., & Onyango, V. (2013). Supporting 'Young Carers' in Kenya: From Policy Paralysis to Action. *Child Care in Practice*, 19(4), 318-339.
- Skovdal, M., & Ogutu, V. O. (2009). "I Washed and Fed My Mother before Going to School": Understanding the Psychosocial Well-Being of Children Providing Chronic Care for Adults Affected by HIV/AIDS in Western Kenya. *Globalization and Health*, 5, 8-8.
- Skovdal, M., Ogutu, V. O., Aoro, C., & Campbell, C. (2009). Young Carers as Social Actors: Coping Strategies of Children Caring for Ailing or Ageing Guardians in Western Kenya. *Social Science & Medicine*, 69(4), 587-595.
- Slocombe, P. (2003). Using Strengths-Based Practice to Support Culture Change: An Australian Experience. *Journal of Social Work in Long-Term Care*, 2(3/4), 307-323.

- Small, N., Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., & Garriballa, S. (2009). Dying, Death and Bereavement: A Qualitative Study of the Views of Carers of People with Heart Failure in the UK. *BMC Palliative Care*, 8(6).
- Small, N., Harrison, J., & Newell, R. (2010). Carer Burden in Schizophrenia: Considerations for Nursing Practice. *Mental Health Practice*, 14(4), 22-25.
- Smart, M. (2004). Transition Planning and the Needs of Young People and Their Carers: The Alumni Project. *British Journal of Special Education*, 31(3), 128-137.
- Smit, D., te Boekhorst, S., De Lange, J., Depla, M. F., Eefsting, J. A., & Pot, A. M. (2011). The Long-Term Effect of Group Living Homes Versus Regular Nursing Homes for People with Dementia on Psychological Distress of Informal Caregivers. *Aging and Mental Health*, 15(5), 557-561.
- Smith, C. (2006). Looking after Our Old: Who Cares? *Nursing in Practice* (29), 22-24.
- Smith, C., Snelgrove, S., Armstrong-Esther, C., & Clark, J. (2003). Is There a Future for the Informal Home care of Older People in a Changing Society? *Quality in Ageing and Older Adults*, 4(1), 12-21.
- Smith, F., Francis, S.-A., & Gray, N. (2009). How Pharmacists Can Support Carers. *The Pharmaceutical Journal*.
- Smith, G. (2000). Better Safety, Better Quality of Life. *Management Issues in Social Care*, 7(3), 10-14.
- Smith, J., Forster, A., & Young, J. (2004). A Randomized Trial to Evaluate an Education Programme for Patients and Carers after Stroke. *Clin Rehabil*, 18(7), 726-736.
- Smith, L. N., Lawrence, M., Kerr, S. M., Langhorne, P., & Lees, K. R. (2004). Informal Carers' Experience of Caring for Stroke Survivors. *Journal of Advanced Nursing*, 46(3), 235-244.
- Smith, P. (2009). The Family Caregivers Journey in End-of-Life Care: Recognizing and Identifying with the Role of Carer. *International Journal on Disability and Human Development*, 8(1), 67-73.
- Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P., Cook, J. C., Murray, J., Prince, M., Levin, E., Mann, A., & Knapp, M. (2005). What Constitutes Health-Related Quality of Life in Dementia? Development of a Conceptual Framework for People with Dementia and Their Carers. *International Journal of Geriatric Psychiatry*, 20(9), 889-895.
- Smyth, C. (2008). Commentary on Jarvis a, Worth a and Porter M (2006). The Experience of Caring for Someone over 75 Years of Age: Results from a Scottish General Practice Population. *Journal of Clinical Nursing* 15, 1450-1459. *Journal of Clinical Nursing*, 17(13), 1814-1817.
- Smyth, C., Blaxland, M., & Cass, B. (2011). 'So That's How I Found out I Was a Young Carer and That I Actually Had Been a Carer Most of My Life'. Identifying and Supporting Hidden Young Carers. *Journal of Youth Studies*, 14(2), 145-160.
- Smyth, C., Cass, B., & Hill, T. (2011). Children and Young People as Active Agents in Care-Giving: Agency and Constraint. *Children and Youth Services Review*, 33(4), 509-514.
- Sneddon, D., Robinson, C., Reeves, C., Tommis, Y., Woods, B., & Russell, I. (2007). In Their Own Right: Translating the Policy of Carer Assessment into Practice. *British Journal of Social Work*, 37(8), 1335-1352.
- Sole-Auro, A. (2014). Who Cares? A Comparison of Informal and Formal Care Provision in Spain, England and the USA. *Ageing & Society*, 34(3), 495-517.
- Somerville, J. (2001). Palliative Care: The Experience of Informal Carers within the Bangladeshi Community. *International Journal of Palliative Nursing*, 7(5), 240-247.

- Sommerlad, A., Manela, M., & Cooper, C. (2014). Start (Strategies for Relatives) Coping Strategy for Family Carers of Adults with Dementia: Qualitative Study of Participants' Views About the Intervention. *BMJ Open*, 4.
- Song Beeber, A., & Zimmerman, S. (2012). Adapting the Family Management Style Framework for Families Caring for Older Adults with Dementia. *J Fam Nurs*, 18(1), 123-145.
- Soothill, K., Francis, B., Awwad, F., Morris, S. M., Thomas, C., & McIlmurray, M. B. (2004). Grouping Cancer Patients by Psychosocial Needs. *Journal of Psychosocial Oncology*, 22(2), 89-109.
- Soothill, K., Morris, S., & Harman, J. (2001). Informal Carers of Cancer Patients: What Are Their Unmet Psychological Needs? *Health and Social Care in the Community (Print edition)*, 9(6), 464-475.
- Sørbye, L. W., Finne-Soveri, H., Ljunggren, G., Topinkova, E., Garms-Homolova, V., Jensdóttir, A. B., & Bernabei, R. (2009). Urinary Incontinence and Use of Pads - Clinical Features and Need for Help in Home Care at 11 Sites in Europe. *Scandinavian Journal of Caring Sciences*, 23(1), 33-44.
- Sowney, M., & Barr, O. G. (2006). Caring for Adults with Intellectual Disabilities: Perceived Challenges for Nurses in Accident and Emergency Units. *Journal of Advanced Nursing*, 55(1), 36-45.
- Spall, P., McDonald, C., & Zetlin, D. (2005). Fixing the System? The Experience of Service Users of the Quasi-Market in Disability Services in Australia. *Health and Social Care in The Community*, 13(1), 56-63.
- Spanakis, E. G., Chiarugi, F., Kouroubali, A., Spat, S., Beck, P., Asanin, S., Rosengren, P., Gergely, T., & Thestrup, J. (2012). Diabetes Management Using Modern Information and Communication Technologies and New Care Models. *Journal of Medical Internet Research*, 14(5).
- Sparks, L., Bevan, J. L., & Rogers, K. (2012). An Intergroup Communication Approach to Understanding the Function of Compliance, Outgroup Typicality, and Honest Explanations in Distant Caregiving Relationships: Validation of a Health-Care Communication Scale. *Journal of communication in healthcare*, 5(1), 12-22.
- Sparks, L., Travis, S. S., & Thompson, R. S. (2005). Listening for the Communicative Signals of Humor, Narratives, and Self-Disclosure in the Family Caregiver Interview. *Health and Social Work*, 30(4), 340-343.
- Spatharakis, G. (2011). Palliative Care for Heart Failure in Greece. *European Geriatric Medicine*, 2(1), 44-45.
- Spector, A., Gardner, C., & Orrell, M. (2011). The Impact of Cognitive Stimulation Therapy Groups on People with Dementia: Views from Participants, Their Carers and Group Facilitators. *Aging and Mental Health*, 15(8), 945-949.
- Spiess, C. K., & Schneider, A. U. (2003). Interactions between Care-Giving and Paid Work Hours among European Midlife Women, 1994 to 1996. *Ageing and Society*, 23, 41-68.
- Srinivasan, N. (2000). Families as Partners in Care: Perspectives from Amend. *Indian Journal of Social Work*, 61(3), 351-365.
- St. John, T. (2004). Hidden Shame: A Review of the Needs of Asian Elders with Dementia and Their Carers in a Kent Community. *Journal of Integrated Care*, 12(3), 20-26.
- Stajduhar, K., Funk, L., Jakobsson, E., & Ohlen, J. (2010). A Critical Analysis of Health Promotion and 'Empowerment' in the Context of Palliative Family Care-Giving. *Nursing*, 17(3), 221-230.



- Stajduhar, K., Funk, L., Tove, C., Grande, G., Aoun, S., & Todd, C. (2010). Part 1: Home-Based Family Caregiving at the End of Life: A Comprehensive Review of Published Quantitative Research (1998-2008). *Palliat Med*, 24(6), 573-593.
- Stajduhar, K. I. (2013). Burdens of Family Caregiving at the End of Life. *Clinical and Investigative Medicine*, 36(3), E121-E126.
- Staley, K., Ashcroft, J., Doughty, L., & Szmukler, G. (2016). Making It Clear and Relevant: Patients and Carers Add Value to Studies through Research Document Reviews. *Mental Health and Social Inclusion*, 20(1), 36-43.
- Stamatopoulos, V. (2015). One Million and Counting: The Hidden Army of Young Carers in Canada. *Journal of Youth Studies*, 18(6), 809-822.
- Stamatopoulos, V. (2016). Supporting Young Carers: A Qualitative Review of Young Carer Services in Canada. *International Journal of Adolescence and Youth*, 21(2), 178-194.
- Stanbridge, R. (2012). Including Families and Carers: An Evaluation of the Family Liaison Service on Inpatient Psychiatric Wards in Somerset, UK. *Mental Health Review Journal*, 17(2), 70-80.
- Stanbridge, R., & Burbach, F. (2004). Enhancing Working Partnerships with Carers and Families: A Strategy and Associated Training Programme. *Mental Health Review Journal*, 9(4), 32-37.
- Stanley, B., & Standen, J. P. (2000). Carers' Attributions for Challenging Behaviour. *British Journal of Clinical Psychology*, 39(2), 157-168.
- Stanley, S., Balakrishnan, S., & Ilangoan, S. (2016). Correlates of Caregiving Burden in Schizophrenia: A Cross-Sectional, Comparative Analysis from India. *Social Work in Mental Health*, 15332985.15332016.11220440.
- Stansfeld, S., Smuk, M., Onwumere, J., Clark, C., Pike, C., McManus, S., Harris, J., & Bebbington, P. (2014). Stressors and Common Mental Disorder in Informal Carers – an Analysis of the English Adult Psychiatric Morbidity Survey 2007. *Social Science & Medicine*, 120, 190-198.
- Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2014). Factors Influencing Decision-Making in Relation to Timing of Gastrostomy Insertion in Patients with Motor Neurone Disease. *BMJ Supportive and Palliative Care*, 4(1), 57-63.
- Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2016). The Impact of Gastrostomy in Motor Neurone Disease: Challenges and Benefits from a Patient and Carer Perspective. *BMJ Supportive & Palliative Care*, 6(1), 52-59.
- Steffen, A. M., & Grant, J. R. (2016). A Telehealth Behavioral Coaching Intervention for Neurocognitive Disorder Family Carers. *International Journal of Geriatric Psychiatry*, 31(2), 195-203.
- Stella, F., Banzato, C. E., Quagliato, E. M., Viana, M. A., & Christofolletti, G. (2009). Psychopathological Features in Patients with Parkinson's Disease and Related Caregivers' Burden. *International Journal of Geriatric Psychiatry*, 24(10), 1158-1165.
- Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the Literature on the Effects of Caring for a Patient with Cancer. *Psycho-Oncology*, 19(10), 1013-1025.
- Stenberg, U., Ruland, C. M., Olsson, M., & Ekstedt, M. (2012). To Live Close to a Person with Cancer - Experiences of Family Caregivers. *Social Work in Health Care*, 51(10), 909-926.
- Stephan, A., Möhler, R., Renom-Guiteras, A., & Meyer, G. (2015). Successful Collaboration in Dementia Care from the Perspectives of Healthcare Professionals and Informal Carers in Germany: Results from a Focus Group Study. *BMC Health Services Research*, 15(1).

- Stern, A., Valaitis, R., & Weir, R. (2012). Use of Home Telehealth in Palliative Cancer Care: A Case Study. *Journal of Telemedicine & Telecare*, 18(5), 297-300.
- Stewart, A. (2014). Informal Carers and Private Law. *Social & Legal Studies*, 23(3), 474-477.
- Stewart, M., Hart, G., Mann, K., Jackson, S., Langille, L., & Reidy, M. (2001). Telephone Support Group Intervention for Persons with Hemophilia and HIV/AIDS and Family Caregivers. *International Journal of Nursing Studies*, 38(2), 209-225.
- Stock, C., & Lambert, S. (2011). Who Cares Wins? Carers' Experiences of Assessment since the Introduction of the Carers (Equal Opportunities) Act 2004. *Research Policy and Planning*, 28(3), 173-184.
- Stoltz, P., Udden, G., & Willman, A. (2004). Support for Family Carers for an Elderly Person at Home: A Systematic Literature Review. *Scandinavian Journal of Caring Services*, 18(2), 111-119.
- Stoltz, P., Willman, A., & Uden, G. (2006). The Meaning of Support as Narrated by Family Carers Who Care for a Senior Relative at Home. *Qualitative Health Research*, 16(5), 594-610.
- Stone, L. J., & Clements, J. A. (2009). The Effects of Nursing Home Placement on the Perceived Levels of Caregiver Burden. *Journal of Gerontological Social Work*, 52(3), 193-214.
- Strang, V. R., Koop, P. M., & Peden, J. (2002). The Experience of Respite During Home-Based Family Caregiving for Persons with Advanced Cancer. *Journal of Palliative Care*, 18(2), 97-104.
- Strauss, J. R. (2013). Caregiving for Parents and in-Laws: Commonalities and Differences. *Journal of Gerontological Social Work*, 56(1), 49-66.
- Stringer, B., van Meijel, B., Koekkoek, B., Kerkhof, A., & Beekman, A. (2011). Collaborative Care for Patients with Severe Borderline and Nos Personality Disorders: A Comparative Multiple Case Study on Processes and Outcomes. *BMC Psychiatry*, 11.
- Strömberg, A., & Luttik, M. L. (2015). Burden of Caring: Risks and Consequences Imposed on Caregivers of Those Living and Dying with Advanced Heart Failure. *Current Opinion in Supportive and Palliative Care*, 9(1), 26-30.
- Stypinska, J., & Perek-Bialas, J. (2014). Working Carers in Poland - Successful Strategies for Reconciliation of Work and Care of an Older Adult. *Anthropological Notebooks*, 20(1), 87-103.
- Suh, M., Kim, K., & Kim, I. (2005). Caregiver's Burden, Depression and Support as Predictors of Post-Stroke Depression: A Cross-Sectional Survey. *International Journal of Nursing Studies*, 42(6), 611-618.
- Summerton, H. (2000). Who Cares? *Nursing Times*, 30-31.
- Sutcliffe, C. L., Giebel, C. M., Jolley, D., & Challis, D. J. (2016). Experience of Burden in Carers of People with Dementia on the Margins of Long-Term Care. *International Journal of Geriatric Psychiatry*, 31(2), 101-108.
- Sutherland, G., Hoey, L., White, V., Jefford, M., & Hegarty, S. (2008). How Does a Cancer Education Program Impact on People with Cancer and Their Family and Friends? *Journal of Cancer Education*, 23(2), 126-132.
- Svanberg, E., Stott, J., & Spector, A. (2010). 'Just Helping': Children Living with a Parent with Young Onset Dementia. *Aging & Mental Health*, 14(6), 740-751.
- Svendsboe, E., Terum, T., Testad, I., Aarsland, D., Ulstein, I., Corbett, A., & Rongve, A. (2016). Caregiver Burden in Family Carers of People with Dementia with Lewy Bodies and Alzheimer's Disease. *International Journal of Geriatric Psychiatry*, 31(9), 1075-1083.
- Swinson, T., Wenborn, J., Hynes, S., Orrel, M., Stansfeld, J., Rooks, S., & Ledgerd, R. (2003). Community Occupational Therapy for People with Dementia and Their Family Carers: A

- National Survey of United Kingdom Occupational Therapy Practice. *British Journal of Occupational Therapy*, 79(2), 85-91.
- Sykes, N. (2015). One Chance to Get It Right: Understanding the New Guidance for Care of the Dying Person. *British Medical Bulletin*, 115(1), 143-150.
- Syron, M., & Shelley, E. (2001). The Needs of Informal Carers: A Proposed Assessment Tool for Use by Public Health Nurses. *Journal of Nursing Management*.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. *Journal of Intellectual Disabilities*, 16(3), 217-234.
- Takai, Y., Yamamoto-Mitani, N., Okamoto, Y., Fukahori, H., Ko, A., & Tanaka, M. (2013). Family Caregiver Strategies to Encourage Older Relatives with Dementia to Use Social Services. *Journal of Advanced Nursing*, 69(12), 2675-2685.
- Tambuyzer, E. v., & van Audenhove, C. (2013). Service User and Family Carer Involvement in Mental Health Care: Divergent Views. *Community Mental Health Journal*, 49(6), 675-685.
- Tammsaar, K., Laidmae, V. I., Tulva, T., & Saia, K. (2014). Family Caregivers of the Elderly: Quality of Life and Coping in Estonia. *European Journal of Social Work*, 17(4), 539-555.
- Tattan, T., & Tarrier, N. (2000). The Expressed Emotion of Case Managers of the Seriously Mentally Ill: The Influence of Expressed Emotion on Clinical Outcomes. *Psychological Medicine*, 30(1), 195-204.
- Taylor, E. J., & Mamier, I. (2005). Spiritual Care Nursing: What Cancer Patients and Family Caregivers Want. *Journal of Advanced Nursing*, 49(3), 260-267.
- Taylor, I., & le Richie, P. (2006). What Do We Know About Partnership with Service Users and Carers in Social Work Education and How Robust Is the Evidence Base? *Health Soc Care Community*, 14(5), 418-425.
- Taylor, J., & Davies, P. (2012). The Medicines Management Needs of Carers During an Episode of Mental Health Crisis. *Journal of Psychiatric & Mental Health Nursing*, 19(2), 190-192.
- Taylor, L., Leam, C., & Harding, R. (2000). The 90-Minute Group: Developing a Short-Term Intervention for Informal Carers of Patients with Advanced Cancer. *Psycho-Oncology*, 9(4), 360-361.
- Teng, J., Mayo, N. E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R., & Scott, S. (2003). Costs and Caregiver Consequences of Early Supported Discharge for Stroke Patients. *Stroke*, 34(2), 528-536.
- ter Meulen, R., & van der Made, J. (2000). The Extent and Limits of Solidarity in Dutch Health Care. *International Journal of Social Welfare*, 9(4), 250-260.
- Tetley, J., & Draper, J. (2013). Transforming Dementia and End-of-Life Care by Investing in Learning and Development. *International Practice Development Journal*, 3, 1-2.
- Theobald, H. (2012). Home-Based Care Provision within the German Welfare Mix. *Health & Social Care in the Community*, 20(3), 274-282.
- Thiébaud, S. P., Ventelou, B., Garcia-Penalosa, C., & Trannoy, A. (2012). A Microeconomic Analysis of the Impact of Estate Recovery for Long-Term Care. *Revue Economique*, 63(2), 339-372.
- Thomas, C. (2008). Cancer Narratives and Methodological Uncertainties. *Qualitative Research*, 8(3), 423-433.
- Thomas, C., & Morris, S. (2002). Informal Carers in Cancer Contexts. *European Journal of Cancer Care*, 11(3), 178-182.

- Thomas, C., Morris, S. M., & Clark, D. (2004). Place of Death: Preferences among Cancer Patients and Their Carers. *Social Science & Medicine*, 58(12), 2431.
- Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through Cancer: The Care Given by Informal Carers in Cancer Contexts. *Social Science and Medicine*, 54(4), 529-544.
- Thomas, C., Reeve, J., Bingley, A., Brown, J., Payne, S., & Lynch, T. (2009). Narrative Research Methods in Palliative Care Contexts: Two Case Studies. *Journal of Pain & Symptom Management*, 37(5), 788.
- Thomas, D. R., Chantry, K., Aubrey, F., Beaven, S., Bowen, C., Fairley, J., Roberts, A., Cottrell, S., & Roberts, R. (2008). Influenza Immunisation Uptake in Carers. *Vaccine*, 26(52), 6746-6748.
- Thomas, G. P. A., Saunders, C. L., Roland, M. O., & Paddison, C. A. M. (2015). Informal Carers' Health-Related Quality of Life and Patient Experience in Primary Care: Evidence from 195,364 Carers in England Responding to a National Survey. *BMC Family Practice*, 16, 62-62.
- Thomas, K., Hudson, P., Oldham, L., Kelly, B., & Trauer, T. (2010). Meeting the Needs of Family Carers: An Evaluation of Three Home-Based Palliative Care Services in Australia. *Palliat Med*, 24(2), 183-191.
- Thomas, K., Hudson, P., Trauer, T., Remedios, C., & Clarke, D. (2014). Risk Factors for Developing Prolonged Grief During Bereavement in Family Carers of Cancer Patients in Palliative Care: A Longitudinal Study. *Journal of Pain and Symptom Management*, 47(3), 531-541.
- Thomas, K., & Moore, G. (2015). The Development and Evaluation of a Multimedia Resource for Family Carers of Patients Receiving Palliative Care: A Consumer-Led Project. *Palliative & Supportive Care*, 13(3), 417-423.
- Thomas, N., Stainton, T., Jackson, S., Cheung, W. Y., Doubtfire, S., & Webb, A. (2003). 'Your Friends Don't Understand': Invisibility and Unmet Need in the Lives of 'Young Carers'. *Child & Family Social Work*, 8(1), 35-46.
- Thomas, P. (2005). Elderly People Suffering from Dementia Going into a Home Pixel Study. *Gerontologie et Societe*, 112(1), 141-156.
- Thomas, P., Hazif-Thomas, C., Viéban, F., Faugeron, P., Peix, R., & Clément, J. P. (2006). The Gpcog for Detecting a Population with a High Risk of Dementia. *Psychologie et NeuroPsychiatrie du Vieillissement*, 4(1), 69-77.
- Thomas, P., Ingrand, P., Lalloue, F., Hazif-Thomas, C., Billon, R., Vieban, F., & Clement, J. P. (2004). Reasons of Informal Caregivers for Institutionalising Dementia Patients Previously Living at Home: The Pixel Study. *International Journal of Geriatric Psychiatry*, 19(2), 127-135.
- Thomas, P. J., Hazif-Thomas, C., Lalloue, F., & Clement, J. P. (2003). Alzheimer's Patients Informal Carers' Difficulties at Home, at Entry into Institution, and in an Institution. *International Psychogeriatrics*, 15, 182-183.
- Thomas, V. J., Gruen, R., & Shu, S. (2001). Cognitive-Behavioural Therapy for the Management of Sickle Cell Disease Pain: Identification and Assessment of Costs. *Ethnicity and Health*, 6(1), 59-67.
- Thommessen, B., Wyller, T. B., Bautz-Holter, E., & Laake, K. (2001). Acute Phase Predictors of Subsequent Psychosocial Burden in Carers of Elderly Stroke Patients. *Cerebrovascular Diseases*, 11(3), 201-206.
- Thompson, A., & Lovestone, S. (2002). Out of Sight out of Mind? Support and Information Given to Distant and near Relatives of Those with Dementia. *International Journal of Geriatric Psychiatry*, 17(9), 804-807.

- Thompson, D. (2001). Futures Planning for People with Learning Disabilities Living with Older Family Carers. *Journal of Integrated Care*, 9(2), 3-7.
- Thompson, D. (2001). Working with Older Family Carers and Relatives with Learning Disabilities. *Living Well*, 1(2), 6-12.
- Thompson, D. (2002). Growing Older with Learning Disabilities: The Gold Programme. *Tizard Learning Disability Review*, 7(2), 19-26.
- Thompson, D. (2011). Younger Onset Dementia Often Ignored. *Social Policy Research Centre Newsletter* (109), 1, 4-6.
- Thompson, D. (2013). Commentary on "Growing Older Together: Ageing and People with Learning Disabilities and Their Family Carers". *Tizard Learning Disability Review*, 18(3), 120-123.
- Thompson, D. J., Ryrie, I., & Wright, S. (2004). People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17(1), 101-108.
- Tilse, C., Setterlund, D., Wilson, J., & Rosenman, L. (2005). Minding the Money: A Growing Responsibility for Informal Carers. *Ageing and Society*, 25, 215-227.
- Tilse, C., Wilson, J., Setterlund, D., & Rosenman, L. (2007). The New Caring. *Annals of the New York Academy of Sciences*, 1114, 355-361.
- Tobias, M., Yeh, L., & Johnson, E. (2008). Burden of Alzheimer's Disease: Population-Based Estimates and Projections for New Zealand, 2006-2031. *Australian & New Zealand Journal of Psychiatry*, 42(9), 828-836 829p.
- Toofany, S. (2008). Hospital at Home: A Resurgence. *Primary Health Care*, 18(7), 20-23.
- Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of Nursing Home Placement for Older People with Dementia: A Systematic Review and Meta-Analysis. *International Psychogeriatrics*, 29(2), 195-208.
- Tooth, L., McKenna, K., Barnett, A., Prescott, C., & Murphy, S. (2005). Caregiver Burden, Time Spent Caring and Health Status in the First 12 Months Following Stroke. *Brain Injury*, 19(12), 963-974.
- Tooth, L., & Mishra, G. (2014). Socioeconomic Factors Associated with Trajectories of Caring by Young and Mid-Aged Women: A Cohort Study. *BMC Public Health*, 14, 74.
- Topcu, G., Buchanan, H., Aubeeluck, A., & Garip, G. (2016). Caregiving in Multiple Sclerosis and Quality of Life: A Meta-Synthesis of Qualitative Research. *Psychology and Health*, 31(6), 693-710.
- Torge, C. J. (2014). Freedom and Imperative Mutual Care between Older Spouses with Physical Disabilities. *Journal of Family Nursing*, 20(2), 204-225.
- Torge, C. J. (2014). Mutual Care between Older Spouses with Physical Disabilities. *Journal of Family Nursing*, 20(2), 204-225.
- Torjesen, I. (2015). Hospices Outperform Hospitals on Care Quality. *BMJ: British Medical Journal*, 351(8017), h3776-h3776.
- Torp, S., Bing-Jonsson, P. C., & Hanson, E. (2013). Experiences with Using Information and Communication Technology to Build a Multi-Municipal Support Network for Informal Carers. *Informatics for Health & Social Care*, 38(3), 265-279.
- Torp, S., Hanson, E., Hauge, S., Ulstein, I., & Magnusson, L. (2008). A Pilot Study of How Information and Communication Technology May Contribute to Health Promotion among Elderly Spousal Carers in Norway. *Health & Social Care in The Community*, 16(1), 75-85 11p.

- Torres-Gonzalez, F., Runte-Geidel, A., Antonioli, C., Wagner, L. C., Ballester, D., de Almeida, J. M. C., Galende, E., Vicente, B., Xavier, M., Gómez-Beneyt, M., King, M. B., & Saldivia, S. M. (2012). Standardised Measures of Needs, Stigma and Informal Care in Schizophrenia Using a Bottom-up, Cross-Cultural Approach. *Mental Health in Family Medicine*, 9(2), 125-134.
- Toscan, J., Mairs, K., Hinton, S., & Stolee, P. (2012). Integrated Transitional Care: Patient, Informal Caregiver and Health Care Provider Perspectives on Care Transitions for Older Persons with Hip Fracture. *Int J Integr Care* (Apr-Jun).
- Toye, C., Blackwell, S., Maher, S., Currow, D. C., Holloway, K., Tieman, J., & Hegarty, M. (2012). Guidelines for a Palliative Approach for Aged Care in the Community Setting: A Suite of Resources. *Australasian Medical Journal*, 5(11), 569-574.
- Train, G. H., Nurock, S. A., Manela, M., Kitchen, G., & Livingston, G. A. (2005). A Qualitative Study of the Experiences of Long-Term Care for Residents with Dementia, Their Relatives and Staff. *Aging and Mental Health*, 9(2), 119-128.
- Traynor, V., Pritchard, E., & Dewing, J. (2004). Illustrating the Importance of Including the Views and Experiences of Users and Carers in Evaluating the Effectiveness of Drug Treatments for Dementia. *Dementia: The International Journal of Social Research and Practice*, 3(2), 145-159.
- Treas, J., & Mazumdar, S. (2004). Kin keeping and Caregiving: Contributions of Older People in Immigrant Families. *Journal of Comparative Family Studies*, 35(1), 105-122.
- Treasure, J., Whitaker, W., Whitney, J., & Schmidt, U. (2005). Working with Families of Adults with Anorexia Nervosa. *Journal of Family Therapy*, 27(2), 158-170.
- Treloar, A., Cooper, B., Sweeney, J., & Kelly, N. (2001). Night Respite Care: Relieving the Burden on People Caring for Relatives with Dementia. *Nursing Older People*, 13(3), 14-15.
- Treloar, A., & Dimitrios, A. (2005). Sharing Letters with Patients and Their Carers: Problems and Outcomes in Elderly and Dementia Care. *B J Psych Bulletin*.
- Tsai, P.-F., & Jirovec, M. M. (2005). The Relationships between Depression and Other Outcomes of Chronic Illness Caregiving. *BMC Nursing*, 4(3).
- Tsegai, A., & Gamiz, R. (2014). Messages for Integration from Working with Carers. *Journal of Integrated Care*, 22(3), 99-107.
- Tsianakas, V., Robert, G., Richardson, A., Verity, R., Oakley, C., Murrells, T., Flynn, M., & Ream, E. (2015). Enhancing the Experience of Carers in the Chemotherapy Outpatient Setting: An Exploratory Randomised Controlled Trial to Test Impact, Acceptability and Feasibility of a Complex Intervention Co-Designed by Carers and Staff. *Supportive Care in Cancer*, 23(10), 3069-3080.
- Tsianakas, V., Verity, R., Oakley, C., Murrells, T., Robert, G., Richardson, A., & Ream, E. (2014). Using Experience-Based Co-Design (EBCD) to Enhance Support for Carers in the Chemotherapy Outpatient Setting. *European Journal of Oncology Nursing*, 18, S13-S14.
- Tuncay, T., & Isikhan, V. (2010). Psychological Symptoms, Illness-Related Concerns and Characteristics of Relatives of Turkish Patients with Cancer. *Asian Pacific Journal of Cancer Prevention*, 11(6), 1659-1667.
- Tunney, A. M., & Ryan, A. (2014). Listening to Carers' Views on Stroke Services. *Nursing Older People*, 26(1), 28-31.
- Turner, P., Sheldon, F., Coles, C., Mountford, B., Hillier, R., Radway, P., & Wee, B. (2000). Listening to and Learning from the Family Carer's Story: An Innovative Approach in Interprofessional Care. *Journal of Interprofessional Care*, 14(4).

- Turner, S., Sweeney, M., Kennedy, C., & MacPherson, L. (2008). The Oral Health of People with Intellectual Disability Participating in the Uk Special Olympics. *Journal of Intellectual Disability Research*, 52(1), 29-36.
- Turney, D. (2003). Respecting Data Confidentiality: Maintaining Effective Care. *Nursing & Residential Care*, 5(3), 135-137.
- Tynan, H., & Allen, D. (2002). The Impact of Service User Cognitive Level on Carer Attributions for Aggressive Behaviour. *Journal of Applied Research in Intellectual Disabilities*, 15(3), 213-223.
- Ubiergo, M. C. U., Ruiz, S. R., Gavilán, M. V. V., & Molina, R. R. (2005). Nursing Support and Caregiver Strain. *Enfermeria Clinica*, 15(4), 199-205 197p.
- Ugalde, A., Krishnasamy, M., & Schofield, P. (2011). Supporting Informal Caregivers of People with Advanced Cancer: A Literature Review. *Australian Journal of Cancer Nursing*, 12(2), 12-16 15p.
- Ugalde, A., Krishnasamy, M., & Schofield, P. (2012). Role Recognition and Changes to Self-Identity in Family Caregivers of People with Advanced Cancer: A Qualitative Study. *Supportive Care in Cancer*, 20(6), 1175-1181.
- Ugalde, A., Krishnasamy, M., & Schofield, P. (2013). Development of an Instrument to Measure Self-Efficacy in Caregivers of People with Advanced Cancer. *Psycho-Oncology*, 22(6), 1428-1434.
- Ulstein, I., Wyller, T., & Engedal, K. (2007). High Score on the Relative Stress Scale, a Marker of Possible Psychiatric Disorder in Family Carers of Patients with Dementia. *International Journal of Geriatric Psychiatry*, 22(3), 195-202.
- Ulstein, I., Wyller, T. B., & Engedal, K. (2007). The Relative Stress Scale, a Useful Instrument to Identify Various Aspects of Carer Burden in Dementia? *International Journal of Geriatric Psychiatry*, 22(1), 61-67.
- Ulstein, I., Wyller, T. B., & Engedal, K. (2008). Correlates of Intrusion and Avoidance as Stress Response Symptoms in Family Carers of Patients Suffering from Dementia. *International Journal of Geriatric Psychiatry*, 23(10), 1051-1057.
- Ume, E., & Evans, B. (2011). Chaos and Uncertainty: The Post-Caregiving Transition. *Geriatric Medicine*, 32(4), 288-293.
- Ungerson, C. (2000). Thinking About the Production and Consumption of Long-Term Care in Britain: Does Gender Still Matter? *Journal of Social Policy*, 29(4), 623-643.
- Upton, N., & Reed, V. (2006). The Influence of Social Support on Caregiver Coping. *Int J Psychiatr Nurs Res*, 11(2), 1256-1267.
- Upton, N., & Reed, V. (2006). What Does Phenomenology Offer to the Study of Care-Giving? *Int J Psychiatr Nurs Res*, 11(2), 1241-1254.
- Ussher, J. M., Perz, J., Hawkins, Y., & Brack, M. (2009). Evaluating the Efficacy of Psycho-Social Interventions for Informal Carers of Cancer Patients: A Systematic Review of the Research Literature. *Health Psychology Review*, 3(1), 85-107.
- Ussher, J. M., & Sandoval, M. (2008). Gender Differences in the Construction and Experience of Cancer Care: The Consequences of the Gendered Positioning of Carers. *Psychology & Health*, 23(8), 945-963.
- Ussher, J. M., Sandoval, M., Perz, J., Wong, W. K. T., & Butow, P. (2013). The Gendered Construction and Experience of Difficulties and Rewards in Cancer Care. *Qualitative Health Research*, 23(7), 900-915.
- Ussher, J. M., Wong, T. W. K., & Perz, J. (2011). A Qualitative Analysis of Changes in Relationship Dynamics and Roles between People with Cancer and Their Primary Informal

- Carer. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine*, 15(6), 650-667.
- van Berg, B. (2005). Economic Valuation of Informal Care: The Contingent Valuation Method Applied to Informal Caregiving. *Health Economics*, 14(2), 169-183.
- van Campen, C., de Boer, A. H., & Iedema, J. (2013). Are Informal Caregivers Less Happy Than Non-caregivers? Happiness and the Intensity of Caregiving in Combination with Paid and Voluntary Work. *Scandinavian Journal of Caring Sciences*, 27(1), 44-50.
- van den Anker, C., Pangsapa, P., Cohen, S., Belser, P., & Ndiaye, N. (2007). Global Social Policy Forum. *Global Social Policy*, 7(1), 5-22.
- van den Berg, B., & Spauwen, P. (2006). Measurement of Informal Care: An Empirical Study into the Valid Measurement of Time Spent on Informal Caregiving. *Health Economics*, 15(5), 447-460.
- van den Dungen, P., van Charante, E. P. M., van Marwijk, H. W. J., van der Horst, H. E., van de Ven, P. M. V., & van Hout, H. P. J. (2012). Case-Finding of Dementia in General Practice and Effects of Subsequent Collaborative Care; Design of a Cluster Rct. *BMC Public Health*, 12.
- van den Dungen, P., van Marwijk, H. W., van der Horst, H. E., Moll van Charante, E. P., Macneil Vroomen, J., van de Ven, P. M., & van Hout, H. P. (2012). The Accuracy of Family Physicians' Dementia Diagnoses at Different Stages of Dementia: A Systematic Review. *International Journal of Geriatric Psychiatry*, 27(4), 342-354 313p.
- van den Heuvel, E. T., de Witte, L. P., Schure, L. M., Sanderma, R., & Meyboom-de Jong, B. (2001). Risk Factors for Burn-out in Caregivers of Stroke Patients, and Possibilities for Intervention. *Clin Rehabil*, 15(6), 669-677.
- van der Cammen, T. J. M., & Stuit, D. H. (2002). Dementia and Ethics: Views of Informal Carers [8]. *Journal of The Royal Society of Medicine*, 95(8), 428.
- van der Geest, S., Mul, A., & Vermeulen, H. (2004). Linkages between Migration and the Care of Frail Older People: Observations from Greece, Ghana and the Netherlands. *Ageing and Society*, 24(3), 431-450.
- van der Plas, A. G. M., Francke, A. L., Vissers, K. C., Jansen, W. J. J., Deliëns, L., & Onwuteaka-Philipsen, B. D. (2015). Case Management in Primary Palliative Care Is Associated More Strongly with Organisational Than with Patient Characteristics: Results from a Cross-Sectional Prospective Study. *BMC Palliative Care*, 14(1), 1-10.
- van der Plas, A. G. M., Vissers, K. C., Francke, A. L., Donker, G. A., Jansen, W. J. J., Deliëns, L., & Onwuteaka-Philipsen, B. D. (2015). Involvement of a Case Manager in Palliative Care Reduces Hospitalisations at the End of Life in Cancer Patients; a Mortality Follow-Back Study in Primary Care. *PLoS ONE*, 10(7).
- van der Roest, H. G., Meiland, F. J. M., Comijs, H. C., Derksen, E., Jansen, A. P. D., van Hout, H. P. J., Jonker, C., & Droses, R. M. (2009). What Do Community-Dwelling People with Dementia Need? A Survey of Those Who Are Known to Care and Welfare Services. *International Psychogeriatrics*, 21(5), 949-965.
- van der Roest, H. G., Meiland, F. J. M., Haaker, T., Reitsma, E., Wils, H., Jonker, C., & Dröes, R. M. (2008). Finding The Service You Need: Human Centered Design of a Digital Interactive Social Chart in Dementia Care (Dem-Disc). *Studies in Health Technology and Informatics*, 137, 210-224.
- van der Roest, H. G., Meiland, F. J. M., Jonker, C., & Droses, R. (2010). User Evaluation of the Dementia-Specific Digital Interactive Social Chart (Dem-Disc). A Pilot Study among Informal Carers on Its Impact, User Friendliness and, Usefulness. *Aging & Mental Health*, 14(4), 461-470 410p.



- van der Roest, H. G., Meiland, F. J. M., van Hout, H. P. J., Jonker, C., & Droes, R. M. (2008). Validity and Reliability of the Dutch Version of the Camberwell Assessment of Need for the Elderly in Community-Dwelling People with Dementia. *International Psychogeriatrics*, 20(6), 1273-1290.
- van Dijk, H. M., Cramm, J. M., & Nieboer, A. P. (2013). The Experiences of Neighbour, Volunteer and Professional Support-Givers in Supporting Community Dwelling Older People. *Health & Social Care in the Community*, 21(2), 150-158.
- van Dongen, I., Josephsson, S., & Ekstam, L. (2014). Changes in Daily Occupations and the Meaning of Work for Three Women Caring for Relatives Post-Stroke. *Scandinavian Journal of Occupational Therapy*, 21(5), 348-358.
- van Dyke, N. (2009). Methodological Issues in the Design and Conduct of Public Health Computer Assisted Telephone Interview Surveys: The Case of Informal Carers in Australia. *Australian Journal of Primary Health*, 15(2), 132-138.
- van Exel, N. J. A., Brouwer, W. B., van den Berg, B., Koopmanschap, M. A., & van den Bos, G. A. (2004). What Really Matters: An Inquiry into the Relative Importance of Dimensions of Informal Caregiver Burden. *Clin Rehabil*, 18(6), 683-693.
- van Haeften-van Dijk, A. M., Meiland, F. J. M., Hattink, B. J. J., Bakker, T., & Droes, R. M. (2016). Community Day Care with Carer Support Versus Usual Nursing Home-Based Day Care: Effects on Needs, Behavior, Mood, and Quality of Life of People with Dementia. *International Psychogeriatrics*, 28(4), 631-645.
- van Haeften-van Dijk, A. M., Meiland, F. J. M., van Mierlo, L. D., & Droes, R. M. (2015). Transforming Nursing Home-Based Day Care for People with Dementia into Socially Integrated Community Day Care: Process Analysis of the Transition of Six Day Care Centres. *International Journal of Nursing Studies*, 52(8), 1310-1322.
- van Haeften-van Dijk, M. A., Hattink, B. J. J., Meiland, F. J. M., Bakker, T. J. E. M., & Dröes, R.-M. (2016). Is Socially Integrated Community Day Care for People with Dementia Associated with Higher User Satisfaction and a Higher Job Satisfaction of Staff Compared to Nursing Home-Based Day Care? *Aging & Mental Health*, 1-10.
- van Houtven, C. H., Coe, N. B., & Skira, M. M. (2013). The Effect of Informal Care on Work and Wages. *Journal of Health Economics*, 32(1), 240-252.
- van Houtven, C. H., Friedemann-Sanchez, G., Clothier, B., Levison, D., Taylor, B. C., Jensen, A. C., Phelan, S. M., & Griffin, J. M. (2012). Is Policy Well-Targeted to Remedy Financial Strain among Caregivers of Severely Injured Us Service Members? *Inquiry-the Journal of Health Care Organization Provision and Financing*, 49(4), 339-351.
- van Meer, N., Truyen, J., Gorissen, H., Mekers, G., & Buntinx, F. (2012). Using a Formal Observation Scale to Report Signs of Possible Cognitive Problems at Home. *Tijdschrift voor Geneeskunde*, 68(20), 986-994.
- van Mierlo, L. D., Meiland, F., van der Roest, H. G., & Droes, R.-M. (2012). Personalised Caregiver Support: Effectiveness of Psychosocial Interventions in Subgroups of Caregivers of People with Dementia. *International Journal of Geriatric Psychiatry*, 27(1), 1-14.
- Van Mierlo, L. D., Meiland, F. J. M., van de Ven, P. M., Van Hout, H. P. J., & Dröes, R.-M. (2015). Evaluation of Dem-Disc, Customized E-Advice on Health and Social Support Services for Informal Carers and Case Managers of People with Dementia; a Cluster Randomized Trial. *International Psychogeriatrics*, 27(8), 1365-1378 1314p.
- van Mierlo, L. D., Meiland, F. J. M., van Hout, H. P. J., & Droes, R. M. (2016). Toward an Evidence-Based Implementation Model and Checklist for Personalized Dementia Care in the Community. *International Psychogeriatrics*, 28(5), 801-813.

- van Os, A. J., Aziz, L., Schalkwijk, D., Schols, J., & de Bie, R. A. (2012). Effectiveness of Physio Acoustic Sound (Pas) Therapy in Demented Nursing Home Residents with Nocturnal Restlessness: Study Protocol for a Randomized Controlled Trial. *Trials*, 13.
- van 't Leven, N., & de Lange, J. (2010). Quality Time: Professional Care for Informal Carers of Community-Living Older Persons with Dementia...Fourth European Nursing Congress. *Journal of Clinical Nursing*, 19, 64-64 61p.
- van Teijlingen, E. R., Friend, E., & Kamal, A. D. (2001). Service Use and Needs of People with Motor Neurone Disease and Their Carers in Scotland. *Health and Social Care in the Community*, 9(6), 397-403.
- van Vliet, D. (2010). Impact of Early Dementia on Caregivers: A Review. *Int J Geriatr Psychiatry*, 25(11), 1091-1100.
- van Wezel, N., Francke, A. I., Kayan-Acun, E., Deville, W. L., van Grondelle, N. J., & M., B. M. (2016). Family Care for Immigrants with Dementia: The Perspectives of Female Family Carers Living in the Netherlands. *Dementia: The International Journal of Social Research and Practice*, 15(1), 69-84.
- Vandall-Walker, V., Jensen, L., & Oberle, K. (2007). Nursing Support for Family Members of Critically Ill Adults. *Qual Health Res*, 17(9), 1207-1218.
- Vandana, N. N., & Bowden, S. (2008). Early Intervention in Psychosis: Client and Carer Perspectives. *Nursing Times*, 104(18), 32-33.
- van't Netta, L., & de Jacomine, L. (2010). Quality Time: Professional Care for Informal Carers of Community-Living Older Persons with Dementia. *Journal of Clinical Nursing*, 19, 64-64.
- Vasse, E., Vernooij-Dassen, M., Cantegreil, I., Franco, M., Dorenlot, P., Woods, B., & Moniz-Cook, E. (2012). Guidelines for Psychosocial Interventions in Dementia Care: A European Survey and Comparison. *International Journal of Geriatric Psychiatry*, 27(1), 40-48.
- Vecchio, N. (2008). Understanding the Use of Respite Services among Informal Carers. *Australian Health Review*, 32(3), 459-467 459p.
- Vecchio, N., Cybinski, P., & Stevens, S. (2009). The Effect of Disability on the Needs of Caregivers. *International Journal of Social Economics*, 36(7), 782-796.
- Venables, D., Clarkson, P., Hughes, J., Burns, A., & Challis, D. (2006). Specialist Clinical Assessment of Vulnerable Older People: Outcomes for Carers from a Randomised Controlled Trial. *Ageing & Society*, 26, 867-882.
- Verkade, P. J., van Meijel, B., Brink, C., van Os-Medendorp, H., Koekkoek, B., & Francke, A. L. (2010). Delphi-Research Exploring Essential Components and Preconditions for Case Management in People with Dementia. *BMC Geriatrics*, 10.
- Vermanderea, M., Decloedt, P., & de Lepeleire, J. (2012). Care Diagnosis for Demented Patients Living at Home. A New Concept. *Tijdschrift Voor Gerontologie En Geriatrie*, 43(1), 25-32.
- Vickers, M. H., & Bailey, J. G. (2003). Women as Parents, Workers, Carers and Survivors: A Research Design to Explore Lives and Share Support. *Australian Journal of Psychology*, 55, 147-147.
- Vickland, V., Werner, J., Morris, T., McDonnell, G., Draper, B., Low, L. F., & Brodaty, H. (2011). Who Pays and Who Benefits? How Different Models of Shared Responsibilities between Formal and Informal Carers Influence Projections of Costs of Dementia Management. *BMC Public Health*, 11.
- Vilaplana Prieto, C., & Jiménez-Martín, S. (2015). Unmet Needs in Formal Care: Kindling the Spark for Caregiving Behavior. *Int J Health Econ Manag.*, 15(2), 153-184.

- Vincent, J., van Den Muijsenbergh, M., & Lagro-Janssen, T. (2007). Gender Differences as Regards the Place of Death. *Huisarts en Wetenschap*, 50(3), 86-90.
- Visser, G., Klinkenberg, M., & van Groenou, M. (2004). The End of Life: Informal Care for Dying Older People and Its Relationship to Place of Death. *Palliative Medicine*, 18(5), 468-477.
- Visser-Meily, A., Post, M., Gorter, J. W., Berlekom, S. B. V., van den Bos, T., & Lindeman, E. (2006). Rehabilitation of Stroke Patients Needs a Family-Centred Approach. *Disability and Rehabilitation*, 28(24), 1557-1561.
- Visser-Meily, J. M., Post, M. W., Riphagen, L. L., & Lindeman, E. (2004). Measures Used to Assess Burden among Caregivers of Stroke Patients: A Review. *Clin Rehabil*, 18(6), 601-623.
- Vitali, S. F., Guaita, A., & Lionello, V. (2005). Monitoring the Formal and Informal Carers' Stress in the Alzheimer Special Care Units: Methodology and Results. *Giornale di Gerontologia*, 53(5), 350-354.
- Vlachantoni, A. (2010). The Demographic Characteristics and Economic Activity Patterns of Carers over 50: Evidence from the English Longitudinal Study of Ageing. *Population Trends*, 141, 54-76.
- Vlachantoni, A., Evandrou, M., Falkingham, J., & Robards, J. (2013). Informal Care, Health and Mortality. *Maturitas*, 74(2), 114-118.
- von Kutzleben, M., Reuther, S., Dortmann, O., & Holle, B. (2016). Care Arrangements for Community-Dwelling People with Dementia in Germany as Perceived by Informal Carers - a Cross-Sectional Pilot Survey in a Provincial-Rural Setting. *Health & Social Care in the Community*, 24(3), 283-296.
- Vreugdenhil, A. (2014). 'Ageing-in-Place': Frontline Experiences of Intergenerational Family Carers of People with Dementia. *Health Sociology Review*, 23(1), 43-52.
- Vreugdenhil, A., Cannell, J., Davies, A., & Razay, G. (2012). A Community-Based Exercise Programme to Improve Functional Ability in People with Alzheimer's Disease: A Randomized Controlled Trial. *Scandinavian Journal of Caring Sciences*, 26(1), 12-19.
- Wagland, R., Ellis, J., Bailey, C., Haines, J., Caress, A., Williams, M., Lorigan, P., Smith, J., Tishelman, C., Booton, R., Luker, K., Blackhall, F., & Molassiotis, A. (2012). Considerations in Developing and Delivering a Non-Pharmacological Intervention for Symptom Management in Lung Cancer: The Views of Health Care Professionals. *Supportive Care in Cancer*, 20(10), 2565-2574.
- Waite, A., Bebbington, P., Skelton-Robinson, M., & Orrell, M. (2004). Social Factors and Depression in Carers of People with Dementia. *International Journal of Geriatric Psychiatry*, 19(6), 582-587.
- Walczak, A., Butow, P., Clayton, J., Tattersall, M., Davidson, P. M., Young, J., & Epstein, R. M. (2014). Discussing Prognosis and End-of-Life Care in the Final Year of Life: A Randomised Controlled Trial of a Nurse-Led Communication Support Programme for Patients and Caregivers. *BMJ Open*, 4.
- Wald, C., Fahy, M., Walker, Z., & Livingston, G. (2003). What to Tell Dementia Caregivers: The Rule of Threes. *International Journal of Geriatric Psychiatry*, 18(4), 313-317.
- Waldron, E., Janke, E., Bechtel, C., Ramirez, M., & Cohen, A. (2013). A Systematic Review of Psychosocial Interventions to Improve Cancer Caregiver Quality of Life. *Psycho-Oncology*, 22, 1200-1207.
- Wales, J., & Prymachuk, S. (2009). Mental Health Care Co-Ordinators' Perspectives on Carers' Assessments. *Mental Health Review Journal*, 14(4), 46-55.

- Walker, C. (2015). Ageing and People with Learning Disabilities: In Search of Evidence. *British Journal of Learning Disabilities*, 43(4), 246-253.
- Walker, C., & Ward, C. (2013). Growing Older Together: Ageing and People with Learning Disabilities and Their Family Carers. *Tizard Learning Disability Review*, 18(3), 112-119.
- Walker, E., & Dewar, B. J. (2001). How Do We Facilitate Carers' Involvement in Decision Making? *Journal of Advanced Nursing*, 34(3), 329-337 329p.
- Walker, H. (2004). Using Psychosocial Interventions within a High-Security Hospital. *Nursing Times* (3.8.04), 36-39.
- Wallace, J. C., Chambers, M. G. A., & Hobson, R. A. (2011). A Knowledge-Based Multimedia Telecare System to Improve the Provision of Formal and Informal Care for the Elderly and Disabled. *Journal of Telemedicine & Telecare*, 7(1), 54-55.
- Wallengren, C., Friberg, F., & Segesten, K. (2008). Like a Shadow - on Becoming a Stroke Victim's Relative. *Scandinavian Journal of Caring Sciences*, 22(1), 48-55.
- Walsh, K., Jones, L., Tookman, A., Mason, C., McLoughlin, J., Blizard, R., & King, M. (2007). Reducing Emotional Distress in People Caring for Patients Receiving Specialist Palliative Care - Randomised Trial. *British Journal of Psychiatry*, 190, 142-147.
- Walters, K., Iliffe, S., & Orrell, M. (2001). An Exploration of Help-Seeking Behaviour in Older People with Unmet Needs. *Family Practice*, 18(3), 277-282.
- Walters, K., Iliffe, S., Tai, S. S., & Orrell, M. (2000). Assessing Needs from Patient, Carer and Professional Perspectives: The Camberwell Assessment of Need for Elderly People in Primary Care. *Age & Ageing*, 29(6), 505-510 506p.
- Walton, P., & Latham, N. (2005). Complementary Therapy Services for Mental Health Service Users: Results of a Consultation Project. *Health Education Journal*, 64(4), 347-362.
- Wane, J., Larkin, M., Earl-Gray, M., & Smith, H. (2009). Understanding the Impact of an Assertive Outreach Team on Couples Caring for Adult Children with Psychosis. *Journal of Family Therapy*, 31(3), 284-309.
- Wang, L.-Q., Chien, W.-T., & Ym Lee, I. (2012). An Experimental Study on the Effectiveness of a Mutual Support Group for Family Caregivers of a Relative with Dementia in Mainland China. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 40(2), 210-224.
- Ward, G., Williams, S., & Fielden, S. (2013). Using Technology to Support People at Risk of Falling. *International Journal of Integrated Care (IJIC)*, 13, 1-2.
- Ward, R., Campbell, S., Kehoe, P., Raja, A., Hardman, P., & Inchbold, D. (2011). Remember the Body: Promoting Physical Health in Dementia Care. *Journal of Dementia Care*, 19(2), 26-29.
- Ward, R., Clark, A., & Hargreaves, M. (2012). What Does 'Neighbourhood' Mean for Carers of People with Dementia? *Journal of Dementia Care*, 20(2), 33-36.
- Ward, S., Opie, J., & O'Connor, D. W. (2003). Family Carers' Responses to Behavioural and Psychological Symptoms of Dementia. *International Journal of Geriatric Psychiatry*, 18(11), 1007-1012.
- Ward-Griffin, C., McWilliam, C. L., & Oudshoorn, A. (2012). Relational Experiences of Family Caregivers Providing Home-Based End-of-Life Care. *Journal of Family Nursing*, 18(4), 491-516.
- Ware, T., Matosevic, T., Hardy, B., & Knapp, M. (2003). Commissioning Care Services for Older People in England: The View from Care Managers, Users and Carers. *Ageing & Society*, 23(4), 411-428.
- Warren, J. (2005). Carers. *Research Matters* (19), 5-10.

- Warren, J. (2005). How the Lives of Young Carers Differ from Those of Young Non-Carers and How Their Efforts Sometimes Go Unsupported. *Research Matters*.
- Warren, T. (2007). Conceptualizing Breadwinning Work. *Work, Employment and Society*, 21(2), 317-336.
- Wasner, M. (2008). Resilience among Patients with Amyotrophic Lateral Sclerosis (ALS) and Their Caregivers. *Schweizer Archiv fur Neurologie und Psychiatrie*, 159(8), 500-505.
- Watchman, K. (2003). Critical Issues for Service Planners and Providers of Care for People with Down's Syndrome and Dementia. *British Journal of Learning Disabilities*, 31(2), 81-84.
- Watchman, K. (2008). Changes in Accommodation Experienced by People with Down Syndrome and Dementia in the First Five Years after Diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, 5(1), 65-68.
- Waterhouse, H. (2013). Non-Malignant Palliative Care: Striving for Equity. *Practice Nurse*, 43(8), 45-49.
- Watkins, J., Stanton, L., Saunders, B., Lasocki, G., Chung, P., & Hibberd, P. (2011). Working in Partnership with Family Carers: The Importance of Learning from Carers' Experiences. *Quality in Ageing and Older Adults*, 12(2), 103-108.
- Watson, P. (2016). Embedding the Ethos of Identifying Military Young Carers. *British Journal of Community Nursing*, 21, S42-S42.
- Watts, L., & Hodgson, D. (2015). Assessing the Needs of Carers of People with Mental Illness: Lessons from a Collaborative Study. *Practice*, 1-18.
- Weaver, F., & Weaver, B. (2014). Does Availability of Informal Care within the Household Impact Hospitalisation? *Health Economics, Policy and Law*, 91(1), 71-93.
- Webber, M., & Robinson, K. (2011). The Meaningful Involvement of Service Users and Carers in Advanced-Level Post-Qualifying Social Work Education: A Qualitative Study. *British Journal of Social Work*, 42(7), 1256-1274.
- Weeks, L. E., Nilsson, T., Bryanton, O., & Kozma, A. (2009). Current and Future Concerns of Older Parents of Sons and Daughters with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6(3), 180-188.
- Weibull, A., Asbjorn, M., & Olesen, F. (2008). Caregivers' Active Role in Palliative Home Care: To Encourage or to Dissuade? A Qualitative Descriptive Study. *BMC Palliative Care*, 16(7).
- Weinberg, A., & Huxley, P. (2000). An Evaluation of the Impact of Voluntary Sector Family Support Workers on the Quality of Life of Carers of Schizophrenia Sufferers. *Journal of Mental Health*, 9(5), 495-503.
- Wenger, G. C., Scott, A., & Seddon, D. (2002). The Experience of Caring for Older People with Dementia in a Rural Area: Using Services. *Ageing and Mental Health*, 6(1), 30-38.
- Wennman-Larsen, A., & Tishelman, C. (2002). Advanced Home Care for Cancer Patients at the End of Life: A Qualitative Study of Hopes and Expectations of Family Caregivers. *Scandinavian Journal of Caring Sciences*, 16(3), 240-247.
- Wheelwright, S., Darlington, A. S., Fitzsimmons, D., Hopkinson, J., & Johnson, C. (2013). Quality of Life in the Informal Carers of Cancer Patients with Cachexia. *Psycho-Oncology*, 22, 153-153.
- Wheelwright, S., Darlington, A. S., Hopkinson, J. B., Fitzsimmons, D., & Johnson, C. (2016). A Systematic Review and Thematic Synthesis of Quality of Life in the Informal Carers of Cancer Patients with Cachexia. *Palliative Medicine*, 30(2), 149-160.

- While, C., Duane, F., Beanland, C., & Koch, S. (2013). Medication Management: The Perspectives of People with Dementia and Family Carers. *Dementia: The International Journal of Social Research and Practice*, 12(6), 734-750.
- While, C., & Jocelyn, A. (2009). Observational Pain Assessment Scales for People with Dementia: A Review. *British Journal of Community Nursing*, 14(10).
- White, C., Marsland, D., & Manthorpe, J. (2016). Relocation, Portability and Social Care Practice: A Scoping Review. *Journal of Social Work*, 16(5), 521-540.
- White, E. B., & Montgomery, P. (2014). Electronic Tracking for People with Dementia: An Exploratory Study of the Ethical Issues Experienced by Carers in Making Decisions About Usage. *Dementia: The International Journal of Social Research and Practice*, 13(2), 216-232.
- White, E. B., Montgomery, P., & McShane, R. (2010). Electronic Tracking for People with Dementia Who Get Lost Outside the Home: A Study of the Experience of Familial Carers. *British Journal of Occupational Therapy*, 73(4), 152-158.
- White, K., D'Abrew, N., & Auret, K. (2008). Learn Now; Live Well: An Educational Programme for Caregivers. *International Journal of Palliative Nursing*, 14(10), 497-501.
- White, L., Klinner, C., & Carter, S. (2012). Consumer Perspectives of the Australian Home Medicines Review Program: Benefits and Barriers. *Research in Social & Administrative Pharmacy*, 8(1), 4-16.
- White-Means, S. I., & Rubin, R. M. (2008). Parent Caregiving Choices of Middle-Generation Blacks and Whites in the United States. *Journal of Aging and Health*, 20(5), 560-582.
- Whitney, J., Haigh, R., Weinmann, R., & Treasure, J. (2007). Caring for People with Eating Disorders: Factors Associated with Psychological Distress and Negative Caregiving Appraisals in Carers of People with Eating Disorders. *British Journal of Clinical Psychology*, 46(4), 413-428.
- Whittingham, K. (2016). Capturing the Carer's Experience: A Researcher's Reflections. *Nurse Researcher*, 23(5), 31-35.
- Whittingham, K., Barnes, S., & Gardiner, C. (2013). Tools to Measure Quality of Life and Carer Burden in Informal Carers of Heart Failure Patients: A Narrative Review. *Palliative Medicine*, 27(7), 596-607.
- Whittock, M., Edwards, C., McLaren, S., & Robinson, O. (2002). 'The Tender Trap': Gender, Part-Time Nursing and the Effects of 'Family-Friendly' Policies on Career Advancement. *Sociology of Health and Illness*, 24(3), 305-326.
- Wignall, B. L. (2013). Development of an Integrated External and Internal Location System with Activity Monitoring. *International Journal of Integrated Care (IJIC)*, 13, 1-2.
- Wija, P. (2015). Formal and Informal Long-Term Care and the Role of Family Carers: Czech Republic. *European Journal of Mental Health*, 10(2), 233-244.
- Wilbram, M., Kellett, S., & Beail, N. (2008). Compulsive Hoarding: A Qualitative Investigation of Partner and Carer Perspectives. *British Journal of Clinical Psychology*, 47(1), 59-73.
- Wilde, A., & Glendinning, C. (2012). 'If They're Helping Me Then How Can I Be Independent?' the Perceptions and Experience of Users of Home-Care Re-Ablement Services. *Health and Social Care in the Community*, 20(6), 583-590.
- Wiles, J. (2003). Informal Caregivers' Experiences of Formal Support in a Changing Context. *Health and Social Care in the Community*, 11(3), 189-207.
- Wilks, S. E. (2009). Support for Alzheimer's Caregivers. *Research on Social Work Practice*, 19(6), 722-729.

- Willems, C. G., Spreeuwenberg, M. D., van Der Heide, L., Glascock, A. P., Kutzik, D. L., de Witte, L., & Rietman, J. (2011). Activity Monitoring to Support Independent Living in Dutch Homecare Support. *Everyday technology for independence and care*.
- Williams, A. M., Wang, L., & Kitchen, P. (2014). Differential Impacts of Care- Giving across Three Caregiver Groups in Canada: End- of- Life Care, Long- Term Care and Short- Term Care. *Health & Social Care in the Community*, 22(2), 187-196.
- Williams, C., & Gardiner, C. (2015). Preference for a Single or Shared Room in a Uk Inpatient Hospice: Patient, Family and Staff Perspectives. *BMJ Supportive & Palliative Care*, 5(2), 169-174.
- Williams, K., & Weatherhead, I. (2013). Improving Nutrition and Care for People with Dementia. *British Journal of Community Nursing*, 18(5 SUPPL.5).
- Williams, L. (2007). Whatever It Takes: Informal Caregiving Dynamics in Blood and Marrow Transplantation. *Oncology Nursing Forum*, 34(2), 379-387.
- Williams, S., Dagnan, D., Rodgers, J., & McDowell, K. (2012). Changes in Attributions as a Consequence of Training for Challenging and Complex Behaviour for Carers of People with Learning Disabilities: A Systematic Review. *Journal of Applied Research in Intellectual Disabilities*, 25(3), 203-216.
- Williams, V., & Robinson, C. (2001). 'He Will Finish up Caring for Me': People with Learning Disabilities and Mutual Care. *British Journal of Learning Disabilities*, 29(2), 56-62.
- Williams, V., & Robinson, C. (2001). More Than One Wavelength: Identifying, Understanding and Resolving Conflicts of Interest between People with Intellectual Disabilities and Their Family Carers. *Journal of Applied Research in Intellectual Disabilities*, 14(1), 30-46.
- Williams, V., Simons, K., Gramlich, S., McBride, G., Snelham, N., & Myers, B. (2003). Paying the Piper and Calling the Tune? The Relationship between Parents and Direct Payments for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16(3), 219-228.
- Williamson, C., Simpson, J., & Murray, C. D. (2008). Caregivers' Experiences of Caring for a Husband with Parkinson's Disease and Psychotic Symptoms. *Soc Sci Med*, 67(4), 583-589.
- Willis, D. (2015). Inconsistencies in the Roles of Family- and Paid- Carers in Monitoring Health Issues in People with Learning Disabilities: Some Implications for the Integration of Health and Social Care. *Journal of Applied Research in Intellectual Disabilities*, 43(1), 24-31.
- Willis, D. S., Wishart, J. G., & Muir, W. J. (2010). Carer Knowledge and Experiences with Menopause in Women with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 42-48.
- Willis, P., Ward, N., & Fish, J. (2011). Searching for LGBT Carers: Mapping a Research Agenda in Social Work and Social Care. *British Journal of Social Work*, 41(7), 1304-1320.
- Willis, R. (2008). Ethnicity and Family Support. *Working with Older People*, 12(3), 27-30.
- Wills, W., & Soliman, A. (2001). Understanding the Needs of the Family Carers of People with Dementia. *Mental Health Review Journal*, 6(2), 25-28.
- Wilner, P., & Morgannwg, B. (2006). Readiness for Cognitive Therapy in People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 5-16.
- Wilson, A. (2002). Patient and Carer Satisfaction with 'Hospital at Home': Quantitative and Qualitative Results from a Randomised Controlled Trial. *British Journal of General Practice*, 52(474).
- Wilson, A. (2012). Improving Life Satisfaction for the Elderly Living Independently in the Community: Care Recipients' Perspective of Volunteers. *Social Work in Health Care*, 51(2), 125-139.

- Wilson, C., Fothergill, A., & Rees, H. (2010). A Potential Model for the First All Wales Mental Health Service User and Carer-Led Research Group. *J Psychiatr Ment Health Nurs*, 17(1), 31-38.
- Wilson, C., & Mansell, I. (2010). Access to Health and Social Care Services and Information. *Learning Disability Practice*, 13(5), 32-38 37p.
- Wilson, K., Pateman, B., Beaver, K., & Luker, K. A. (2002). Patient and Carer Needs Following a Cancer-Related Hospital Admission: The Importance of Referral to the District Nursing Service. *J Adv Nurs*, 38(3), 245-253.
- Wilson, V. (2004). Supporting Family Carers in the Community Setting. *Nursing Standard*, 18(29), 47-53.
- Wimo, A., & Norlund, A. (2007). Cost-Effectiveness of Treatments for Alzheimer's Dementia. *Expert Review of Pharmacoeconomics and Outcomes Research*, 7(1), 83-90.
- Winkler, M., Bedford, V., Northcott, S., & Hilari, K. (2014). Aphasia Blog Talk: How Does Stroke and Aphasia Affect the Carer and Their Relationship with the Person with Aphasia? *Aphasiology*, 28(11), 1301-1319.
- Witham, M. D., Daykin, A. R., & McMurdo, M. E. (2008). Pilot Study of an Exercise Intervention Suitable for Older Heart Failure Patients with Left Ventricular Systolic Dysfunction. *European Journal of Cardiovascular Nursing*, 7(4), 303-306 304p.
- Wittenberg-Lyles, E., Kruse, R. L., Oliver, D. P., Demir, G., & Petroski, G. (2014). Exploring the Collective Hospice Caregiving Experience. *J Palliat Med*, 17(1), 50-55.
- Wodehouse, G., & McGill, P. (2009). Support for Family Carers of Children and Young People with Developmental Disabilities and Challenging Behaviour: What Stops It Being Helpful? *Journal of Intellectual Disability Research*, 53(7), 644-653.
- Wolf, D. A., & Ballal, S. S. (2006). Family Support for Older People in an Area of Demographic Change and Policy Constraints. *Ageing & Society*, 26(5), 693-706.
- Wong, D. F. K. (2000). Stress Factors and Mental Health of Carers with Relatives Suffering from Schizophrenia in Hong Kong: Implications for Culturally Sensitive Practices. *British Journal of Social Work*, 30(3), 365-382.
- Wong, G. C. T., & Chan, Z. C. Y. (2012). Carer Participation: Training for People with Intellectual Disabilities in a Chinese Society. *Journal of Family Social Work*, 15(2), 157-167.
- Wong, W., & Ussher, J. (2009). Bereaved Informal Cancer Carers Making Sense of Their Palliative Care Experiences at Home. *Health and Social Care in the Community (Print edition)*, 17(3), 274-282.
- Wong, W. K. T., Ussher, J., & Perz, J. (2009). Strength through Adversity: Bereaved Cancer Carers' Accounts of Rewards and Personal Growth from Caring. *Palliative and Supportive Care*, 7(2), 187-196.
- Woo, J., Lo, R., & Cheng, J. (2011). Quality of End-of-Life Care for Non-Cancer Patients in a Non-Acute Hospital. *Journal of Clinical Nursing*, 20(13-14), 1834-1841.
- Wood, H., Lea, L., & Holtum, S. (2013). Finding the Personal in the Clinical Psychology Swamp. *Journal of Mental Health Training, Education and Practice*, 8(1), 15-25.
- Wood, M. (2003). Disability, Participation and Welfare to Work in Staffordshire. *Journal of Integrated Care*, 11(2), 43-48.
- Wood, V. J., Curtis, S. E., Gesler, W., Spencer, I. H., Close, H. J., Mason, J., & Reilly, J. G. (2013). Creating 'Therapeutic Landscapes' for Mental Health Carers in Inpatient Settings: A Dynamic Perspective on Permeability and Inclusivity. *Social Science & Medicine*, 91, 122-129.



- Woodford, J., Farrand, P., Richards, D., & Llewellyn, D. J. (2013). Psychological Treatments for Common Mental Health Problems Experienced by Informal Carers of Adults with Chronic Physical Health Conditions (Protocol). *Systematic reviews*, 2, 9.
- Woodford, J., Farrand, P., Richards, D. A., & Llewellyn, D. (2012). Coping in Informal Carers of Stroke Survivors: A Comparison of Coping Strategies Used by Depressed and Non-Depressed Informal Carers. *International Journal of Stroke*, 7, 55-55.
- Woodford, J., Farrand, P., Watkins, E. R., Richards, D. A., & Llewellyn, D. J. (2014). Supported Cognitive-Behavioural Self-Help Versus Treatment-as-Usual for Depressed Informal Carers of Stroke Survivors (Cedars): Study Protocol for a Feasibility Randomized Controlled Trial. *Trials*, 15.
- Woods, R. T., Bruce, E., Edwards, R. T., Elvish, R., Hoare, Z., Hounscome, B., Keady, J., Moniz-Cook, E., Orgeta, V., Orrell, M., Rees, J., & Russell, I. T. (2012). Remcare: Reminiscence Groups for People with Dementia and Their Family Caregivers - Effectiveness and Cost-Effectiveness Pragmatic Multicentre Randomised Trial. *Health Technology Assessment*, 16(48), 1-116.
- Woods, R. T., Willis, W., J., H. I., Hobbins, J., & Whitby, M. (2003). Support in the Community for People with Dementia and Their Carers: A Comparative Outcome Study of Specialist Mental Health Service Interventions. *International Journal of Geriatric Psychiatry*, 18(4), 298-307.
- Wooff, D., J., S., Carpenter, J., & Brandon, T. (2003). Correlates of Stress in Carers. *Journal of Mental Health*, 12(1), 29-40.
- Woolrych, R., & Sixsmith, J. (2013). Toward Integrated Services for Dementia: A Formal Carer Perspective. *Journal of Integrated Care*, 21(4), 208-220.
- Worth, A., Boyd, K., Kendall, M., Heaney, D., Macleod, U., Comie, P., Hockley, J., & Murray, S. (2006). Out-of-Hours Palliative Care: A Qualitative Study of Cancer Patients, Carers and Professionals. *British Journal of General Practice*, 56(522), 6-13.
- Wouters, E. J. M., Roijers, S. M., & Overdiep, R. A. (2011). Early Detection of Dementia and Ict: Signs from Practice. *Assistive Technology Research Series*, 29, 65-74.
- Wray, A. (2012). Patterns of Formulaic Language in Alzheimer's Disease: Implications for Quality of Life. *Quality in Ageing and Older Adults*, 13(3), 168-175.
- Wright, A., Crettenden, A., & Skinner, N. (2016). Dads Care Too! Participation in Paid Employment and Experiences of Workplace Flexibility for Australian Fathers Caring for Children and Young Adults with Disabilities. *Community, Work & Family*, 19(3), 340-361.
- Wright, F. (2000). Continuing to Pay: The Consequences for Family Caregivers of an Older Person's Admission to a Care Home. *Social Policy & Administration*, 34(2), 191-205.
- Wright, J., McDonald, P., Rickards, H., & de Souza, J. (2013). The Attitudes of People with Huntington's Disease and Their Carers to Research. *Social Care and Neurodisability*, 4(3), 105-113.
- Wright, J. M., Heathcote, K., & Wibberley, C. (2014). Fact or Fiction: Exploring the Use of Real Stories in Place of Vignettes in Interviews with Informal Carers. *Nurse Researcher*, 21(4), 39-43.
- Yakubovich, A. R., Sherr, L., Cluver, L. D., Skeen, S., Hensels, I. S., Macedo, A., & Tomlinson, M. (2016). Community-Based Organizations for Vulnerable Children in South Africa: Reach, Psychosocial Correlates, and Potential Mechanisms. *Children & Youth Services Review*, 62, 58-64.
- Yamada, H., & Shimizutani, S. (2015). Labor Market Outcomes of Informal Care Provision in Japan. *The Journal of the Economics of Ageing*, 6, 79-88.

- Yang, Y. T., & Gimm, G. (2013). Caring for Elder Parents: A Comparative Evaluation of Family Leave Laws. *Journal of Law, Medicine & Ethics*, 41(2), 501-513.
- Yeandle, S. (2016). From Provider to Enabler of Care? Reconfiguring Local Authority Support for Older People and Carers in Leeds, 2008 to 2013. *Journal of Social Service Research*, 42(2), 218-232.
- Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., uipers, E., & Kendall, T. (2015). Interventions to Improve the Experience of Caring for People with Severe Mental Illness: Systematic Review and Meta-Analysis. *The British Journal of Psychiatry: The Journal of Mental Science*, 206(4), 268-274.
- Yeung, S., Lui, M. H., Ross, F., & Murrells, T. (2007). Family Carers in Stroke Care: Examining the Relationship between Problem-Solving, Depression and General Health. *J Clin Nurs*, 16(2), 344-352.
- Yip, K.-S. (2005). A Strengths Perspective in Working with People with Alzheimer's Disease. *Dementia: The International Journal of Social Research and Practice*, 4(3), 434-441.
- Yong, A. S. L., & Price, L. (2014). The Human Occupational Impact of Partner and Close Family Caregiving in Dementia: A Meta-Synthesis of the Qualitative Research, Using a Bespoke Quality Appraisal Tool. *British Journal of Occupational Therapy*, 77(8).
- Yoon, H. (2003). Factors Associated with Family Caregivers' Burden and Depression in Korea. *International Journal of Aging & Human Development*, 57(4), 291-311.
- Yoong, A., & Koritsas, S. (2012). The Impact of Caring for Adults with Intellectual Disability on the Quality of Life of Parents. *Journal of Intellectual Disability Research*, 56(6), 609-619.
- You, E., Dunt, D., Doyle, C., & Hsueh, A. (2012). Effects of Case Management in Community Aged Care on Client and Carer Outcomes: A Systematic Review of Randomized Trials and Comparative Observational Studies. *BMC Health Services Research*, 12(395).
- Young, A., Rogers, A., & Addington-Hall, J. (2008). The Quality and Adequacy of Care Received at Home in the Last 3 Months of Life by People Who Died Following a Stroke: A Retrospective Survey of Surviving Family and Friends Using the Views of Informal Carers Evaluation of Services Questionnaire. *Health and Social Care in the Community (Print edition)*, 16(4), 419-428.
- Young, A., Rogers, A., & Dent, L. (2009). Experiences of Hospital Care Reported by Bereaved Relatives of Patients after a Stroke: A Retrospective Survey Using the Voices Questionnaire. *Journal of Advanced Nursing*, 65(10), 2161-2174.
- Young, A. F., Chesson, R. A., & Wilson, A. J. (2007). People with Learning Disabilities, Carers and Care Workers Awareness of Health Risks and Implications for Primary Care. *Fam Pract*, 24(6), 576-584.
- Young, H., & Grundy, E. (2008). Longitudinal Perspectives on Caregiving, Employment History and Marital Status in Midlife in England and Wales. *Health Soc Care Community*, 16(4), 388-399.
- Young, H., Grundy, E., & Kalogirou, S. (2005). Who Cares? Geographic Variation in Unpaid Caregiving in England and Wales: Evidence from the 2001 Census. *Population Trends*, 120, 23-34.
- Young, M. E., Lutz, B. J., Creasy, K. R., Cox, K. J., & Martz, C. (2014). A Comprehensive Assessment of Family Caregivers of Stroke Survivors During Inpatient Rehabilitation. *Disability and Rehabilitation*, 36(22), 1892-1902.
- Young, T., & Manthorp, C. (2009). Towards a Code of Practice for Effective Communication with People with Dementing Illnesses. *Journal of Language and Social Psychology*, 28(2), 174-189.

- Yuey-Ching, C., Lin, L.-C., Chang, A.-L., & Schalock, R. L. (2007). The Quality of Life of Family Caregivers of Adults with Intellectual Disabilities in Taiwan. *Journal of Applied Research in Intellectual Disabilities*, 20(3), 200-210.
- Yun, Y. H., Han, K. H., Park, S., Park, B. W., Cho, C. H., Kim, S., Lee, D. H., Lee, S. N., Lee, E. S., Kang, J. H., Kim, S. Y., Lee, J. L., Heo, D. S., Lee, C. G., Lim, Y. K., Kim, S. Y., Choi, J. S., Jeong, H. S., & Chun, M. (2011). Attitudes of Cancer Patients, Family Caregivers, Oncologists and Members of the General Public Toward Critical Interventions at the End of Life of Terminally Ill Patients. *CMAJ*, 183(10), E673-679.
- Zapart, S., Kenny, P., & Hall, J. (2007). Home-Based Palliative Care in Sydney, Australia; the Carer's Perspective on the Provision of Informal Care. *Health and Social Care in the Community (Print edition)*, 15(2), 97-107.
- Zechmeister, I., & Österle, A. (2007). Informal Care of People with Mental Disorders: Does the Austrian Long-Term Care System Provide Adequate Support? *Neuropsychiatrie*, 21(1), 29-36.
- Zegwaard, M., Aartsen, M., & Cuijpers, P. (2011). Review: A Conceptual Model of Perceived Burden of Informal Caregivers for Older Persons with a Severe Functional Psychiatric Syndrome and Comcomitant Problematic Behaviour. *Journal of Clinical Nursing*, 20(15-16), 2233-2258.
- Zhang, L., Li, X., Kaljee, L., Fang, X., Lin, X., Zhao, G., Zhao, J., & Hong, Y. (2009). 'I Felt I Have Grown up as an Adult': Caregiving Experience of Children Affected by HIV/AIDS in China. *Child: Care, Health and Development*, 35(4), 542-550.
- Ziegert, K., Fridlund, B., & Lidell, E. (2006). Health in Everyday Life among Spouses of Haemodialysis Patients: A Content Analysis. *Scandinavian Journal of Caring Sciences*, 20(2), 223-228.
- Ziviani, J., Lennox, N., Allison, H., Lyons, M., & del Mar, C. (2004). Meeting in the Middle: Improving Communication in Primary Health Care Consultations with People with an Intellectual Disability. *Journal of Intellectual and Developmental Disability*, 29(3), 211-225.
- Zwahlen, D., Hagenbuch, N., Carley, M. I., Recklitis, C. J., & Buchi, S. (2008). Screening Cancer Patients' Families with the Distress Thermometer (Dt): A Validation Study. *Psycho-Oncology*, 17(10), 959-966.

## Letters

Falconer, L. (2004). More than a footnote *Community Care* (pp. 24-24): Reed Business Information Limited.

Fellowes, T. (2008). Help for young carers...'So many contradictions', p 18, 6 December *Community Care* (pp. 12-12). Reed Business Information Limited.

Frank, J. (2007). Young carers' needs *Mental Health Practice* (Vol. 10, pp. 9-9): RCNi.

Frank, J. (2007). Young carers' needs. *Learning Disability Practice* (Vol. 10, pp. 8-8): RCNi.

Grande, G., & Ewing, G. (2008). Death at home unlikely if informal carers prefer otherwise: implications for policy, *Palliative Medicine* (Vol. 22, pp. 971).

## Magazine Articles

- Cultural Differences Limit Carers. (2004). *Nursing Standard*, 18, 27.
- New Study Finds a Million Young Carers. (2004). *Community Care*, 1538, 10.
- Psychological Well-Being of Spouses of Stroke Patients During the First Year after Stroke. (2004). *Current Medical Literature: Stroke Review*, 8, 19-20.
- Social Care Workforce Election Briefing. (2005). *Community Care*, 1565, 3-12.
- Working with Carers in the Bangladeshi Community. (2005). *Nursing Standard* 20, 14.
- Young Carers' Health at Risk. (2005). *Community Practitioner*, 78, 192.
- Young Carers Short of Support in Wales. (2005). *Community Care*, 1588, 13.
- Caring for Carers: Recognising, Valuing and Supporting the Caring Role. (2006). *Nursing Older People*, 18, 35-35.
- Include Impact on Informal Carers in Economic Evaluations. (2006). *PharmacoEconomics & Outcomes News*, 497, 3.
- Study Warns over Kin Carers' Support. (2006). *Community Care*, 1647, 11.
- A Caring 'Time Bomb'. (2007). Working with Older People: Community Care Policy & Practice, 11, 6.
- How to Support Young Carers. (2007). *Community Care*, 1670, 33-35.
- Research Abstracts: Young Carers. (2007). *Community Care*, 1702, 25.
- Resource Pack Designed for Young Carers. (2007). *Mental Health Practice*, 11, 8.
- Young Carers Day 2007. (2007). *Community Care*, 1681, 4.
- Children Who Care for Parents with Mental Health Problems. (2008), May 9. *Community Care*.
- Little Chef. (2008). *Community Care*, 1720, 4.
- Research Abstracts: Parents with a Mental Illness. (2008). *Community Care*, 1720, 29.
- Website Focus. (2009). *Community Care*, 1767, 20.
- Support Scheme Was 'Not Helping Enough Carers'. (2010). *Community Care*, 1826, 4.
- Young Carers of Parents with Mental Health Issues. (2010). *Community Care*, 1834, 33.
- Funding Chief Rules Out Free Care. (2011). *Community Care*, 1856, 9.
- Welfare Changes May Cost Young Carers £3,500 a Year. (2011). *Community Care*, 1875, 8.
- The Important Things in Life. (2012). *Viewpoint*, 131, 14-17.
- Many Young Carers Are Being Punished in Schools. (2012). *British Journal of School Nursing*, 7, 372.
- Righead's "Unsung Hero". (2012). *Reform Magazine*, November, 3-4.
- School Nurses to Have 'Leading Role' in Supporting Young Carers. (2013). *Community Practitioner*, 86, 8-8.
- Surrey Churches Host Events for Young Carers. (2013). *Reform Magazine*, May, 2.
- Clinical Digest. Profiling of Young Carers Could Lead to Better Support from Health Professionals. (2014). *Nursing Standard*, 29, 16-17.
- Research Highlights the Bullying Faced by Young Carers Because of Their Caring Role. (2014). *British Journal of School Nursing*, 9, 373.

- School Nurses to Take Greater Responsibility for Young Carers. (2014). *Nursing Standard*, 28, 30.
- University Application Help for Young Carers. (2014). *British Journal of School Nursing*, 9, 8, 373.
- Young Carers Get Help and Support through Innovative Pilot Scheme. (2014). *Nursing Standard*, 29, 11, 12.
- Young Carers Take Their Message to the Top of the NHS. (2014). *Nursing Standard*, 29, 10, 10.
- Young Carers' Health Helped by Tailored Assessment Plan. (2014). *Nursing Children & Young People*, 26, 10, 7.
- Schools Recognised for Young Carer Support in New National Awards. (2015). *Education Journal*, 231, 9.
- Young Adult Carers Feel Double the Pressure at Exam Time. (2015). *Education Journal*, 237, 12.
- Carers Are Not Always Seeking out the Support They May Need. (2016). *Nursing Older People*, 28, 6, 12.
- Data Suggests That Thousands of Young Carers Remain 'Hidden' in Our Schools. (2016). *British Journal of School Nursing*, 11, 4, 162.
- Making School Nurses 'Carer Aware'. (2016). *Nursing Children & Young People*, 28, 1, 11.
- Ahmed, M. (2007). Happy and Excited Despite Heavy Caring Commitment. *Community Care*, 1702, 11.
- Ahmed, M. (2007). 'Painful' Plight of Young Carers Revealed by Study. *Community Care*, 1673, 6.
- Alexander, L. (2004). Alexander Technique. *Community Care*, 26.8.04, 36-37.
- Allan, I. (2001). My Mum, My Dad, My Daughter and the NHS. *Health Service Journal*.
- Anfilogoff, S. (2007). It's Time to Give Young Carers What They've Been Asking For. *Community Care*, 1671, 27.
- Aspis, S. (2000). Private Members Bill Will Give Carers Right to Assessments. *Community Living*, 13, 4, 4.
- Attfield, E. (2009). Blue Sky Thinking? I Don't Think So. *Advances in Mental Health and Learning Disabilities*, 3, 2, 36-39.
- Bailey, J., & Moriarty, J. (2006). Alzheimer's Society Derby Branch: A Comprehensive Programme of Support for People with Dementia and Their Carers. *Dementia: The International Journal of Social Research and Practice*, 5, 2, 293-296.
- Barber, C. (2009). Employment Rights for Informal Carers. *British Journal of Healthcare Assistants*, 3, 2, 100.
- Barber, C. (2010). Celebrate Carers All Year Round. *British Journal of Healthcare Assistants*, 4, 7, 358.
- Barber, C. (2011). Learning Disabilities and Valuing Informal Carers. *British Journal of Healthcare Assistants*, 5, 8, 397-398.
- Barber, C. (2012). Family Care-Givers: The Role of the Healthcare Assistant. *British Journal of Healthcare Assistants*, 6, 9, 428-431.
- Barber, C. (2012). Hidden Caregivers: Providing Appropriate Services. *British Journal of Healthcare Assistants*, 6, 11, 530-533.

- Barber, C. (2012). It Is Time to Recognise Our 6 Million UK Care-Givers. *British Journal of Healthcare Assistants*, 6, 7, 320-323.
- Barnes, C. (2003). Chatter Matters: Advice on Communication for Carers. *Journal of Dementia Care*, 11, 5, 19-21.
- Barry, C. (2003). Website Reviews. *Community Care*, 1470, 48.
- Bhaduri, R. (2001). Separating the Personal from the Professional. *Professional Social Work*, 14-15.
- Bostock, A. (2012). Ensuring That Young Carers Have the Support They Need in School. *British Journal of School Nursing*, 7, 8, 406-407.
- Briggs, S. (2001). Family Ties. *Nursing Standard*, 15, 38, 28.
- Brody, S. (2007). New Light Cast on Extent of Elder Abuse. *Community Care*, 1678, 12-13
- Bunham, D. (2001). Ticket to Ride. *Community Care*, 8.2.01, 24-25.
- Bunn, V., & Baker, C. (2006). What a Difference Three Hours Can Make. *Journal of Dementia Care*, 14, 4, 10-11.
- Burrows, G. (2001). Services, but at a Price. *Community Care*, 15.3.01, 12.
- Burstow, P. (2010). Burstow to Shift Carers' Funding in Bid to Improve Quality of Life. *Community Care*, 1839, 5.
- Callaghan, D. (2000). A Land Not Fit for Heroes. *Community Care*, 15.6.00, 12.
- Campbell, J. (2007). 'We Are Now the Go-It-Alone Society'. *Community Care*, 1702, 28.
- Carson, G. (2006). Flexible Working Plan 'Ignores Realities of Caring'. *Community Care*, 1622, 18-19.
- Carson, G. (2010). Budgets Door Ajar for Carers. *Community Care*, 28.10.10, 22-23.
- Cass, E. (2005). Act of Guidance. *Community Care*, 27.10.05, 38-39.
- Cass, E. (2005). Unravelling the Carers Act. *Professional Social Work*, 16-17.
- Charles, G. (2012). Making the Invisible, Visible. *Relational Child & Youth Care Practice*, 25, 3-4.
- Clements, L. (2000). A Duty of Care to Carers. *Community Care*, 28.9.00, 30.
- Clements, L. (2001). Top Guidance for Carers. *Community Care*, 12.4.01, 28.
- Clibbens, R. (2007). Services for People with Dementia Are Not Meeting Families' Expectations. *Nursing Times*, 103, 14, 12.
- Cogan, N. A. (2004). Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals Children of Disabled Parents: New Thinking About Families Affected by Disability and Illness. *Child & Family Social Work*, 9, 3, 313.
- Cozens, A. (2002). Carers Promise. *Community Care*, 13.6.02, 32-33.
- Cragg, S. (2001). So, What Will Carers Gain? *Community Care*, 15.3.01, 28.
- Cullen, P. (2000). Carers' Benefits. *Benefits*, 28, 35-37.
- Dent, E. (2013). Piece of My Mind. *Health Service Journal*, 123, 6354, 1-4.
- Devabhai, N. (2007). Beyond We Care Too. *CDX Magazine*, 53, 20-21.
- Dewar, H. (2008). Going All Inclusive? *Viewpoint*, 16-19.
- Dobson, A. (2002). Taking the Job Home. *Care and Health Guide*, 10, 10-11.
- Dobson, A. (2004). Paying Third Parties. *Care and Health Magazine*, 30.11.04, 22-23.

- Donovan, T. (2014). Family Carers Will Not Be Able to Meet Need for Support by 2017, Warns Think-Tank. *Community Care*.
- Dugdale, C. (2000). The Role of a Dementia Trailblazer. *Nursing Times*, 21.9.00, 46-47.
- Eastman, D., & Parratt, N. (2007). Who Cares for the Carers? *Therapy Today*, 18, 5, 36-37.
- English, F. (2001). Dementia Doesn't Discriminate. *Journal of Dementia Care*, 9, 4, 8.
- Ewing, W. A. (2005). Land of Forgetfulness: Dementia Care as a Spiritual Formation. *Journal of Gerontological Social Work*, 45, 3, 301-311.
- Fallon, D., Warne, T., McAndrew, S., & McLaughlin, H. (2012). An Adult Education: Learning and Understanding What Young Service Users and Carers Really, Really Want in Terms of Their Mental Well Being. *Nurse Education Today*, 32, 2, 128-132.
- Farmer, J. (2004). Coffee, Cakes and Mutual Support. *Journal of Dementia Care*, 12, 2, 14-15.
- Farmer, P. (2000). Rescue Me. *Community Care*, 13.7.00, 26-27.
- Farmer, P. (2005). The Future's Bright, but Only If We Get It Right Now. *Mental Health Review*, 10, 4, 4-7.
- Fawcett, E. (2005). Calling for Clarity over Carer's Allowance. *Viewpoint*, 88, 16-17.
- Feeney, J., John, D., & Maciejewski, C. (2010). Primrose: An Alzheimer's Society Branch on Wheels. *Journal of Dementia Care*, 18, 3, 12-14.
- Ferguson, H. (2006). Carers' Human Rights Being Breached. *Scope*, 17.
- Fox, A. (2004). 'Who Cares About Us?': The Unmet Needs of Young Carers. *Childright*, 209, 17-18.
- Fox, A. (2006). Young Carers. *Community Practitioner*, 79, 10, 313-314.
- Fox, A. (2007). Caring for Young Carers. *British Journal of School Nursing*, 2, 5.
- Fox, A. (2008). The Cost of Unpaid Caring. *Working with Older People*, 12, 4, 22-26.
- Fox, A. (2008). Well Suited or Stitched Up? *Community Care*, 5.6.08, 16-17.
- Francis, H. (2004). Out of the Shadows. *Adults Learning*, 15, 7, 22-23.
- Garnham, J., & Foley, C. (2001). Standard Six: Caring About Carers. *Mental Health and Learning Disabilities Care*, 4, 12, 396-397.
- Gates, B. (2010). Editorial. *Journal of Intellectual Disabilities*, 14, 1, 5-8.
- George, M. (2000). The Right to Leave. *Nursing Standard*, 14, 16.
- George, M. (2003). Carers. *Care and Health Magazine*, 22.10.03, 40-41.
- George, M. (2003). Taking the Time to Care. *Care and Health Magazine*, 50, 26-27.
- George, M. (2003). The Test of Time. *Care and Health Magazine*, 38, 16-18.
- George, M. (2005). Your Guide To: April Deadlines. *Care and Health Magazine*, 29.03.05, 30-31.
- George, M., & Needham, C. (2001). Making Headway. *Community Care*, 14.6.01, 32-33.
- Gilbert, H. (2004). Heart of the Matter. *Care and Health Magazine*, 30.11.04, 26-27.
- Gillam, T. (2004). Family Fortunes. *Nursing Standard*, 19, 12, 20-21.
- Gillen, S. (2010). Carers' Plight. *Community Care*, 1822, 22-23.
- Graham, B. (2011). Why Do Young Carers Fail to Use Services? *Community Care*.
- Greenwood, L. (2002). Caring for the Carers. *NHS Magazine*, 2, 13, 20-21.



- Griffin, J. S. (2012). Carrying the Weight. *Relational Child & Youth Care Practice*, 25, 2, 47-48.
- Griffiths, J. (2008). Caring for Carers. *Independent Nurse*, 40-43.
- Griffiths, R. (2013). A New Direction. *Mental Health Today*, 8-9.
- Hammond, B. (2000). Joint Working Success. *Journal of Dementia Care*, 8, 4, 12-13.
- Hare, P. (2003). Finding Your Carers. *Health Management*, 7, 17, 16-17.
- Hare, P. (2004). Keeping Carers Healthy: The Role of Community Nurses and Colleagues. *British Journal of Community Nursing*, 9, 4, 155-159.
- Hare, P. (2004). Short and Sweet. *Community Care*.
- Harrison, J. (2000). Improving Quality of Life for Carers. *British Journal of Community Nursing*, 5, 8, 368.
- Harrison, J. (2011). Exploring Unforeseen Outcomes - Examining the Potential That Personalised Technology Can Have for Changing the Behaviour Patterns of People with Learning Disabilities. *Journal of Assistive Technologies*, 5, 1, 45-50.
- Hayes, D. (2007). 'The Biggest Worry Is What She's Missing Out On'. *Community Care*, 1072, 22-23.
- Heiser, S. (2003). Taking Things One Day at a Time. *Journal of Dementia Care*, 11, 2, 15.
- Henderson, J. (2007). Palliative Care in Dementia: Caring at Home to the End. *Journal of Dementia Care*, 15, 3, 22-23.
- Heng, S. (2004). The Simon Heng Column. *Community Care*, 1536, 20-21.
- Heng, S. (2005). The Simon Heng Column. *Community Care*, 1569, 22-23.
- Heng, S. (2006). It's Time to Accept Help. *Community Care*, 2.3.06, 42-43.
- Heng, S. (2007). Children in Exclusion Zone. *Community Care*, 10-10.
- Heng, S. (2008). Dear Gordon Brown. *Community Care*, 10-10.
- Hepworth, D. (2001). Beyond Caring. *Community Care*, 1388, 20.
- Hibberd, P. (2008). Meaningful Involvement: Carers as Students. *Journal of Dementia Care*, 16, 3, 14-15.
- Hibberd, P., & Vougioukalou, S. (2012). Flexible, Immediate Support and Signposting. *Journal of Dementia Care*, 20, 5, 12-13.
- Hill, L. (2005). Young Carers Short of Support in Wales. *Community Care*, 1588, 13.
- Hopkins, G. (2002). Policies at Odds. *Community Care*, 21.3.02, 44.
- Hopkins, G. (2005). Burden Weighs Heavily. *Community Care*, 01.12.05, 40-41.
- Hopkins, G. (2006). A Burden Shared. *Community Care*, 40-41.
- Housing, L. I. N. (2005). Organising and Supporting Direct Payments. *Housing Care and Support*, 8, 4, 28-33.
- Howorth, M., Riley, C., Drummond, G., & Keady, J. (2011). The Open Doors Network: A Pioneering Scheme. *Journal of Dementia Care*, 19, 3, 20-21.
- Hunt, L. (2008). Abuse of Power. *Nursing Times*, 104, 43, 14-15.
- Hunter, M. (2007). Helping Carers Back to Work. *Community Care*, 17.05.07. 18-20.
- Hunter, M. (2007). A New Deal for Carers. *Community Care*, 05.04.07. 26-27.
- Ingram, P. (2004). Partners in Care: Sharing. *Psychiatric Bulletin*, 28, 9, 335-336.

- Innes, A., Mason, A., Cox, S., Ribiero, P., & Smith, A. (2003). Dementia Services in Remote and Rural Areas. *Journal of Dementia Care*, 11, 4, 33-39.
- Ivory, M. (2007). We Know the Price but Not the Value. *Community Care*, 1702, 26-27.
- Jacobs, N. (2007). Young Carers Say: 'Read All About Us!'. *Community Care*, 1685, 20-21.
- James, I., & Powell, I. (2001). Cognitive Therapy for Carers: Distinguishing Fact from Fiction. *Journal of Dementia Care*, 9, 6, 24-26.
- Janssen, R. (2004). Learning While Caring. *Adults Learning*, 16, 2, 12-13.
- Jerram, S., Morgan, A., Barker, W., Frazer, A., Hayes, N., Nazarko, L., & Jackson, J. (2006). Ask the Experts. *Nursing Older People*, 18, 7, 10-11 12p.
- Jones, E. (2000). A Lifeline for Carers in Rural Communities. *Journal of Dementia Care*, 8, 3, 10-11.
- Jones, G. M. M., & Miesen, B. M. L. (2011). Dementia Care: Involving People in Alzheimer's Cafes. *Nursing and Residential Care*, 13, 9, 442-445.
- Jones, R. (2006). Money for Old Hope. *Public Finance*, 13.01.06, 17.
- Jupp, K. (2008). Broadening Horizons. *Learning Disability Today*, September, 28-29.
- Keady, J., & Adams, T. (2001). Community Mental Health Nurses in Dementia Care: Their Role and Future. *Journal of Dementia Care*, 9, 2, 33-37.
- Kehoe, S., & Haigh, S. (2003). Sharing Standards. *Openmind*, 121, 22.
- Kelly, K. (2010). Three Decades of Caring. *Aging Today*, 31, 6, 7-7.
- Kelly, M. A. (2002). Tree of Life...This Practice Profile Is Based on Ns72 Armstrong M (2001) the Pressure Felt by Informal Carers of People with Dementia. *Nursing Standard* 15, 17, 47-53. *Nursing Standard*, 16, 21, 24.
- Kempenaar, L., & Creaney, W. (2002). An Investigation into a Short-Term Group Carer Education Programme for the Informal Carers of People with Dementia. *Journal of Dementia Care*, 10, 5, 32.
- Kenny, C. (2002). Money Going in, But Will Care Come Out? *Nursing Times*, 98, 32, 10-11.
- Kerr, D. (2004). Developing Dementia Care Services across India. *Journal of Dementia Care*, 12, 4, 20-21.
- King, N. (2002). Staying Put: Keeping the Family Home for Adults with a Learning Disability. *Care Plan*, 8, 3, 9-13.
- King, N. (2003). Choice of Where and How You Live: How Families Can Create New Solutions to a Familiar Problem. *Housing Care and Support*, 6, 1, 27-32.
- King, V. (2008). What Is Disability Discrimination? *Access by Design*, 115, 16-17.
- Kitchen, G. (2005). Older Carers and Dementia. *Working with Older People*, 9, 1, 17-20.
- Kuzmanov, C. (2005). Home Entertainment. *Journal of Dementia Care*, 13, 5, 18-19.
- Leason, K. (2002). Give Me a Break. *Community Care*, 1436, 30-31.
- Leason, K. (2004). Final Farewell. *Community Care*, 3.6.04, 28-29.
- Leece, J. (2002). Extending Direct Payments to Informal Carers: Some Issues for Local Authorities. *Practice*, 14, 2, 31-44.
- Lewis, B. (2014). Joan's Family Bill of Rights: A Charter for Patients and Carers. *BMJ*, 349, 7983, 6022.
- Lomas, C. (2006). Listening to Carers. *Nursing Times*, 102, 1, 16-17.

- Lunde, L., & Moen, A. (2016). Carer support - an Innovative Approach to Informal Carers' Training and Collaboration. *Studies in Health Technology and Informatics*, 225, 919-920.
- MacSween, L., & Maule, D. (2012). Young Carers' Movement in Toronto. *Relational Child & Youth Care Practice*, 25, 2, 61-65.
- Maloney, R., Dearden, C., & McDermott, N. (2010). Better Support for an 11-Year-Old Carer. *Community Care*, 28.10.10. 20-21.
- Malthouse, R., & Fox, F. (2014). Active Living: What Works. *Journal of Dementia Care*, 22, 4, 10-11.
- Manthorpe, J., & Iliffe, S. (2002). What Carers Want to Know. *Community Care*, 13.6.02, 34-35.
- Manthorpe, J., Watson, R., & Stimpson, A. (2003). Cooking up a Problem in the Kitchen. *Journal of Dementia Care*, 11, 5, 16-17.
- Manthorpe, J., Watson, R., & Stimpson, A. (2003). Relatives' Views on Mouth Care. *Journal of Dementia Care*, 11, 2, 28-29.
- Marshall, A., Bucks, R., & Mander, H. (2005). A Long-Term Support Group for People with Dementia. *Journal of Dementia Care*, 13, 5, 36-37.
- Martin, J. (2010). Don't Let Carers Slip Off the Radar. *Community Care*, 1822, 24-24.
- Martin, W. (2015). The Children Caring for Adults. *TES: Times Educational Supplement*, 23.10.15. 11.
- Martin, W. (2016). Sector Must Show That It Cares About Young Carers. *TES: Times Educational Supplement*, 15.4.16. 54-55.
- Mason, T., & Slack, G. (2013). The Debenham Project: Research into the Dementia/Memory Loss Journey for Cared-for and Carer: 2012-13. (Report on Research Project into Early Diagnosis, Early Engagement with Services, and the Dementia/Memory Loss Journey for Carers and Cared-For.). *Journal of Dementia Care*; 22, 5, 32-34.
- McCrae, N., Cook, J., & Norman, I. (2015). Evaluating the SPECAL Approach to Care. *Journal of Dementia Care*, 23, 3, 24-27.
- McGrath, S. (2001). Many Carers Need an Outside Interest, and Susan McGrath Explains How This Is Being Achieved in a Project in East Sussex. *Learning Disability Bulletin*, 123.
- McIntyre, P. (2001). Asian Community Groups Campaign for Equal Rights. *Viewpoint*, 56, 3.
- McKendrick, D. (2011). Listen to the True Voices. *Rostrum Magazine*, 105. 14-15.
- McMillan, I. (2001). Informal Carers Lack Support. *Mental Health Practice*, 4, 8, 2.
- McMillan, I. (2008). Let Relatives Have a Bigger Role in Care. *Learning Disability Practice*, 11, 2, 29-29.
- McNicol, A. (2014). Mental Health Teams Should Assess Support Needs of Carers of People with Schizophrenia, Say NICE. *Community Care*. 12.02.14.
- Mellor, C., & Glover, S. (2000). In Partnership with Carers. *Journal of Dementia Care*, 8, 6, 14.
- Mendham, S. (2007). Evaluating Carer Information Groups. *Journal of Dementia Care*, 15, 6, 37-38.
- Mickel, A. (2008). Too Many Forms Too Little Benefit. *Community Care*, 5.6.08, 14-15.
- Mickel, A. (2008). Treatment Orders Leave Carers Anxious. *Community Care*, 30.10.08, 28-29.
- Miller, A. (2001). Shared Care in Sheffield. *Community Care*, 13.12.01, 42.

- Miller, A. (2003). Link No Longer Missing. *Community Care*, 4.12.03, 38.
- Miller, A. (2005). Access All Areas. *Community Care*. 24.3.05.
- Minnema, N. (2008). A Cuppa in the Country. *Journal of Dementia Care*, 16, 6, 20-21.
- Montgomery, A., & Holzhausen, E. (2003). Caregivers in the United States and the United Kingdom: Different Systems, Similar Challenges. *Generations*, 27, 4, 61-67.
- Montgomery-Smith, C. (2006). Musical Exercises for the Mind. *Journal of Dementia Care*, 14, 3, 10-11.
- Newbigging, K. (2005). Making a Real Difference. *Mental Health Today*, September, 27-30.
- Nolan, A. (2006). How to Give Users and Carers a Voice. *Health Service Journal*, 16.03.06. 10-11.
- O'Dowd, A. (2006). Supporting the Carers. *Local Government Chronicle*, 16.02.06, 16-17.
- Otto, J. (2001). Losing the Living. *Community Care*, 12.7.01, 24.
- Oxtoby, K. (2009). Caring for Carers. *Nursing Times*, 105, 12, 12-13.
- Parks, S. (2014). Young Carers. *The British Journal of General Practice*, 64, 629, 616.
- Partridge, P. (2003). Sharing Care. *Mental Health Today*, March. 14-15.
- Penn, S. (2014). Assessment and Awareness of the Challenges Can Help Young People. *Nursing Children and Young People*, 26, 10, 13.
- Perkins, D. (2008). Mental Health Academics in the University Departments of Rural Health: Roles and Contributions. *Australian Journal of Rural Health*, 16, 325-326.
- Pitkeathley, J. (2013). The Impact of the Carers Movement. *Journal of Care Services Management*, 7, 2, 58-60.
- Pitt, V. (2010). Putting the Dementia Strategy to Work. *Community Care*, 11.2.10, 28-30.
- Pitt, V. (2010). Safeguarding in a Personalised Era. *Community Care*. 04.11.10.
- Pitt, V. (2011). Help at Hand for the Hidden Carer. *Community Care*, 16.6.11, 27-23.
- Plumb, R. (2004). Where Have All the Carers Gone? *Nursing & Residential Care*, 6, 8, 366-367.
- Podgson, R. (2015). A Dementia First Aid Course for Family Carers. *Nursing Times*, 111, 41, 24.
- Pointon, B. (2001). Money Matters: A System Fraught with Glaring Inequality. *Journal of Dementia Care*, 9, 6, 27-29.
- Price, M., Sherratt, C., & Stein, D. (2004). Still a Long Way to Go in Responding to People's Needs. *Journal of Dementia Care*, 12, 3, 18-20.
- Rachel, F. (2013). What Makes Santander a Great Place to Work; Bank Delivers Wide Range of Benefits for All. *Human Resource Management International Digest*, 21, 4, 14-17.
- Rank, E., & Holman, A. (2007). Who Cares for Us? *Community Living*, 20, 3, 12-13.
- Rapaport, J. (2002). What's in a Name. *Professional Social Work*, March, 12-13.
- Rea, H., Kenealy, T., Sheridan, N., & Gorman, D. (2010). Invisible Care: Do We Need a Code of Rights to Protect Family and Informal Carers? *New Zealand Medical Journal*, 123, 1317.
- Redmond, I. (2008). The Care Conundrum. *Working with Older People*, 12, 3, 23-26.
- Redwood, K. (2001). All in the Same Boat. *Journal of Dementia Care*, 9, 1, 9.

- Redwood, P., Robinson, D., & Price, J. (2005). De Caf: A Meeting Place and Therapeutic Resource. *Journal of Dementia Care*, 13, 4, 20-22.
- Reinhard, S., Brooks-Danso, A., & Kelly, K. (2008). How Are You Doing? *American Journal of Nursing*, 108, 9, 4-5.
- Renvoize, E., & Patel, J. (2002). Consumer Voices Steer the Course of Research. *Journal of Dementia Care*, 10, 5, 37-38.
- Rickell, A. (2002). In Our Own Words. *Professional Social Work*, October, 10-11.
- Ross, C. (2012). Remembering Together. *Journal of Dementia Care*, 20, 3, 22-23.
- Rylance, R., Pendleton, J., Woods, L., & Nielson, S. (2015). 'A Brilliant Thing...Just Doing My Own Little Bit'. *Journal of Dementia Care*, 23, 3, 10-11.
- Sadler, C. (2003). Too Much Too Young. *Nursing Standard*, 18, 7, 16-18.
- Sainsbury, R. (2009). The Princess Royal Trust for Carers in Association with Young Carers International Research and Evaluation. *Benefits: The Journal of Poverty & Social Justice*, 17, 1, 75-78.
- Salari, N. (2009). A Lifeline for Carers. *Community Care*. 30.07.09.
- Sale, A. U. (2003). Does Every Child Really Matter? *Community Care*, 1491, 36-37.
- Sale, A. U. (2004). Caring but Not Coping. *Community Care*, 29.04.04. 32-33.
- Sale, A. U. (2004). Shifting the Burden. *Community Care*, 29.01.04. 28-29.
- Sale, A. U. (2006). Carers at Home and at Work. *Community Care*, 25.05.06. 28-29.
- Sale, A. U. (2006). Pamela Pushes Barriers Aside. *Community Care*, 19.01.06. 32.
- Samuel, M. (2010). 'For Many Carers, It's Too Much Hassle'. *Community Care*, 25.11.10. 24.
- Samuel, M. (2013). Few Staff or Carers Prosecuted for Abusing Vulnerable Adults, Finds Research. *Community Care*, 05.09.13.
- Sanders, S., & Pearce, S. (2010). The Oxford Friends and Family Empowerment (OFAFE) Service: Support and Education for Those Affected by Friends or Family with Personality Disorder. *Mental Health Review Journal*, 15, 4, 58-62.
- Schofield, J., & Mellor, J. B. (2006). One of Our Own Kind: Carer Liaison at Work. *Journal of Dementia Care*, 14, 5, 12-13.
- Schunk, M. (2000). A Place for Support: New Policies for Informal Carers in Long-Term Programmes. *Benefits*, 28, 22-25.
- Schwehr, B. (2013). New Rights under the Care and Support Bill. *Community Living*, 27, 2, 10-11.
- SCIE. (2007). Carers Support and Assessments. *Community Care*, 1694, 40-41.
- Seneviratna, C. (2007). They Are Not Asking a Lot. *Community Care*, 1678, 20-21.
- Sewter, E., Jones, R., Hart, I., & Dyer, C. (2014). Charting Carer Satisfaction: The Hospital Experience. *Journal of Dementia Care*, 22, 5, 19-21.
- Shellenbarger, S. (2003). Little-Known Program Offers Help to People Caring for Aging Relatives. *Wall Street Journal - Eastern Edition*, 242, 115, D1-D1.
- Sherratt, C. (2010). Lighting Up: Lessons Learned in Establishing an Arts Project. *Journal of Dementia Care*, 18, 6, 22-24.
- Shooter, M. (2004). Partners in Care: Who Cares for the Carers? *Psychiatric Bulletin*, 28, 9, 313-314.

- Simon, C. (2002). The Role of the Primary Care Team in Support of Informal Carers. *British Journal of Community Nursing*, 7, 1, 6.
- Simpson, A. (2008). Professional Backup. *Nursing Standard*, 22, 38, 62-63.
- Sims, B. (2008). A Helping Hand for Carers. *Nursing & Residential Care*, 10, 8, 371.
- Sims, B. (2008). In Safe Hands. *Nursing & Residential Care*, 10, 3, 112.
- Sims, J. (2004). All Together Now. *Care and Health Magazine*, 3.8.04, 27-28.
- Sims, J. (2004). Sam's Bill. *Care and Health Magazine*, 4.02.04, 25.
- Sloman, M. (2004). My Practice. *Community Care*, 1549, 43-43.
- Smith, J., Baldwin, M., Dervis, M., & Crumbie, A. (2009). Readers Panel. Just the Job for Young Carers. *Nursing Standard*, 23, 42, 28-29.
- Smith, N. (2009). FAls: Issues for Families and Carers. *SCOLAG Journal*, 379, 120-121.
- Social Care Institute for Excellence. (2008). Communicating with Service Users and Their Carers. *Community Care*, 16.10.08, 34-35.
- Stalker, K. (2003). Policy into Practice: Carers. *Research Policy and Planning*, 21, 2, 57-62.
- Stanistreet, P. (2005). Care and the Community. *Adults Learning*, 17, 1, 22-24.
- Starr, M. (2003). Training for Jobcentre Plus: Meeting the Needs of Carers. *Benefits*, 11, 1, 27-31.
- Stewart, W. (2008). Vulnerable Pupils Go Unnoticed. *TES: Times Educational Supplement*, 4776, 13-13.
- Stokes, G. (2010). Explaining About ... Day-to-Day Living with Dementia. *Working with Older People*, 14, 1, 5-7.
- Sugarman, S. (2001). Carers' Rights. *Mental Health and Learning Disabilities Care*, 4, 9, 316.
- Swenson, C. R. (2004). Dementia Diary: A Personal and Professional Journal. *Social Work*, 49, 3, 451-460.
- Swinburne, C. (2011). A Lifeline for Carers. *Nursing Standard*, 25, 23, 24-25.
- Symington, J. (2010). Carers Included. *Mental Health Today*, 36-37.
- Taylor, A. (2003). Councils Struggle to Justify Wide Variations in Assessment Rates. *Community Care*, 12.06.03, 18-19.
- Taylor, A. (2003). Low Benefits Take-up Is Barrier to a Better Quality of Life for Carers. *Community Care*, 11.12.03, 18-19.
- Taylor, A. (2007). So Many Contradictions. *Community Care*. 05.12.07.
- Taylor, A. (2008). Pause for Thought. *Community Care*. 10.04.08.
- Taylor, A. (2010). Confidence Boost for Carers. *Community Care*, 07.01.10. 30-31.
- Taylor, A., Brody, S., & Garboden, M. (2007). Carers Forced to Fill Gaps but Receive Little in Return from Councils. *Community Care*. 17.01.07.
- Taylor, J. (2009). Why the NHS Must Look after Its Hidden Workers. *Health Service Journal*, 119, 6167, 18.
- The Alzheimer's Society Lesbian and Gay Carers Network. (2002). Two Years On. *Working with Older People*, 6, 4, 29-30.
- Thomas, D. (2006). Time to Care for the UK's Carers. *Personnel Today*. 04.04.06.
- Thomas, G. (2008). Carers. *Education Parliamentary Monitor*, 13, 12, 1131.

- Thompson, A. (2009). 'Pick and Mix': Supporting Carers to Have a Break. *Community Connecting*, 22, 14-15.
- Thorp, S. (2003). Fixing up Families. *Care and Health Magazine*, 27, 20-21.
- Tottie, J. (2010). A Carer's Perspective of Coping with Dementia. *Working with Older People*, 14, 1, 26-28.
- Trueland, J. (2012). Family Lifeline. *Nursing Standard*, 26, 42, 24-25.
- Turnbull, A. (2014). Young Carers Meet with Top Health Figures. *Independent Nurse*, 11.10.14. 65.
- Turner, S. (2006). Starting Out. *Nursing Times*, 102, 50, 13.
- Turner, T. (2004). Young and Free. *Nursing Standard*, 18, 24, 25.
- Valios, N. (2001). Wheeling-Dealing Therapies. *Community Care*, 7.6.01, 30-31.
- Valios, N. (2005). 'What Did We Learn?'. *Community Care*, 1600, 32-33.
- Valios, N. (2006). We're All Going on a Summer Holiday. *Community Care*, 17.08.06, 28-30.
- Valios, N. (2010). Helping Dementia Patients with a Wider Family Circle. *Community Care*. 04.11.10.
- Valios, N. (2013). Cuts and Lack of Assessments Leave Carers 'at Breaking Point'. *Community Care*. 11.02.13.
- Vaux, G. (2000). Can Tax Credits Work for Carers? *Benefits*, 28, 43-46.
- Vaux, G. (2003). Winners Are Losers. *Community Care*, 6.2.03, 43.
- Warner, K., & Jorgensen, S. (2009). Carer's Choir - Giving Carers a Voice through Art. *Llais*, 93, 14-15.
- Watson, S. (2011). The Reluctant Carer. *HIV Nursing*, 11, 2, 15-17.
- Watt, M. (2000). Supporting Carers - Dilemmas for Care Agencies. *Management Issues in Social Care*, 7, 4, 21-23.
- Webb, R. (2015). Informal Carers: If We Don't Know, How Can We Help? *Journal of Wound Care*, 24, 11, 487-487.
- While, A. (2010). Society Owes Carers a Debt of Thanks. *British Journal of Community Nursing*, 15, 1, 50.
- Whitman, L. (2009). The Importance of Listening to Family Carers. *Journal of Dementia Care*, 17, 5, 24-27.
- Whittle, B. (2010). Help at Home Worth £6 Billion. *Nursing & Residential Care*, 12, 9, 416.
- Williams, C. (2007). Scots Pioneers. *Community Care*, 6.12.07, 32-33.
- Williams, C. (2007). When Carers Need Caring. *Community Care*, 07.06.07. 32-33.
- Williams, C. (2012). Chronic Illness and Informal Carers: 'Non-Persons' in the Health System, Neither Carers, Workers or Citizens. *Health Sociology Review*, 21, 1, 58-68.
- Williams, E. (2005). Young Carers. TES: Times Educational Supplement, 4652, 13-16.
- Williams, F. (2004). Advice for Black and Minority Ethnic Elders. *London Age*, Autumn, 4-5.
- Williamson, T. (2007). Decisions, Decisions. *Mental Health Today*, October, 27-29.
- Williamson, T. (2009). Out of the Shadows: Attending to Its Message. *Journal of Dementia Care*, 17, 3, 26-27.

- Winchester, R. (2000). Authorities Fail to Deliver on Respite Promise. *Community Care*, 24.02.00, 10-11.
- Winter, J. (2008). Young Carers. *Paediatric Nursing*, 20, 3, 6-6.
- Wykes, T. (2003). Blue Skies in the "Journal of Mental Health"? Consumers in Research. Editorial. *Journal of Mental Health*, 12, 1, 1-6.
- Wynn-Jones, F., Fordham, K., & Hill, V. (2010). 'A Whole Month of Pleasure' - Making Music on the South Downs. *Journal of Dementia Care*, 18, 4, 28-30.
- Yeandle, S. (2007). Carers UK: Why a Social Contract Is Needed. *Community Care*. 05.12.07
- Yeandle, S. (2007). A Social Contract? *Community Care*. 1702.
- Young, A. (2004). Commercial Break. *Community Care*, 16.09.04, 40-41.



## Press Releases

Care There. (2000). Carethere. PR Newswire July 28

Carers UK/Counsel and Care. (2008). It's Everybody's Business: Care and Support for the 21st Century.

Department of Health. (2000). Parkinson's Disease Society Launch First Guide for Carers: Health Minister Gisela Stuart Welcomes New Initiative to Support Family and Friends of Patients.

Department of Health. (2010). New Strategy Will Help Identify Carers Earlier.

Department of Health. (2013). Support for Working Carers Needed to Help Businesses and Boost the Economy.

Evercare. (2006). Evercare Study Finds Stress, Depression, Fatigue Propel Caregivers into Downward Health Spiral; First Comprehensive Look at Health Impact of Caring for Loved Ones. PR Newswire

Global Social Enterprise Initiative. (2015). Unintended Consequences: Caregivers May Be a Barrier to the Aging Becoming Tech Savvy.

Policy Press. (2016). International Journal of Care and Caring.

## Reports & Papers

- ADASS. (2010). *Carers as partners in hospital discharge: a review*. ADASS.
- Afiya Trust. (2008). *Beyond we care too: putting black carers in the picture*. Afiya Trust.
- Aldridge, J. (2002). *Children caring for parents with severe and enduring mental illness*. Loughborough University.
- Arksey, H. (2001). *Employers' Provisions for Carers*. Social Policy Research Unit, University of York.
- Arksey, H. (2003). *Access to Health Care for Carers: Intervention evaluations: Supplementary report*. London: NCCSDO.
- Arksey, H., & Hepworth, D. (2000). *Carers' Needs and The Carers Act: An evaluation of the process and outcomes of assessment*. University of York: Social Policy Research Unit.
- Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Newbronner, E., & Baldwin, S. (2004). *Review of respite services and short-term breaks for carers of people with dementia*. London: NCCSDO.
- Arksey, H., Jackson, K., Wallace, A., Baldwin, S., Golder, S., Newbronner, E., & Hare, P. (2004). *Access to health care for carers: barriers and interventions: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*.
- Arksey, H., Kemp, P., Glendinning, C., Inna, K., & Tozer, R. (2005). *Carer's aspirations and decisions around work and retirement*. Department for Work and Pensions.
- Arksey, H., O'Malley, L., Baldwin, S., & Harris, J. (2002). *Services to support carers of people with mental health problems: overview report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D*. NCCSDO.
- Audit Commission. (2004). *Support for carers of older people*. Audit Commission.
- Audit Commission. (2004). *Support for carers of older people: independence and well-being*. London: The Audit Commission.
- Audit Scotland. (2014). *Self-directed support*. Edinburgh: Audit Scotland
- Austin, K. (2003). *8 out of 10 carers at breaking point*. Mencap.
- Bamford, C., Arksey, H., Poole, M., Kirkley, C., Hughes, J., Corner, L., & Bond, J. (2009). *Person and carer-centred respite care for people with dementia: developing methods for evaluating the effectiveness of different models*. NCCSDO.
- Banks, P., Gallagher, E., Hill, M., & Riddell, S. (2002). *Literature review of identification, needs assessment and service provision for young carers and their families*. Scottish Executive Central Research Unit.
- Banks, P., & Roberts, E. (2001). *More breaks for carers? An analysis of local authority plans and progress reports on the use of the Carers Special Grant*. The King's Fund.
- Barbabella, F., Schmidt, A., Lamontagne-Godwin, F., & Lamura, G. (2012). *Assessing the Impact of IVT-Based Solutions for Carers in Europe: Preliminary Findings from the CARICT Project*. Centre for Social Innovation.
- Becker, F., & Becker, S. (2008). *Young adult carers in the UK: experiences, needs and services for carers aged 16-24*. Princess Royal Trust for Carers.
- Beresford, B. (2013). *Making a difference for young adult patients*. Transition Partnership.
- Brooks, J., Mitchell, W., & Glendinning, C. (2015). *Personalisation, Personal Budgets and Family Carers*. Social Policy Research Unit, University of York.

- Broughton, A. (2016). *Creating longer more fulfilling working lives: Employer practice in five European countries*. IES/CIPD.
- Buckner, L., & Yeandle, S. (2007). *Valuing carers: calculating the value of unpaid care*. Carers UK.
- Buckner, L., & Yeandle, S. (2011). *Valuing Carers 2011 - Calculating the value of carers' support*. Carers UK.
- Burgdorf, G. (2011). *How can the web support carers?* Princess Royal Trust for Carers.
- Burns, N., & Watson, N. (2009). *Evaluation of the Adults with Incapacity (Scotland) Act 2000 part 4* (978 0 7559 7332 6). Edinburgh: Scotland. Scottish Government Social Research.
- Carers Trust. (2016). *Care Act for Carers. One Year on*. Carers Trust/University of Birmingham.
- Carers Trust. (2016). *Invisible and in distress: prioritising the mental health of England's young carers*. Carers Trust.
- Carers UK. (2008). *Choice or chore? Carers' experiences of direct payments*. Carers UK.
- Carers UK. (2011). *The cost of caring: how money worries are pushing carers to breaking point*. Carers UK.
- Carers UK. (2011). *Half a million voices: improving support for BAME carers*. Carers UK.
- Carers UK. (2012). *Care and technology in the 21st century*. Carers UK.
- Carers UK. (2012). *Carers and telecare*. Carers UK.
- Carers UK. (2012). *In sickness and in health: a survey of 3,400 UK carers about their health and well-being*. Carers UK and 7 other charities.
- Carers UK. (2012). *Malnutrition and caring: the hidden cost for families*. London: Carers UK.
- Carers UK. (2013). *The case for care leave: families, work and the ageing population*. Carers UK.
- Carers UK. (2013). *State of Caring 2013*. London: Carers UK.
- Carers UK. (2013). *Supporting working carers: the benefits to families, business and the economy: final report of the carers in employment task and finish group: executive summary*. London: Carers UK.
- Carers UK. (2014). *Care Act 2014*. London: Carers UK.
- Carers UK. (2014). *Need to know. Transitions in and out of caring: the information challenge*. London: Carers UK.
- Carers UK. (2014). *State of Caring 2014*. London: Carers UK.
- Carers UK. (2015). *Caring into later life: the growing pressure on older carers*. London: Carers UK.
- Carers UK. (2015). *Facts about Carers*. London: Carers UK.
- Carers UK. (2015). *State of Caring 2015*. London: Carers UK.
- Carers UK. (2016). *Caring Homes: how the Carers Strategy can make housing suitable for carers*. London: Carers UK.
- Carers UK. (2016). *State of Caring 2016*. London: Carers UK.
- Carers UK and Age UK. (2016). *Walking the tightrope. The challenges of combining work and care in later life*. Carers UK and Age UK.

- Carers UK Wales/Marie Curie Cancer Care. (2012). *Committed to carers: supporting carers of people at the end of life*. Carers UK/Marie Curie.
- Carers UK/Employers for Carers. (2012). *Sandwich caring: combining childcare with caring for older or disabled relatives*. Carers UK.
- Carers UK/Employers for Carers. (2014). *Supporting employees who are caring for someone with dementia*. Carers UK/Employers for Carers.
- Carers Week Consortium. (2016). *Building carer friendly communities*. Carers Week.
- Cattan, M., & Giuntoli, G. (2010). *Care and support for older people and carers in Bradford: their perspectives, aspirations and experiences*. Joseph Rowntree Foundation.
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of London*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the East Midlands*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the East of England*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the North East*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the North West*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the South East*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the South West*. London: Great Britain. Department of Health
- Centre for International Research on Care Labour Equalities University of Leeds, & Great Britain Department of Health. (2010). *Carers in the Region: A Profile of the West Midlands*. London: Great Britain. Department of Health
- Centre for Social Justice. (2010). *The Forgotten Age. Understanding poverty and social exclusion in later life. Interim report*. The Centre for Social Justice
- Clifford, J., Theobald, C., & Mason, S. (2011). *The Princess Royal Trust for Carers: social impact evaluation of five carers' centres using social return on investment*. Princess Royal Trust for Carers
- Commission for Social Care Inspection. (2005). *The state of social care in England 2004-05*. London: Commission for Social Care Inspection
- Commission for Social Care Inspection. (2005). *The state of social care in England 2004-05: a summary*. London: Commission for Social Care Inspection
- Cools, F., Gerard, M., & Valsamis, D. (2013). *European evidence paper on the development of personal and household services and the sector's potential to increase employment in Europe*. Carers UK/Employment for Carers
- Cools, F., Gerard, M., & Valsamis, D. (2013). *European evidence paper Summary*.

- Counsel and Care. (2010). *Smarter spending for better care: ten ideas to make better use of social care funding for older people and carers*.
- Croisdale-Appleby, D. (2014). *Re-visioning social work education: an independent review*. London: Department of Health
- Deacon, K. (2001). *2001 census testing program: report on the quantitative test of the new carers question (June & July 1999)*. London: Office for National Statistics
- Dearden, C., & Becker, S. (2004). *Young carers in the UK: the 2004 report*. Carers UK/The Children's Society
- Department of Health. (2010). *Carers in DH what makes a difference*. London: Department of Health
- Di Novi, C., Jacobs, R., & Migheli, M. (2013). *The quality of life of female informal caregivers: from Scandinavia to the Mediterranean Sea*. Centre for Health Economics, University of York
- Edwards, L., Brooks, R., & Regan, S. (2001). *Age old attitudes? Planning for retirement, means-testing, inheritance and informal care*. IPPR
- Ellins, J., Glasby, J., & Tanner, D. (2012). *Understanding and improving transitions of older people: a user and carer centred approach*. NIHR Service Delivery and Organisation programme
- English National Board for Nursing, M. a. H. V. (2002). *Longitudinal study of the effectiveness of educational preparation to meet the needs of older people and their carers: The Advancing Gerontological Education in Nursing (the AGEIN) Project*. ENB
- Equalities Task Force. (2008). *New Deal for Carers: revision of the Prime Minister's 1999 Strategy on Carers: Equalities Task Force report*. Equalities Task Force
- Fevang, E., Kverndokk, S., & Røed, K. (2008). *Informal Care and Labor Supply*. IZA
- Fry, G., Price, C., & Yeandle, S. (2009). *Local authorities' use of carers grant: a report prepared for the Department of Health*. Leeds: University of Leeds
- Galliford, A. (2015). *Who will care after I'm gone? An insight into the pressures facing parents of people with learning disabilities*. Fitzroy
- Gasior, K., Huber, M., & Lamura, G. e. (2012). *Facts and figures on Healthy Ageing and Long-term Care*. Vienna: European Centre for Social Welfare Policy and Research
- Geerts, J., Willemé, P., & Mot, E. (2012). *Long-term care use and supply in Europe: projections for Germany, the Netherlands, Spain and Poland*. European Network of Economic Policy Research Institutes
- General Social Care Council. (2006). *Working towards full participation: a report on how social work degree courses, which started in 2003, have begun to involve service users and carers in social work training*. London: General Social Care Council
- George, M. (2001). *It could be you: a report on the chances of becoming a carer*. Carers UK
- Glasby, J., Ham, C., & Littlechild, R. (2010). *The case for social care reform - the wider economic and social benefits*. HSMC University of Birmingham
- Glendinning, C. (2004). *Support for carers of older people: some intranational and national comparisons: a review of the literature prepared for the Audit Commission*.
- Glendinning, C., Arksey, H., Jones, K., Moran, N., Netten, A., & Rabiee, P. (2009). *The Individual Budgets Pilot Projects: impact and outcomes for carers*. University of York: Social Policy Research Unit

- Glendinning, C., Arksey, H., Tjadens, F., Moree, M., Moran, N., & Nies, H. (2009). *Care provision within families and its socio-economic impact on care providers*. University of York: Social Policy Research Unit
- Glendinning, C., Mitchell, W., & Brooks, J. (2013). *Carers and Personalisation. Discussion paper for the Department of Health*. Social Policy Research Unit, University of York
- Great Britain House of Commons. Health Committee. (2010). *Social care: third report of session 2009-10: volume 1: report, together with formal minutes*. London: Stationery Office
- Great Britain House of Commons. Health Committee. (2010). *Social care: third report of session 2009-10: volume 2: oral and written evidence*. London: Stationery Office
- Gregory, C. (2010). *Improving health and social care support for carers from black and minority ethnic communities*. Race Equality Foundation.
- Griffiths, R., Landau, C., & Miller, T. (2001). *Supporting carers in primary health care: a report on a pilot project in Shropshire and Telford and Wrekin*. Shrewsbury: Community Council of Shropshire
- Harris, J., Piper, S., Morgan, H., McClimens, A., Shah, S., Reynolds, H., Baldwin, S., Arksey, H., & Qureshi, H. (2003). *Carers' experience of providing care for people with long term conditions*. University of York: Social Policy Research Unit
- Harrison, D., & M., J. (2015). *Living well with dementia: A participation and engagement programme for people with dementia and their carers. Development and evaluation report*. North of England Mental Health Development Unit
- Hatton, C., & Waters, J. (2015). *Personal health budget holders and family carers. The POET Surveys 2015*. In Control/TLAP/Lancaster University
- Health and Social Care Information Centre. (2015). *Personal social services survey of adult carers in England, 2014-15*.
- Heitmueller, A., & Michaud, P.-C. (2006). *Informal Care and Employment in England: Evidence from the British Household Panel Survey*. St. Louis:
- Henwood, M., & Waddington, E. (2002). *Outcomes of Social Care for Adults (OSCA): user and carer messages*. University of Leeds: Nuffield Institute for Health
- Hill, M., & MacGregor, G. (2001). *Health's forgotten partners? How carers are supported through hospital discharge*. Carers UK
- Hirst, M. (2002). *Costing adult care: comments on the ONS validation of unpaid adult care*. University of York: Social Policy Research Unit
- Hirst, M. (2004). *Health inequalities and informal care: end of project report*. University of York: Social Policy Research Unit
- Hirst, M. (2004). *Hearts and minds: the health effects of caring*. Carers Scotland
- Holzhausen, E. (2001). *Caring on the breadline: the financial implications of caring: executive summary (1873747209)*. London: Carers' National Association
- Holzhausen, E. (2002). *Without us? Calculating the value of carers' support*. Carers UK
- Hounsell, D. (2013). *Hidden from View: The experiences of young carers in England*. The Children's Society
- Howard, M. (2001). *Paying the price: carers, poverty and social exclusion*. CPAG
- Hutton, S., & Hirst, M. (2000). *Caring Relationships Over Time*. University of York: Social Policy Research Unit
- Institute for Employment Studies. (2013). *Improving employment opportunities for carers: identifying and sharing good practice*. NIHR School for Social Care Research

- IRISS. (2012). *Rest assured? A study of unpaid carers' experiences of short breaks*. Institute for Research and Innovation in Social Sciences
- Ismail, S., Thorlby, R., & Holder, H. (2014). *Focus on social care for older people*. Quality Watch
- Jones, A., Howe, A., Tilse, C., Bartlett, H., & Stimson, B. (2010). *Service integrated housing for Australians in later life*. Australian Housing and Urban Research Institute
- Jungblut, J.-M. (2015). *Working and Caring: Reconciliation measures in times of demographic change*. European Foundation for the Improvement of Living and Working Conditions
- Keeley, B., & Clarke, M. (2002). *Carers speak out project: report on findings and recommendations*. Princess Royal Trust for Carers
- Keeley, B., & Clarke, M. (2003). *Primary carers: identifying and providing support to carers in primary care*. Princess Royal Trust for Carers
- Kelly, P. (2016). *Pippa Kelly: A former carer's perspective*. NHS Confederation
- Keohane, N. (2016). *Longer lives, stronger families? The changing nature of intergenerational support*. The Social Market Foundation
- Khan, O., Ahmet, A., & Victor, C. (2014). *Caring and earning among low-income Caribbean, Pakistani and Somali people*. Joseph Rowntree Foundation
- Khan, O., Ahmet, A., & Victor, C. (2014). *Poverty and ethnicity. Balancing caring and earning for British Caribbean, Pakistani and Somali People*. Joseph Rowntree Foundation
- Kilbride, L., & Glasby, J. (2001). *Informing our care: the provision of information to the carers and care staff of people with dementia in Birmingham*. Centre for Health Action Research and Training
- Lundsgaard, J. (2005). *Consumer direction and choice in long-term care for older persons, including payments for informal care: how can it help improve care outcomes, employment and fiscal sustainability?* OECD
- Macmillan Cancer Relief. (2006). *Worried sick: the emotional impact of cancer*. Macmillan Cancer Relief
- Macmillan Cancer Support. (2012). *More than a million: understanding the UK's carers of people with cancer*.
- Maher, J., & Green, H. (2002). *Carers 2000: results from the carers module of the General Household Survey 2000*. London: Office for National Statistics
- Mais, J. (2003). *The impact of caring on carers: Associative and predictive factors relating to the general well-being of carers supporting a person diagnosed with Progressive Supranuclear Palsy (PSP)*. Loughborough: Faculty of Social Science and Humanities Loughborough University
- Marcinkowska, I., & Sowa, A. (2011). *Determinants of the probability of obtaining formal and informal long-term care in European countries*. ENEPRI
- McCartney, C. (2016). *Creating an enabling future for carers in the workplace*. CIPD
- McDaid, D., & Sassi, F. (2002). *The burden of informal care for Alzheimer's Disease: carer perceptions from an empirical study in England, Italy and Sweden*. PSSRU:
- McGregor, G., & Hill, M. (2003). *Missed opportunities: the impact of new rights for carers*. Carers UK
- McIntosh, J., MacAskill, S., Eadie, D., Curtice, J., McKeganey, N., Hastings, G., Hay, G., & Gannon, M. (2006). *Substance misuse research: evaluation and description of drug projects: working with young people and families*. Edinburgh: Scotland. Scottish Executive

- Medical Advisory Secretariat. (2008). *Caregiver- and patient-directed interventions for dementia: an evidence-based analysis*. Medical Advisory Secretariat
- Mencap. (2003). *Breaking point: a report on caring without a break for children and adults with severe or profound learning disabilities*. Mencap
- Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C., & Owen, C. (2001). *Caring in later life: reviewing the role of older carers*. London: Help the Aged
- Milne, A., & Williams, J. (2003). *Women at the crossroads: a literature review of the mental health risks facing women in mid-life*. Pennell Initiative for Women's Health/The Mental Health Foundation
- Mitchell, W. (2013). *Practice often fails to take carers' own wider needs into account during service user personalisation*. NIHR School for Social Care Research
- Mitchell, W., Baxter, K., & Glendinning, C. (2012). *Updated review of research on risk and adult social care in England*. York: Joseph Rowntree Foundation
- Moriarty, J. (2014). *BME groups and personalisation*. Race Equality Foundation
- Mowlam, A., Rosalind, T., Dixon, J., & McCreddie, C. (2007). *UK study of abuse and neglect of older people: qualitative findings*. London: National Centre for Social Research
- Muir, R., & Quilter-Pinner, H. (2015). *Powerful People. Reinforcing the power of citizens and communities in health and care*. IPPR
- NAO. (2009). *Supporting carers to care: report by the Comptroller and Auditor General*. NAO
- National Audit, O. (2015). *Care Act first-phase reforms: report by the Comptroller and Auditor General*. London: National Audit Office
- National Audit Office. (2010). *Improving dementia services in England: an interim report*. London: Stationery Office
- National Audit Office. (2014). *Adult social care in England: overview: report by the Comptroller and Auditor General*. London: National Audit Office
- Netten, A. (2013). *Many carers are invisible to councils*. NIHR School for Social Care Research
- Newbronner, E., & Hare, P. (2002). *Services to support carers of people with mental health problems: consultation report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D*. NCCSDO
- Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M., & Glendinning, C. (2013). *A Road Less Rocky - Supporting carers of people with dementia*. London: Carers Trust
- Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B., & Glendinning, C. (2011). *Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers*. SCIE
- NIACE. (2012). *Voices of young adult carers: stories of young adult carers' experiences of caring and learning*. NIACE
- NICE. (2007). *Dementia: Supporting people with dementia and their carers in health and social care (1358-0574)*. NICE
- Office For National Statistics. (2013). *What does the 2011 Census tell us about the "oldest old" living in England & Wales?* ONS
- OFSTED. (2009). *Supporting young carers: identifying, assessing and meeting the needs of young carers and their families*. OFSTED



- Parker, G., Arksey, H., & Harden, M. (2010). *Meta review of international evidence on interventions to support carers*. Social Policy Research Unit/Centre for Reviews and Dissemination
- Parkinson's Disease Society. (2008). *Life with Parkinson's today: room for improvement. Results of the UK's largest ever survey of people with Parkinson's and carers*. Parkinson's Society
- Pearlman, V., & Holzhausen, E. (2002). *Adding value: carers as drivers of social change*. London: Carers UK
- Pettitt, G., & Kenny, D. (2000). *Carers count: a research report on carers in London*. Princess Royal Trust for Carers
- Phillips, J., Bernard, M., & Chittenden, M. (2002). *Juggling work and care: the experiences of working carers of older adults*. Joseph Rowntree Foundation
- Pickard, L. (2004). *Caring for older people and employment: a review of the literature prepared for the Audit Commission*. Audit Commission/PSSRU
- Pickard, L. (2004). *The effectiveness and cost-effectiveness of support and services to informal carers of older people: a review of the literature prepared for the Audit Commission*. London. Audit Commission/PSSRU
- Pickard, L. (2008). *Informal care for older people provided by their adult children: projections of supply and demand to 2041 in England*. PSSRU
- Pickard, S., & Glendinning, C. (2001). *Older carers of frail older people and the interfaces with primary care services*. Manchester: NPCRDC
- Pinfold, V., & Corry, P. (2003). *Under pressure: the impact of caring on people supporting family members or friends with mental health problems*. Rethink
- Platt, L. (2006). *Social participation: how does it vary with illness, caring and ethnic group?* ISER University of Essex
- Princess Royal Trust for Carers. (2011). *Always on call, always concerned: a survey of the experiences of older carers*. The Princess Royal Trust for Carers
- Princess Royal Trust for Carers. (2011). *Putting people first without putting carers second*. The Princess Royal Trust for Carers
- Princess Royal Trust for Carers/ADASS. (2010). *Supporting carers: early interventions and better outcomes*.
- Princess Royal Trust for Carers/Crossroads Care. (2011). *NHS not making the break for carers: a report on the implementation of the Carers Strategy by primary care trusts*.
- Rai-Atkins, A., Ali Jama, A., Wright, N., Velma Scott, Perring, C., Craig, G., & Katbamna, S. (2002). *Mental health advocacy for black and minority ethnic users and carers*. Joseph Rowntree Foundation
- Ramsden, S. (2010). *Practical approaches to co-production: building effective partnerships with people using services, carers, families and citizens*. London: Great Britain. Department of Health
- Rethink. (2003). *Who cares? The experiences of mental health carers accessing services and information*. Rethink
- Right care Right deal coalition. (2008). *It's everybody's business: care and support for the 21st century*.
- Ronicle, J., & Kendall, S. (2011). *Improving support for young carers: family-focused approaches*. Department for Education

- Rowbotham, D., Beecham, E., Jackson, C., & Penketh, K. (2010). *MyCare: the challenges facing young carers of parents with a severe mental illness*. Mental Health Foundation
- Savitch, N., Abbott, E., & Parker, G. (2015). *Dementia through the eyes of women*. Joseph Rowntree Foundation
- Sempik, K., & S., B. (2014). *Young adult carers at college and university*. Carers Trust
- Sheffield Carers Centre. (2001). *Who cares? Reminiscences of Yemeni carers in Sheffield*. Sheffield: Princess Royal Trust Sheffield Carers Centre
- Singleton, N., Aye Maung, N., Cowie, A., Sparks, J., Bumpstead, R., & Meltzer, H. (2002). *Mental health of carers* (0 11 621554 2). Norwich: Stationery Office/Great Britain. Office for National Statistics
- Social Care Institute for Excellence. (2012). *People not processes: the future of personalisation and independent living*. London: Social Care Institute for Excellence
- Social Policy Research Unit. (2014). *Household finances of Carer's Allowance recipients*. Department for Work and Pensions
- Social Services Inspectorate Wales. (2010). *A preliminary analysis of dementia in Wales*. Cardiff: Care and Social Services Inspectorate Wales
- Strategy on Carers: Income Task Force. (2008). *New Deal for Carers: revision of the Prime Minister's 1999 Strategy on Carers: Income Task Force report*. Strategy on Carers: Income Task Force
- Tabreham, J. D. (2008). *"Carers behind bars": the hidden world of caring in English prisons*. Nottingham: The Carers Federation
- Tew, J., Foster, S., & Gell, C. (2004). *Learning from experience: involving service users and carers in mental health education and training*. Mental Health in Higher Education
- Thomas, S., Dalton, J., Harden, M., Eastwood, A., & Parker, G. (2016). *Updated Meta-Review of Evidence on Support for Carers*. NIHR HS&DR:
- Vernooij-Dassen, M., Draskovic, I., McCleery, J., & Downs, M. (2011). *Cognitive reframing for carers of people with dementia*. Cochrane Library:
- Vickerstaff, S., Loretto, W., Milne, A., Alden, E., Billings, J., & White, P. (2009). *Employment support for carers* (9781847126306). London: The Stationery Office
- Victor, E. (2009). *A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence*. London: Princess Royal Trust for Carers
- Walker, C., Magrill, D., & Walker, A. (2002). *Preparing for the future: people with learning disabilities and their ageing family carers*. Joseph Rowntree Foundation
- Warner, L., Mariathan, J., Lawton-Smith, S., & Samele, C. (2006). *Choice literature review: a review of the literature and consultation on choice and decision-making for users and carers of mental health and social care services*. King's Fund/Sainsbury Centre for Mental Health
- Wayman, S., Raws, P., & Leadbitter, H. (2016). *There's nobody is there - no one who can actually help?* The Children's Society
- Wigfield, A. (2011). *New approaches to supporting carers' health and well-being: evidence from the National Carers' Strategy Demonstrator Sites programme*. University of Leeds: Centre for International Research on Care, Labour and Equalities
- Yeandle, S., & Buckner, L. (2007). *Carers, employment and services: Time for a new social contract?* Carers UK/University of Leeds
- Yeandle, S., Cinnamon, B., Buckner, L., Shipton, L., & Suokas, A. (2006). *Who cares wins: the social and business benefits of supporting working carers*. Carers UK

Yeandle, S., & Wiffield, A. (2011). *Training and Supporting Carers: The National Evaluation of the Caring with Confidence Programme*. University of Leeds: CIRCLE: Centre for International Research on Care

Yeandle, S., & Wiffield, A. E. (2011). *New approaches to supporting carers' health and well-being: evidence from the national carers' strategy demonstrator sites programme: report summary*. Leeds: School of Sociology and Social Policy University of Leeds

## Standard

National Collaborating Centre for Mental Health. (2012). *Autism in Adults: Diagnosis and Management*. London: National Institute for Health and Clinical Excellence.

National Institute for Health and Care Excellence. (2015). *Bipolar Disorder in Adults: Qs95*. London: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence. (2015). *Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities Whose Behaviour Challenges: Ng11*. London: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence. (2015). *Psychosis and Schizophrenia in Adults: Qs80* (pp. 55). London: National Institute for Health and Care Excellence.

## Thesis

Jacobs, A. (2013). *Employment and Coping Strategies in Carers of People with Young Onset Dementia*. (D.Clin.Psych.), University of London, Royal Holloway College (United Kingdom).

Jones, C. L. (2013). *Application of the Capability Approach to Health Economics Research Involving Informal Carers of People with Dementia*. (Ph.D.), University of Wales, Bangor (United Kingdom).

O'Donovan, S. (2004). *Dementia Caregiving Burden and Breakdown*. University of Glasgow.

Pungchompoo, W. (2013). *Experiences and Health Care Needs of Older People with End Stage Renal Disease Managed without Dialysis in Thailand During the Last Year of Life*. (D.Clin.Prac.), University of Southampton (United Kingdom).

Yanni, C. K. (2008). *Caring Women, Shrewd Strategies: The Organizational Dynamics of Home Health Care*. (Ph.D.), Yale University.

## Toolkits, training & multi-media

- Department of Health. (2010). *Dementia Awareness Campaign*.
- Dixon, J. (2007). *Ispeak at Home*.
- Garthwaite, T., & Cicero, R. (2016). *Population Assessment Toolkit*.
- Gramlich, S., McBride, G., Snelham, N., Myers, B. A., Williams, V., & Simons, K. (2003). *Journey to Independence: How to Run Your Life with Direct Payments*.
- Great Britain Department of Health. (2006). *Self-Assessment Toolkit: From Values to Action: The Chief Nursing Officer's Review of Mental Health Nursing*.
- Hardie, E., Lawton, A., & Bickerton, S. (2008). *Induction Award: Supporting People Who Have a Learning Disability: Trainer Pack with Cd-Rom*.
- Harvey, M., & Russell, G. (2001). *Perspectives on Young Carers: A Resource Bank*.
- Health Education England, K., Surrey and Sussex, (2014). *Developing Skills and Knowledge: Improving Dementia Care*.
- Jack, B., Paasche-Orlow, M., Mitchell, S., Forsythe, S., & Martin, J. (2013). *Re-Engineered Discharge (RED) Toolkit*.
- Munday, S. (2009). *Getting It Right: Assessments for Black and Minority Ethnic Carers and Service Users*.
- Princess Royal Trust for Carers/ADASS. (2010). *Commissioning Better Outcomes for Carers: And Knowing If You Have: A Local Needs and Response Audit Support Tool*.
- Research in Practice for Adults. (2016). *Social Work Practice with Carers*.
- Royal College of General Practitioners Clinical Innovation Research Centre. (2016). *Autistic Spectrum Disorders Toolkit*.
- Royal College of General Practitioners Clinical Innovation Research Centre Marie Curie. (2016). *Palliative and End of Life Care Toolkit*.
- Scottish Institute for Excellence in Social Work Education. (2007). *Leap Framework*.
- Scottish Social Services Council. (2013). *Enhanced Dementia Practice for Social Workers*.
- Social Care Institute for Excellence. (2009). *Interprofessional and Inter-Agency Collaboration (IPIAC): An Introduction to Interprofessional and Inter-Agency Collaboration*.
- Social Care Institute for Excellence. (2011). *Windows of Opportunity: Prevention and Early Intervention in Dementia: A Tool for Commissioners and Providers*.
- Social Care Institute for Excellence, Green, L., Statham, D., & Brand, D. (2010). *Fair Access to Care Services (FACS) 2010 Training Module*.
- Social Care Institute for Excellence, Lefevre, M., Richards, S., & Trevithick, P. (2008). *Communication Skills: Forming and Maintaining Relationships with Service Users, Carers, Professionals and Others*.
- Social Care Institute for Excellence, Milne, A., Gearing, B., & Warner, J. (2007). *An Introduction to the Mental Health of Older People: Understanding Later Stage Dementia*.
- Social Services Improvement Agency. (2011). *Getting Engaged: Notable Practice Database*.
- The Children's Society. (2011). *Engage Toolkit: Supporting Black and Minority Ethnic Family Carers*.
- TLAP. (2012). *Making It Real for Carers*.

University of Nottingham. (2015). *Supporting Carers in End of Life Care: An Introductory Programme*.