



# What is important to people with dementia?

Statements to help assess healthcare quality based on empirical research

## Scope

The Health Innovation Network is the Academic Health Science Network (AHSN) for South London, collaborating with partners from the NHS, universities, local government, industry, the third sector and service users and the public to promote innovation and best practice. Improving dementia care is one of the key clinical priorities for the Health Innovation Network.

The term 'dementia' is used to describe a collection of symptoms including loss of memory, mood changes, feeling sad, angry or frightened, communication problems and a gradual loss of the skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases. Dementia is a progressive condition and symptoms become more severe over time. Each person's experience of dementia will vary depending on the type of dementia, their physical make up, their emotional resilience and the support available to them. There is not currently a cure for dementia although medication can reduce symptoms and slow progression in some people. A range of support may improve people's quality of life.<sup>1</sup>

The Health Innovation Network is developing ways to measure the experience of health services among people with dementia and their carers. The process of developing the metrics is as important as the final outcome so people with dementia, carers, patient and carer representative organisations, professionals and other stakeholders are being engaged using a Delphi technique to elicit opinions. People will be asked questions and invited to rate the importance of various things. Their responses will be summarised and circulated for discussion in repeated rounds until consensus is reached. The Health Innovation Network wanted to ensure that the statements used in the Delphi process were based on research evidence so this document presents statements about **what matters to people with dementia and their carers** that could be used as part of quality measurement standards or indicators. The statements are drawn from empirical literature, specific to dementia.

Much work has been done about what matters to patients generally.<sup>2</sup> There are a number of frameworks for considering important aspects. For instance, building on the six-item US Institute of Medicine framework for person-centred care,<sup>3</sup> the Picker Institute framework includes eight domains: respect for patient-centred values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support; involvement of family and friends; transition and continuity; and access to care.<sup>4</sup> A meta-synthesis of different frameworks and proposed sets of domains of patient-centred care found that most contained similar concepts.<sup>5</sup> The Kings Fund reviewed literature about 'what matters' to patients and undertook case studies and analyses of survey data.<sup>6</sup> There have also been many thousands of studies published about improving patient experience<sup>7,8</sup> and measuring patient experience.<sup>9,10,11</sup> This document differs in that it draws on **empirical evidence about dementia care** to cross-check whether the things that people with dementia and their carers say are important to them match with more general characterisations about what is important for person-centred care.

## Compiling evidence

To compile a list of statements that could be used to test what matters most to patients, an independent team examined all documents compiled by the Health Innovation Network as a starting point to draw out important topic areas. Most of this material was not empirical literature relating to people's experiences of dementia care or what people and families wanted from dementia care. The material was largely descriptive, such as examples of small improvement projects, opinion pieces, editorials or material that did not relate to measurement.

After reviewing background materials, general frameworks about what is important in patient experience were examined followed by a search for empirical research specifically about patient experience in dementia.

Three bibliographic databases were searched for research published up until April 2014. Studies were eligible for inclusion if they focused on the experiences of people with dementia or their carers. This included studies asking people what was important to them as well as studies asking people to reflect on the quality of care received. Search terms included dementia, experience, carers, person-centred and Alzheimer's disease. There were no geographic or temporal restrictions.

In total, 2,971 studies were screened. From these, 162 relevant studies were identified and the full text reviewed. All of this material was drawn together into a list of statements reflecting key themes in what is important to people with dementia in terms of health and social care. The review was not focused on describing the findings of individual studies, but rather of creating a checklist of statements that people with dementia might make when commenting on the quality of services.

## Quality statements

The result of the review was a list of statements that people with dementia and their carers have made when assessing the quality of healthcare. The statements focus on:

- a) what care is provided
- b) how care is provided
- c) and how people feel as a result of the care provided

The statements can be divided into six domains:

- learning about dementia
- using services
- dignity and empathy
- involvement
- ongoing support
- and support to maintain some independence

The quality statements are listed in Box 1. Citations are provided by each statement to illustrate the empirical evidence base from which they have been adapted. Only empirical evidence is listed in the citations, though there are many other supporting documents such as the National Dementia Strategy and NICE quality standards.<sup>12,13,14,15</sup>

The statements are all worded positively, to highlight aspects that people with dementia and their carers think are important. However, in studies themselves, the concepts were equally likely to have been expressed as negative statements such as 'I have not been given enough information' or 'there is a lack of partnership working.' The statements should not be taken as verbatim comments or reflections of how people see current levels of care, but rather an extraction of what people would like to see or thought was important.

It is acknowledged that people with dementia may not always be able to respond to questions about their experience of care, especially in the later stages. It is also true that the statements in Box 1 are not necessarily worded in the most appropriate manner for speaking with someone with dementia or their carers. The quality statements are not meant to be used as presented without modification, but rather are a way of **summarising the types of comments people have made in the empirical literature about what is important to them.**

*Box 1: Statements made by people with dementia and their carers in the empirical literature about the quality of health services*

**Topic 1: What care is provided**

**1.1 Learning about dementia**

- My family and I were told I had dementia in a sensitive way.<sup>16,17,18,19</sup>
- It was quick to be diagnosed with dementia.<sup>20,21,22,23,24,25,26,27,28,29,30,31,32,33</sup>
- Professionals have been open with me about my dementia and my care.<sup>34,35,36</sup>
- I have been given clear information about dementia.<sup>37,38,39,40</sup>
- Professionals use language that is easy to understand.<sup>41</sup>
- I have been given enough information about dementia.<sup>42,43,44,45,46,47</sup>
- I have been given enough information to plan for the future.<sup>48,49,50</sup>
- I have been given a chance to ask questions.<sup>51</sup>
- I have been told about the risks and benefits of treatment in a way I can understand.<sup>52</sup>
- I have had an opportunity to meet other people with dementia and their families.<sup>53,54,55,56</sup>

**1.2 Using services**

- I get the treatment and support that is best for me and my life.<sup>57,58,59</sup>
- I can easily get services when I need to.<sup>60,61</sup>
- I do not have to wait too long when I need care.<sup>62</sup>
- I get a check-up regularly without asking for it.<sup>63</sup>
- I have enough help from health and social services.<sup>64</sup>
- My family or other important people have enough help from health and social services.<sup>65, 66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83</sup>
- I only go to hospital when I really need to.<sup>84</sup>
- I have all the equipment, furniture and privacy I need to be comfortable.<sup>85,86,87,88,89,90,91</sup>
- Health services tell me about other services in the community that could help me or my family.<sup>92,93,94,95</sup>

## **Topic 2: How care is provided**

### **2.1 Dignity and empathy**

- I am treated as a person, not a number.<sup>96,97,98,99,100</sup>
- Health and social services are designed around my needs.<sup>101,102,103,104</sup>
- Services take account of my age, ethnicity, religion, sexuality and other things that are important to me.<sup>105,106,107,108,109,110,111</sup>
- Services treat me with dignity and respect.<sup>112,113,114,115,116</sup>
- Staff try to put themselves in my shoes and understand what things are like for me.<sup>117,118</sup>
- Professionals are usually friendly and kind.<sup>119,120,121,122</sup>
- I feel supported and understood.<sup>123,124,125,126</sup>

### **2.2 Involvement**

- I feel listened to by professionals.<sup>127,128,129,130</sup>
- I can be involved in decisions about my care if I want to.<sup>131,132,133,134,135</sup>
- My care is a partnership between me, my family and professionals.<sup>136,137,138,139</sup>
- My family or other important people have been involved as much as I would like.<sup>140,141,142,143,144,145</sup>
- I know what I can do to help look after myself.<sup>146,147</sup>
- My family and I have been involved in planning what will happen in later life.<sup>148,149,150,151,152,153,154,155,156</sup>

### **2.3 Ongoing support**

- I trust the health and social services teams that support me.<sup>157</sup>
- There is good continuity in the care I receive over time.<sup>158,159,160</sup>
- There are good links between services so one service knows what another is doing.<sup>161,162</sup>
- There are smooth transitions between services.<sup>163</sup>

## **Topic 3: How people feel as a result of care**

### **3.1 Support to maintain some independence**

- We are supported so I don't feel like a burden to my family.<sup>164,165,166,167,168,169,170,171,172,173,174,175,176</sup>
- I am supported so I don't feel lonely.<sup>177,178,179,180</sup>
- I am supported so I feel part of a community.<sup>181,182,183,184,185,186,187,188,189,190</sup>
- I am supported to keep my identity and continue activities I enjoy.<sup>191,192,193,194,195,196,197,198,199,200,201</sup>
- I am supported so I don't usually feel depressed or anxious.<sup>202,203,204,205,206,207,208,209,210</sup>
- I have practical support with things like nutrition, sleep and hygiene.<sup>211,212,213,214,215,216,217,218</sup>
- My family have been helped with grief and coping.<sup>219,220,221,222,223,224,225,226,227,228,229,230,231,232,233,234,235,236,237,238,239,240,241,242,243,244,245,246,247,248,249,250,251,252</sup>

## Things to bear in mind

The quality statements in Box 1 include both functional aspects of the quality of care (what is provided) and relational aspects (how people experience care). There are likely to be too many statements to act as quality indicators because research suggests that people prefer short and simple statements when rating the quality of care. The purpose of this review of empirical literature was to amass a wide range of statements, and these will be further refined and prioritised via the Delphi process.

It is important to note that much of the research from which these statements are drawn relates to the caregivers of people with dementia rather than statements made by people with dementia themselves. Furthermore, the majority of research is based on qualitative interviews with small samples of people. Despite these caveats, the compilation does provide an empirically-based starting point to begin testing the most important domains to measure.

The statements broadly map to the Picker Institute framework of person-centred care, but there are some differences specific to dementia care. Table 1 illustrates how the literature about what is important to people with dementia maps to the eight domains in the Picker Institute framework.

*Table 1: Mapping statements from people with dementia onto the Picker Institute framework*

Domains identified in research	Domains in the Picker Institute framework
1.1 - Learning about dementia	Communication and education
1.2 - Using services	Access to care Physical comfort
2.1 - Dignity and empathy	Respect for patient-centred values, preferences and expressed needs Emotional support
2.2 - Involvement	Involvement of family and friends
2.3 - Ongoing support	Coordination and integration of care Transition and continuity
3.1 - Support to maintain some independence	

The empirical evidence provides few examples of people with dementia and their families focusing on physical comfort (such as food and noise) or integration. Statements about involvement, dignity and empathy are more common. This is not to suggest that some aspects are more important to people with dementia than others. Such comments could only be made following empirical testing. Rather, this observation is made to highlight that there are some **differences in the priorities expressed in published studies about dementia care** compared to generic frameworks about patient experience. Whilst the broad principles may be similar, the extent of prioritisation may differ. An example is statements about maintaining independence. Dementia research sometimes prioritises services that help to reduce isolation, loneliness and carer burden, whereas these concepts are not always included in more generic frameworks about person-centred experience.

In the US, a 'Person-Centred Dementia Care Framework' has been developed based on a literature review about dementia care and input from a wide range of experts.<sup>253</sup> The framework contains four levels as illustrated in Figure 1:

- The person living with dementia and their family is at the centre of care. The innermost ring signifies the network of people who care about the person.
- The next level focuses on the core values and philosophy underpinning person-centred care and this is linked to the domain of relationships and community.
- The next level focuses on structural domains deemed to be important for person-centred dementia care. These include a meaningful life, accountability, governance, leadership, workforce, services and the environment.
- Radiating from these domains are specific operational and individualised practices to support person-centred care.

The 'quality statements' identified from the current review for the Health Innovation Network span the four levels of this framework, though there is most emphasis on the core values (dignity, involvement, independence) and on the way these are operationalised in services rather than the structural elements. As with the mapping onto the Picker Institute framework, this again reinforces that empirical research with people with dementia and their carers has emphasised relational aspects of care rather than environmental or functional issues.

*Figure 1: Person-centred dementia care framework developed in the US<sup>254</sup>*



The next phase of the Health Innovation Network's project is to test the quality statements with people with dementia, their carers and stakeholder organisations in order to narrow down the list into those most useful and appropriate for measuring the quality of dementia care.



## References

- 1 NHS London. *London Dementia Needs Assessment 2011. Planning dementia services and delivering QIPP for London clusters*. London: NHS London, 2011.
- 2 Shaller D. *Patient-Centered Care: what does it take?* US: The Commonwealth Fund, 2006.
- 3 US Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. US: Institute of Medicine, 2001.
- 4 <http://pickerinstitute.org/about/picker-principles/>
- 5 Cronin C. *Patient-Centered Care: An Overview of Definitions and Concepts*. US: National Health Council, 2004.
- 6 The King's Fund. *What Matters to Patients? Developing the Evidence Base for Measuring and Improving Patient Experience*. London: Kings College London and the King's Fund.
- 7 Coulter A, Ellins J. *Patient-Focused Interventions: A Review of the Evidence*. London: Picker Institute Europe, 2006.
- 8 The King's Fund. *Reading List. The Point of Care: improving patients' experience*. London: The King's Fund, 2012.
- 9 de Silva D. *Helping measure person-centred care*. London: The Health Foundation 2014.
- 10 Collins A. *Measuring what really matters. Towards a coherent measurement system to support person-centred care*. London: The Health Foundation 2014.
- 11 Coulter A, Fitzpatrick R, Cornwell J. *The Point of Care. Measures of patients' experience in hospital: purpose, methods and uses*. London: The King's Fund, 2009.
- 12 Alzheimer's Society. *Counting the cost: Caring for people with dementia on hospital wards*. London: Alzheimer's Society, 2009.
- 13 Department of Health. *Living well with dementia: A National Dementia Strategy*. London: Department of Health, 2009.
- 14 Department of Health. *Quality outcomes for people with dementia – building on the work of the National Dementia Strategy*. London: Department of Health, 2010.
- 15 National Institute for Health and Clinical Excellence. *Dementia Quality Standard advice to the Secretary of State for Health*. NICE, 2010.
- 16 Robinson L, Gemski A, Abley C, Bond J, Keady J, Campbell S, Samsi K, Manthorpe J. [The transition to dementia - individual and family experiences of receiving a diagnosis: a review](#). *Int Psychogeriatr* 2011;23(7):1026-1043.
- 17 Laakkonen ML, Raivio MM, Eloniemi-Sulkava U, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH. [How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?](#) *J Med Ethics* 2008;34(6):427-430.
- 18 Mormont E, de Fays K, Jamart J. [Experiences of the patients and their caregivers regarding the disclosure of the diagnosis of Alzheimer's disease: a Belgian retrospective survey](#). *Acta Neurol Belg* 2012;112(3):249-254.
- 19 Shimizu MM, Raicher I, Takahashi DY, Caramelli P, Nitrini R. [Disclosure of the diagnosis of Alzheimer's disease: caregivers' opinions in a Brazilian sample](#). *Arq Neuropsiquiatr* 2008;66(3B):625-630.
- 20 Ducharme F, Kergoat MJ, Antoine P, Pasquier F, Coulombe R. [The unique experience of spouses in early-onset dementia](#). *Am J Alzheimers Dis Other Dement* 2013;28(6):634-641.
- 21 Engberink AO, Pimouguet C, Amouyal M, Gerassimo O, Bourrel G, Berr C. [Determinants of support for dementia patients in general practice: a qualitative approach based on an epidemiological cohort](#). *Geriatr Psychol Neuropsychiatr Vieil* 2013;11(2):157-167.
- 22 Robinson L, Gemski A, Abley C, Bond J, Keady J, Campbell S, Samsi K, Manthorpe J. [The transition to dementia - individual and family experiences of receiving a diagnosis: a review](#). *Int Psychogeriatr* 2011;23(7):1026-1043.
- 23 Prorok JC, Horgan S, Seitz DP. [Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies](#). *CMAJ* 2013;185(14):E669-E680.
- 24 Górska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, Flockhart J, Fairnie J, Reid J. [Service-related needs of older people with dementia: perspectives of service users and their unpaid carers](#). *Int Psychogeriatr* 2013;25(7):1107-1114.
- 25 Carpentier N, Bernard P, Grenier A, Guberman N. [Using the life course perspective to study the entry into the illness trajectory: the perspective of caregivers of people with Alzheimer's disease](#). *Soc Sci Med* 2010;70(10):1501-1508.
- 26 Boustani MA, Justiss MD, Frame A, Austrom MG, Perkins AJ, Cai X, Sachs GA, Torke AM, Monahan P, Hendrie HC. [Caregiver and noncaregiver attitudes toward dementia screening](#). *J Am Geriatr Soc* 2011;59(4):681-686.

- 27 Innes A, Szymczynska P, Stark C. [Dementia diagnosis and post-diagnostic support in Scottish rural communities: experiences of people with dementia and their families.](#) *Dementia* 2014;13(2):233-247.
- 28 Singh P, Hussain R, Khan A, Irwin L, Foskey R. [Dementia care: intersecting informal family care and formal care systems.](#) *J Aging Res* (Published online February 2014).
- 29 van Vliet D, de Vugt ME, Bakker C, Koopmans RT, Pijnenburg YA, Vernooij-Dassen MJ, Verhey FR. [Caregivers' perspectives on the pre-diagnostic period in early onset dementia: a long and winding road.](#) *Int Psychogeriatr* 2011;23(9):1393-1404.
- 30 Samsi K, Abley C, Campbell S, Keady J, Manthorpe J, Robinson L, Watts S, Bond J. [Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia.](#) *Int J Geriatr Psychiatry* 2014;29(1):58-67.
- 31 Chrisp TA, Tabberer S, Thomas BD, Goddard WA. [Dementia early diagnosis: triggers, supports and constraints affecting the decision to engage with the health care system.](#) *Aging Ment Health* 2012;16(5):559-565.
- 32 Justiss MD, Boustani M, Fox C, Katona C, Perkins AJ, Healey PJ, Sachs G, Hui S, Callahan CM, Hendrie HC, Scott E. [Patients' attitudes of dementia screening across the Atlantic.](#) *Int J Geriatr Psychiatry* 2009;24(6):632-637.
- 33 Boustani M, Perkins AJ, Monahan P, Fox C, Watson L, Hopkins J, Fultz B, Hui S, Unverzagt FW, Callahan CM, Hendrie HC. [Measuring primary care patients' attitudes about dementia screening.](#) *Int J Geriatr Psychiatry* 2008;23(8):812-820.
- 34 Laakkonen ML, Raivio MM, Eloniemi-Sulkava U, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH. [How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?](#) *J Med Ethics* 2008;34(6):427-430.
- 35 Gruetzner H, Ellor JW, Back N. [Identifiable grief responses in persons with Alzheimer's disease.](#) *J Soc Work End Life Palliat Care* 2012;8(2):151-164.
- 36 Holroyd S, Turnbull Q, Wolf AM. [What are patients and their families told about the diagnosis of dementia? Results of a family survey.](#) *Int J Geriatr Psychiatry* 2002;17(3):218-221.
- 37 Ducharme F, Lévesque L, Lachance L, Kergoat MJ, Coulombe R. [Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study.](#) *Int J Nurs Stud* 2011;48(9):1109-1119.
- 38 van der Steen JT, Arcand M, Toscani F, de Graas T, Finetti S, Beaulieu M, Brazil K, Nakanishi M, Nakashima T, Knol DL, Hertogh CM. [A family booklet about comfort care in advanced dementia: three-country evaluation.](#) *J Am Med Dir Assoc* 2012;13(4):368-375.
- 39 Chan WC, Ng C, Mok CC, Wong FL, Pang SL, Chiu HF. [Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study.](#) *East Asian Arch Psychiatry* 2010;20(4):163-168.
- 40 Quinn C, Clare L, Pearce A, van Dijkhuizen M. [The experience of providing care in the early stages of dementia: an interpretative phenomenological analysis.](#) *Aging Ment Health* 2008;12(6):769-778.
- 41 Prorok JC, Horgan S, Seitz DP. [Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies.](#) *CMAJ* 2013;185(14):E669-E680.
- 42 Engberink AO, Pimouguet C, Amouyal M, Gerassimo O, Bourrel G, Berr C. [Determinants of support for dementia patients in general practice: a qualitative approach based on an epidemiological cohort.](#) *Geriatr Psychol Neuropsychiatr Vieil* 2013;11(2):157-167.
- 43 Melunsky N, Crellin N, Dudzinski E, Orrell M, Wenborn J, Poland F, Woods B, Charlesworth G. [The experience of family carers attending a joint reminiscence group with people with dementia: a thematic analysis.](#) *Dementia* (Published online February 2014).
- 44 Stokes LA, Combes H, Stokes G. [Understanding the dementia diagnosis: the impact on the caregiving experience.](#) *Dementia* 2014;13(1):59-78.
- 45 McDonnell E, Ryan AA. [The experience of sons caring for a parent with dementia.](#) *Dementia* (Published online April 2013).
- 46 de Jong JD, Boersma F. [Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers.](#) *Int Psychogeriatr* 2009;21(2):268-277.
- 47 Holroyd S, Turnbull Q, Wolf AM. [What are patients and their families told about the diagnosis of dementia? Results of a family survey.](#) *Int J Geriatr Psychiatry* 2002;17(3):218-221.
- 48 Ducharme F, Kergoat MJ, Antoine P, Pasquier F, Coulombe R. [The unique experience of spouses in early-onset dementia.](#) *Am J Alzheimers Dis Other Dement* 2013;28(6):634-641.
- 49 Ducharme F, Lévesque L, Lachance L, Kergoat MJ, Coulombe R. [Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study.](#) *Int J Nurs Stud* 2011;48(9):1109-1119.
- 50 Forbes DA, Finkelstein S, Blake CM, Gibson M, Morgan DG, Markle-Reid M, Culum I, Thiessen E. [Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study.](#) *Rural Remote Health* 2012;12(4):2201.

- 51 Laakkonen ML, Raivio MM, Eloniemi-Sulkava U, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH. [How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?](#) *J Med Ethics* 2008;34(6):427-430.
- 52 Prorok JC, Horgan S, Seitz DP. [Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies.](#) *CMAJ* 2013;185(14):E669-E680.
- 53 Taşç S, Tekinsoy Kartn P, Ceyhan O, Sungur G, Göriş S. [Living with an Alzheimer patient in Turkey.](#) *J Neurosci Nurs* 2012;44(4):228-234.
- 54 de Witt L, Ploeg J, Black M. [Living alone with dementia: an interpretive phenomenological study with older women.](#) *J Adv Nurs* 2010;66(8):1698-1707.
- 55 Blake M. [Group reminiscence therapy for adults with dementia: a review.](#) *Br J Community Nurs* 2013;18(5):228-233.
- 56 Wang LQ, Chien WT, Lee IY. [An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China.](#) *Contemp Nurse* 2012;40(2):210-224.
- 57 Chou HK, Yan SH, Lin IC, Tsai MT, Chen CC, Woung LC. [A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers.](#) *J Nurs Res* 2012;20(3):169-180.
- 58 Prorok JC, Horgan S, Seitz DP. [Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies.](#) *CMAJ* 2013;185(14):E669-E680.
- 59 Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. [A videophone psychosocial intervention for dementia caregivers.](#) *Am J Geriatr Psychiatry* 2013;21(11):1071-1081.
- 60 Chou HK, Yan SH, Lin IC, Tsai MT, Chen CC, Woung LC. [A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers.](#) *J Nurs Res* 2012;20(3):169-180.
- 61 Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. [A videophone psychosocial intervention for dementia caregivers.](#) *Am J Geriatr Psychiatry* 2013;21(11):1071-1081.
- 62 Górska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, Flockhart J, Fairnie J, Reid J. [Service-related needs of older people with dementia: perspectives of service users and their unpaid carers.](#) *Int Psychogeriatr* 2013;25(7):1107-1114.
- 63 Keady J, Jones L, Ward R, Koch S, Swarbrick C, Hellström I, Davies-Quarrell V, Williams S. [Introducing the bio-psycho-social-physical model of dementia through a collective case study design.](#) *J Clin Nurs* 2013;22(19-20):2768-2777.
- 64 Górska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, Flockhart J, Fairnie J, Reid J. [Service-related needs of older people with dementia: perspectives of service users and their unpaid carers.](#) *Int Psychogeriatr* 2013;25(7):1107-1114.
- 65 Ducharme F, Kergoat MJ, Antoine P, Pasquier F, Coulombe R. [The unique experience of spouses in early-onset dementia.](#) *Am J Alzheimers Dis Other Demen* 2013;28(6):634-641.
- 66 Chou HK, Yan SH, Lin IC, Tsai MT, Chen CC, Woung LC. [A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers.](#) *J Nurs Res* 2012;20(3):169-180.
- 67 Madsen R, Birkelund R. ['The path through the unknown': the experience of being a relative of a dementia-suffering spouse or parent.](#) *J Clin Nurs* 2013;22(21-22):3024-3031.
- 68 Robinson L, Gemski A, Abley C, Bond J, Keady J, Campbell S, Samsi K, Manthorpe J. [The transition to dementia - individual and family experiences of receiving a diagnosis: a review.](#) *Int Psychogeriatr* 2011;23(7):1026-1043.
- 69 Hsiao HC, Chao HC, Wang JJ. [Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience.](#) *Geriatr Nurs* 2013;34(5):361-365.
- 70 Taşç S, Tekinsoy Kartn P, Ceyhan O, Sungur G, Göriş S. [Living with an Alzheimer patient in Turkey.](#) *J Neurosci Nurs* 2012;44(4):228-234.
- 71 Simpson C, Carter P. [Dementia behavioural and psychiatric symptoms: effect on caregiver's sleep.](#) *J Clin Nurs* 2013;22(21-22):3042-3052.
- 72 Digby R, Moss C, Bloomer M. [Transferring from an acute hospital and settling into a subacute facility: the experience of patients with dementia.](#) *Int J Older People Nurs* 2012;7(1):57-64.
- 73 Melunsky N, Crellin N, Dudzinski E, Orrell M, Wenborn J, Poland F, Woods B, Charlesworth G. [The experience of family carers attending a joint reminiscence group with people with dementia: a thematic analysis.](#) *Dementia* (Published online February 2014).
- 74 Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. [A videophone psychosocial intervention for dementia caregivers.](#) *Am J Geriatr Psychiatry* 2013;21(11):1071-1081.
- 75 Qadir F, Gulzar W, Haqqani S, Khalid A. [A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia.](#) *Care Manag J* 2013;14(4):230-240.
- 76 Vellone E, Piras G, Venturini G, Alvaro R, Cohen MZ. [The experience of quality of life for caregivers of people with Alzheimer's disease living in Sardinia, Italy.](#) *J Transcult Nurs* 2012;23(1):46-55.

- 77 Botsford J, Clarke CL, Gibb CE. [Dementia and relationships: experiences of partners in minority ethnic communities](#). *J Adv Nurs* 2012;68(10):2207-2217.
- 78 Merrick K, Camic PM, O'Shaughnessy M. [Couples constructing their experiences of dementia: a relational perspective](#). *Dementia* (Published online December 2013).
- 79 Quinn C, Clare L, Woods RT. [Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia](#). *Dementia* (Published online July 2013).
- 80 Mushi D, Rongai A, Paddick SM, Dotchin C, Mtuya C, Walker R. [Social representation and practices related to dementia in Hai District of Tanzania](#). *BMC Public Health* 2014;14(1):260.
- 81 Duggleby WD, Swindle J, Peacock S, Ghosh S. [A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease](#). *BMC Geriatr* 2011;11:88.
- 82 Nichols KR, Fam D, Cook C, Pearce M, Elliot G, Baago S, Rockwood K, Chow TW. [When dementia is in the house: needs assessment survey for young caregivers](#). *Can J Neurol Sci* 2013;40(1):21-28.
- 83 Innes A, Morgan D, Kosteniuk J. [Dementia care in rural and remote settings: a systematic review of informal/family caregiving](#). *Maturitas* 2011;68(1):34-46.
- 84 Peacock S, Duggleby W, Koop P. [The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia](#). *Palliat Support Care* 2014;12(2):117-126.
- 85 Keady J, Jones L, Ward R, Koch S, Swarbrick C, Hellström I, Davies-Quarrell V, Williams S. [Introducing the bio-psycho-social-physical model of dementia through a collective case study design](#). *J Clin Nurs* 2013;22(19-20):2768-2777.
- 86 Peacock S, Duggleby W, Koop P. [The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia](#). *Palliat Support Care* 2014;12(2):117-126.
- 87 Digby R, Bloomer MJ. [People with dementia and the hospital environment: the view of patients and family carers](#). *Int J Older People Nurs* 2014;9(1):34-43.
- 88 Brittain K, Corner L, Robinson L, Bond J. [Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments](#). *Social Health Illn* 2010;32(2):272-287.
- 89 Moyle W, Murfield J, Venturto L, Griffiths S, Grimbeek P, McAllister M, Marshall J. [Dementia and its influence on quality of life and what it means to be valued: family members' perceptions](#). *Dementia* (Published online February 2013).
- 90 Aminzadeh F, Dalziel WB, Molnar FJ, Garcia LJ. [Meanings, functions, and experiences of living at home for individuals with dementia at the critical point of relocation](#). *J Gerontol Nurs* 2010;36(6):28-35.
- 91 Edvardsson D, Nordvall K. [Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia](#). *J Clin Nurs* 2008;17(4):491-498.
- 92 Ducharme F, Lévesque L, Lachance L, Kergoat MJ, Coulombe R. [Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study](#). *Int J Nurs Stud* 2011;48(9):1109-1119.
- 93 Taşç S, Tekinsoy Kartn P, Ceyhan O, Sungur G, Göriş S. [Living with an Alzheimer patient in Turkey](#). *J Neurosci Nurs* 2012;44(4):228-234.
- 94 Forbes DA, Finkelstein S, Blake CM, Gibson M, Morgan DG, Markle-Reid M, Culum I, Thiessen E. [Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study](#). *Rural Remote Health* 2012;12(4):2201.
- 95 Sussman T, Regehr C. [The influence of community-based services on the burden of spouses caring for their partners with dementia](#). *Health Soc Work* 2009;34(1):29-39.
- 96 Moyle W, Gracia N, Murfield JE, Griffiths SG, Venturato L. [Assessing quality of life of older people with dementia in long-term care: a comparison of two self-report measures](#). *J Clin Nurs* 2012;21(11-12):1632-1640.
- 97 Hsiao HC, Chao HC, Wang JJ. [Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience](#). *Geriatr Nurs* 2013;34(5):361-365.
- 98 Moyle W, Venturato L, Cooke M, Hughes J, van Wyk S, Marshall J. [Promoting value in dementia care: staff, resident and family experience of the capabilities model of dementia care](#). *Aging Ment Health* 2013;17(5):587-594.
- 99 Nowell ZC, Thornton A, Simpson J. [The subjective experience of personhood in dementia care settings](#). *Dementia* 2013;12(4):394-409.
- 100 Moyle W, Murfield J, Venturto L, Griffiths S, Grimbeek P, McAllister M, Marshall J. [Dementia and its influence on quality of life and what it means to be valued: family members' perceptions](#). *Dementia* (Published online February 2013).
- 101 Moyle W, Venturato L, Cooke M, Hughes J, van Wyk S, Marshall J. [Promoting value in dementia care: staff, resident and family experience of the capabilities model of dementia care](#). *Aging Ment Health* 2013;17(5):587-594.

- 102 Nowell ZC, Thornton A, Simpson J. [The subjective experience of personhood in dementia care settings.](#) *Dementia* 2013;12(4):394-409.
- 103 de Jong JD, Boersma F. [Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers.](#) *Int Psychogeriatr* 2009;21(2):268-277.
- 104 Morhardt D, Pereyra M, Iris M. [Seeking a diagnosis for memory problems: the experiences of caregivers and families in 5 limited English proficiency communities.](#) *Alzheimer Dis Assoc Disord* 2010;24 Suppl:S42-S48.
- 105 Qadir F, Gulzar W, Haqqani S, Khalid A. [A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia.](#) *Care Manag J* 2013;14(4):230-240.
- 106 Caldwell L, Low LF, Brodaty H. [Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds.](#) *Int Psychogeriatr* 2014;26(3):413-424.
- 107 Botsford J, Clarke CL, Gibb CE. [Dementia and relationships: experiences of partners in minority ethnic communities.](#) *J Adv Nurs* 2012;68(10):2207-2217.
- 108 van der Steen JT, Arcand M, Toscani F, de Graas T, Finetti S, Beaulieu M, Brazil K, Nakanishi M, Nakashima T, Knol DL, Hertogh CM. [A family booklet about comfort care in advanced dementia: three-country evaluation.](#) *J Am Med Dir Assoc* 2012;13(4):368-375.
- 109 Hodge DR, Sun F. [Positive feelings of caregiving among Latino Alzheimer's family caregivers: understanding the role of spirituality.](#) *Aging Ment Health* 2012;16(6):689-698.
- 110 Olson MC. "The heart still beat, but the brain doesn't answer". [Perception and experience of old-age dementia in the Milwaukee Hmong community.](#) *Theor Med Bioeth* 1999;20(1):85-95.
- 111 Price E. [Coming out to care: gay and lesbian carers' experiences of dementia services.](#) *Health Soc Care Community* 2010;18(2):160-168.
- 112 Prorok JC, Horgan S, Seitz DP. [Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies.](#) *CMAJ* 2013;185(14):E669-E680.
- 113 Crowther J, Wilson KC, Horton S, Lloyd-Williams M. [Compassion in healthcare - lessons from a qualitative study of the end of life care of people with dementia.](#) *J R Soc Med* 2013;106(12):492-497.
- 114 Samsi K, Manthorpe J. [Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers.](#) *Int Psychogeriatr* 2013;25(6):949-961.
- 115 Heggstad AK, Nortvedt P, Slettebø Å. ['Like a prison without bars': dementia and experiences of dignity.](#) *Nurs Ethics* 2013;20(8):881-892.
- 116 Russell C, Middleton H, Shanley C. [Dying with dementia: the views of family caregivers about quality of life.](#) *Australas J Ageing* 2008;27(2):89-92.
- 117 Digby R, Moss C, Bloomer M. [Transferring from an acute hospital and settling into a subacute facility: the experience of patients with dementia.](#) *Int J Older People Nurs* 2012;7(1):57-64.
- 118 Crowther J, Wilson KC, Horton S, Lloyd-Williams M. [Compassion in healthcare - lessons from a qualitative study of the end of life care of people with dementia.](#) *J R Soc Med* 2013;106(12):492-497.
- 119 Prorok JC, Horgan S, Seitz DP. [Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies.](#) *CMAJ* 2013;185(14):E669-E680.
- 120 Digby R, Moss C, Bloomer M. [Transferring from an acute hospital and settling into a subacute facility: the experience of patients with dementia.](#) *Int J Older People Nurs* 2012;7(1):57-64.
- 121 Crowther J, Wilson KC, Horton S, Lloyd-Williams M. [Compassion in healthcare - lessons from a qualitative study of the end of life care of people with dementia.](#) *J R Soc Med* 2013;106(12):492-497.
- 122 Innes A, Surr C. [Measuring the well-being of people with dementia living in formal care settings: the use of dementia care mapping.](#) *Aging Ment Health* 2001;5(3):258-268.
- 123 Moyle W, Venturato L, Cooke M, Hughes J, van Wyk S, Marshall J. [Promoting value in dementia care: staff, resident and family experience of the capabilities model of dementia care.](#) *Aging Ment Health* 2013;17(5):587-594.
- 124 Hochgraeber I, Riesner C, Schoppmann S. [The experience of people with dementia in a social care group: case study.](#) *Dementia* 2013;12(6):751-768.
- 125 Moyle W, O'Dwyer S. [Quality of life in people living with dementia in nursing homes.](#) *Curr Opin Psychiatry* 2012;25(6):480-484.
- 126 Moyle W, Murfield J, Venturto L, Griffiths S, Grimbeek P, McAllister M, Marshall J. [Dementia and its influence on quality of life and what it means to be valued: family members' perceptions.](#) *Dementia* (Published online February 2013).
- 127 Hsiao HC, Chao HC, Wang JJ. [Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience.](#) *Geriatr Nurs* 2013;34(5):361-365.
- 128 Helgesen AK, Larsson M, Athlin E. [How do relatives of persons with dementia experience their role in the patient participation process in special care units?](#) *J Clin Nurs* 2013;22(11-12):1672-1681.
- 129 Jurgens FJ, Clissett P, Gladman JR, Harwood RH. [Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study.](#) *BMC Geriatr* 2012;12:57.

- 130 Hong SI, Luo N, Yap P. [Maximizing a nurturing care style for persons with dementia: a person-centered analysis.](#) *Am J Geriatr Psychiatry* 2013;21(10):987-998.
- 131 Hsiao HC, Chao HC, Wang JJ. [Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience.](#) *Geriatr Nurs* 2013;34(5):361-365.
- 132 Digby R, Moss C, Bloomer M. [Transferring from an acute hospital and settling into a subacute facility: the experience of patients with dementia.](#) *Int J Older People Nurs* 2012;7(1):57-64.
- 133 Samsi K, Manthorpe J. [Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers.](#) *Int Psychogeriatr* 2013;25(6):949-961.
- 134 Smebye KL, Kirkevold M, Engedal K. [How do persons with dementia participate in decision making related to health and daily care? A multi-case study.](#) *BMC Health Serv Res* 2012;12:241.
- 135 Brataas HV, Bjugan H, Wille T, Hellzen O. [Experiences of day care and collaboration among people with mild dementia.](#) *J Clin Nurs* 2010;19(19-20):2839-2848.
- 136 Stephan A, Afram B, Renom Guiteras A, Gerlach A, Meyer G. [Persons with dementia in the nursing home: family caregivers provide information on grounds for admission and how they experience the situation afterward. Accompaniment and support in the transition phase.](#) *Pflege Z* 2013;66(4):208-212.
- 137 Helgesen AK, Larsson M, Athlin E. [How do relatives of persons with dementia experience their role in the patient participation process in special care units?](#) *J Clin Nurs* 2013;22(11-12):1672-1681.
- 138 Tanner D. [Co-research with older people with dementia: experience and reflections.](#) *J Ment Health* 2012;21(3):296-306.
- 139 de Jong JD, Boersma F. [Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers.](#) *Int Psychogeriatr* 2009;21(2):268-277.
- 140 Stephan A, Afram B, Renom Guiteras A, Gerlach A, Meyer G. [Persons with dementia in the nursing home: family caregivers provide information on grounds for admission and how they experience the situation afterward. Accompaniment and support in the transition phase.](#) *Pflege Z* 2013;66(4):208-212.
- 141 Helgesen AK, Larsson M, Athlin E. [How do relatives of persons with dementia experience their role in the patient participation process in special care units?](#) *J Clin Nurs* 2013;22(11-12):1672-1681.
- 142 Kwon S, Tae YS. [The experience of adult Korean children caring for parents institutionalized with dementia.](#) *J Korean Acad Nurs* 2014;44(1):41-54.
- 143 Shim B, Barroso J, Gilliss CL, Davis LL. [Finding meaning in caring for a spouse with dementia.](#) *Appl Nurs Res* 2013;26(3):121-126.
- 144 Givens JL, Lopez RP, Mazor KM, Mitchell SL. [Sources of stress for family members of nursing home residents with advanced dementia.](#) *Alzheimer Dis Assoc Disord* 2012;26(3):254-259.
- 145 Raymond M, Warner A, Davies N, Illiffe S, Manthorpe J, Ahmedzhai S. [Palliative care services for people with dementia: a synthesis of the literature reporting the views and experiences of professionals and family carers.](#) *Dementia* 2014;13(1):96-110.
- 146 Martin F, Turner A, Wallace LM, Choudhry K, Bradbury N. [Perceived barriers to self-management for people with dementia in the early stages.](#) *Dementia* 2013;12(4):481-493.
- 147 Martin F, Turner A, Wallace LM, Stanley D, Jesuthasan J, Bradbury N. [Qualitative evaluation of a self-management intervention for people in the early stage of dementia.](#) *Dementia* (Published online August 2013).
- 148 Samsi K, Manthorpe J. [Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers.](#) *Int Psychogeriatr* 2013;25(6):949-961.
- 149 Forbes DA, Finkelstein S, Blake CM, Gibson M, Morgan DG, Markle-Reid M, Culum I, Thiessen E. [Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study.](#) *Rural Remote Health* 2012;12(4):2201.
- 150 Goodman C, Amador S, Elmore N, Machen I, Mathie E. [Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes.](#) *Int J Nurs Stud* 2013;50(12):1639-1647.
- 151 Givens JL, Lopez RP, Mazor KM, Mitchell SL. [Sources of stress for family members of nursing home residents with advanced dementia.](#) *Alzheimer Dis Assoc Disord* 2012;26(3):254-259.
- 152 van Uden N, Van den Block L, van der Steen JT, Onwuteaka-Philipsen BD, Vandervoort A, Vander Stichele R, Deliens L. [Quality of dying of nursing home residents with dementia as judged by relatives.](#) *Int Psychogeriatr* 2013;25(10):1697-1707.
- 153 Ashton S, Roe B, Jack B, McClelland B. [A study to explore the experience of advanced care planning among family caregivers and relatives of people with advanced dementia.](#) *BMJ Support Palliat Care* 2011;1(1):91.
- 154 Deep KS, Hunter A, Murphy K, Volandes A. ["It helps me see with my heart": how video informs patients' rationale for decisions about future care in advanced dementia.](#) *Patient Educ Couns* 2010;81(2):229-234.
- 155 Dening KH, Greenish W, Jones L, Mandal U, Sampson EL. [Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study.](#) *BMJ Support Palliat Care* 2012;2(2):103-107.

- 156 Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. [Patients dying with dementia: experience at the end of life and impact of hospice care.](#) *J Pain Symptom Manage* 2008;35(5):499-507.
- 157 Helgesen AK, Larsson M, Athlin E. [How do relatives of persons with dementia experience their role in the patient participation process in special care units?](#) *J Clin Nurs* 2013;22(11-12):1672-1681.
- 158 Laakkonen ML, Raivio MM, Eloniemi-Sulkava U, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH. [How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?](#) *J Med Ethics* 2008;34(6):427-430.
- 159 Górska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, Flockhart J, Fairnie J, Reid J. [Service-related needs of older people with dementia: perspectives of service users and their unpaid carers.](#) *Int Psychogeriatr* 2013;25(7):1107-1114.
- 160 von Kutzleben M, Schmid W, Halek M, Holle B, Bartholomeyczik S. [Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia.](#) *Aging Ment Health* 2012;16(3):378-390.
- 161 Stephan A, Afram B, Renom Guiteras A, Gerlach A, Meyer G. [Persons with dementia in the nursing home: family caregivers provide information on grounds for admission and how they experience the situation afterward. Accompaniment and support in the transition phase.](#) *Pflege Z* 2013;66(4):208-212.
- 162 Stokes LA, Combes H, Stokes G. [Understanding the dementia diagnosis: the impact on the caregiving experience.](#) *Dementia* 2014;13(1):59-78.
- 163 Stephan A, Afram B, Renom Guiteras A, Gerlach A, Meyer G. [Persons with dementia in the nursing home: family caregivers provide information on grounds for admission and how they experience the situation afterward. Accompaniment and support in the transition phase.](#) *Pflege Z* 2013;66(4):208-212.
- 164 Ducharme F, Kergoat MJ, Antoine P, Pasquier F, Coulombe R. [The unique experience of spouses in early-onset dementia.](#) *Am J Alzheimers Dis Other Demen* 2013;28(6):634-641.
- 165 Ducharme F, Lévesque L, Lachance L, Kergoat MJ, Coulombe R. [Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study.](#) *Int J Nurs Stud* 2011;48(9):1109-1119.
- 166 Peacock SC. [The experience of providing end-of-life care to a relative with advanced dementia: an integrative literature review.](#) *Palliat Support Care* 2013;11(2):155-168.
- 167 Kindell J, Sage K, Wilkinson R, Keady J. [Living with semantic dementia: a case study of one family's experience.](#) *Qual Health Res* 2014;24(3):401-411.
- 168 Papastavrou E, Charalambous A, Tsangari H, Karayiannis G. [The burdensome and depressive experience of caring: what cancer, schizophrenia, and Alzheimer's disease caregivers have in common.](#) *Cancer Nurs* 2012;35(3):187-194.
- 169 Hydén LC, Nilsson E. [Couples with dementia: positioning the 'we'.](#) *Dementia* (Published online October 2013).
- 170 de la Cuesta-Benjumea C. [Strategies for the relief of burden in advanced dementia care-giving.](#) *J Adv Nurs* 2011;67(8):1790-1799.
- 171 Ablitt A, Jones G, Muers J. [Awareness of carer distress in people with dementia.](#) *Int J Geriatr Psychiatry* 2010;25(12):1246-1252.
- 172 Papastavrou E, Andreou P, Middleton N, Papacostas S, Georgiou IK. [Factors associated with quality of life among family members of patients with dementia in Cyprus.](#) *Int Psychogeriatr* 2014;26(3):443-452.
- 173 Sun F. [Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia.](#) *Dementia* (Published online April 2013).
- 174 Ablitt A, Jones GV, Muers J. [Living with dementia: a systematic review of the influence of relationship factors.](#) *Aging Ment Health* 2009;13(4):497-511.
- 175 Sussman T, Regehr C. [The influence of community-based services on the burden of spouses caring for their partners with dementia.](#) *Health Soc Work* 2009;34(1):29-39.
- 176 Liken MA. [\(Not\) a Hallmark holiday. Experience of family caregivers of a relative with Alzheimer's disease.](#) *J Psychosoc Nurs Ment Health Serv* 2001;39(12):32-37.
- 177 Kasper JD, Black BS, Shore AD, Rabins PV. [Evaluation of the validity and reliability of the Alzheimer disease-related quality of life assessment instrument.](#) *Alzheimer Dis Assoc Disord* 2009;23(3):275-284.
- 178 Harris PB. [Dementia and friendship: the quality and nature of the relationships that remain.](#) *Int J Aging Hum Dev* 2013;76(2):141-164.
- 179 Shub D, Bass DM, Morgan RO, Judge KS, Snow AL, Wilson NL, Walder A, Murry B, Kunik ME. [Irritability and social isolation in dementia patients with and without depression.](#) *J Geriatr Psychiatry Neurol* 2011;24(4):229-234.
- 180 Moyle W, Jones C, Cooke M, O'Dwyer S, Sung B, Drummond S. [Connecting the person with dementia and family: a feasibility study of a telepresence robot.](#) *BMC Geriatr* 2014;14:7.

- 181 Mazaheri M, Eriksson LE, Heikkilä K, Nasrabadi AN, Ekman SL, Sunvisson H. [Experiences of living with dementia: qualitative content analysis of semi-structured interviews.](#) *J Clin Nurs* 2013;22(21-22):3032-3041.
- 182 Górska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, Flockhart J, Fairmie J, Reid J. [Service-related needs of older people with dementia: perspectives of service users and their unpaid carers.](#) *Int Psychogeriatr* 2013;25(7):1107-1114.
- 183 Hochgraeber I, Riesner C, Schoppmann S. [The experience of people with dementia in a social care group: case study.](#) *Dementia* 2013;12(6):751-768.
- 184 Harris PB. [Dementia and friendship: the quality and nature of the relationships that remain.](#) *Int J Aging Hum Dev* 2013;76(2):141-164.
- 185 Lawrence V, Samsi K, Banerjee S, Morgan C, Murray J. [Threat to valued elements of life: the experience of dementia across three ethnic groups.](#) *Gerontologist* 2011;51(1):39-50.
- 186 Moyle W, O'Dwyer S. [Quality of life in people living with dementia in nursing homes.](#) *Curr Opin Psychiatry* 2012;25(6):480-484.
- 187 Brooker DJ, Argyle E, Scally AJ, Clancy D. [The enriched opportunities programme for people with dementia: a cluster-randomised controlled trial in 10 extra care housing schemes.](#) *Aging Ment Health* 2011;15(8):1008-1017.
- 188 Johannessen A, Möller A. [Experiences of persons with early-onset dementia in everyday life: a qualitative study.](#) *Dementia* 2013;12(4):410-424.
- 189 Lopez RP, Mazor KM, Mitchell SL, Givens JL. [What is family-centered care for nursing home residents with advanced dementia?](#) *Am J Alzheimers Dis Other Demen* 2013;28(8):763-768.
- 190 Brataas HV, Bjugan H, Wille T, Hellzen O. [Experiences of day care and collaboration among people with mild dementia.](#) *J Clin Nurs* 2010;19(19-20):2839-2848.
- 191 Caddell LS, Clare L. [A profile of identity in early-stage dementia and a comparison with healthy older people.](#) *Aging Ment Health* 2013;17(3):319-327.
- 192 Genoe MR, Dupuis SL. [The role of leisure within the dementia context.](#) *Dementia* 2014;13(1):33-58.
- 193 Mak W. [Self-reported goal pursuit and purpose in life among people with dementia.](#) *J Gerontol B Psychol Sci Soc Sci* 2011;66(2):177-184.
- 194 Martin F, Turner A, Wallace LM, Stanley D, Jesuthasan J, Bradbury N. [Qualitative evaluation of a self-management intervention for people in the early stage of dementia.](#) *Dementia* (Published online August 2013).
- 195 Lopez RP, Mazor KM, Mitchell SL, Givens JL. [What is family-centered care for nursing home residents with advanced dementia?](#) *Am J Alzheimers Dis Other Demen* 2013;28(8):763-768.
- 196 Clare L, Rowlands J, Bruce E, Surr C, Downs M. [The experience of living with dementia in residential care: an interpretative phenomenological analysis.](#) *Gerontologist* 2008;48(6):711-720.
- 197 Clark-McGhee K, Castro M. [A narrative analysis of poetry written from the words of people given a diagnosis of dementia.](#) *Dementia* (Published online May 2013).
- 198 Clemerson G, Walsh S, Isaac C. [Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed.](#) *Dementia* (Published online February 2013).
- 199 Harmer BJ, Orrell M. [What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers.](#) *Aging Ment Health* 2008;12(5):548-558.
- 200 Phinney A. [Living with dementia from the patient's perspective.](#) *J Gerontol Nurs* 1998;24(6):8-15.
- 201 Edvardsson D, Nordvall K. [Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia.](#) *J Clin Nurs* 2008;17(4):491-498.
- 202 Moyle W, Gracia N, Murfield JE, Griffiths SG, Venturato L. [Assessing quality of life of older people with dementia in long-term care: a comparison of two self-report measures.](#) *J Clin Nurs* 2012;21(11-12):1632-1640.
- 203 Peacock SC. [The experience of providing end-of-life care to a relative with advanced dementia: an integrative literature review.](#) *Palliat Support Care* 2013;11(2):155-168.
- 204 Laakkonen ML, Raivio MM, Eloniemi-Sulkava U, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH. [How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?](#) *J Med Ethics* 2008;34(6):427-430.
- 205 Mazaheri M, Eriksson LE, Heikkilä K, Nasrabadi AN, Ekman SL, Sunvisson H. [Experiences of living with dementia: qualitative content analysis of semi-structured interviews.](#) *J Clin Nurs* 2013;22(21-22):3032-3041.
- 206 Dawson NT, Powers SM, Krestar M, Yarry SJ, Judge KS. [Predictors of self-reported psychosocial outcomes in individuals with dementia.](#) *Gerontologist* 2013;53(5):748-759.
- 207 Wolverson Radbourne EL, Clarke C, Moniz-Cook E. [Remaining hopeful in early-stage dementia: a qualitative study.](#) *Aging Ment Health* 2010;14(4):450-460.
- 208 de Boer ME, Hertogh CM, Dröes RM, Riphagen II, Jonker C, Eefsting JA. [Suffering from dementia - the patient's perspective: a review of the literature.](#) *Int Psychogeriatr* 2007;19(6):1021-1039.



- 209 de Souza-Talarico JN, Chaves EC, Nitrini R, Caramelli P. [Stress and coping in older people with Alzheimer's disease.](#) *J Clin Nurs* 2009;18(3):457-465.
- 210 Lin Kiat Yap P, Yen Ni Goh J, Henderson LM, Min Han P, Shin Ong K, Si Ling Kwek S, Yi Hui Ong E, Pui Kwan Loh D. [How do Chinese patients with dementia rate their own quality of life?](#) *Int Psychogeriatr* 2008;20(3):482-493.
- 211 Silva P, Kergoat MJ, Shatenstein B. [Challenges in managing the diet of older adults with early-stage Alzheimer dementia: a caregiver perspective.](#) *J Nutr Health Aging* 2013;17(2):142-147.
- 212 McLaren AN, Lamantia MA, Callahan CM. [Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia.](#) *Aging Ment Health* 2013;17(6):655-666.
- 213 Hsiao HC, Chao HC, Wang JJ. [Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience.](#) *Geriatr Nurs* 2013;34(5):361-365.
- 214 Simpson C, Carter P. [Dementia caregivers' lived experience of sleep.](#) *Clin Nurse Spec* 2013;27(6):298-306.
- 215 Johansson L, Christensson L, Sidenvall B. [Managing mealtime tasks: told by persons with dementia.](#) *J Clin Nurs* 2011;20(17-18):2552-2562.
- 216 Barnes S, Wasielewska A, Raiswell C, Drummond B. [Exploring the mealtime experience in residential care settings for older people: an observational study.](#) *Health Soc Care Community* 2013;21(4):442-450.
- 217 Quinn C, Clare L, Woods B. [The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review.](#) *Aging Ment Health* 2009;13(2):143-154.
- 218 McCarthy M, Addington-Hall J, Altmann D. [The experience of dying with dementia: a retrospective study.](#) *Int J Geriatr Psychiatry* 1997;12(3):404-409.
- 219 Madsen R, Birkelund R. ['The path through the unknown': the experience of being a relative of a dementia-suffering spouse or parent.](#) *J Clin Nurs* 2013;22(21-22):3024-3031.
- 220 Robinson L, Gemski A, Abley C, Bond J, Keady J, Campbell S, Samsi K, Manthorpe J. [The transition to dementia - individual and family experiences of receiving a diagnosis: a review.](#) *Int Psychogeriatr* 2011;23(7):1026-1043.
- 221 Peacock SC. [The experience of providing end-of-life care to a relative with advanced dementia: an integrative literature review.](#) *Palliat Support Care* 2013;11(2):155-168.
- 222 Taşç S, Tekinsoy Kartn P, Ceyhan O, Sungur G, Göriş S. [Living with an Alzheimer patient in Turkey.](#) *J Neurosci Nurs* 2012;44(4):228-234.
- 223 Laakkonen ML, Raivio MM, Eloniemi-Sulkava U, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH. [How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?](#) *J Med Ethics* 2008;34(6):427-430.
- 224 García-Alberca JM, Cruz B, Lara JP, Garrido V, Lara A, Gris E, Gonzalez-Herero V. [The experience of caregiving: the influence of coping strategies on behavioural and psychological symptoms in patients with Alzheimer's disease.](#) *Aging Ment Health* 2013;17(5):615-622.
- 225 Simpson C, Carter P. [Dementia behavioural and psychiatric symptoms: effect on caregiver's sleep.](#) *J Clin Nurs* 2013;22(21-22):3042-3052.
- 226 Duggleby W, Schroeder D, Nekolaichuk C. [Hope and connection: the experience of family caregivers of persons with dementia living in a long term care facility.](#) *BMC Geriatr* 2013;13:112.
- 227 Papastavrou E, Charalambous A, Tsangari H, Karayiannis G. [The burdensome and depressive experience of caring: what cancer, schizophrenia, and Alzheimer's disease caregivers have in common.](#) *Cancer Nurs* 2012;35(3):187-194.
- 228 Lockeridge S, Simpson J. [The experience of caring for a partner with young onset dementia: how younger carers cope.](#) *Dementia* 2013 Sep;12(5):635-651.
- 229 Liddle J, Smith-Conway ER, Baker R, Angwin AJ, Gallois C, Copland DA, Pachana NA, Humphreys MS, Byrne GJ, Chenery HJ. [Memory and communication support strategies in dementia: effect of a training program for informal caregivers.](#) *Int Psychogeriatr* 2012;24(12):1927-1942.
- 230 Vellone E, Piras G, Venturini G, Alvaro R, Cohen MZ. [The experience of quality of life for caregivers of people with Alzheimer's disease living in Sardinia, Italy.](#) *J Transcult Nurs* 2012;23(1):46-55.
- 231 Chan D, Livingston G, Jones L, Sampson EL. [Grief reactions in dementia carers: a systematic review.](#) *Int J Geriatr Psychiatry* 2013;28(1):1-17.
- 232 Zhang H, Xiong RH, Hujiken S, Zhang JJ, Zhang XQ. [Psychological distress, family functioning, and social support in family caregivers for patients with dementia in the mainland of China.](#) *Chin Med J* 2013;126(18):3417-3421.
- 233 Liu J, Wang LN, Tan JP, Ji P, Gauthier S, Zhang YL, Ma TX, Liu SN. [Burden, anxiety and depression in caregivers of veterans with dementia in Beijing.](#) *Arch Gerontol Geriatr* 2012;55(3):560-563.
- 234 Takai M, Takahashi M, Iwamitsu Y, Ando N, Okazaki S, Nakajima K, Oishi S, Miyaoka H. [The experience of burnout among home caregivers of patients with dementia: relations to depression and quality of life.](#) *Arch Gerontol Geriatr* 2009;49(1):e1-e5.

- 235 Miller EA, Rosenheck RA, Schneider LS. [Caregiver burden, health utilities, and institutional service costs among community-dwelling patients with Alzheimer disease.](#) *Alzheimer Dis Assoc Disord* 2010;24(4):380-389.
- 236 Bass DM, Judge KS, Snow AL, Wilson NL, Looman WJ, McCarthy C, Morgan R, Ablorh-Odjidja C, Kunik ME. [Negative caregiving effects among caregivers of veterans with dementia.](#) *Am J Geriatr Psychiatry* 2012;20(3):239-247.
- 237 Fonareva I, Oken BS. [Physiological and functional consequences of caregiving for relatives with dementia.](#) *Int Psychogeriatr* 2014;26(5):725-747.
- 238 Pesonen HM, Remes AM, Isola A. [Diagnosis of dementia as a turning point among Finnish families: a qualitative study.](#) *Nurs Health Sci* 2013;15(4):489-496.
- 239 Holst G, Edberg AK. [Wellbeing among people with dementia and their next of kin over a period of 3 years.](#) *Scand J Caring Sci* 2011;25(3):549-557.
- 240 Li R, Cooper C, Bradley J, Shulman A, Livingston G. [Coping strategies and psychological morbidity in family carers of people with dementia: a systematic review and meta-analysis.](#) *J Affect Disord* 2012 Jun;139(1):1-11.
- 241 Riley GA, Fisher G, Hagger BF, Elliott A, Le Serve H, Oyebode JR. [The Birmingham relationship continuity measure: the development and evaluation of a measure of the perceived continuity of spousal relationships in dementia.](#) *Int Psychogeriatr* 2013;25(2):263-274.
- 242 Shim B, Barroso J, Davis LL. [A comparative qualitative analysis of stories of spousal caregivers of people with dementia: negative, ambivalent, and positive experiences.](#) *Int J Nurs Stud* 2012;49(2):220-229.
- 243 Fernández-Lansac V, Crespo López M, Cáceres R, Rodríguez-Poyo M. [Resilience in caregivers of patients with dementia: a preliminary study.](#) *Rev Esp Geriatr Gerontol* 2012;47(3):102-109.
- 244 Hennings J, Froggatt K, Payne S. [Spouse caregivers of people with advanced dementia in nursing homes: a longitudinal narrative study.](#) *Palliat Med* 2013;27(7):683-691.
- 245 Bursch HC, Butcher HK. [Caregivers' deepest feelings in living with Alzheimer's disease: a Ricoeurian interpretation of family caregivers' journals.](#) *Res Gerontol Nurs* 2012;5(3):207-215.
- 246 Sanders S, Ott CH, Kelber ST, Noonan P. [The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia.](#) *Death Stud* 2008;32(6):495-523.
- 247 Bull MJ. [Strategies for sustaining self used by family caregivers for older adults with dementia.](#) *J Holist Nurs* (Published online November 2013).
- 248 Large S, Slinger R. [Grief in caregivers of persons with Alzheimer's disease and related dementia: a qualitative synthesis.](#) *Dementia* (Published online July 2013).
- 249 van Vliet D, de Vugt ME, Bakker C, Koopmans RT, Verhey FR. [Impact of early onset dementia on caregivers: a review.](#) *Int J Geriatr Psychiatry* 2010;25(11):1091-1100.
- 250 Ott CH, Sanders S, Kelber ST. [Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias.](#) *Gerontologist* 2007;47(6):798-809.
- 251 Kim Y. [Korean American family postcaregivers on dementia caregiving: a phenomenological inquiry.](#) *J Gerontol Soc Work* 2009;52(6):600-617.
- 252 Massimo L, Evans LK, Benner P. [Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses.](#) *Geriatr Nurs* 2013;34(4):302-306.
- 253 <http://www.ccal.org/wp-content/uploads/Dementia-Initiative-Lit-Review.pdf>
- 254 <http://asaging.org/blog/person-centered-care-people-dementia-theoretical-and-conceptual-framework>