

Supplementary material

Table 1. Quality Assessment of 81 Studies Included in this Systematic Review

Table 2. Characteristics and key findings of the included studies in this systematic review (n=81)

Table 3. Summary of methods and participants of 81 studies included in this systematic review

Additional file 1 | Search strategy

Additional file 2 | PRISMA Checklist

Table 1. Quality Assessment of 81 Studies Included in this Systematic Review

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Aminzadeh <i>et al.</i> , 2007)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	1.No discussion on contradictory data 2.No discussion on researcher bias
Berry <i>et al.</i> , 2015)	Yes	Yes	Yes	yes	1. No discussion about saturation data	No details	No information on ethical issues	1.No discussion on contradictory data 2.No in-depth description of the data analysis process
(Boots LM <i>et al.</i> , 2015)	Yes	Yes	No discussion about why selecting the Grounded Theory Approach Modified	Yes	1. No discussion on why selecting the interview approach	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Boughtwood <i>et al.</i> , 2011)	Yes	Yes	No discussion about the study design	Yes	1. No discussion on why selecting the focus group approach	No details	Yes	1.No discussion on contradictory data 2.No in-depth description about how themes were identified
(Bunn <i>et al.</i> , 2017)	Yes	Yes	No discussion about the study design	Yes	1. No in-depth information on interview schedule 2. No discussion about saturation data 3. No details about family caregivers relation to the patient	No details	Yes	1.No discussion on contradictory data 2.No in-depth description about how themes were identified
(Butcher <i>et al.</i> , 2001)	Yes	Yes	Yes	Yes	1. No in-depth information on interview schedule 2. No discussion about saturation data	No details	Yes, but no details about how researchers explained issues to participants	1.No discussion on contradictory data 2.No discussion on researcher bias
(Byszewski <i>et al.</i> , 2007)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about family caregivers gender, relation to the patient or age	No details	Yes	Yes
(Chang <i>et al.</i> , 2010)	Yes	Yes	No discussion about why selecting the Phenomenology Approach (<i>described by Colaizzi</i>)	Yes	1. No in-depth information on interview schedule 2. No discussion about saturation data	No details	Yes	1.No in-depth description about how themes were identified

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Connell <i>et al.</i> , 2004)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 2. No details about care recipient gender or age	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Duxury <i>et al.</i> , 2013)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate 2. No discussion on what participant selection criteria were used	1. No discussion about saturation data 2. No details about caregiver gender, age or relation to patient 3. No details about care recipient gender or age	No details	Yes	1. No discussion on contradictory data 2.No discussion on researcher bias 3. No in-depth description about how themes were identified
(Elliott <i>et al.</i> , 2009)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about family caregivers and care recipients age	No details	Yes	Yes
(Fjellstrom <i>et al.</i> , 2010)	Yes	Yes	Yes	Yes	1. No in-depth information on interview schedule 2. No details about family caregivers relation to the care recipient 3. No details about care recipients age	No details	Yes	1.No discussion on contradictory data 2. No in-depth description about how themes were identified
(Fleming <i>et al.</i> , 2015)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about family caregivers and care recipients age	No details	Yes	1.No discussion on contradictory data 2. No in-depth description about how themes were identified
(Forbes <i>et al.</i> , 2000)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data	No details	Information on how researchers explained issues to participants No information about the signature of the informed consent	Yes
(Forbes <i>et al.</i> , 2008)	Yes	Yes	No discussion about the study design	Yes	Yes	No details	Yes	1.No discussion on contradictory data 2. No in-depth description about how themes were identified
(Frank <i>et al.</i> , 2006)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data	No details	Yes	1.No discussion on contradictory data 2. No in-depth description about how themes were identified

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Garcia <i>et al.</i> , 2012), Canada	Yes	Yes	No discussion about the study design	Yes	1. No details about family caregivers relation to the care recipient 2. No details about family caregivers age	No details	Yes	1. No discussion on the use of quotations to support the findings
(Gennip <i>et al.</i> , 2014)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about family caregivers age	No details	Yes	1. No in-depth description about how themes were identified
(Gessert <i>et al.</i> , 2001)	Yes	Yes	Yes	1. No discussion on what participant selection criteria were used	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about family caregivers and care recipient age	No details	No information on ethical issues	1. No in-depth description about how themes were identified
(Gessert <i>et al.</i> , 2006)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data	No details	No information on ethical issues	1. No in-depth description about how themes were identified
(Givens <i>et al.</i> , 2012)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about care recipient age	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Glass, 2016)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate 2. No discussion on what participant selection criteria were used	Yes	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Habermann, <i>et al.</i> , 2013)	Yes	Yes	Yes	Yes	1. No in-depth information on interview schedule 2. No discussion about saturation data	No details	Yes, but no details about how researchers explained issues to participants	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias
(Harmer and Orrel, 2008)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Harris, 2013)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias
(Hemingway <i>et al.</i> , 2016)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data
(Huis in het Veld <i>et al.</i> , 2016)	Yes	Yes	No discussion about the study design	Yes	1. No details about care recipient age	No details	Yes	1.No discussion on contradictory data
(Innes <i>et al.</i> , 2005)	Yes	Yes	No discussion about the study design	Yes	Yes	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias
(Innes <i>et al.</i> , 2011)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about care recipient age	No details	Yes	Yes
(Ivey <i>et al.</i> , 2012)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data No details about care recipient age	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Jamieson <i>et al.</i> , 2016)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data 2. No details about family caregivers and care recipient age	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias
(Jennings <i>et al.</i> , 2017)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data	No details	Yes	Yes
(Juozapavicius and Weber, 2001)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data	No details	No information on ethical issues	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Karlin <i>et al.</i> , 2001)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 2. No details about care recipient age	No details	No information on ethical issues	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias
(Karlsson <i>et al.</i> , 2014)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Kunneman <i>et al.</i> , 2017)	Yes	Yes	No discussion about the study design	Yes	1. No details about family caregivers relation to the care recipient	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data
(Lach and Chang, 2007)	Yes	Yes	Yes	Yes	1. No details about family caregivers age	No details	Yes	Yes
(Lamahewa <i>et al.</i> , 2017)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about family caregivers and care recipient age	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data
(Lamech <i>et al.</i> , 2017)	Yes	Yes	Yes	Yes	1. No details about family caregivers relation to the care recipient 2. No details about care recipient age	No details	Yes	Yes
(Lamech <i>et al.</i> , 2017)	Yes	Yes	Yes	Yes	1. No details about family caregivers relation to the care recipient 2. No details about care recipient age	No details	Yes	Yes
(Lampley-Dallas <i>et al.</i> , 2001)	Yes	Yes	Yes	Yes	1. No details about care recipient age	No details	Yes, but no details about how researchers explained issues to participants	1. No in-depth description about how themes were identified
(Lethin <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Levkoff and Hinton, 1999)	Yes	Yes	Yes	1. No discussion on what participant selection criteria were used	1. No discussion about saturation data	No details	No information on ethical issues	1. No in-depth description about how themes were identified

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Lian <i>et al.</i> , 2017)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	Yes
(Livingston <i>et al.</i> , 2010)	Yes	Yes	Yes	Yes	Yes	No details	Yes	1. No in-depth description about how themes were identified
(Madsen and Birkelund, 2013)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate 2. No discussion on what participant selection criteria were used	1. No in-depht information on interview schedule	No details	Yes	Yes
(Manthorpe <i>et al.</i> , 2013)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	Yes
(McCabe <i>et al.</i> , 2017)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about family caregivers relation to the care recipient 3. No details about family caregivers and care recipient age	No details	Yes	1. No in-depth description about how themes were identified
(Meyer, 2015)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 3. No in-depht information on interview schedule	No details	Yes	1. No in-depth description about how themes were identified
(Milte <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	Yes
(Moreno-Cámara <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No details about care recipient age	No details	Yes	Yes
(Morgan <i>et al.</i> , 2002)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No in-depht information on interview schedule 3. No details about family caregivers and care recipient age	No details	Yes	1. No in-depth description about how themes were identified
(Moyle <i>et al.</i> , 2002)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about family caregivers and care recipient age or relation	No details	Yes	1.No discussion on contradictory data 2.No discussion on researcher bias

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Oliveira <i>et al.</i> , 2017)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about care recipient age	No details	Yes	Yes
(Paton <i>et al.</i> , 2004)	Yes	Yes	No discussion about the study design	Yes	1. No discussion about saturation data 2. No details about care recipient age	None were family caregivers (all female)	Yes	1.No discussion on contradictory data 2.No discussion on researcher bias
(Peel and Harding, 2013)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	1. No in-depth description about how themes were identified
(Phillipson and Jones, 2011)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate 2. No discussion on what participant selection criteria were used	1. No discussion about saturation data	No details	Yes	1. No in-depth description about how themes were identified 2.No discussion on contradictory data 3.No discussion on researcher bias
(Polenick <i>et al.</i> , 2018)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data	No details	Yes	Yes
(Polenick <i>et al.</i> , 2018)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data	No details	Yes	Yes
(Poole <i>et al.</i> , 2018)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data 2. No details about familiar caregivers and care recipient age	No details	Yes	Yes
(Polenick <i>et al.</i> , 2018)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data	No details	Yes	Yes
(Polenick <i>et al.</i> , 2018)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data	No details	Yes	Yes

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Poole <i>et al.</i> , 2018)	Yes	Yes	No discussion about the study design	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data 2. No details about familiar caregivers and care recipient age	No details	Yes	Yes
(Popham and Orrell, 2012)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate	1. No discussion about saturation data 2. No details about familiar caregivers age	No details	Yes	Yes
(Prorok <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	Yes	No details	Yes	Yes
(Qazi <i>et al.</i> , 2010)	Yes	Yes	Yes	1. No discussion on what participant selection criteria were used	1. No discussion about saturation data	No details	Yes	1.No discussion on researcher bias
(Quinn <i>et al.</i> , 2014)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate 2. No discussion on what participant selection criteria were used	1. No discussion about saturation data	No details	Yes	Yes
(Robinson <i>et al.</i> , 2008)	Yes	Yes	Yes	1. No discussion on why these participants were the most appropriate 2. No discussion on what participant selection criteria were used	1. No discussion about saturation data 2. No details about familiar caregivers age or relation to the patient	No details	Yes	1. No discussion on the use of quotations to support the findings
(Sarabia-Cobo <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes, but no details about how researchers explained issues to participants	Yes
(Scott <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	Yes
(Skaalvik <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about familiar caregivers age or relation to the patient	No details	Yes	Yes

Studies	Clear statement of study aims	Qualitative methodology appropriate	Study design appropriate to address the study aim	Recruitment appropriate	Data collection	Relationship between research and participants	Ethical issues considered	Data analysis
(Skaalvik <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No discussion about saturation data 2. No details about familiar caregivers age or relation to the patient	No details	Yes	Yes
(Song <i>et al.</i> , 2018)	Yes	Yes	Yes	Yes	1. No discussion about saturation data	No details	Yes	Yes
(Sutcliffe <i>et al.</i> 2015)	Yes	Yes	No discussion about the study design	Yes	1. No details about familiar caregivers relation to the patient	No details	Yes	1. No in-depth description about how themes were identified
(Taşc <i>et al.</i> , 2012)	Yes	Yes	No discussion about the study design	Yes	1. No in-depth information on interview schedule 2. No discussion about saturation data 3. No details about care recipient age	No details	Yes	1. No in-depth description about how themes were identified 2. No discussion on contradictory data 3. No discussion on researcher bias
(Toot <i>et al.</i> , 2013)	Yes	Yes	No discussion about the study design	Yes	Yes	No details	Yes	Yes
(Ven LG <i>et al.</i> 2017)	Yes	Yes	No discussion about the study design	Yes	1. No details about family caregivers age	No details	Yes	Yes
(Wang <i>et al.</i> , 2018)	Yes	Yes	Yes	Yes	Yes	No details	Yes	1. No in-depth description about how themes were identified
(Wezel, <i>et al.</i> , 2016)	Yes	Yes	Yes	Yes	1. No details about care recipient age	No details	Yes	1. No in-depth description about how themes were identified

Table 2. Characteristics and key findings of the included studies in this systematic review (n=81)

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Aminzadeh <i>et al.</i> , 2007), Canada	To examine the emotional impact of disclosure of a dementia diagnosis on people with dementia both from their perspectives and those of their caregivers	Interviews following focus groups Thematic analysis	Quality of life Negative aspects
(Berry <i>et al.</i> , 2015), United States	To fill an important gap in research about how family members manage the risks of functional decline at home	Interviews Grounded theory analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Boots LM <i>et al.</i> , 2015), Netherlands	To gain insight into the problems, needs and wishes that caregivers of persons with dementia during the early stages of the disease; To explore if an early stage intervention for dementia caregivers would be helpful and to explore which factors influence caregivers' perspectives	Focus Group Thematic analysis	Quality of life Positive and negative aspects
(Boughtwood <i>et al.</i> , 2011), Australia	To explore Arabic-speaking, Chinese-speaking, Italian-speaking and, Spanish-speaking communities caregivers' experiences and perceptions regarding caregiving and being a carer for a person with dementia	Focus Group Thematic analysis	Quality of life Illness progression Activities of daily living Costs Negative aspects
(Bunn <i>et al.</i> , 2017), United Kingdom	To explore the impact of dementia on access to non-dementia services and identify ways of improving service delivery for these persons with dementia	Interviews and focus groups Thematic analysis	Illness progression Costs Negative aspects
(Butcher <i>et al.</i> , 2001), United States	To describe the essential structure of the lived experience of caring for a family member with AD and related dementia among a large and diverse sample of informal family caregivers	Interviews Phenomenological analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Byszewski <i>et al.</i> , 2007), Canada	To report the findings of a descriptive, exploratory, qualitative study of patient and caregiver perspectives of the disclosure of a dementia diagnosis	Interviews following focus groups Thematic analysis	Quality of life Activities of daily living Negative aspects
(Chang <i>et al.</i> , 2010), United Kingdom	To report the lived experience and perceived service needs of caregivers of persons with dementia in Hong Kong	Focus Group Thematic analysis	Quality of life Negative aspects
(Connell <i>et al.</i> , 2004), United States	To examine the attitudes of caregivers and physicians toward assessing and diagnosing dementia with an emphasis on how a diagnosis is disclosed	Interviews following focus groups Thematic analysis	Quality of life Negative aspects
(Duxury <i>et al.</i> , 2013), United Kingdom	To explore the views of nursing staff and relatives and identify the reasons for and ways of responding to aggressive behaviour	Focus groups Thematic analysis	Quality of life Illness progression Activities of daily living Positive and negative aspects
(Elliott <i>et al.</i> , 2009), United States	To describe and understand the ethical thinking used in end-of-life decision-making by family surrogates on behalf of their cognitively impaired elders	Focus group Thematic analysis	Quality of life Negative aspects
(Fjellstrom <i>et al.</i> , 2010), Sweden	To examine how people living with persons with Alzheimer's disease perceived everyday life aspects of food choices, cooking and food-related work	Focus Group Thematic analysis	Quality of life Activities of daily living Negative aspects
(Fleming <i>et al.</i> , 2015), Australia	To identify the environmental features that are desirable in buildings used and identify ways to improve provided care for people with dementia nearing the end of their lives	Focus Group Thematic analysis	Quality of life Illness progression Negative aspects

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Forbes <i>et al.</i> , 2000), United States	To describe families' decision-making processes, both cognitive and affective, regarding end-of-life treatments for nursing home residents with severe dementia	Focus group Thematic analysis	Quality of life Illness progression Negative aspects
(Forbes <i>et al.</i> , 2008), Canada	To describe experiences of family caregivers who received Canadian home and community-based services that aim to assist them in caring for their family member with dementia	Focus Group and interview Thematic analysis	Quality of life Costs Negative aspects
(Frank <i>et al.</i> , 2006), United Kingdom and United States	To identify key aspects of the impact of cognitive impairment on patients with MCI and mild probable AD and their informants, and identify overlap and differences between the groups	Focus group Thematic analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Garcia <i>et al.</i> , 2012), Canada	To explore the perceptions of family and staff members on the potential contribution of environmental factors that influence disruptive behaviours and quality of life of residents with dementia living in long-term care homes	Focus Group Thematic analysis	Quality of life Negative aspects
(Gennip <i>et al.</i> , 2014), Netherlands	To examine how dementia affects personal dignity in individuals with mild to moderate dementia from their perspective	Interview Thematic analysis	Quality of life Activities of daily living Positive aspects
(Gessert <i>et al.</i> , 2001), United States	To identify areas where better communication between health professionals and patients/families might be expected to be most beneficial to families facing end-of-life decisions	Focus group Phenomenological analysis	Quality of life Illness progression Negative aspects
(Gessert <i>et al.</i> , 2006), United States	To describe and understand rural and urban differences in attitudes toward death and in end-of-life decision making	Focus group Thematic analysis	Quality of life Negative aspects
(Givens <i>et al.</i> , 2012), United States	To describe the sources of stress for families of nursing home residents with advanced dementia	Interview Thematic analysis	Quality of life Illness progression Negative aspects
(Glass, 2016), United States	To document and examine the context of the environment and the role of hospice in the experience of caring for persons with dementia	Interview Phenomenological analysis	Quality of life Negative aspects
(Habermann, <i>et al.</i> , 2013), United States	To explore the positive aspects experienced by adult children in providing care to their parent who either has Parkinson's or Alzheimer's disease	Interview Content analysis	Quality of life Activities of daily living Positive and negative aspects
(Harmer and Orrel, 2008), United Kingdom	To explore the concept of meaningful activity for older people with dementia in care homes, from the perspectives of the care staff, family caregivers and residents themselves	Focus Group Thematic analysis	Activities of daily living Positive aspects
(Harris, 2013), United States	To examine the quality of the friendships that remain and continue, despite a diagnosis of some type of dementia	Interviews and focus groups Thematic analysis	Quality of life Positive and negative aspects
(Hemingway <i>et al.</i> , 2016), Canada	To better understand the lived experience of spousal caregivers providing care to partners with AD and related dementias resident in a care facility	Interview and Focus Group Thematic analysis	Quality of life Illness progression Costs Negative aspects
(Huis in het Veld <i>et al.</i> , 2016), Netherlands	To give insight into why changes in behaviour and mood are stressful for family caregivers and what self-management strategies family caregivers use when managing these changes and the stress they experience	Focus Group Thematic analysis	Quality of life Negative aspects

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Innes <i>et al.</i> , 2005), United Kingdom	To develop a qualitative understanding of service use from the point of view of people with dementia and their caregivers in rural Scotland	Interview and Focus Group Thematic analysis	Quality of life Costs Negative aspects
(Innes <i>et al.</i> , 2011), United Kingdom	To report on the views of people with dementia who live in care homes and their family caregivers on aspects of design that are important to them, discussing the relation to developing physical care environments as a respond to the wishes of people with dementia and their family	Focus Group Thematic analysis	Quality of life Positive aspects
(Ivey <i>et al.</i> , 2012), United States	To examine participants' daily life experiences as informal caregivers to individuals with dementia and explore how experiences and concerns may differ by ethnicity	Focus Group Thematic analysis	Quality of life Illness progression Activities of daily living Costs Negative aspects
(Jamieson <i>et al.</i> , 2016), Australia	To investigate the experiences of people with dementia and their caregivers when transitioning home from hospital	Interview and Focus Group Thematic analysis	Quality of life Negative aspects
(Jennings <i>et al.</i> , 2017), United States	To explore the goals of people with dementia, both from the perspective of people living with early-stage disease and from the perspective of caregivers of people with all stages of dementia	Focus group Thematic analysis	Quality of life Illness progression Activities of daily living Costs Positive and negative aspects
(Juozapavicius and Weber, 2001), United States	To explore the issues faced by former Alzheimer's caregivers identifying the factors which precipitated the beginning of the caregiver role and use the reflective information to identify the stages which comprise the transition out of the caregiver role	Interview Thematic analysis	Quality of life Costs Negative aspects
(Karlin <i>et al.</i> , 2001), United States	To investigate the experience of caregiving for family members with Alzheimer's disease	Interview Thematic analysis	Quality of life Positive aspects
(Karlsson <i>et al.</i> , 2014), England, Estonia, Finland, France, Germany, Netherlands, Spain and Sweden	To investigate persons with dementia and their informal caregivers' views of inter-sectoral information, communication and collaboration throughout the trajectory of dementia care in eight European countries	Focus Group Thematic analysis	Illness progression Negative aspects
(Kuneman <i>et al.</i> , 2017), Netherlands	To assess patients' and caregivers' views on and experiences with decisions about diagnostic testing for Alzheimer's disease and receiving test results	Focus group Content analysis	Quality of life Costs Negative aspects
(Lach and Chang, 2007), United States	To explore caregivers' perceptions of safety problems and identify how they manage safety concerns and explore the application of health behaviour change models to the caregiver situation	Focus group Thematic analysis	Quality of life Activities of daily living Negative aspects
(Lamahewa <i>et al.</i> , 2017), United Kingdom	To explore difficulties in decision making for practitioners and family caregivers at the end of life for people with dementia	Focus Group and interview Thematic analysis	Quality of life Negative aspects
(Lamech <i>et al.</i> , 2017), India	To explore the needs of family caregivers of persons with dementia in India	Focus Group and interview Thematic analysis	Quality of life Activities of daily living Costs Negative aspects
(Lampléy-Dallas <i>et al.</i> , 2001), United States	To assess the perceived needs of African-American caregivers and their expectations of the health care system, perceived level of success and satisfaction in meeting their needs and their level of distress	Focus group Thematic analysis	Quality of life Costs Positive and negative aspects

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Lethin <i>et al.</i> , 2016), Sweden	To investigate caregivers' experiences of formal care when caring for a person with dementia through the process of the disease	Focus Group Content analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Levkoff and Hinton, 1999), United States	To show how family caregivers draw on their cultural/personal resources to create stories about the nature and meaning of illness and to ask how ethnic identity may influence the kinds of stories family caregivers tell	Interview Thematic analysis	Quality of life Illness progression Negative aspects
(Lian <i>et al.</i> , 2017), China	To understand the experiences of people with dementia and their caregivers in engaging in dementia diagnosis	Focus Group and interview Thematic analysis	Quality of life Activities of daily living Costs Negative aspects
(Livingston <i>et al.</i> , 2010), United Kingdom	To identify common difficult decisions made by family caregivers on behalf of people with dementia and facilitators of and barriers to such decisions in order to produce information about overcoming barriers	Focus Group and interview Thematic analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Madsen and Birkelund, 2013), Denmark	To examine the experiences family caregivers of persons with dementia highlighting these similarities or differences	Focus group Phenomenological analysis	Quality of life Negative aspects
(Manthorpe <i>et al.</i> , 2013), United Kingdom	To increase understanding of the experiences of people developing dementia and of their caregivers and to inform practice and decision making	Interview Thematic analysis	Quality of life Negative aspects
(McCabe <i>et al.</i> , 2017), United Kingdom	To understand the strategies for everyday life with dementia by scaffolding and working together in community and formal support	Focus group and interviews Thematic analysis	Quality of life Illness progression Activities of daily living Costs Negative aspects
(Meyer, 2015), United States	To describe the beliefs and experiences of Vietnamese caregivers caring for a family member with dementia and to elicit their ideas about promising interventions	Interview Thematic analysis	Quality of life Negative aspects
(Middlemass <i>et al.</i> 2018), United Kingdom	To explore the experiences/perceptions of informal caregivers of people with dementia when interacting with the health care system and to investigate healthcare professionals' views and current practice regarding people with dementia and their interactions with informal caregivers	Focus Group and interview Thematic analysis	Quality of life Illness progression Costs Negative aspects
(Milte <i>et al.</i> , 2016), Australia	To describe the meaning of quality residential care from the perspective of people with cognitive impairment and their family members	Focus Group and interview Thematic analysis	Costs Positive and negative aspects
(Moreno-Cámara <i>et al.</i> , 2016), Spain	Identify and analyse the problems that arise in the adaptation process of the caregiver to changes during family care to a person affected by dementia	Focus group Grounded Theory	Quality of life Illness progression Costs Negative aspects
(Morgan <i>et al.</i> , 2002), Canada	To obtain input from decision-makers and others to develop the objectives and design for a study of rural dementia care to fight the low use of formal supportive services such as home care and support groups by family caregivers	Focus Group Thematic analysis	Quality of life Costs Negative aspects
(Moyle <i>et al.</i> , 2002), Australia	To investigate family caregivers' perceptions of having a relative in a dementia care unit	Focus group Content analysis	Quality of life Illness progression Positive and negative aspects

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Oliveira <i>et al.</i> , 2017), United Kingdom	To explore how persons with dementia make sense of their own quality of life and to identify the factors that enhance or compromise their quality of life	Focus group Phenomenological analysis	Quality of life Activities of daily living Costs Positive and negative aspects
(Paton <i>et al.</i> , 2004), United Kingdom	To gain insight into caregivers' understanding of the causes of behaviours they find problematic in people with Alzheimer's disease in order to inform the development of educational strategies	Interview Thematic analysis	Illness progression Negative aspects
(Peel and Harding, 2013), United Kingdom	To explore the issue of accessing health and social care support services from caregivers' own perspectives	Focus group, interview and questionnaires (online and paper) Thematic analysis	Quality of life Costs Negative aspects
(Phillipson and Jones, 2011), Australia	To explore the utility of behavioural theories to identify the beliefs that contribute to service non-use and to determine whether the beliefs of service users and non-users differ	Focus Group and interview Content analysis	Quality of life Negative aspects
(Polenick <i>et al.</i> , 2018), United States	To examine causal attributions about BPSD among individuals caring for a family member with dementia	Focus Group Thematic analysis	Quality of life Activities of daily living Costs Negative aspects
(Polenick <i>et al.</i> , 2018), United States	To examine family caregivers' strategies for managing behaviour and psychological symptoms of dementia	Focus Group Thematic analysis	Quality of life Positive and negative aspects
(Poole <i>et al.</i> , 2018), United Kingdom	To investigate the views of people with dementia and the views of their family caregivers on important factors regarding care at end of life	Focus Group and interview Thematic analysis	Quality of life Illness progression Positive aspects
(Popham and Orrell, 2012), United Kingdom	To determine to what extent the care home environment met the requirements of residents with dementia in the context of the views of managers, family caregivers and staff	Focus Group and interview Thematic analysis	Quality of life Illness progression Positive and negative aspects
(Prorok <i>et al.</i> , 2016), Canada	To examine the perceived primary care health care experiences of both persons with dementia and their caregivers	Focus Group Thematic analysis	Quality of life Costs Negative aspects
(Qazi <i>et al.</i> , 2010), United Kingdom	To identify symptoms, risk factors and intervention strategies for anxiety of people with dementia, family caregivers and care staff	Focus Group Mind-map technique	Quality of life Illness progression Activities of daily living Negative aspects
(Quinn <i>et al.</i> , 2014), United Kingdom	To explore how family members and care staff understand awareness in people with severe dementia and what this awareness means to them	Focus Group Thematic analysis	Quality of life Negative aspects
(Robinson <i>et al.</i> , 2008), Australia	To reveal views about dementia diagnosis derived from a larger study of information needs of caregivers of people with dementia in Australia	Focus Group Thematic analysis	Quality of life Negative aspects
(Sarabia-Cobo <i>et al.</i> , 2016), Spain	To describe the processes of decision-making used by families regarding treatments at the end of life of institutionalized patients with advanced stages of dementia	Focus Group Thematic analysis	Quality of life Negative aspects
(Scott <i>et al.</i> , 2016), United Kingdom	To develop an understanding of challenging behaviour and how it impacted on the lives of family caregivers	Focus group Content analysis	Quality of life Negative aspects

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Skaalvik <i>et al.</i> , 2016), Norway	To describe how people with AD express their sense of self in accordance with the theory of selfhood described by Harré (1998)	Interview Phenomenological and thematic analysis	Quality of life Activities of daily living Negative aspects
(Song <i>et al.</i> , 2018), Korea	To identify family caregivers' experiences in managing the BPSD with particular focus on their interpersonal interactions with patient with dementia	Focus group Content analysis	Quality of life Activities of daily living Negative aspects
(Sutcliffe <i>et al.</i> 2015), United Kingdom	To present the views of people with dementia and caregivers on a range of topics including their positive and negative experiences of dementia care; access to information and its communication; and suggestions to improve dementia care	Focus Group Thematic analysis	Quality of life Illness progression Costs Negative aspects
(Taşç <i>et al.</i> , 2012), Turkey	To examine the physical and psychological demands experienced by caregivers of patients with AD in light of the lack of home care support in Turkey	Focus Group Thematic analysis	Quality of life Activities of daily living Negative aspects
(Toot <i>et al.</i> , 2013), United Kingdom	To identify which factors may lead to crisis for people with dementia and their caregivers and identify interventions these individuals believe could help in crisis	Focus Group Thematic analysis	Quality of life Negative aspects
(Ven LG <i>et al.</i> 2017), Netherlands	To explore how people with dementia, their informal caregivers and their professionals participate in decision making about day-care and to develop a typology of participation trajectories	Interview Content analysis	Quality of life Illness progression Activities of daily living Positive and negative aspects
(Wang <i>et al.</i> , 2018), China	To develop a theoretical model explaining the longitudinal changes in the caregiving process for family caregivers of persons with mild cognitive impairment in Taiwan	Interview Content analysis	Quality of life Illness progression Activities of daily living Costs Negative aspects
(Wezel, <i>et al.</i> , 2016), Netherlands	To describe the perspectives of female Turkish, Moroccan and Surinamese Creole family caregivers in the Netherlands about providing family care to a close relative with dementia	Focus Group and interview Content analysis	Quality of life Illness progression Positive and negative aspects
(Wijngaarden <i>et al.</i> , 2018), Netherlands	To develop an in-depth understanding of what it means to live with dementia and to gain insight into what constitutes the art of living with dementia, both from the perspective of family caregivers	Focus Group and interview Thematic analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Wolfs <i>et al.</i> , 2012), Netherlands	To gain caregivers' insights into the decision-making process in dementia patients with regard to treatment and care	Focus groups and Interviews Grounded Theory Analysis	Quality of life Illness progression Negative aspects
(Xiao <i>et al.</i> , 2013), Australia	To explore the experiences of family caregivers from Chinese, Greek, Italian and Vietnamese groups in utilising dementia service	Interview and focus groups Thematic analysis	Quality of life Illness progression Activities of daily living Negative aspects
(Xiao <i>et al.</i> , 2014), Australia and China	To compare socially and culturally constructed enablers and barriers pertinent to dementia caregivers in one capital city in Australia and one capital city in China through critical reflection on the caregivers' subjective and objective experiences for the improvement of dementia care services in both countries	Focus Group and interview Giddens' Structuration Theory	Quality of life Activities of daily living Negative aspects

Authors, publication years & countries	Study aims	Data collection & analysis	Aspects focused
(Xiao <i>et al.</i> , 2015), Australia	To explore the perceived challenges of dementia care from Vietnamese family caregivers and Vietnamese care workers in South Australia	Focus Group and interview Thematic analysis	Quality of life Illness progression Activities of daily living Costs Negative aspects
(Zabalegui <i>et al.</i> , 2008), Spain	To better understand informal caregivers' views about the resources that are available to them or should be available to them	Focus group Content analysis	Quality of life Costs Negative aspects

MCI: Mild Cognitive Impairment; AD: Alzheimer's Disease; BPSD: Behaviour and psychological symptoms of dementia

Table 3. Summary of methods and participants of 81 studies included in this systematic review

	People with AD/Dementia	Family Caregivers	Former Caregivers	Dyads	Number of studies
Focus group	10	41	1	0	52
Qualitative interview	4	15	1	0	20
Questionnaire	0	1	0	0	1
Mixed methods	9	24	2	2	37
Number of studies	23	81	4	2	108

Additional file 1 | Search strategy

Proposed Medline Search Terms*

Controlled vocabulary and text/key words

“Alzheimer Disease” [MeSH Major Topic] OR “Mild cognitive impairment” OR “Cognitive Dysfunction” [MeSH Major Topic] Dementia [Title/Abstract]

Method

"Interviews as Topic" [MeSH] OR Interview* [Title/Abstract]
"Surveys and Questionnaires" [MeSH] OR Survey* OR Questionnaire* [Title/Abstract]
"Focus Groups" [MeSH]
"Geriatric Assessment" [MeSH] OR "Health Impact Assessment" [MeSH]

Population Terms

"Caregivers" [MeSH]
Caregiver* OR Carer [Title/Abstract]
"Family" [MeSH]
Famil* [Title/Abstract]
"Patient Care" [MeSH]

Outcome

"Illness Behavior" [MeSH]
"Cost of Illness" [MeSH]
"Activities of Daily Living" [MeSH]
"Quality of Life" [MeSH]
"Self Concept" [MeSH]
"Stress, Psychological" [MeSH]
"Sick Role" [MeSH]
"Outcome Assessment Health Care" [MeSH]
"Health Expenditures" [MeSH]
"Health Care Costs" [MeSH]
Self-Perception [Title/Abstract]

Studies Terms

“cohort studies” [MeSH]
“longitudinal studies” [MeSH]
“follow-up studies” [MeSH]
“prospective studies” [MeSH]
“retrospective studies” [MeSH]
Cohort OR Longitudinal OR Prospective OR Retrospective [all fields]

Filters activated

Publication date from 01.01.1998 to 15.07.20 (present)

*Search terms and strategy will be adapted to database: Embase, PsycInfo, Web of Science and Scopus

Additional file 2 | PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4-6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Available from author
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4-6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Figure 1 Additional file 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Figure 1 Additional file 1
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4-6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4-6

Additional file 2 | PRISMA Checklist

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	4-6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I ²) for each meta-analysis.	6