

Supplementary Table S1. Search strategies

#	MEDLINE 1946 to 6th July 2018 Total search results = 629	Embase 1947 to 6th July 2018 Total search results = 948	PsycINFO 1806 to 6th July 2018 Total search results = 363	CINAHL 1905 to 6th July 2018 Total search results = 688
1	exp Adult/	exp Adult/	exp Patients/	exp Adult/
2	exp Patients/	exp Patients/	exp Caregivers/	exp Patients/
3	exp Caregivers/	exp Caregivers/	exp Family/	exp Caregivers/
4	exp Family/	exp Family/	exp Spouses/	exp Family/
5	exp Spouses/	exp Spouse/	exp Aging/	exp Spouses/
6	exp Aged/	exp Aged/	exp Guardianship/	exp Aged/
7	exp Legal Guardians/	exp Legal Guardians/	Client*.tw.	exp Guardianship, Legal/
8	Client*.tw.	exp Proxy/	Or/1-7	Client*.tw.
9	Or/1-8	Client*.tw.	exp Dementia/	Or/1-8
10	exp Dementia/	Or/1-9	exp Alzheimer's Disease/	exp Delirium, Dementia, Amnestic, Cognitive Disorders/
11	exp Neurocognitive Disorders/	exp Dementia/	Dement*.tw.	exp Dementia
12	Dement*.tw.	exp disorders of higher cerebral function	Alzheimer*.tw.	Dement*.tw.
13	Alzheimer*.tw.	Dement*.tw.	mild cognitive impair*.tw.	Alzheimer*.tw.
14	mild cognitive impair*.tw.	Alzheimer*.tw.	lewy bod*.tw.	mild cognitive impair*.tw.
15	lewy bod*.tw.	lewy bod*.tw.	vascular cognitive impair*.tw.	lewy bod*.tw.
16	vascular cognitive impair*.tw.	vascular cognitive impair*.tw.	Or/9-15	vascular cognitive impair*.tw.

17	Or/10-16	Or/11-16	8 and 16	Or/10-16
18	9 and 17	10 and 17	exp advance directives/	9 and 17
19	exp advance care planning/	exp living will/	Advance care plan*.tw.	exp decision making/
20	exp advance directives/	advance care plan*.tw.	living will*.tw.	Advance care plan*.tw.
21	living will*.tw.	advance directive*.tw.	exp decision making/	exp advance directives/
22	exp decision making/	exp decision making/	exp life-sustaining treatment/	life-sustaining treatment preference*.tw.
23	life-sustaining treatment preference*.tw.	exp life-sustaining treatment/	life-sustaining treatment preference*.tw.	exp Terminal Care
24	exp Terminal Care/	exp Terminal Care/	Terminal*.tw.	exp emergency treatment/
25	end-of-life*.tw.	end-of-life*.tw.	end-of-life*.tw.	end-of-life*
26	exp Attitude to Death/	exp Attitude to Death/	exp Death and Dying/	exp Attitude to Death/
27	exp Palliative care/	exp Palliative therapy/	exp Death Attitudes	exp Palliative care/
28	Or/19-27	Or/19-27	exp Palliative care/	Or/19-27
29	18 and 28	18 and 28	Or/18-28	18 and 28
30	exp qualitative research/	exp qualitative research/	17 and 29	exp qualitative studies/
31	Qualitative*.tw.	Qualitative*.tw.	exp qualitative methods/	Qualitative*.tw.
32	interview*.tw.	interview*.tw.	exp qualitative research/	interview*.tw.
33	focus group*.tw.	focus group*.tw.	Qualitative*.tw.	focus group*.tw.
34	thematic*.tw.	thematic*.tw.	interview*.tw.	thematic*.tw.
35	grounded theory.tw.	grounded theory.tw.	focus group*.tw.	grounded theory.tw.

36	phenomenol*.tw.	phenomenol*.tw.	thematic*.tw.	phenomenol*.tw.
37	content analysis.tw.	content analysis.tw.	grounded theory.tw.	content analysis.tw.
38	ethnograph*.tw.	ethnograph*.tw.	phenomenol*.tw.	ethnograph*.tw.
39	or/30-38	or/30-38	content analysis.tw.	or/30-38
40	29 and 39	29 and 39	ethnograph*.tw.	29 and 39
41			or/31-40	
42			30 and 41	

Supplementary Table S2. Characteristics of the Included Studies

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Albinsson ¹ (2011)	SE	-	-	20	[42-81]	Nursing home; daycare centre; private group dwelling	Moderately severe or severe (advanced-stage) dementia	Alzheimer's (n=12)	Qualitative design	Explorative interviews (face-to-face)	Hermeneutic approach	Existential concerns at End-of-Life
Almberg ² (2000)	SE	-	-	30	71 [49-88]	Nursing home (institutionalised)	NS	Alzheimer's (n=53); Frontal temporal lobe (n=5); Lewy body (n=7); Parkinson's disease (n=1); Vascular (n=6); Wernicke-Korsakoff (n=1); Mixed (n=3); Unknown (n=8)	Qualitative design	Face-to-face interviews with open-ended questions	Content analysis	Bereavement and social support at End-of-Life
Andrews ³ (2017)	AU	-	-	10	NS	Dementia specific care unit	Advanced dementia	NS	Qualitative design	Semi-structured, audio-recorded individual interviews	Thematic analysis	Family members' understandings about the terminal nature of dementia
Ashton ⁴ (2016)	UK	-	-	12	[35-82]	Nursing home	Advanced dementia	Alzheimer's; Huntington's disease; Lewy bodies; Vascular; mixed-type; early onset dementia	Descriptive qualitative design (based on principles of naturalistic inquiry)	Semi-structured, in-depth interviews	Content analysis	Experiences of Advance Care Planning
Beernaert ⁵ (2016)	NL	6	[67-86]	-	-	Community	NS	Alzheimer's (n=5)	NS	Face-to-face semi-structured interviews	Thematic content and narrative analysis	Palliative care in patients with life-limiting illnesses
Beernaert ⁶ (2015)	NL	6	[67-86]	-	-	Community	NS	Alzheimer's (n=1)	NS	Face-to-face semi-structured interviews	Thematic content analysis	Family physicians' role in palliative care
Beiseker ⁷ (1997)	US	-	-	104	63.6 [27-88]	Community; Nursing home; Veterans Administration facility	NS	Alzheimer's (n=16); Mixed-type (n=3); Vascular (n=1)	NS	Semi-structured interviews	NS	Communication between carers and physicians
Black ⁸ (2009)	US	-	-	34	61 [37-79]	Nursing home	NS	Alzheimer's (n=16); Vascular (n=18); Mixed-type (n=7); Lewy bodies (n=2); Frontotemporal (n=1)	Descriptive qualitative	Face-to-face, Semistructured field guides	Iterative process	SDM's understanding of patient preferences

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Bonnel ⁹ (1996)	US	-	-	1	79	Community ; Nursing home	Advanced-stage dementia	Alzheimer's (n=20)	Qualitative case report	Broad open-ended interviews	Content analysis	Spouse experience of Alzheimer's Disease
Bosek ¹⁰ (2003)	US	-	-	57	NS	Nursing home	NS	Alzheimer's (n=3); Lewy body (n=2); Pick's disease (n=1); Vascular/multi-infarct (n=2); Unspecified (n=6)	NS	Semi structured, in-depth interviews	NS	Having a "good death"
Boyd ¹¹ (2011)	SL	12	NS	12	NS	NS	Early-stage dementia	Alzheimer's 104	NS	Interviews	NS	End-of-Life care
Cahill ¹² (2012)	IE	-	-	16	77 [62-88]	Nursing home; hospital	End-stage dementia	Alzheimer's disease	NS	In-depth qualitative interviews	Qualitative thematic analysis	Carer experience at End of Life
Cairns ¹³ (2012)	UK	-	-	5	[62-84]	Residential care	NS	Alzheimer's late onset (n=4); Mixed-type Alzheimer's (n=4); Alzheimer's of unspecified type (n=1)	Psychodynamic	Semi-structured interviews	NS	Residential care placement
Caron ¹⁴ (2005)	CA	-	-	24	[40-83]	Long-term care facility	Advanced-stage dementia	Alzheimer's late onset (n=5); Mixed-type Alzheimer's (n=1)	Grounded theory	Open-ended interviews	Constant-comparative method; line-by-line/dimensional analysis	End-of-Life decision making
Caron ¹⁵ (2005)	CA	-	-	24	[40-83]	Long-term care facility	Advanced-stage dementia	NS	Grounded theory	Open-ended interviews	Constant-comparative method; line-by-line/dimensional analysis	End-of-Life decision making
Cronfalk ¹⁶ (2017)	SE	-	-	10	NS	Nursing home	NS	NS	Descriptive design	face-to-face interviews	Qualitative content analysis	Nursing home placement
Crowther ¹⁷ (2013)	UK	-	-	40	[18-86]	Community ; District general hospital; Care home	NS	NS	Grounded Theory and phenomenology.	Unstructured narrative interviewing	NS	End-of-Life care
Davies ¹⁸ (2017)	UK	-	-	47	[39-90]	Community ; Hospital; Care home; Hospice	NS	NS	Qualitative methods	Face-to-face, in-depth interviews	Thematic analysis	Quality End-of-Life care

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
de Boer ¹⁹ (2012)	NL	24	76.3 [65-89]	-	-	Community	Early-stage dementia	NS	NS	Semi-structured interview guides, face-to-face with open-ended questions	Iterative analysis	ACP
de Vries ²⁰ (2013)	UK	-	-	2	NS	Hospital; Hospice	NS	NS	Inductive approach through grounded theory methodology	Single interviews	NS	End-of-Life care
Dening ²¹ (2012)	UK	-	-	7	NS	NS	NS	NS	NS	Topic guide to lead semi-structured interviews	Thematic content analysis	Barriers to End-of-Life care
Dening ²² (2013)	UK	8	83.3	9	69.2	Community	NS	NS	NS	Modified nominal group technique	Qualitative content analysis	Preferences for End-of-Life care
Dening ²³ (2017)	UK	6	77.6 [70-88]	7	73.4 [49-85]	Community	NS	NS	Qualitative approach (naturalistic interpretative)	Semi-structured interview with three open-ended questions	Content analysis	Health-care decision making in dementia
Dickinson ²⁴ (2013)	UK	17	[46-96]	29	[44-89]	NS	Mild to moderate dementia	NS	NS	Semi-structured interviews	Thematic analysis	Views on ACP
Fethertonhough ²⁵ (2017)	AU	-	-	34	57.4	Community ; RACF	NS	NS	Qualitative design	Semi-structured face-to-face or telephone interviews	Thematic analysis	Surrogate decision-making
Fleming ²⁶ (2015)	AU	2	NS	11	NS	NS	Severe stage dementia	NS	Mixed-method design	Focus groups	NS	Environmental design at End-of-Life in dementia
Forbes ²⁷ (2012)	CA	5	77.4 [63-95]	14	60.3 [39-91]	Community	NS	NS	Qualitative interpretative descriptive approach	Face-to-face interviews	Lubrosky's thematic analysis	Stages of dementia care journey
Forbes ²⁸ (2000)	US	-	-	28	66 [41-85]	Nursing home	Moderately severe or severe dementia	NS	Naturalistic approach	Qualitative focus groups	Qualitative content analysis	End-of Life decision making

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Gessert ²⁹ (2006)	US	35	88	38	62	Nursing home	Severe cognitive impairment;	NS	NS	Focus groups with interview guide	NS	Attitudes towards end-of-life decision making
Gessert ³⁰ (2000)	US	-	-	28	NS	Nursing home	Moderately severe to severe dementia	NS	Qualitative design	Focus groups with interview guide	Qualitative content analysis	End-of Life decision making
Givens ³¹ (2012)	US	-	-	16	62	Nursing home	Advanced dementia	NS	NS	Semi-structured interviews	NS	Carer burden
Glass ³² (2016)	US	-	-	4	[65-80s]	Community ; Hospice; Nursing home;	NS	NS	Phenomenological qualitative approach; multiple case design	Narrative interview (interview guide with open-ended questions)	NS	Site for End-of-Life care
Godwin ³³ (2009)	UK	12	NS	12	NS	Hospital wards; Hospice; Nursing home	Advanced dementia	NS	NS	Interviews with open-ended questions	NS	End-of-Life care
Goodman ³⁴ (2013)	UK	18	[68.7-92]	-	-	Care homes	NS	NS	Exploratory qualitative	Semistructured, conversational interviews	NS	Preferences for End-of-Life care
Groen van de Ven ³⁵ (2016)	NL	23	[62-89]	44	NS	Community ; Institutions (sheltered and Nursing homes)	Beginning , moderate, and advanced dementia	NS	Prospective, qualitative, multi-perspective design	Semistructured interviews using an interview guide	Content analysis; timeline method; constant comparative method	Decision trajectories in dementia care
Groen van de Ven ³⁶ (2016)	NL	23	[62-89]	44	NS	Community ; Institutions (sheltered and Nursing homes)	Beginning , moderate, and advanced dementia	NS	Qualitative, multi-perspective design	Semistructured interviews using an interview guide	Content analysis; constant comparative method	Challenges of shared decision making in dementia
Hill ³⁷ (2016)	UK	14	NS	43	NS	NS	Early-stage dementia	NS	Q-methodology	Q-methodology post-sort questions	NS	End-of-Life care
Hirschman ³⁸ (2006)	US	-	-	30	64.3 [42-93]	Community home; Assisted living facility	Advanced dementia	NS	NS	Semi-structured interviews	NS	Barriers to substitute decision making
Hirschman ³⁹ (2008)	US	-	-	30	64.3 [42-93]	Community home; Assisted living facility	Advanced dementia	NS	NS	Semi-structured interviews	NS	Barriers to /facilitators to advance care planning

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Gil ⁴⁰ (2018)	IL	-	-	17	[40-70s]	Hospital	Advanced dementia	NS	NS	Observation and interviews	Thematic approach	End-of-life decision making
Hovland ⁴¹ (2016)	US	-	-	30	[45-88]	Community ; Hospital; Hospice; Skilled or rehab nursing centre	NS	NS	Qualitative descriptive approach	In-depth, qualitative interviews	Qualitative content analysis	Preparedness for death
Jenning ⁴² (2017)	SZ	7	71 [73-92]	36	63 [42-85]	Community	Early-stage dementia	NS	NS	Focus groups	NS	Goals for dementia care
Jox ⁴³ (2011)	GER	-	-	32	61 [31-82]	RACF	NS	NS	Qualitative study	Audiotaped verbalisations to vignettes	Qualitative content analysis	Surrogate decision making
Juozapavicius ⁴⁴ (2001)	US	-	-	20	63.9 [35 - >86]	Community	NS	NS	NS	Interview with guide	Constant comparative method	Caregiving experience in Alzheimer's
Lamahewa ⁴⁵	UK	-	-	46	NS	Community ; Hospital	NS	NS	Qualitative study	Semi-structured interviews and focus groups	Thematic analysis	Decision-making at end-of-life
Lawrence ⁴⁶ (2011)	UK	-	-	27	NS	Care home; Community ; Continuing care unit; General hospital	NS	NS	NS	In-depth interviews	NS	Dying well and End-of-Life care
Lewis ⁴⁷ (2014)	US	-	-	11	NS	Community ; Hospitals; Hospice; Nursing homes	NS	NS	Descriptive phenomenological method	Interviews	Colaizzi method	Carer's experience with seeking hospice care
Lewis ⁴⁸ (2015) ^a	US	-	-	101	NS	Community ; Hospital; Hospice; Assisted living; Nursing home	NS	NS	Grounded theory	In-person interviews, online interviews, book and blog memoirs of caregivers, and participant observation.	Constant comparative method	Caregiving at End-of-Life; Theory-making
Livingston ⁴⁹ (2010)	UK	-	-	46	62	Community ; Care home	NS	NS	Qualitative study/ Grounded Theory	In-depth, semi-structured interviews	Thematic analysis	Barriers to /facilitators of substitute decision making

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Livings-ton ⁵⁰ (2013)	UK	-	-	20	[33-95]	Care home	NS	NS	NS	Qualitative interview, open questions with an interview guide	Thematic analysis	Intervention study at End-of-Life
Mann ⁵¹ (2013)	US	-	-	16	NS	Nursing home	NS	NS	NS	Semi-structured qualitative interviews	Constant comparative method	Do-not-hospitalise orders
Muders ⁵² (2015)	GER	-	-	85	NS	NS	NS	NS	NS	Cross-sectional survey, open-ended questions	Qualitative content analysis	Carer's experience with caring for Person with dementia at end-of-life
Mulqueen ⁵³ (2017)	IE	NS	NS	-	-	RACF	Mild dementia	NS	NS	Nominal group technique	Manifest content analysis method	Preferences for end-of-life care
Noh ⁵⁴ (2016)	US	-	-	20	63.4	Community ; Other unspecified	NS	NS	NS	Semi-structured telephone or face-to-face interviews	Thematic analysis	Proxies' perception of support in end-of-life decision making
Pasman ⁵⁵ (2004)	NL	-	-	32	NS	Nursing home	Middle-stage to severe (as per 3 case studies)	NS	NS	Participant observation	Constant comparison method	Decision making on artificial nutrition and hydration
Peacock ⁵⁶ (2014)	CA	-	-	11	[49-89]	Long-term care home	Advanced dementia	NS	Munhall's methodology for interpretive phenomenology	In-depth, open-ended interviews	Hermeneutic approach	End-of-life dementia caregiving experience
Peacock ⁵⁷ (2014)	CA	-	-	11	[49-89]	Community ; Long-term care home	NS	NS	NS	Open-ended interviews	Qualitative description approach	Dementia caregiving journey of bereaved carers
Poole ⁵⁸ (2017)	EN	11	NS	25	NS	Community living; supported living; group living; standard nursing/residential care	Advanced Dementia	NS	Social constructivist epistemological	Q-sort methodology, with open-ended questions; face-to-face semi-structured qualitative interviews	Thematic analysis	End-of-life care in dementia
Poppe ⁵⁹ (2013)	UK	12	NS	8	NS	Community	Mild dementia	NS	NS	In-depth, open-ended interviews	Constant comparison method	Advance care planning in early dementia

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Powers ⁶⁰ (2008)	US	6	NS	NS	NS	Hospice; Nursing home	NS	NS	Concurrent mixed methods design (Qual strand: ethnographic field study)	Interviews with guides	Content analysis	Palliative end-of-life care in dementia
Robinson ⁶¹ (2000)	US	-	-	12	[51-79]	Long-term care facility	Advanced dementia	NS	Phenomenological study	Interviews	VanManen's selective and highlighting approach, with Linguistic transformation?	SDM's experience of implementing and advance care plan
Rosemond ⁶² (2017)	US	-	-	16	NS	Nursing home	Advanced dementia	NS	Qualitative study	Semi-structured interviews	Qualitative description approach	SDM's experience of goals-of-care decision making
Russell ⁶³ (2008)	AU	-	-	15	[35-75]	Community ; Hospital; Nursing home	Advanced to terminal dementia	NS	NS	Semistructured in-depth interviews, with open-ended questions	Thematic analysis	Carer's view on quality of life in advanced-terminal dementia
Saini ⁶⁴ (2016)	UK	-	-	4	[54-76]	Nursing home	Advanced dementia	NS	Ethnography	Semi-structured interviews using open-ended questions	Thematic analysis	End-of-life discussions
Samia ⁶⁵ (2012)	US	-	-	26	<60-84]	Community ; Other	NS	NS	Qualitative descriptive study	Focus groups	Content analysis	Learning needs/ challenges of carers participating in psychoeducation program
Sanders ⁶⁶ (2009)	US	-	-	27	[38-83]	Community ; long-term care facility (assisted living or nursing home); hospice	End-stage dementia	NS	Ethnomethodology	Semi-structured interviews	Constant comparative method;	Carers' response to end-stage dementia care
Sarabia-Cobo ⁶⁷ (2016)	SPN	-	-	84	66 [36-87]	Nursing home	Moderate to severe dementia	NS	Naturalistic approach	Qualitative focus groups (Krueger method)	Qualitative content analysis	End-of-Life decision making
Shanley ⁶⁸ (2017)	AU	-	-	34	57.4	Community ; RACF	NS	NS	Qualitative study	Semi-structured face-to-face or telephone interviews	Thematic analysis	SDM's support needs

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Shanley ⁶⁹ (2011)	AU	-	-	15	[35-75]	Community ; Hospital; Nursing home	Advanced and terminal stage dementia	NS	NS	Semi-structured in-depth interviews with open-ended questioning	Thematic analysis	Family carer support needs
Shuter ⁷⁰ (2014)	AU	-	-	13	[54-82]	Community ; Hospital; RACF	NS	NS	Kramer's Conceptual Model of Carer Adaptation; Cognitive-based Behavioural Conceptualisation of Complicated Grief	Semi-structured interviews with open-ended questions	Problem-Driven Content Analysis	Grief and health outcomes of dementia carers
Slape ⁷¹ (2014)	AU	-	-	10	NS	RACF	NS	NS	Hermeneutic phenomenological approach	Semi-structured in-depth interviews	In-depth qualitative analysis	Spiritual needs of family members
Snyder ⁷² (2013) ^b	US	-	-	126	59.3	Nursing home	Advanced dementia	NS	NS	Semi-structured interviews, open-ended questions about the advantages and disadvantages	NS	SDM's perceptions of feeding options
Stewart ⁷³ (2011)	US	-	-	2	NS	Residential and nursing care homes	NS	NS	NS	Semi-structured interviews	Framework analysis	ACP
Stewart - Archer ⁷⁴ (2015)	CA	136	NS	-	-	Community ; Supportive housing; Personal care home	NS	NS	NS	Open-ended face-to-face interviews	Qualitative content analysis	End-of-life care preferences
Stirling ⁷⁵ (2014)	AU	-	-	11	NS	NS	NS	NS	NS	Family interviews	Thematic analysis	Development of "dying" discussion tool
Tarter ⁷⁶ (2016)	US	-	-	51	62.4	Hospice	NS	NS	NS	Secondary data from audio-recordings of therapy intervention session	Thematic analysis	Hospice pain management
The ⁷⁷ (2002)	NL	35	[61-98]	32	NS	Nursing home	NS	NS	Ethnography	Comprehensive notes of observations and informal; formal interviews	NS	Withholding artificial administration of fluids and food

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Thuné-Boyle ⁷⁸ (2010)	UK	-	-	20	[44-89]	Community ; Nursing/residential home; Hospital	Advanced dementia	NS	Qualitative methodology	Semi-structured interviews	Framework analysis	End-of-life care needs
Treloar ⁷⁹ (2009)	UK	-	-	14	68.1 [36-91]	Community ; Hospital; Nursing care home	Scores of 6-7 (severe to very severe cognitive decline) as rated on Functional Assessment Staging (FAST). Stage 7 is the most advanced category of dementia.	NS	NS	Qualitative semi-structured questionnaire (allowing for free interview)	NS	Palliative and end of life care of dementia at home
van der Steen ⁸⁰ (2017)	NL	-	-	10	[59-86]	Community ; Nursing home	Advanced, terminal phase dementia	NS	NS	Focus groups	Thematic analysis	Palliative care service development for terminal dementia
van Soest-Poortvliet ⁸¹ (2015)	NL	-	-	20	61 [46-68]	Nursing home	Score 13 mean (8-20 range) on Bedford Alzheimer Nursing Severity-Scale (BANS-S); (Rating from 7-28; higher score means more severe dementia.	NS	Qualitative descriptive methodology	Explorative, qualitative in-depth interviews	Thematic analysis	ACP
Volicer ⁸² (2016)	US	-	-	15	NS	Hospice	Advanced dementia	Variant Creutzfeldt-Jakob disease (vCJD)	NS	Focus groups	NS	Acceptability of food-limiting advance directive
Wakunami ⁸³ (2009)	JPN	-	-	4	[59-78]	Community ; Hospital; Nursing home	NS		Qualitative methodology	Semi-structured interviews	NS	Introducing end-of-life care to families

Study	Country	No. of Person with dementia	Person with dementia age (mean [range])	No. of CG	CG age (mean [range])	Care Setting	Dementia Stage	Dementia Type	Methodology	Qualitative Data Collection	Analysis	Topic
Wladkowski ⁸⁴ (2016) ^c	US	-	-	24	63 [48–78]	Community living facility; Assisted living facility; Skilled nursing facility; Hospice home	NS	NS	NS	Semi-structured face-to-face or telephone interviews	Thematic analysis	Carer grief over live hospice discharge

Abbreviations and definitions: ACP, advance care planning; AU, Australia; CA, Canada, Colaizzi method, analytical method using descriptive phenomenology; content analysis, deductive methodology that involves identification of codes prior to searching for their occurrence in the data; EoL, end of life; ethnography, to discover and describe individual social and cultural groups; GER, Germany; IE, Ireland; IS, Israel; JPN, Japan; mixed methods, include quantitative and qualitative methods; NL, Netherlands; nominal group technique, semi-evaluation method involving qualitative and quantitative approaches; NS, not state; phenomenology, to study peoples' understanding and interpretations of their experiences in their own terms and emphasizing these as explanations for their actions; Q-methodology, a mixed method combining qualitative and quantitative techniques to study subjectivity; RACF, residential aged care facility; SDM, substitute decision maker; SE, Sweden; SPN, Spain; SWZ, Switzerland; thematic analysis, concepts and theories are inductively derived from the data; UK, United Kingdom; US, United States.

a theoretical sample of 101 participants

b demographics based on 127 participants

c only 18 of 24 participants reported their ages

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