


Dignifying and undignifying aspects of care for people with dementia: a narrative review

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Background: The progressive disease trajectory makes people with dementia increasingly vulnerable and gradually more dependent on others which can lead to admission to a nursing home. Special interest in dignity in people with dementia has led to a growing body of knowledge towards promoting or hindering their dignity.

Aim: The aim of this narrative review was to synthesise dignifying and undignifying aspects of formal and informal care for people with dementia within nursing homes.

Method: The electronic databases CINAHL, SCOPUS, PsycInfo and PubMed were systematically searched with the terms 'dementia' and 'dignity', complemented with the use of snowballing and reference check. A total of 789 unique items were found. The search and selection process was structured by the PRISMA framework, and both authors formulated the criteria of eligibility. A methodological check was performed using the critical appraisal tool of Hawker. This process led to inclusion of 29 articles which were reviewed with the help of the guidelines for narrative synthesis by Popay et al.

Findings: The emerged dignifying and undignifying aspects of formal and informal care are characterised by either a successful or unsuccessful process of adjustment towards changing abilities, preferences and care needs of people with dementia. Three themes appeared as undignifying aspects of care: 'Stigmatisation and objectivation', 'Scarcity and hastiness' and 'Impending estrangement and misunderstanding'. Four themes were identified as dignifying aspect of care: 'Personalisation', 'Respect, attentiveness and encouragement', 'Attention for physical care and bodily gestures', and 'Foster belonging'. Literature synthesis showed mostly relational aspects of care concerning dignity in people with dementia. Formal and informal caregivers are important in maintaining and promoting their dignity.

Keywords: narrative review, dementia, dignity, indignity, dementia care, nursing home care, elderly care, care ethics.

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Introduction

Dementia is a syndrome that refers to more than fifty diseases with deterioration of cognitive functioning as main characteristic and of which Alzheimer's Disease is most common (1). Worldwide, around 50 million people have dementia, and it is one of the major causes of disability and dependency among older people (2,3). Depending on the type of dementia, the progressive nature of the disease follows a pattern in which different stages can be distinguished, from a mild de-orientation and memory loss towards an increased forgetfulness and need for assistance until a near total dependence and inactivity (4). Dementia is a chronic and progressive

illness that eventually leads towards death, although this is not always recognised (5,6).

The disease trajectory makes people with dementia increasingly vulnerable and gradually more dependent on others. When cognitive decline leads to an increased need of care, people with dementia may come to live in nursing homes. Dignity preservation of those in need of care can be seen as one of the aims inherent to nursing care (7–9). Gastmans (8) argues that the ethical essence of nursing is 'providing care in response to the vulnerability of a human being in order to maintain, protect and promote his or her dignity as much as possible (p. 146)'. Unfortunately, even though studies report the importance of maintaining dignity of persons facing a terminal illness (10–12), people with dementia often receive undignifying treatment and are ending their lives in pain (13,14).

While dignity is sometimes referred to as a vague concept, empirical and theoretical literature on the subject in

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general, and preserving dignity specifically, is extensive (15). In the past decennia, multiple studies built the conceptualisation of dignity based on experiences of terminally ill and chronically ill patients in different stages of their disease, as well as those of nursing home residents (10,12,16–20). Chochinov's (10) dignity model describes a broad spectrum of dignity-related themes, showing the complexity of how dignity is experienced by terminally ill cancer patients. The model consists of three major dignity categories: illness-related concerns, a dignity-conserving repertoire and a social dignity inventory. Different authors reflect on the multiple levels of and perceptions on dignity and their interrelatedness, aiming to further clarify the concept (21–23). Consistently, dignity is perceived as something intrinsically held, a human characteristic, and as well depending on and influenced by external factors. Experiences of patients in institutional settings confirm these insights (15,20,24). The attitudes and behaviours of staff appear highly influential on whether residents' dignity is bolstered or fractured (11,19). Asymmetrical relationships might endorse violations of dignity, as well as processes of rudeness, indifference and disregard. (25).

Increased interest into the dignity of people with dementia has led to a growing body of knowledge in recent years which help to further conceptualise dignity for this patient group (26). A better understanding of undignifying dementia care practices might provide important knowledge for dignity preservation. To our knowledge, a review incorporating the different perspectives within the care-triad and including both dignity-enhancing and hindering characteristics of care has not yet been performed. The aim of this narrative review was to synthesise dignifying and undignifying aspects of formal and informal care for people with dementia. The leading question guiding this review process was 'Which aspects of formal and informal care can be described as dignifying or undignifying, for people with dementia?'

Methodology

A narrative approach was chosen for this literature review, aiming to synthesise findings within and between studies towards dignifying and undignifying aspects of care. In order to structure the search and selection process the Preferred, Reporting items of Systematic Reviews and Meta-Analyses (PRISMA) (27) was followed. The consecutive phases of the narrative synthesis framework of Popay et al. (28) were used to guide the analysing process. First we developed a primary theory through interpretation of the findings (step 1) followed by a preliminary synthesis through establishing patterns (step 2). Thereafter, we explored the relationships in and between the included studies (step 3). The analysis ended with assessing the robustness of the synthesis (step 4)

including a critical reflection on possible assumptions made which stimulated reflection on own perspectives and expectations of both authors.

Data search

A systematic search with the use of the terms 'dementia' and 'dignity' was performed. The electronic databases CINAHL, SCOPUS, PsychINFO and PubMed were used during September and October of 2018 (see Table 1). Thereafter, searching techniques such as snowballing and reference check amplified the search strategy. This process resulted in a total of 1233 items transferred into RefWorks which excluded 442 duplicates leaving a total of 791 unique items.

Data selection on eligibility

These items were screened on title and abstract by the first author, based on the following primary inclusion and exclusion criteria: written in English, published between 2003 and 2018, peer-reviewed, and having a clear relation or relevance to the topics of dementia and dignity. This first step of exclusion left 273 selected items which were transferred into Covidence for a second screening. Subsequently, more specific criteria for eligibility were formulated by both authors; studies that used a qualitative research method to investigate/explore the phenomenon, and performed within a comparable context, meaning countries with a similar welfare state and elderly care facilities (see Table 2).

Both authors separately screened the titles and abstracts, followed by a dialogue in which three clusters of articles appeared. Articles with a specific focus on (a) dignity and dementia, (b) dignity within nursing homes and (c) end-of-life care for people with dementia. The authors decided that for inclusion, articles should belong to one of these clusters, in line with eligibility criteria four. This process left a selection of 65 articles for full-text screening and further dialogue about their applicability, mainly based on the used methodology or research setting. This resulted in the inclusion of 29 articles (see Fig. 1. PRISMA flow chart).

Table 1 Electronic database search strategies

Database	Search strategy	Items
CINAHL	Find all my search terms: 'dementia AND dignity'	266
PsychINFO	(Dementia and dignity).ab	154
PubMed	("dementia"[MeSH Terms] OR "dementia"[All Fields]) AND dignity[All Fields]	255
Scopus	Dementia AND dignity (filter: open access)	120
	Dementia AND dignity (<i>Title+Abstract+Keyword</i> s)	380

Table 2 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1. Articles written in English, peer-reviewed, published between 2003 and 2018. Full-text available	1. Editorials, book reviews, open letters, pictorials, brief items, comments, book(chapters), thesis, conference proceedings
2. Geographic: European, North American, Canada, Australia (other Western countries)	2. Geographic: India, Japan, Saudi Arabia, South Africa, Korea, Russian (other non-Western countries)
3. Studies that used a qualitative research method to investigate/explore the phenomenon	3. Quantitative, theoretical studies and review articles
4. Articles focussing on combination of at least two of the following themes: dementia, dignity, dignity-enhancing care, end-of-life care and nursing home care. Articles belonging to one of the three formulated clusters	4. Articles focussing on incontinence, technology, feeding or nutrition, shoe-fitting, mouth-care, sexuality, medicine, physical restraints, clothing, doll/art/music/creative therapy without a main focus on dignity

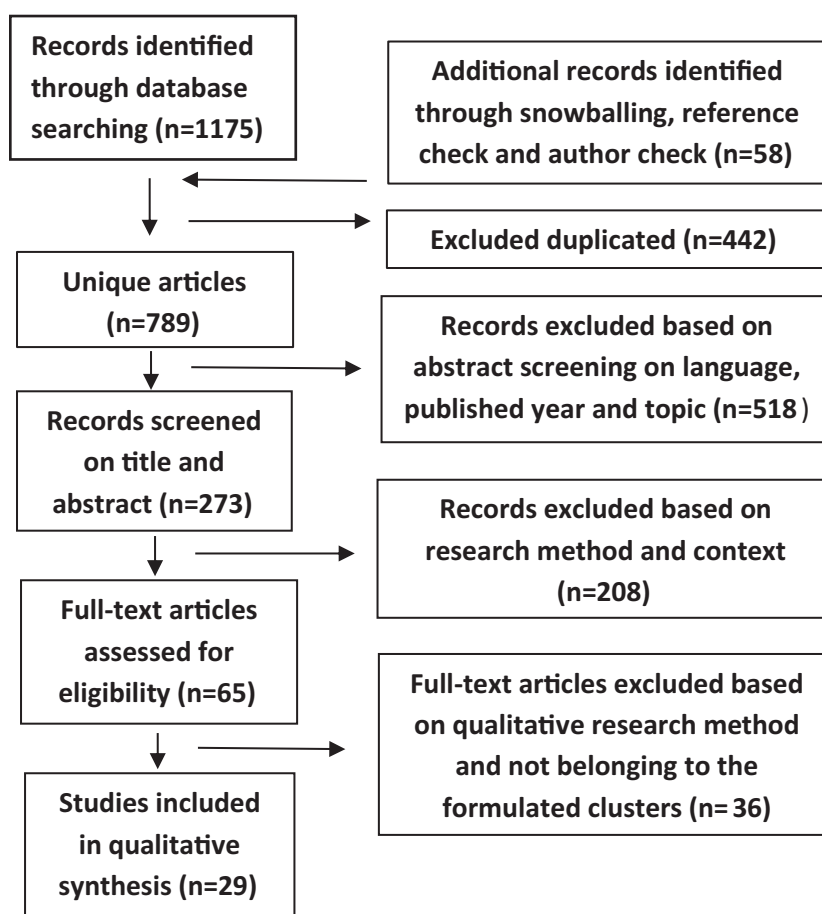


Figure 1 Prisma flow chart (1).

Quality assessment

The selected articles were checked on quality of methodology by using the critical appraisal tool of Hawker (29). This enabled the validation of methodological rigour on nine aspects possibly cumulating to a maximum of 36 points. Through appraising, 23 included articles were classified as fair (27–35 points) and six were

classified as poor (18–26). In dialogue, the authors decided in light of the scarcity of studies found, when substantively relevant, not to exclude the items with a poor score. Studies belonging to this group were discussed during analysis, and findings were properly weighed throughout the narrative synthesis using the framework of Popay et al. (28). See Table 3 for all characteristics of the included articles.

Table 3 Characteristics of included studies, key findings, cluster division and methodological rigour

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Chochinov, 2012, Canada (1)	Dignity therapy: A feasibility study of elders in long-term care	The purpose of this study was to assess the feasibility of dignity therapy for the frail elderly	N = 12 Residents Family members of cognitive impaired Participated professionals number unknown	Feasibility study using Dignity Therapy and interviews	The majority of proxy participants indicated that dignity therapy would be helpful to them and their families. In both groups, healthcare professionals reported the benefits of dignity therapy in terms of changing the way they perceived the resident, teaching them things about the resident they did not previously know	Dignity + Dementia + Nursing home	29
Davies, 2017, UK (2)	Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study	To explore the views of family caregivers about quality end-of-life care for people with dementia	N = 47 Family caregivers of recently diagnosed relative, caring for someone with dementia and bereaved family	Qualitative study using in-depth interviews and analysed using thematic analysis	End-of-life care does not differ from care through the disease trajectory using a palliative approach. Three main themes of quality of end of life; maintaining the person within, fostering respect and dignity and showing compassion and kindness. The study highlights the importance of psycho-social care	Dignity + Dementia + End of life + Nursing home	32
Dening, 2013, UK (3)	Preferences for end-of-life care: A nominal group study of people with dementia and their family carers	To explore whether people with dementia and their caregivers were able to generate and prioritise preferences for end-of-life care. We examined whether carers influenced the choices made by the people with dementia	Recruited purposeful sample from memory service. N = 6 People with dementia, N = 5 Carers and N = 6 dyads of people with dementia and carers	Nominal group technique with a qualitative content analyses	Underlying wishes and preferences of people with dementia and their family carers may differ. Quality of care, family contact, dignity and respect were ranked as significant themes by all groups	End of life + Dementia + Dignity	30

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Dwyer, 2009, Sweden (4)	Dignity as experienced by nursing home staff	To explore nursing home staff members' experiences of what dignity in end-of-life care means to older people and to themselves	Purposeful sampling. N = 4 Managers N = 5 Registered nurses, N = 12 Nurses assistants	Qualitative descriptive study. Interviews and content analysis	Maintaining dignity for the older person means basic care needs met, feeling of trust, respect and privacy and being seen as a person. Nursing home staff deal with a moral conflict between what they are able to deliver and what they would like to provide. This threatened their sense of self-respect as well as meaningfulness and the possibility of providing dignity promoting care	Dignity + Nursing home	30
Fleming, 2015, Australia (5)	'I want to feel at home': establishing what aspects of environmental design are important to people with dementia nearing the end of life	To explore the views of people with dementia, family carers and professionals on what aspects of the physical environment would be important to support a good quality of life to the very end	Three focus groups N = 18 Participants; 2 with dementia, 11 bereaved family, 5 practitioners. N = 21 experts in Delphi process	Focus groups followed by Modified Delphi process	Three main design features with ten subthemes are formulated: (1) Engagement, with the senses, spiritual, social and with nature; (2) Calmness which is familiar and homely feel and (3) Care aiming for dignity, privacy, reduce physical stress, safety and security	Dignity + Dementia End of life + Nursing home	27
Hall, 2014, UK (6)	Maintaining dignity for residents of care homes: A qualitative study of the views of care home staff, community nurses, residents and their families	To explore and compare the views of care providers, residents and their families on dignity and how to maintain it	Sampling within 34/38 care homes for older people in London area. N = 33 Care home managers, N = 29 Care assistants, N = 18 Care home nurses, N = 10 Community nurses, N = 16 Residents N = 15 Members of residents' families	Qualitative descriptive design, semi-structured interviews and framework approach to qualitative analysis	Issues of dignity are embedded in the everyday interactions between residents and care providers. The main themes were: independence and privacy; followed by comfort and care, individuality, respect, communication, physical appearance and being seen as human. Maintaining dignity and focusing on fostering dignity, can be a starting point for improving the quality of care and quality of life of residents	Dignity + Nursing home	30

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Heggstad, 2013, Norway (7)	'Like a prison without bars': Dementia and experiences of dignity	To investigate how life in Norwegian nursing homes may affect experiences of dignity among people with dementia	N = 5 Residents diagnosed with dementia and living in the unit where the overall study took place	Qualitative design and a phenomenological and hermeneutic approach. Participant observation combined with qualitative interviews	Residents feel captive and homesick. The need for confirmation, freedom and belonging are intertwined and linked to experience of dignity. It is important to confirm the resident as an individual person and try to make the nursing home feel less institutional and more home like in order to maintain their dignity	Dignity + Dementia + Nursing home	31
Heggstad, 2015a, Norway (8)	Dignity and care for people with dementia living in nursing homes	The aim of this study was to gain more knowledge about how people with dementia, and their relatives, experience that dignity being maintained or harmed in nursing homes	N = 15 Residents diagnosed with dementia, living in the units of study. N = 7 Relatives of the residents diagnosed with dementia	Phenomenological and hermeneutic design. Participant observations and thematic interviews	Relatives saw as most important that their family member with dementia was taken seriously and confirmed as a relational human being. That professionals show respect and care with compassion and empathy. However, relatives experienced lack of resources and task-centred care as threats to confirming, relational care and to the dignity of the patients	Dignity + Dementia + Nursing home	29
Heggstad, 2015b, Norway (9)	How individuals with dementia in nursing homes maintain their dignity through life storytelling – a case study	To present and discuss findings on what individuals with dementia do by themselves to maintain or promote their dignity of identity within a nursing home	N = 3 Cases of life storytelling of people with dementia within nursing homes	Phenomenological and hermeneutic design. Participant observation and qualitative interviews	Individuals with dementia living in nursing homes may use life storytelling or narratives to manage chaos and to find safety in their lives. Storytelling is also used as a way to present and maintain identity. We can see this as a way of maintaining dignity of identity or social dignity. Health care professionals should be open to listen to these life stories	Dignity + Dementia + Nursing home	28

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Jakobsen, 2010, Norway (10)	Dignity of older people in a nursing home: Narratives of care providers	To illuminate the ethically difficult situations experienced by care providers working in a nursing home	N = 23 Staff members of a nursing home with different functions; nurses, department head, physiotherapist and social worker	Phenomenological-hermeneutic. Qualitative interviews and narrative approach	The findings showed that care providers experience ethical challenges in their everyday work. The informants in this study found the balance between the ideal, autonomy and dignity to be a daily problem. Frustration and feelings of powerlessness were related to jeopardisation of patient's dignity	Dignity + Nursing home	27
Johnston, 2016, UK (11)	Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy	To assess the feasibility, acceptability and potential effectiveness of Dignity Therapy to improve the quality of life and reduce psychological and spiritual distress in older people with early-stage dementia	N = 7 People with early diagnosed dementia. Recruited from postdiagnosis dementia service. N = 7 Family N = 7 Stakeholders N = 6 Members of focus groups	Feasibility Mixed-method study. Interviews pre- and postdignity therapy using three outcome measures	Three main themes were formulated: A life in context, a key to connect and personal legacy. This study demonstrated that Dignity Therapy is feasible, acceptable and potentially effective for older people with dementia. It has the potential to improve the quality of life and enhance person-centred care for people with dementia	Dignity + Dementia	33
Johnston, 2017, UK (12)	'This is my story, how I remember it': In-depth analysis of Dignity Therapy documents from a study of Dignity Therapy for people with early-stage dementia	To explore and examine the thematic features and shared narrative dimensions of Dignity Therapy documents in order to gain a fuller understanding of the value of using Dignity Therapy for people with early-stage dementia	N = 7 people with early diagnosed dementia. Recruited from postdiagnosis dementia service. N = 7 Family N = 7 Stakeholders N = 6 Members of focus groups	Feasibility Mixed-method study. Generativity documents were analysed using a framework analysis	Four main themes were identified: origin of values, essence and affirmation of self, forgiveness and resolution and existential/meaning in life. The process and documents helped to place the person's life in context of their past and family	Dignity + Dementia	30

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Kelly, 2014, UK (13)	Bodywork in dementia care: recognising the commonalities of selfhood to facilitate respectful care in institutional settings	To explore the practice of bodywork in the care of frail people with dementia in institutional setting. To advance theory and improve practice	N = 15 People with moderate to advanced dementia, with British, in three locked wards	Ethnographic study. Fieldwork, Dementia Care Mapping, video recording, keeping extensive fieldnotes	The importance is stressed of re-viewing the person as more than a body and use commonalities of selfhood. By putting selfhood at the forefront of bodywork will facilitate respectful care that dignifies rather than objectifies the person	Dignity + Dementia + Nursing home	22
Lemos Dekker, 2018, Netherlands (14)	Moral frames for lives worth living: Managing the end of life with dementia	To elaborate on the production of lives (not) worth living and explore how family members welcomed the death of a loved one with dementia	N = 40 Family of people with dementia living in nursing homes. N = 4 focus groups, with family and care professionals	Ethnographic fieldwork In-depth interviews, focus groups and 18 months of observations	The welcoming of death as a relief to suffering and loss of dignity is not an act of indifference but can be seen as a form of care	Dignity + Dementia + End of life + Nursing home	18
Manthopre, 2013, UK (15)	Dementia, dignity and quality of life: nursing practice and its dilemmas	To provide practical examples of the ambition to respect the dignity of older people and may be used in practice development	N = 70 Participants of a UK national networking conference for dementia care practitioners and service managers	Two-hour workshop. A Modified nominal group method was used. Discussing five vignettes	Each vignette promoted discussion of differences of perspectives about the ways to enhance the dignity of people with dementia in hospital, care home and community settings. The discussion confirmed that while dignity may be one quality indicator of good care potentially enhancing quality of life, it is not always straightforward	Dignity + Dementia + Nursing home	23

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Melander, 2018, Sweden (16)	Human capabilities in advanced dementia: Nussbaum's approach	To explore how Martha Nussbaum's approach to human capabilities can apply to dignity in the lives of people with advanced dementia living in nursing homes	N = 4 Women diagnosed with advanced dementia and residing in dementia units	Ethnographic approach. Participatory observation. Analyses using capabilities approach as framework	A dignified life for individuals with advanced dementia requires nursing staff to be present and to provide adapted support to compensate for limitations due to the consequences of the disease. Thereby it's crucial to pay attention to and act upon expressions and to create opportunities for enabling these expressions	Dignity + Dementia + Nursing home	31
Näden, 2013, Nordic countries; Norway, Sweden, Denmark (17)	Aspects of indignity in nursing home residences as experienced by family caregivers	Gain knowledge on how dignity is maintained, promoted or neglected in nursing home residents. This article focuses on deprivation of dignity in care from the perspectives of family	N = 28 Family caregivers in six nursing home residences in three Nordic countries	Explorative design. Interviews Interpretative hermeneutic analyses	The overall theme that emerged was: A feeling of being abandoned. The subthemes: deprived of the feeling of belonging, deprived of dignity due to acts of omission, deprived of confirmation, deprived of dignity due to physical humiliation, deprived of dignity due to psychological humiliation and deprived of parts of life	Dignity + Nursing home	26
Oosterveld-Vlug, 2013a, Netherlands (18)	Nursing home staff's views on residents' dignity: a qualitative interview study	Gain more insight into how nursing home staff perceive and promote the personal dignity of individual residents in daily practice	N = 13 Physicians N = 15 Primary attending nurses Recruitment followed the participation of residents in an earlier study	A qualitative descriptive study. In-depth interviews guided by a topic list. Thematic analyses	Both physicians and nurses view physical impairment and being dependent on others could threaten personal dignity dependent on the resilience of the resident. Individualised dignity-conserving care appeared hard to bring about in daily practice. Physicians and nurses often experienced conflicting values and barriers caused by the lack of resources	Dignity + Nursing home	31

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Oosterveld-Vlug, 2013b, Netherlands (19)	Changes in the Personal Dignity of Nursing Home Residents: A Longitudinal Qualitative Interview Study	To investigate if and how nursing home residents' personal dignity changes over the course of time, and what contributes to this	N = 22 Residents of four nursing homes, with physical diseases and able to understand the study aim and comprehensively Dutch speaking	Longitudinal qualitative study. Multiple in-depth interviews with an interval of six months, total of 83 interviews. Thematic analyses	Although personal dignity is also dependent on one's character and coping capacities, nursing home staff can contribute to dignity by creating optimal conditions that recovers feelings of control and being a worthwhile person	Dignity + Nursing home	30
Oosterveld-Vlug, 2014, Netherlands (20)	Dignity and the factors that influence it according to nursing home residents: a qualitative interview study	To gain insight into the way nursing home residents experience personal dignity and the factors that preserve or undermine it	N = 30 Residents recruited from four nursing homes, sample aimed to maximise the range of residents' characteristics	An explorative and qualitative descriptive study. In-depth interviews with use of a topic list. Thematic analyses	Being ill or frail and residing in a nursing home is not dignity degrading in itself. The consequences of the illness on the individual self, relational self and societal self could cause a decline in personal dignity. Good professional care and a supportive social network can preserve dignity of residents of nursing homes, especially in the way they treat the resident	Dignity + Nursing home	34
Örülv, 2007, Sweden (21)	Dignity work in dementia care. Sketching a micro-ethical analysis	To study conflict-solving dignity work done by staff in dementia care, focusing on the way staff handle (potentially) problematic situations in the interaction between residents – situations where the dignity of one or more persons involved may be threatened or violated	150 hours of video with ethnographic field notes	Ethnographic field work. Observations and video recordings, thematically analysed and discussed by micro-ethical positioning	Various coping strategies are identified in regard to whether or not, as well as when and how to interfere	Dignity + Dementia + Nursing home	25

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Palmer, 2013, USA (22)	Preserving personhood of individuals with advanced dementia: Lessons from family caregivers	To report the family caregivers' efforts to preserve the personhood of individuals with advanced dementia after admission to a long-term care facility	N = 15 family caregivers by convenience sampling by presentation to support groups, distribution of flyers and advertisement	Hermeneutic phenomenological design. Interviews with open-ended questions	Family maintained the personhood through their involvement with care. Disease progression increases vulnerability and reduces self-care. Discount of personhood occurs by disregard for basic care needs, not relate to them as a person, and disrespectful practices. Personhood is been supported by individualised care, staff knowing the attributes that define a person, acknowledging likes and dislikes, interact with the person	Dignity + Dementia + Nursing home	27
Pleschberger, 2007, Austria (23)	Dignity and the challenge of dying in nursing homes: the residents' view	To explore the meaning of dignity with regard to end-of-life issues from the perspective of older nursing home residents in western Germany	N = 17 Heads of nursing homes N = 20 Residents N = 30 Participants (interdisciplinary) for three focus groups. Used theoretical sampling	Grounded Theory approach. Three steps of data generation. Narrative interviews analysed by open coding process	The act of recognition is described as the social construct of intrapersonal and relational dignity. Dignity is challenged by threat of illness and having care needs, fostered by perception of insufficient care. The study emphasises the high vulnerability of nursing home residents with regard to dignity	Dignity + Nursing home	27
Russell, 2008, Australia (24)	Dying with dementia: The views of family caregivers about quality of life	To document the views of family caregivers of people with dementia about quality of life for their relative during the late and terminal stages of the disease	N = 15 Former family caregivers, using purposive sampling through invitation in the <i>InTouch</i> newsletter of Alzheimer's Australia NSW	Exploratory study. Semi-structured in-depth interviews. Thematic analysis	Participants identified three main sets of indicators of quality of life: the physical body, the physical and social environment and treatment with respect and dignity. Caregivers have the important role to interpret and represent the subjective experience of the person with dementia. They should be supported and encouraged in this role	End of life + Dementia	25

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Sagbakken, 2017, Norway (25)	Dignity in people with frontotemporal dementia and similar disorders — a qualitative study of the perspective of family caregivers	To develop knowledge related to dignified or undignified care of patients with FTN and similar conditions, from the perspective of close relatives	N = 9 Relatives of people with FTN and similar conditions living in nursing homes N = 2 Relatives of people living at home, attending day centre 5 days a week	A qualitative, descriptive and explorative design. Semi-structured interviews. Phenomenological hermeneutic analysing approach	Relatives described a transition from being a close relative to someone with little influence. Deprivation of dignity occurs in different ways. This could be prevented through closer cooperation between the institution and family members	Dignity + Dementia + Nursing home	32
Tranvåg, 2015, Norway (26)	Relational interactions preserving dignity experience: Perceptions of persons living with dementia	To explore and describe crucial qualities of relational interactions preserving dignity experience among people with dementia, while interacting with family, social network, and healthcare professionals	N = 11 participants 10 diagnosed with Alzheimer's disease 1 with mild cognitive impairment. Recruited from two Hospital Memory Clinics	Exploratory qualitative design Qualitative interviews. Interpretative approach	Cognitive decline influences relational interaction and makes interplay with others increasingly demanding. Dignity preserving interactions: (1) Experiencing love and confirmation within the family; (2) Experiencing social inclusion and fellowship within the social network and (3) Experiencing human warmth, understanding, and being met as an equal human being by health care professionals	Dignity + Dementia	32
Tranvåg, 2016, Norway (27)	Crucial dimensions constituting dignity experience in persons living with dementia	To develop increased knowledge on crucial dimensions within the foundation of dignity experience among persons living with dementia	N = 11 Participants, 10 diagnosed with Alzheimer's Disease, 1 with mild cognitive impairment. Recruited from two Hospital Memory Clinics	Exploratory qualitative design Qualitative interviews. Using a hermeneutical interpretative approach in analysing	Three themes with several subthemes are crucial for constituting the experience of dignity. (1) Personal background, acknowledging one's own life projects and history (2) Internal evaluation, self-value and meaningfulness in the present and (3) Being part of a caring and confirming communion	Dignity + Dementia	30

Table 3 (Continued)

Author(s), year, country	Title	Aim	Sample (N)	Methodological approach	Key findings	Cluster	Hawker score
Van Gennip, 2016, Netherlands (28)	How Dementia Affects Personal Dignity: A Qualitative Study on the Perspective of Individuals With Mild to Moderate Dementia	Explore how dementia may affect personal dignity of individuals with mild to moderate dementia who live at home. Gain insight into the factors that threaten or preserve the personal dignity	N = 14 Respondents with mild to moderate dementia who lived at home. They participated in the Advance Directive Cohort Study	Qualitative cross-sectional study. In-depth interviews and thematic analysis	In general participants felt reasonably dignified. The decline in personal dignity was caused by cognitive impairments resulting in diminished autonomy and changes to the individual's former identity. The intensity of experienced decline in personal dignity depended to a large degree on the social context of the individual, with differences between the home and external social environment	Dignity + Dementia	32
Van Wijngaarden, 2018, Netherlands (29)	Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers	To develop an in-depth understanding of what it means to live with dementia and what constitutes the art of living with dementia	N = 47 Interviews with Dutch family caregivers N = 10 participants in two focus groups. As part of the Dementia verhalenbank-project	Qualitative interview study. 47 interviews and 2 focus groups both meeting three times. An phenomenological inspired Thematic Analyses Approach was used	Living with dementia is understood as becoming entangled in uncertainty and isolation. Before the diagnosis there is a growing unease that something is amiss. The diagnoses is an uncertain and upsetting relief, followed by an isolated and exhausting life at home. Admission to a nursing home causes caregivers to be torn between relief and guilt. To face tragedy, discovering meaning and dignity becomes an art of living with dementia	Dignity + Dementia	33

Findings

Included articles originated from the United Kingdom (N = 6), United States of America (N = 2), Australia (N = 1), Canada (N = 1), the Netherlands (N = 5), Norway (N = 7), Sweden (N = 3), a combination of Nordic countries (N = 1) and Austria (N = 1). Two third of the included articles (N = 21) had a specific focus on people with dementia and dignity (30–50). The qualitative data within the other studies addressing dignity within the nursing home (N = 8) occasionally showed the inclusion of this patient group and were therefore included (51–58).

From the included studies, 12 address the main topics of this review, namely 'dignity, dementia and nursing home care' (30,31,33–36,39–44,46). Only three studies were found explicitly focusing on dignity in end-of-life care for people with dementia within a long-term care setting, demonstrating the scarcity of research on this specific topic (31,33,40) (see Fig. 2. Clusters). None of the included studies referred to a specific scale to determine the stage of dementia but address them by ranking from a mild cognitive impairment, to moderate dementia until advanced dementia. The setting of the studies [e.g. home, day-care or nursing home] together with the use of qualitative data such as fieldnotes and citations helped to empathise with and validate the described stage of dementia to some extent. Within 12 studies, people with dementia were included as participants for interviews, observations and focus groups (32–39,42,47–49). While most studies combine two or more stakeholder groups as participants for data gathering, some studies (N = 6) solely include family caregivers (31,44–46,50,54) or include only healthcare professionals (N = 4) (41,52,53,57). None of the included articles report on

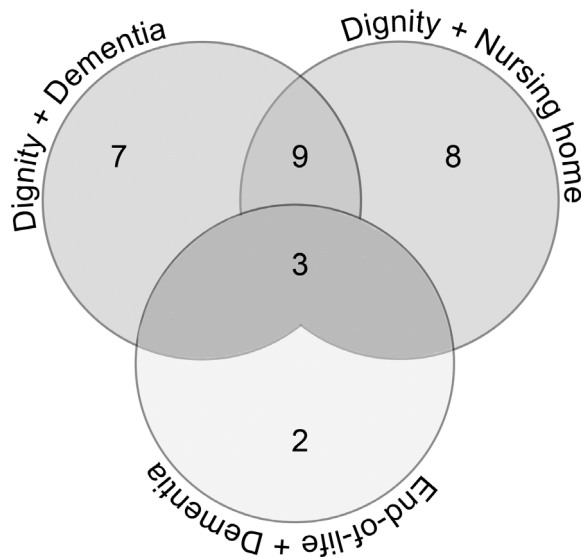


Figure 2 Literature clusters.

informal care of volunteers and their specific contribution in maintaining dignity. All included studies use qualitative methods, and the larger part of the studies is interview-based (N = 18) (30,31,37,38,44–49,51–58). The other studies use observations (39,42), focus groups (32,33,41), a combination of observations and interviews (34–36), focus group and interviews (50), observations and focus groups (43) or all three qualitative research methods (40).

Synthesising the findings within and between the articles, seven themes were identified as main characteristics of dignifying and undignifying aspects of dementia care (see Fig. 3). Three subthemes hindering dignity were identified: 'Stigmatisation and objectivation', 'Scarcity and hastiness' and 'Impending estrangement and misunderstanding'. Four subthemes promoting dignity were established: 'Personalisation', 'Respect, attentiveness and encouragement', 'Attention for physical care and bodily gestures' and 'Foster belonging'. Furthermore, dignifying care practices are characterised by a continuous process of adjusting and conciliating towards changing individual needs, capacities and preferences of people with dementia. In contrast, undignifying aspects of care are characterised by an ignorance or inability to adapt and attune.

Undignifying aspects of dementia care

Stigmatisation and objectivation

Multiple studies (N = 7) refer to generalising processes of stigmatisation, labelling and objectivation as dignity violation (31,35,39,43,48,56,58). These can be practises of stigmatisation of the frail and elderly in general or specifically towards people with dementia (43,48,56,58). Objectivation takes form when patients are reduced to units of work, objects or things to be done to, or when they are treated as vegetables (32,39,54). Professionals depersonalise residents when they approach them as demented or mad and treat them as a homogenous group (31,32,35,39,44,48,52,54). Some studies acknowledge that being ill or being admitted to a nursing home in itself is not hindering dignity (56–58). Rather, people with dementia and nursing home residents fear the loss of identity and individuality (49,55,57,58). Studies show that undignifying situations arise when professionals fail to see residents as unique individuals and when care is not tailored to the individual needs (34,51,57,58). The organisational design can jeopardise person-centred care, and care home rules can undermine residents' choices which sometimes leads to humiliating, infantilising or paternalising processes (31,49,51,52,54). Research indicates that some professional attitudes can intensify these processes such as being bossy, enforcing their will on the person, being disrespectful or rude, not taking the resident seriously or badly disguising a manoeuvre of



Figure 3 Dignifying and undignifying aspects of dementia care.

diversion (43,44,58). When professionals are not communicating with patient or talking over their head, they ignore the relationality of the resident (35,54). Undignifying care practices which objectivate or stigmatise led residents feel worthless, meaningless and useless (47,48,56,58).

Impending estrangement and misunderstanding

The process of dementia makes social interplay increasingly demanding, and people with dementia have difficulties upholding relational connectedness due to their cognitive impairment and physical frailty (48,49,55). Incomprehension between people with dementia living together occur and interactions sometimes lead to undignifying judgements towards each other (43,46). For their own well-being, people with dementia are sometimes placed outside the social group into a more calm and quiet environment (33,42,43). Care practices of outplacement might violate dignity of people with dementia and provoke feelings of abandonment and isolation (34,53,54). In addition, a living environment with locked doors and windows induces feelings of captivity and estrangement and therewith threatens their dignity (34,42,46).

Family caregivers might feel estranged from their own relative when their personality and cognitive abilities change (50). After admission to a nursing home, family can experience mental or physical barriers to stay involved due to the structure of departments or difficulties with the characteristics of the patient group (46). When social networks shrink or when few living family members remain, residents feel further alienated (55,56,58). Limited relationships between residents and few opportunities for dignifying relationships and encounters with care professionals foster estrangement (55).

Some studies suggest that people with dementia are vulnerable to undignifying care practices when their inability to clearly communicate leads to a lack of understanding of their suffering and wishes by the professional care providers (42–44,54). Unnecessary suffering in the end of life is linked to misunderstanding and the lack of acknowledging that someone with dementia is dying can

lead to a confused approach to care (33,40,41,45,51–53,55).

Scarcity and hastiness

Almost a third of the included studies ($N = 9$) addresses the scarcity of time and resources as an important influence in hindering dignity for nursing home residents (31,34,35,43,51,53,56–58). Shortage of time creates a general atmosphere of hastiness and business and lowers the quality of care (31,34,35,52,53,57,58). It forces care professionals to be efficient, prioritise care practices and to be task-centred (35,53,58). Research indicates that professionals under pressure provide basic care and limit their focus to their main responsibilities and getting the job done (31,35,41,52). Unfortunately, hastiness can trickle down to the way care is provided and might lead to ethically questionable situations (53). Some included studies report grave feeding situations in which food is shoved into the mouth of a resident, or every resident is given a sipping cup (31,54). Furthermore, a shortage in staff leads to a lack of time and attention to be spent on the residents (55,58). Research exemplifies the time in which residents are waiting for care as an undignifying situation (51,56–58). When they are cared for by strangers, due to a lack of continuity in staff and a high amount of temporary workers, the ability to establish dignifying relations is limited (31,45,46,51,58). Consequently, scarcity and hastiness of professional caregivers make residents feel neglected, overlooked, forgotten or being left helplessly alone (48,54,56).

Dignifying aspects of dementia care

Personalisation

Over two third of the included studies ($N = 21$) explicitly report that being confirmed as a unique human being, namely a person with a unique personality and identity, is important for dignity preservation (30,31,33–39,42–44,46–49,51,52,54,56,57). Multiple studies ($N = 11$) suggest that personalisation and individualisation are essential dignifying aspects of care (31,34,36,38,39,42,44,46,50–52). Some studies refer to

providing person-centred care (35,44,52), address the importance to continue the self and identity (36,43,56), or point to respect and acknowledging personhood (30,35,44,49). Dignifying professional care practices are characterising the resident, appreciating idiosyncrasies and seeing their personalities by taking interest for their background, past roles, hobbies, beliefs and values (31,35,44,51,52,57). This also means having respect for someone's identity and individuality including their personal choices, beliefs and wishes (35,41,52,55,57). Research suggests the importance for residents to continue enjoyable and identity-strengthening activities, associated with previous or present interest and formal or informal skills (44–49,52,55,57). When cognitively able, storytelling can maintain identity for people with dementia (36). To look back at one's own life and appreciate achievements such as honourable employment and establish a family can induce dignifying feelings of gratitude and pride (36,47,58). Formal and informal caregivers can stimulate to focus on the present, accept the situation and recognise meaning in the here and now, which is suggested to preserve dignity (49,50,58).

Respect, attentiveness and encouragement

Treatment with respect is described in numerous studies (N = 18) as being inherent to dignifying care practices (31,32,35,39,41,42,44,45,47–49,51–,53,55–,58). Studies based on the lived experiences of people with dementia showed their wish of being met as an equal human being with equal human worth (35,42,47–49). Dignifying care practices ensure that residents feel like an active participant and expert on their own life (34–36,42,46,48,49,58). Professionals can show respect for self-determination of residents with mild cognitive impairment by informing about individual preferences and involving them in the care process (51–53,57). Respect for personal boundaries, privacy and personal space preserves dignity of residents (33,42,43,51,52,57). Consequently, care professionals are in need of compromising skills in order to respect wishes and perform the duty of care (41,51). Working with a patient group with possible behavioural difficulties demands knowledge about whether, when, how and why to interfere in potential problematic and dignity-threatening situations (43,46). Professionals need to balance between protecting a resident who is subject to violation and avoiding violation of the acting person while interfering (43,57).

Multiple studies (N = 9) mention insecurities of people with dementia and the need to provide confirmation and encouragement (34,35,42,43,46–48,50,54). Studies report that a dignifying professional attitude is emphatic and compassionate (31,38,39,44). Deterioration of cognitive functioning, gradual loss of control and the prospect of large dependency on others is perceived as an

undesirable situation depriving a person of their dignity (34,40,42,44,45,49,51,57,58). Both formal and informal carers should compensate for inabilities with adjustive and adaptive support (42,46,50). Research suggests the importance of not depriving people with dementia of capacities that are still intact and of not making decisions over their head (43,51–54).

A professional attitude of attentiveness is one of the recommendations provided by the literature for enhancing dignity (31,40,42,50,52). Attentiveness refers to having a genuine interest in the person with dementia, trying to understand them (37,48,50). This can be shown by taking time for the person and listening to them (35,36,48,51,52). Over a third of the studies (N = 11) report that people with dementia and residents of nursing homes feel more dignified when they are taken seriously and listened to (34–36,38,48,49,51–,53,57,58). Practices that make the person feel worthwhile, accepted, understood, acknowledged and loved, enhance dignity (42,44,47–49,51,56).

Attention for physical care and bodily gestures

Studies report that bodily appearance of the resident is important for upholding dignity (44,46,51,57,58). When residents are reliant on others for bodily care, maintaining dignity is related to being clean, looking well-groomed, being dressed nicely, being bathed when desired and having a moisturised skin (44,45,51,57,58). This process can foster feelings of human worth, allowing the person to feel better about themselves, but also prompts respectful treatment by others and promotes their dignity (44).

Various studies (N = 8) suggest the importance of including the body in personalising and approaching people with dementia (39,42,44–46,51,57,58). While their cognitive and verbal capacities are minimising, bodily and facial expressions increasingly take over the communication process. New opportunities and alternatives for understanding people with dementia can be created by being attentive to bodily gestures (35,36,39,42,50). Consequently, nursing home staff needs to be well trained and educated, within the field of dementia care and communication with individuals who no longer have verbal capacity (31,35,41,42,57). Examples of dignifying bodily language of the caregiver are using a certain tone of voice, speaking politely, being calm and friendly, and smiling from time to time (42,44,48). Furthermore, formal and informal carers can consciously activate engagement through the senses for people with dementia (33,42). Dignifying care practices incorporate the use of senses and imagination in order for people with dementia to enjoy their surroundings and facilitate interaction with others (33,42,47). Even for them nearing the end of life, outside spaces can be used to enable sensory engagement

by feeling the sunshine on the skin, hearing birds sing and smelling the scent of flowers (33).

Foster belonging

The quality of relationships and relational interactions is described in a third of the included studies as dignifying aspect of care (35,41,44,47–50,55,56,58). A fair amount of studies (N = 11) point to the dignifying role of family, relatives and loved ones (32,33,37,44,46,48–50,55,56,58). The support of informal caregivers during daily activities while still living at home can preserve a dignified life for people with dementia (48,49). Feelings of belonging can be strengthened through interaction with their children and grandchildren, in which they can feel significant, connected, respected and of value (32,48,50). Engagement with family, continued contact and regular visits can maintain dignity after admission to a nursing home (32,33,45,46). In order to keep a sense of connectedness, family and loved ones have to explore new ways to communicate with their relative and find ways to engage in meaningful activities (42,46,47,49,50). The progressive nature of dementia requires a continuing effort of them to be on the same wavelength, have the ability to calmly attune to their relative with dementia and adjust expectations (46,50).

Professional care has to answer to relational needs, like the need for conversation, involvement and inclusion (35,44,48,55). Studies recommend to communicate and talk to the resident, even when people with dementia have communicative difficulties or have lost dialogical abilities (44,50,51). Thereby, it is important that care professionals compose groups of patients that fit together and facilitate activities and conversations between residents with similar levels of functioning (42,46). These contacts become beneficial relationships and people with dementia experience less disrespect from the outer world in the nursing home (49,56). A homely feel can be created by enabling residents to bring their own possessions such as pictures, furniture and personal items (33,45,49,57).

Besides the social engagement, the nursing home environment and the importance of meaningful relations, studies suggest that dignity is bolstered by spiritual engagement. This can refer to experiencing transcendental and spiritual meaning, maintaining religious beliefs and internal values as well as feelings of closeness to God or sensual connectedness with nature (33,44,47,54,58).

Discussion

Reflections on the findings

This narrative review contributed to the knowledge on both dignifying and undignifying aspects of formal and informal care for people with dementia during their

disease trajectory and while living in a nursing home. Despite differences in scope, perspective and method, the included articles show consistent findings, highlighted through different aspects of care. While existing dignity models are partly constituted of personal factors influencing dignity (10,16,17), this review suggests the predominance of dignifying relational aspects in the context of caring for people with dementia. Although the disease trajectory and future prospects may threaten dignity, the quality of the care relation, being treated with respect and being met as a unique individual with own personality, appears to be of greater importance. Dignifying aspects of formal and informal care are characterised by a process of adjusting and attuning to changing abilities, identity, preferences and care needs of people with dementia. In contrast, undignifying aspects of care emanate from an ignorance of or inability to acknowledge and reconcile with the changing person with dementia. Therewith, a relation can be found between the emerged dignifying and undignifying aspects of care and the formulated malignant social psychology and psychological needs of people with dementia by Kitwood (59). Hence, dignity-enhancing care practices might overlap with person-centred approaches of care (44,52,60,61). In order to preserve and promote the dignity of people with dementia, it is important to acknowledge their personhood and grasp their uniqueness. Personhood can sustain by close emotional bonds between the person with dementia and their family and good relationships with professional caregivers (62).

This review focused on both dignifying and undignifying aspects of formal and informal care for people with dementia from different perspectives: the professional, the family and the patient. Contradictions between perspectives of each stakeholder group on dignifying or undignifying aspects of care were not found. Small discrepancies can be explained by the place of each stakeholder group within the care process and associated experiences. The applicability of some findings can depend on the stage of dementia with corresponding cognitive abilities, and interpretations of dignifying and undignifying aspects of care might differ in the context of an anticipated death. Furthermore, differences between aspects of dignifying and undignifying formal and informal care are to be expected considering their different roles, responsibilities, expectations and relation to the care recipient. For instance, undignifying aspects of care as scarcity and hastiness is generally linked to professional care while family caregivers play an important role in fostering belonging and personalisation. As Lindemann (63) advocates, the family has a special responsibility in holding a person with dementia into their identity. Therewith good identity holding consists of backward-looking stories that are still relevant and forward-looking stories which create space for a person to change. In

contrast, wrong identity holding appears when family persists in stories no longer relevant or untruthful forward-looking stories, for example a miracle curation (63). While knowing the other is important for different dignifying aspects of dementia care, it could also complicate and result in undignifying care practices. For loved ones, it could be harder to adjust and accept the changeability of the relative with dementia which might cause estrangement. Studies suggest that family perceive the disease trajectory and particularly the end of life with dementia as undignifying and dehumanising (40,44,45). They could struggle with letting go of old identity and personality and establish feelings of loss and grieve. A continual tuning in is required, characterised by an openness towards the person with dementia and their ongoing changeability (50). This relational skill can be referred to with the notion of engrossment, as a nonselective attention and an attitude of warm acceptance and trust, which focuses on the receiving of the other (64,65). Engrossment is not a passive receptivity. In order to effectuate the receiving of the other, the caregiver must 'empty' themselves of their own content and own projects need to be set aside (64,66). This might lead to the disclosure of insiderness, the personal world and frame of references of the care receiver, where from a caring response can be generated (67). While it is accepted for family caregivers to focus on their own relative, nursing home staff need to divide their attentiveness in order to avoid objectivation and stigmatisation and provide personalised care.

The progressive nature of the disease challenges both relatives and professionals in disclosing the insiderness and recognising the changing personhood and uniqueness of people with dementia. This is even a greater challenge in the advanced stage of the disease in which people living with dementia are no longer able to actively participate in a relational process of memory sharing and verbally expressing appreciation towards others (4,68). Attention for bodily gestures helps to overcome some of these difficulties. By physical presence, information about the care receiver can be gathered through nonverbal bodily cues, facial expressions and posture (69). Close relatives can be seen as advocates of their loved one and inform professional caregivers on preferences, personal history and help to translate bodily movements and facial expressions. Awareness and deeper understanding of nonverbal behaviour illuminate the richness and significance of behaviour that previously would be unrecognised (39,42,70). This will create new opportunities for communication and ways to develop interpersonal relationships. Nonetheless, although verification and reciprocity in the care relation are important from a care ethical perspective (71), the meaningfulness of provided care should not be dependent on the person's capacity to respond (8).

Methodological rigour and limitations

This narrative review combined methodological procedures to strengthen the quality: PRISMA guidelines structured the selection process, methodological rigour of included articles was checked using Hawker's tool and the four steps of narrative synthesis by Popay et al. directed the analysis (27–29). Despite the comprehensive search and the dialogical and reflective process of selection and analyses, there are some limitations that may have influenced the review findings. Firstly, the literature search was limited to four electronic databases and the terms of 'dignity' AND 'dementia', even though our aim was to also incorporate indignity (see Table 1). This search strategy, combined with snowballing and reference check, generated articles on both dignifying and undignifying aspects of care, but a more extensive search strategy may have resulted in more complete findings. Secondly, the data collection and first screening were performed by the first author and might have led to preliminary exclusion of possible relevant articles. The authors attempted to prevent this bias by formulation of criteria for eligibility prior to this process (see Table 2). Thirdly, limitations of findings might occur due to the decision to only include studies which uses qualitative research methods as well to exclude grey literature and books. Important information and practical experiences on dignity-enhancing dementia care could be missing. Both authors acknowledged possible shortcomings and are aware of the broad field of literature on dementia and dementia care.

Conclusion

This study aimed to synthesise dignifying and undignifying aspects of formal and informal care for people with dementia. Narrative synthesis showed that dignifying aspects of care are characterised by a process of adjusting and attuning to the changing abilities, personality, preferences and care needs of the person with dementia. In contrast, undignifying aspects of care are characterised by unsuccessful processes of acknowledging and conciliating with the changing person with dementia. These processes especially threaten dignity in people with severe dementia because of their total care dependency. Their vulnerability towards undignifying care practices is reinforced by the lack of reciprocity in the care relation and diminished conversation and communication skills. Formal and informal caregivers have the ability to contribute to preserving the dignity of people with dementia, especially in the later stages of the disease.

Practical implication

This narrative synthesis fills a knowledge gap about aspect of care that could enhance or threaten the dignity of persons with dementia. Findings can be used for

reflection on healthcare practices and within educational programmes.

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Conflict of interest

Authors declare there is no conflict of interest.

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Author contributions

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