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Nursing staff needs in providing palliative care for people with dementia at home or in long-term care facilities: A scoping review

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ABSTRACT

Background: Nursing staff caring for people with dementia have a crucial role in addressing palliative care needs and identifying changes in health status. Palliative care for people with dementia is complex and requires specific competences. A lack thereof may lead to unnecessary hospitalizations, poor symptom control and undesirable burdensome treatments. Understanding what nursing staff need to provide palliative care specifically for people with dementia facilitates the development of tailored and feasible interventions.

Objective: To investigate what is known from the literature regarding the needs in providing palliative dementia care as perceived by nursing staff working in home care or in long-term care facilities and to establish an integrated conceptualization of these needs.

Design: A scoping review method combined with thematic analysis methods.

Data sources: Bibliographic databases of PubMed, CINAHL and PsycINFO were searched for primary research studies.

Review methods: Guidelines from the Joanna Briggs Institute were utilized as a framework for setting up and conducting the scoping review. Eligible articles considered nursing staff's perceived needs in providing palliative dementia care at home or in long-term care facilities. Two authors assessed eligibility based on title and abstract, assessed full texts for selected records and assessed the quality of included articles. Thematic analysis methods were used to identify themes from relevant study findings, which were integrated to form a conceptualization.

Results: Of the 15 articles that were included, most used qualitative methods (N = 13) and were conducted in long-term care facilities (N = 14). Themes reflecting nursing staff needs on a direct care-level concern recognizing and addressing palliative care needs (such as comfort), verbal and non-verbal communication, challenging behaviour and familiarity: knowing and understanding the person with dementia. On more distant levels, themes involve a need for interdisciplinary collaboration, training and education and organizational support.

Conclusion: A comprehensive overview of nursing staff perspectives on providing palliative care for people with dementia demonstrates interdependent needs related to recognizing and addressing palliative care needs, communicating, handling challenging behaviour and building close care relationships. These care-related needs occur within workplace and organizational contexts. Organizational support is considered insufficient. Yet, healthcare organizations have the authority to fulfil a facilitating role in implementing nursing interventions tailored to nursing staff needs. Areas for further research include home care settings, the psychosocial and spiritual domains of palliative dementia care, advance care planning and family involvement.

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What is already known about the topic?

- Nursing staff working in home care or long-term care facilities who provide daily care for people with dementia, have a crucial role in addressing palliative care needs of the individuals for whom they care.
- To establish comfort and quality of life for people with dementia, nursing staff should be able to recognize and act upon (changing) symptoms, and interact with individuals with limited capacity to communicate.
- Nursing staff may lack adequate competences and knowledge to provide palliative care for people with dementia, which may have implications for patient care.

What this paper adds

- Nursing staff need to be familiar with persons with dementia whom they care for to improve recognizing and addressing palliative care needs, to communicate well verbally and non-verbally and to deal with challenging behaviour.
- The reported needs of nursing staff in providing palliative dementia care are interdependent and occur within the context of workplace and organization. To fully understand nursing staff needs, they should not be reduced to mere measurement of knowledge and skill.
- Areas that have not been studied extensively in relation to nursing staff needs in providing palliative care for people with dementia include home care settings, psychosocial and spiritual care domains, advance care planning and family involvement.

1. Background

Dementia is a progressive, irreversible and life-limiting condition for which there is currently no cure (Blom et al., 2017; Sachs et al., 2004). Yet, palliative care for people with dementia has not received much attention for long, as opposed to palliative oncological care (Iliffe et al., 2013; Sampson, 2010). A white paper defining optimal palliative care for older people with dementia suggests that for people in moderate to severe stages of the disease, maintaining functioning and maximizing comfort are appropriate goals of care (van der Steen et al., 2014). Rather than life prolongation, the suggested care goals focus on optimizing quality of life and are therefore compatible with palliative care (van der Steen et al., 2014). Palliative care should improve the quality of life of people with a life-limiting illness and their families through addressing physical, psychosocial and spiritual needs (IKNL/Palliactief, 2017; World Health Organization, 2018; Perrar et al., 2015; van der Steen et al., 2014). As a combination of problems in these domains often arises, the palliative care needs of people with dementia may be particularly complex and heterogeneous (Haaksma et al., 2017; Odbehr et al., 2014). Severe cognitive deficits, such as memory loss, apraxia and aphasia are manifest in advanced dementia, as well as comorbid disease, infections and burdensome symptoms such as dyspnoea, pain and agitation (Hendriks et al., 2015). Hence, it is important that people with dementia have the opportunity, along with their loved ones, to discuss their preferences and wishes for future care timely (Dening et al., 2011; van der Steen et al., 2014).

In Western countries, typically more than half of people with dementia ultimately die in long-term care facilities (Houttekier et al., 2010; Reyniers et al., 2015). In the Netherlands, this proportion reaches approximately 92%. Nursing staff working in home care or long-term care facilities usually provide most of the daily care for people with advanced dementia, which allows them to familiarize themselves with usual behavioural patterns, routines and preferences of the people whom they care for. This also indicates they have an important role in the early identification and acting upon changes in the person's physical and cognitive status to prevent or alleviate suffering (De Witt Jansen et al., 2017b). Especially at the end of life of people with dementia, the availability of nursing staff to provide personal attention may contribute to a good quality of dying (De Roo et al., 2014). When aiming to optimize quality of life and ultimately support a 'good death' for people with dementia, there is much to gain in optimizing care provided by nursing staff.

Specific training focusing on palliative care for people with dementia is needed in nursing curricula and practice (Erel et al., 2017; Harris, 2007; Hirakawa et al., 2009; Sachs et al., 2004). Previous studies have indicated that professional caregivers lack knowledge and skills to enforce principles of palliative care in dementia care, lack knowledge about the disease and its prognosis and insufficiently assess and manage pain (Burns and McIlfatrick, 2015b, Chen et al., 2017; Robinson et al., 2014). Professionals' descriptions of other barriers to palliative care for people with dementia involve staff shortages, disconnection between services, the absence of advance directives and staff's lack of self-confidence and self-efficacy (Davies et al., 2014; Erel et al., 2017). These studies demonstrate gaps in knowledge, skills and organizational aspects related to palliative care for people with dementia.

Inferring nursing staff needs from knowledge tests or informant information may be valuable, as incompetence might exist unconsciously or perceptions of one's own competence might be biased. Nonetheless, mere measurement of knowledge and skills does not suffice to address nursing staff's own specific needs in providing palliative dementia care. We need a better understanding of the actual perceived needs of nursing staff to provide high-quality palliative care specifically for people with dementia. Therein, 'needs' may also include perceived 'barriers' to delivering high-quality palliative care, as barriers arise when certain needs are not met, or barriers may induce needs. Solutions built to overcome barriers and to adhere to needs may be viewed as 'facilitators' for high-quality palliative dementia care. An integral understanding of nursing staff needs facilitates the development of tailored interventions that fit daily practices and routines. This may in turn motivate nursing staff to apply these interventions and thereby support real-world implementation.

The main research question of this scoping review is: 'What are the perceived needs of nursing staff in providing palliative care for people with dementia in home care or in long-term care facilities?' In addition, we aimed to establish an integrated conceptualization of these needs that may inform the development of a tailored intervention for nursing staff.

2. Methods

The current scoping review is part of the research project 'DEDICATED: Desired Dementia Care Towards End of Life', which aims to improve palliative care for people with dementia and their loved ones (Academische Werkplaats Ouderenzorg, 2017). The review was conducted according to an adapted framework proposed by the Joanna Briggs Institute (Peters et al., 2015), which builds on previously established guidelines (Arksey and O'Malley, 2005). Moreover, we adhered to the PRISMA statement for systematic review protocols where possible (Moher et al., 2009). For instance, we created a flow chart as proposed in the statement and we assessed the methodological quality of included articles.

2.1. Search strategy

The literature search for this scoping review was carried out in December (22nd) 2017. The search strategy comprised three subsequent steps, as proposed in the Joanna Briggs Institute manual (Peters et al., 2015). First, the databases of CINAHL, PubMed, PsycINFO and the search engine Google Scholar were searched to identify relevant keywords and synonyms regarding the subject. Second, these terms were used to build an elaborated search string. An information specialist and two palliative care and dementia experts helped define terminology and broaden definitions in the search strategy, and the search string was discussed with all authors. The search strategy was improved to increase its sensitivity and to reduce the risk of missing relevant studies (Arksey and O'Malley, 2005). An inclusive approach is recommended for scoping reviews, even though a broad search might result in an increased number of irrelevant articles (i.e. lower specificity). As opposed to systematic reviews, scoping reviews tend to seek breadth rather than depth (Arksey and O'Malley, 2005). The databases of CINAHL, PubMed and PsycINFO were used to search for literature in a stepwise fashion (Table 1). Third, the Joanna Briggs Institute manual recommends hand-searching reference lists of all studies found through database searching (Peters et al., 2015). For feasibility, we searched included articles that fitted our inclusion criteria for references to other relevant articles. We also searched reviews for relevant references to original studies.

2.2. Study selection process

Identified records were imported into EndNote X8 for further investigation and selection. The inclusion criteria for selecting articles were established a priori (Table 2). Studies involving a subset of relevant study participants, along with other participants (for instance, other healthcare professionals, informal carers, nurses working in other settings) were considered for inclusion if results were specified for the population of interest. We sought for studies conducted in countries where palliative care services are at least at a preliminary stage of integration into general healthcare provision, as defined in the Global Atlas of Palliative Care at the End of Life (Connor and Bermedo, 2014). This mainly entails Australia, New Zealand, and countries in Europe, the Northern Americas and Asia.

Initially, author S.B. screened titles and abstracts for possible eligibility. This process was carried out in collaboration with author S.P. to increase reliability. Both authors screened a random selection of 100 titles and abstracts. Any divergences were discussed to reach a consensus, and if in doubt, inclusion was discussed with the other authors. After achieving agreement, author S.B. continued title–abstract screening. After screening titles and abstracts, records that were deemed eligible were obtained as full texts. When there was no online access, authors of the articles were emailed or articles were requested via interlibrary loan services. S.B. and S.P. judged eligibility of a random selection of 20 articles. They reached full agreement, whereupon the first author continued with full-text assessment. The reasons for excluding full-text articles were recorded. An expert in palliative care and dementia research evaluated the final list of included articles to verify that the important literature had been identified through the search.

2.3. Quality appraisal

We included primary research articles and we were interested in the quality of the research and the reporting. We used the quality assessment form developed by Kmet et al., as it allows for rating both quantitative and qualitative studies (Kmet et al., 2004). It involves two separate checklists with scoring manuals developed to assess the internal validity of studies. The checklist for qualitative research comprises 10 items and the checklist for quantitative research comprises 14 items. The items cover study characteristics reflecting methodological quality (e.g. clarity of objective and procedures, appropriate design, reporting of bias) and, upon presence, are scored with a 2 ('yes'), 1 ('partial') or 0 ('no'). A summary score represents the total divided by the maximum score. For the purpose of the current scoping review, there was no cut-off point for inclusion of articles. Quality was assessed after inclusion of articles to explore possible

Table 1
Steps and detailed search terms used in the PubMed search[*].

Step	Search terms
1	*Subject area I: Dementia* ("Dementia"[Mesh] OR “dementias”[Title/Abstract] OR “dementia”[Title/Abstract] OR "alzheimer disease"[MeSH Terms] OR “Alzheimer”[Title/Abstract] OR Alzheimers[Title/Abstract] OR ("alzheimer"[Title/Abstract] AND "disease"[Title/Abstract]) OR "alzheimer disease"[Title/Abstract])
2	*Subject area II: Palliative care* ("palliative care"[MeSH Terms] OR ("palliative"[Title/Abstract] AND "care"[Title/Abstract]) OR "palliative care"[Title/Abstract] OR “palliative treatment”[Title/Abstract] OR “palliative therapy”[Title/Abstract] OR “palliative therapies” [Title/Abstract] OR “Nursing home”[Title/abstract] OR “Home care services”[MeSH Terms] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Hospice Care"[Mesh] OR (“Palliative”[Title/Abstract] AND “Nursing”[Title/Abstract]) OR (“hospice”[Title/Abstract] AND “nursing”[Title/Abstract]) OR ("hospice"[Title/Abstract] AND "care”[Title/Abstract]) OR “hospice care”[Title/Abstract] OR "terminal care"[MeSH Terms] OR ("terminal"[Title/Abstract] AND "care"[Title/Abstract]) OR "terminal care"[Title/Abstract] OR ("end of life"[Title/Abstract] AND "care"[Title/Abstract]) OR "end of life care"[Title/Abstract] OR “long-term care”[MeSH] OR (“long-term”[Title/Abstract] AND “care”[Title/Abstract]) OR (“long”[Title/Abstract] AND “term”[Title/Abstract] AND “care”[Title/Abstract]) OR “aged care”[Title/Abstract])
3	*Subject area III: Nurses* (“Nurses”[MeSH Terms] OR “nurses”[Title/Abstract] OR “nurse”[Title/Abstract] OR ("registered”[Title/Abstract] AND "nurses”[Title/Abstract]) OR "registered nurses”[Title/Abstract] OR "nursing staff"[MeSH Terms] OR ("nursing”[Title/Abstract] AND "staff”[Title/Abstract]) OR "nursing staff”[Title/Abstract] OR “Nurses' aides”[MeSH] OR (“nurses”[Title/Abstract] AND “aides”[Title/Abstract]) OR “Nurses aides”[Title/Abstract] OR ("nursing”[Title/Abstract] AND "personnel”[Title/Abstract]) OR "nursing personnel”[Title/Abstract] OR “nursing aide”[Title/Abstract] OR “nursing aides”[Title/Abstract] OR “nursing assistant”[Title/Abstract] OR “nursing assistants”[Title/Abstract] OR “attendant”[Title/Abstract] OR “attendants”[Title/Abstract] OR “caregiver”[Title/Abstract] OR “caregivers”[Title/Abstract] OR “caregivers”[MeSH Terms] OR “Health personnel”[MeSH] OR (“health”[Title/Abstract] AND “personnel”[Title/Abstract]))
4	*Subject area IV: Needs* (“Attitude of health personnel”[MeSH] OR “Need”[Title/Abstract] OR “needs”[Title/Abstract] OR “demand”[Title/Abstract] OR “demands”[Title/Abstract] OR “barrier”[Title/Abstract] OR “barriers”[Title/Abstract] OR “difficulty”[Title/Abstract] OR “difficulties”[Title/Abstract] OR “facilitator”[Title/Abstract] OR “facilitators”[Title/Abstract] OR “experience”[Title/Abstract] OR “experiences”[Title/Abstract] OR “view”[Title/Abstract] OR “attitude”[Title/Abstract] OR “attitudes”[Title/Abstract] OR “views”[Title/Abstract] OR “perception”[Title/Abstract] OR “perceptions”[Title/Abstract] OR “obstacle”[Title/Abstract] OR “obstacles”[Title/Abstract] OR “challenge”[Title/Abstract] OR “challenges”[Title/Abstract] OR “knowledge”[Title/Abstract] OR “skills”[Title/Abstract] OR “communication”[Title/Abstract])
5	*All subject areas*

[*] Detailed search strategies used in the other databases (CINAHL and PsycINFO) are available upon request.

Table 2
In and exclusion criteria for selecting articles.

Inclusion criteria	Exclusion criteria
• Peer-reviewed, primary research. • Focusing on nursing staff (*population*) *perceived* needs in providing palliative care for older people with moderate to severe dementia (*concept*) in a long-term care facility or at home (*context*). • Studies involving a subset of relevant study participants. • Geographical locations where palliative care services are at least at a preliminary stage of integration into general healthcare provision. • Published between January 2012 and December 2017.	• Not peer-reviewed, primary research. • Systematic reviews and meta-analysis. • Letters, editorials and study protocols with no empirical data. • Not written in Dutch or English.

methodological hiatuses that need closer consideration in future research. The quality assessment was carried out by three researchers and an assessment of weighted kappa between each pair of assessors (respectively $\kappa = 0.399$, 95% CI, .141–.657, $p < .00$, $\kappa = 0.284$, 95% CI, .008–.560, $p < .05$, $\kappa = 0.258$, 95% CI, -.019 to .535, $p < .05$) indicated fair agreement (Landis and Koch, 1977). Overall agreement between the three assessors was fair, as indicated by Fleiss' kappa ($\kappa = 0.279$, 95% CI, .141–.417, $p < .00$). Any interrater discrepancies were discussed to reach consensus and improve the quality of the procedures.

2.4. Synthesis, thematic analysis and conceptualization

One author (S.B.) extracted data from the included studies using a data charting form adapted from Joanna Briggs Institute recommendations (Peters et al., 2015). This form comprised the following elements: authors, year, country, population demographics, study aims and focus, design and methodology. For each article, we added to the form the quality score and findings that were relevant to answer the current research question. For the one quantitative study, this merely concerned findings that the article's authors derived from open-ended questions inquiring about nurses learning needs.

We read the included articles thoroughly to familiarize ourselves with the content of the studies. During a second reading, the research question as defined a priori guided identification and flagging of findings relevant to the research question. The parts of the text that described findings related to perceived needs were then copied onto the data extraction form. Qualitative analysis software Nvivo 11 was used to assist the qualitative analysis. Author S.B. identified themes from the relevant text passages of the included studies using a thematic analysis applying Braun and Clarke's paradigm (Clarke and Braun, 2014). The first step involved initial open coding of the extracted texts reflecting needs and barriers. Thereafter, codes were clustered into themes. Synthetizing themes from the data was an iterative process, guided by the review question, and further informed and refined by regular discussions with all authors. Memos were written throughout this process. Recurring themes and apparent links between themes were discussed with all authors for further interpretation, integrating each team member's knowledge and perspective. This process contributed to establishing a comprehensive conceptualization of nursing staff needs in providing palliative care for people with dementia.

3. Results

3.1. Literature search

After removal of duplicates, the final updated search of the bibliographic databases CINAHL, PsycINFO and PubMed resulted in 1230 articles. After title and abstract screening, 1029 articles were excluded. Full texts of 200 articles were accessed and screened for eligibility. One article was unavailable and therefore excluded. Fig. 1 shows the reasons for excluding full-text articles. Ultimately, 15 articles were included in the scoping review. No additional eligible records were identified through screening reference lists of included articles or the reference lists of systematic reviews.

3.2. Article information

The 15 included articles were written in English (Burns and McIlfatrick, 2015a, De Witt Jansen et al., 2017a, b; Hammar et al., 2016; Hunter et al., 2016; Koppitz et al., 2016; Livingston et al., 2012; Monroe et al., 2015; Ostaszkiewicz et al., 2015; Park et al., 2017; Smith et al., 2016; Talbot and Brewer, 2016; Toivonen et al., 2017; Wang et al., 2013; Wilson et al., 2012). The majority concerned qualitative studies (N = 13), one study used mixed methods and one article described a quantitative study. All articles described distinct studies. The studies were conducted in Europe (N = 8), the Northern Americas (N = 4), Australia (N = 1) and Asia (N = 2). Participants in these studies were nursing assistants (N = 4), registered nurses (N = 4), registered and licensed practical nurses (N = 2), registered nurses and nursing assistants (N = 1) or all three groups (N = 4). One article described a study conducted in a home care setting (Smith et al., 2016); the other articles involved institutional long-term care settings (mostly nursing homes). Supplementary Table 1 presents a summary of the characteristics of the included articles.

3.3. Methodological quality appraisal

Methodological quality scores ranged from 0.65 to 0.95, with a mean score of 0.85 indicating overall good quality. Most items from the checklists were scored with either 'yes' or 'partial'; only two items were scored with 'no' for two different articles. The items 'question/objective sufficiently described?' and 'connection to a theoretical framework/wider body of knowledge?' obtained the optimal score ('yes') in most studies. The items 'sampling strategies described, relevant and justified?', 'conclusions supported by the results?' and 'reflexivity of the account?' (i.e. the description of possible sources influencing the data or causing bias) were frequently scored as 'partial'.

3.4. Narrative summary of themes

Notions reflecting needs in palliative care provision were clustered into the following seven themes: 1) recognizing and addressing palliative care needs; 2) verbal and non-verbal communication; 3) dealing with challenging behaviour; 4) familiarity: knowing and understanding the person; 5) interdisciplinary collaboration; 6) education and training; and 7) organizational support. Table 3 demonstrates examples of citations referring to the seven themes. Supplementary Table 2 presents more elaborate examples of phrases per theme and per article.

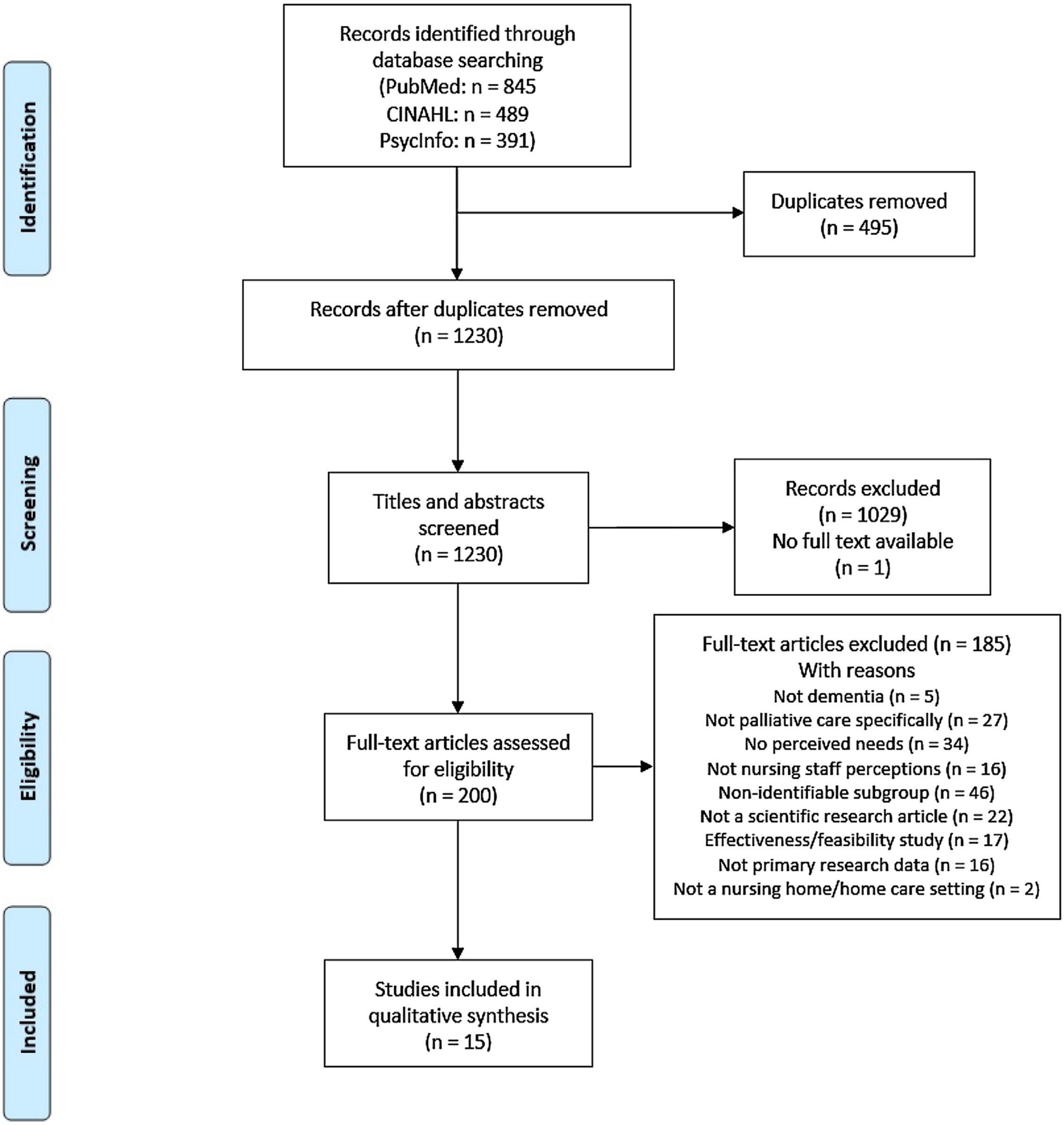

Fig. 1. PRISMA flow diagram (Moher et al., 2009).

3.4.1. Recognizing and addressing palliative care needs

An important need in providing palliative care for people with dementia concerns assessing symptoms and recognizing care needs. Nursing staff experienced difficulties in attending to patients' basic care needs and in optimizing comfort. In particular, recognizing and managing pain and physical discomfort (e.g. stiff muscles, digestive problems, bed sores) in people with dementia is challenging for them; pain may therefore be undertreated (Burns and McIlfatrick, 2015a, De Witt Jansen et al., 2017a, b; Hunter et al., 2016; Koppitz et al., 2016; Monroe et al., 2015; Park et al., 2017; Smith et al., 2016; Wang et al., 2013). In one article, nurses reported that family members are important partners in assessing physical comfort, but that involvement of family may also pose ethical challenges (e.g. balancing family members' wishes and patients' needs) when considering administering analgesics (Monroe et al., 2015). Besides identifying pain, providing psychological support (Hunter et al., 2016) and recognizing the spiritual (Toivonen et al., 2017) and emotional needs (Wang et al., 2013) of people with dementia was concerning nursing staff. Lastly, attending to the individual need for assistance with feeding of persons with moderate to severe dementia during mealtimes was perceived as difficult, leaving nursing staff concerned about nutritional health (Hammar et al., 2016).

3.4.2. Verbal and non-verbal communication

Nursing staff often linked challenges in responding to care needs of people with dementia to the patients' limited ability to communicate and difficulties in understanding the meaning of non-verbal signs (De Witt Jansen et al., 2017b; Koppitz et al., 2016; Monroe et al., 2015; Park et al., 2017; Smith et al., 2016; Toivonen et al., 2017; Wang et al., 2013). Limited possibilities for communication also hindered them in explaining to patients why they would need certain treatments, which sometimes resulted in refusal or resistant behaviour (De Witt Jansen et al., 2017a). Staff reported limited alertness in people with severe dementia (Wilson et al., 2012) and regarded a lack of interaction as a barrier to effective care (Talbot and Brewer, 2016). In one article, nursing staff reported difficulties communicating about death and

Table 3
Example phrases from included studies per theme.

Themes Recognizing and addressing care needs	(Non-verbal) communication	Dealing with behaviour
“These staff reported being **under-skilled in recognizing pain** and relied largely on nurses’ reports (. . .)”(De Witt Jansen et al., 2017b) The caregivers felt that to care for persons with dementia during mealtime is to try to do the “undoable.” (. . .) **feeding persons with dementia according to the individuals’ needs**.”(Hammar et al., 2016) “The process of developing knowledge about **unmet needs** (. . .). During this process there were **uncertainty factors associated with the assessment** due to the unpredictable course of disease (. . .)”(Koppitz et al., 2016) “Nurses reported **difficulty in ascertaining whether a person with dementia was in pain** and further **difficulty determining the magnitude or intensity associated with their pain.**”(Monroe et al., 2015) “The nurses pointed out that the **physical problems and symptoms** of the bedridden elderly with a cognitive disability **were difficult to discover** due to their restricted communication skills.”(Park et al., 2017) “They explained **how difficult it was to assess a patient’s pain** (. . .)”(Smith et al., 2016)	“(. . .) profound deficits in cognition prevented patients from recognizing medications as such, and **impairments in communication removed the possibility of engaging in nurse–patient dialogue** to explain (. . .)”(De Witt Jansen et al., 2017a) “The staff had particular **difficulties when residents talked about their own death** and often distracted them or told them it was not yet time (. . .) The staff also found **talking with relatives about dying** uncomfortable”(Livingston et al., 2012) “(. . .) nurses remained uncertain regarding the residents’ pain experience. The **inability of residents to express themselves is a major challenge**.”(Monroe et al., 2015) “(. . .) however some care assistants reported emotional dissonance in relation to service users with advanced dementia or **a lack of interaction**.”(Talbot and Brewer, 2016) “One of the main challenges discussed by the participants was understanding the personal spiritual needs of older people with severe dementia, **when the ability to express spiritual needs verbally had been lost.**”(Toivonen et al., 2017)	“(. . .) often deal with problematic situations instigated by **aggressive or restless** persons with dementia; **this can raise feelings of insufficiency**”(Hammar et al., 2016) “The **unpredictable nature of residents’ responses and behaviours** meant nurses had to remain vigilant to the constant possibility of an adverse event.”(Ostaszkiewicz et al., 2015) "Nurses indicated they **tried not to take residents’ aggression towards them personally.**"(Ostaszkiewicz et al., 2015) “(. . .) when a resident demonstrated **resistive (i.e., non-verbal non-compliance) or aggressive behaviour, which was noted to be most problematic when assisting residents with severe AD***.”(Wilson et al., 2012) * AD = Alzheimer’s Disease

Themes (continued) Familiarity	Interdisciplinary collaboration	Education/training	Organizational support
“Understanding the residents for whom they cared was perceived to be critical (. . .) difficulties and limitations in recognizing pain in residents with whom they were **unfamiliar.**”(De Witt Jansen et al., 2017b) “Several factors were identified that may assist in clarifying if resident with dementia is experiencing pain. (. . .) and **knowing the resident over an extended period of time**.”(Monroe et al., 2015) “(. . .) they spoke about the importance of **‘knowing’ each individual residents’ life history and personal preferences**.”(Ostaszkiewicz et al., 2015) “**Being familiar with the resident by knowing their personal preferences and personal history** assists in meeting the resident’s needs and interpreting his or her behaviour.”(Wilson et al., 2012)	“Five participants employed in nursing homes reported **problematic relationships with nursing staff and/or physicians**.”(De Witt Jansen et al., 2017b) “**Difficult nurse–physician relationships** were reported by both nursing home and acute care nurses.”(De Witt Jansen et al., 2017a) “Feeling abandoned is also in relation to **the absence of nursing staff**, as one’s own competence as a nursing aid is not always enough.”(Hammar et al., 2016) “Several factors were identified that may assist in clarifying if resident with dementia is experiencing pain. (. . .) **interdisciplinary communication** (. . .)”(Monroe et al., 2015)	“When nurses were asked to **identify their learning needs**; pain management at end of life in dementia, knowledge of analgesic choice, and a better understanding pain assessment tools were identified.”(Burns and McIlfatrick, 2015a) “All respondents believed that access to **ongoing professional development** was critical (. . .).” “All nurses reported **training in pharmacology** was required (. . .).”(De Witt Jansen et al., 2017a) “Death remains a largely taboo area for staff communication, but **the desire to learn skills in this** area may also be a facilitator.”(Livingston et al., 2012) “The majority of nurses in this study believed that **more education was needed about artificial nutrition and hydration and suffering** (. . .)”(Smith et al., 2016)	“(. . .) **professional and practice development were often limited** for acute care and nursing home nurses due to **constraints on staff time, heavy workload** (. . .).”(De Witt Jansen et al., 2017a) “(. . .) struggling between knowing what is best to do and the **organizational structures** that interfere.”(Hammar et al., 2016) (. . .) concern about **lack of time, overwork, the pace of work or routinization of tasks** as impediments to relationships.”(Hunter et al., 2016) “The main challenge (. . .) **work constraints that hindered their efforts** to implement interpersonal approaches (. . .).”(Ostaszkiewicz et al., 2015) “**Staffing** was a particularly common theme (. . .).felt that **residents with severe dementia were being put at risk if there was nobody available** to monitor their behaviour.”(Talbot and Brewer, 2016)

advance care plans with people with dementia and their relatives (Livingston et al., 2012).

3.4.3. Dealing with challenging behaviour

Nursing staff mentioned exposure to certain behaviour, such as non-compliance and resistive or aggressive behaviour, when providing daily care for people with moderate to severe dementia (Hammar et al., 2016; Ostaszkiewicz et al., 2015; Wilson et al., 2012). They regarded this behaviour as challenging when trying to provide high-quality care. Nursing staff reported that encountering challenging behaviour sometimes raised feelings of insufficiency (Hammar et al., 2016). Despite attempts not to take such behaviour personally, they described feelings of hurt and frustration. Moreover, they reported concerns about organizational support, and families and managers not respecting and valuing their demanding work (Ostaszkiewicz et al., 2015). Patient refusal was also an apparent issue in managing pain through administering analgesia, which nursing staff assumed resulted from patients' anxiety and lack of understanding of medication use (De Witt Jansen et al., 2017a). To deal with challenging behaviour, nursing staff need knowledge on individual triggers and preferences of patients and ways to communicate with them (Ostaszkiewicz et al., 2015; Wilson et al., 2012).

3.4.4. Familiarity: knowing and understanding the person

To overcome difficulties in recognizing and addressing palliative care needs, communication or challenging behaviour, nursing staff often reported that they need to be familiar with the person. Nursing staff felt that building a close care relationship is beneficial for both themselves and the person with dementia, as it helps to recognize needs and to individualize palliative care. Learning about the history and preferences of the person with dementia and building a good care relationship through caring for them over an extended period of time were frequently mentioned as prerequisites to providing good care (De Witt Jansen et al., 2017b; Hunter et al., 2016; Koppitz et al., 2016; Monroe et al., 2015; Ostaszkiewicz et al., 2015; Park et al., 2017; Toivonen et al., 2017; Wilson et al., 2012). In nursing homes, the importance of knowing a person's life story and involving family is increasing as people with dementia are generally admitted rather late in the course of the disease due to ageing in place policies (Koppitz et al., 2016). Knowledge about the individual aids decoding non-verbal signals, recognizing changes in, and triggers of behaviour and identifying nursing problems beyond merely the medical aspects. Nursing staff stressed that building close companionship and obtaining this knowledge takes considerable time.

3.4.5. Interdisciplinary collaboration

Nursing staff reported poor collaboration with other disciplines (physicians/other nursing staff members) as a barrier to effective palliative care provision (De Witt Jansen et al., 2017a, b; Hammar et al., 2016). Nursing assistants reported feelings of being unsupported by other staff (Hammar et al., 2016) and being excluded from multidisciplinary team meetings, which raised concerns about missing out on critical information about patients from other disciplines (De Witt Jansen et al., 2017b). Nursing staff emphasized the necessity of interdisciplinary collaboration (Koppitz et al., 2016; Monroe et al., 2015).

3.4.6. Education and training

Nursing staff frequently mentioned a need for training and education (Burns and McIlfatrick, 2015a, De Witt Jansen et al., 2017a, b; Koppitz et al., 2016; Livingston et al., 2012; Smith et al., 2016; Talbot and Brewer, 2016). They stressed that general dementia training does not suffice in developing skills specifically in caring for people with advanced dementia (Talbot and Brewer, 2016). Nursing staff wished to acquire skills and knowledge on pain recognition and management, entailing monitoring and reporting treatment response and side effects, the use of assessment tools and choice of medication. Further, they reported a wish to acquire skills through training in advance care planning, artificial nutrition/hydration and in communicating with families about these matters. Nursing staff preferred opportunities for case-based discussion or mentoring by more experienced staff members (De Witt Jansen et al., 2017a).

3.4.7. Organizational support

Nursing staff reported several factors occurring at the organizational level to be barriers to providing high-quality, person-centred palliative care (De Witt Jansen et al., 2017a, b; Hammar et al., 2016; Hunter et al., 2016; Ostaszkiewicz et al., 2015; Talbot and Brewer, 2016). Hence, this theme comprised divergent elements concerning limited support from the organization towards its employees. This involves understaffing, a heavy workload, limited time to provide care and attend to individual patients, forced task-centred rather than person-centred care and cuts to services delivered by lifestyle staff and allied health staff. Moreover, nursing staff reported inadequate opportunities for professional development, incomplete exchange of information among nursing staff members, insufficient emotional support and feeling undervalued or unrecognized.

3.5. An integrated conceptualization

From these themes, we inferred an integrated conceptualization to outline what nursing staff need in providing palliative care for people with dementia (Fig. 2). Issues arise that directly relate to daily care provision and interaction between nursing staff and the person with dementia (depicted in circles). Beyond these practical concerns, needs arise on a more distant workplace level as preconditions for nursing staff in providing palliative dementia care. These prerequisites exist within the healthcare organization itself (depicted in triangles). When the organization fails to provide nursing staff with sufficient resources to meet their fundamental needs, this likely incites experiencing barriers in daily care practice. Healthcare organizations are well positioned and authorized to establish supportive policies.

4. Discussion

To our knowledge, this scoping review is the first to provide an overview of perceived needs of nursing staff in providing palliative care for people with dementia, at home or in long-term care facilities. It should be noted that terms reflecting 'needs' and 'barriers' are used interchangeably across and within articles. We conceptualized barriers as needs. Therefore, reported barriers to

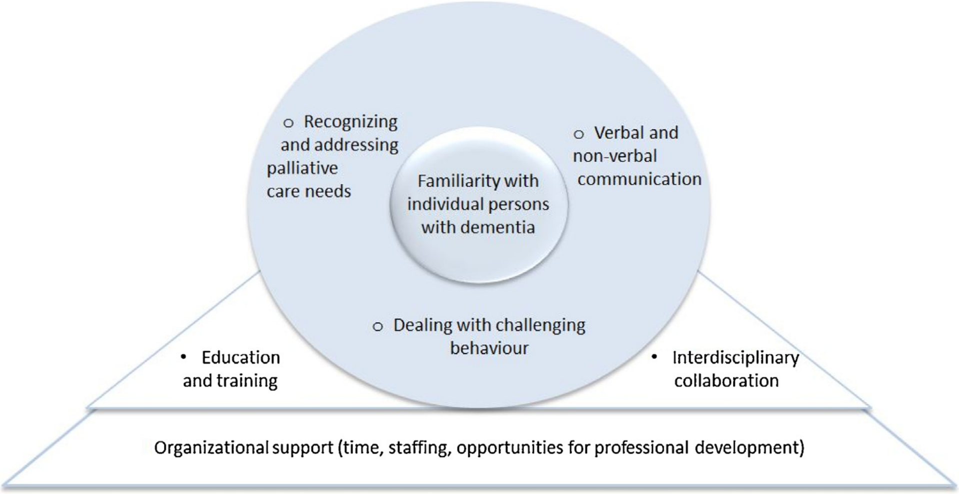

Fig. 2. An integrated conceptualization of nursing staff needs in providing palliative care for people with dementia. The circular elements reflect needs on a direct care-level, whereas the triangular elements reflect needs concerning more distant workplace and organizational levels.

high-quality palliative dementia care (such as difficulties in managing care needs or organizational restraints) were regarded as inverted needs for these aspects to be in place. Nursing staff needs in providing palliative care for people with dementia involve recognizing and addressing care needs (mostly physical pain), verbal and non-verbal communication, and dealing with challenging behaviour. To aid these direct care-related matters, nursing staff need to become familiar with, and learn to understand the people for whom they care. Needs that are more distant from direct care provision include training and education and sufficient interdisciplinary collaboration and information exchange with colleagues. Nursing staff have unmet needs related to organizational support. Inadequate time and staffing and limited opportunities for professional development are a concern. The majority of the included studies were conducted in Western countries and most used qualitative methods, investigating long-term care facilities. Most obtained high quality scores. However, sometimes the rationale for choosing a specific purposive sample was missing, notions in the discussion or conclusion could not be traced back directly to reported results, or claims of generalization were not substantiated with existing literature. Articles rarely mentioned the researchers' personal viewpoints as a possible source of influence on the data. These hiatuses in reporting may reflect points of consideration for future studies.

The importance of familiarity and a familiar environment has been stressed by others (Midtbust et al., 2018; Perrar et al., 2015) and is in line with a person-centred approach; one of the key domains recommended for palliative care for people with dementia (van der Steen et al., 2014). Communication is another core competency needed in addressing the social needs of people with dementia (Perrar et al., 2015) and in establishing person-centred care, shared decision-making and advance care planning (van der Steen et al., 2014). However, nursing staff report that they experience difficulties related to verbal and non-verbal communication with individuals with dementia. Furthermore, nursing staff experience complications in recognizing and addressing physical needs and managing physical discomfort. Yet, these are pivotal elements when providing palliative care in the physical domain (Perrar et al., 2015; van der Steen et al., 2014).

Nursing staff struggle to apply a palliative approach according to the established domains of palliative care in dementia. Previous research indicates that nursing staff may lack sufficient competences, sensitive awareness and an appropriate personal attitude to deal with the complex palliative care demands of people with dementia (Erel et al., 2017; Harris, 2007; van der Steen et al., 2017; van Riet Paap et al., 2015). The failure to deliver high-quality nursing care may result in adverse outcomes for both people with dementia and their formal caregivers. People with dementia may have unmet psychosocial and spiritual needs and face poor symptom control, unnecessary hospitalizations and burdensome interventions (Lloyd-Williams et al., 2017; van Riet Paap et al., 2015). At the end of life, maintaining human dignity may involve a 'mirrored experience', meaning that dignity of the person with dementia is interrelated with the caregiver's own dignity (Pols et al., 2018). Consequently, nursing staff may feel undignified or demoralized themselves if barriers to the delivery of high-quality palliative care cannot be overcome. Factors hindering nursing staff from realizing their personal values in the care they provide may cause strain and burnout (Duffy et al., 2009; Edberg et al., 2008).

Measures of competence or knowledge do not directly translate into tailored solutions that would facilitate nursing staff to overcome barriers. This review adds to known challenges in dementia care as it reflects needs extracted from nursing staff's own accounts. The added value of narrating nursing staff's own expressed *needs* over measuring their *knowledge* or *skills* is that interdependencies between needs and also the context in which they occur are exposed. For instance, recognizing pain is closely linked with learning to interpret nonverbal signals, which requires knowing the person, which in turn may be hampered by having insufficient time. Nursing staff's expressed need for knowing the person with dementia may be a key element in relation to addressing other care issues, which fits in the more general vision that the traditional nursing profession requires treating someone as a whole person (Fitch et al., 2015). A holistic approach to nursing may help nursing staff to build meaningful care relationships and nurture personhood while recognizing losses associated with dementia (Touhy, 2004). This review also shows that to improve holistic palliative care for people with dementia, we need to consider not only specific care-related issues encountered by staff, but also workplace and organizational set-up. Considering Maslow's hierarchy of needs (Maslow, 1943), a facilitating work environment that fulfils physiological and safety needs may allow nursing staff to build close care relationships, feel recognized and self-efficacious and actualize one's personal values in the nursing profession. Fulfilling nursing staff's occupational needs may increase their motivation, job satisfaction and the quality of care they provide (Liu et al., 2016). Pursuing impact of nursing interventions, we recommend developing them in close collaboration and agreement with care organizations to facilitate effective integration in daily nursing practice.

The review also exposes gaps in the current knowledge about nursing staff needs in providing palliative dementia care. Advance care planning from a nursing perspective has not received much attention from the scientific community. Nursing staff providing daily care may often (informally) receive signals that are important to future care. However, they may be unaware of a potential role in care planning or feel that it is not their responsibility or priority to actively engage (Robinson et al., 2013; Ke et al., 2015). Although all articles are about care for people with moderate to severe stages of dementia, palliative care is not always mentioned explicitly. A more explicit palliative approach in future nursing research might trigger greater awareness around the end of life of people with dementia, stimulating nursing staff to express their needs in supporting advance care planning. The same might be true for expressing needs in offering spiritual and psychological support. These domains were referred to only to a limited extent. In a previous ethnographic study, nurses were unaware that in fact they did attend to spiritual needs (Gijsberts et al., 2013). This suggests that a lack of reporting on spiritual matters does not necessarily indicate nursing staff does not provide spiritual care.

It is notable that only one of the included studies concerned a home care setting. Palliative dementia care provided at home may be an under-studied area (D'Astous et al., 2017). Nevertheless, home care services are important as living and dying at one's place of preference is an important element in end-of-life care, and home is often considered a preferred place for people with dementia to reside until the end of life (Harris, 2007; Lloyd-Williams et al., 2017; van der Steen et al., 2017). Community-based palliative care for people with dementia is gaining increasing attention; services require further exploration (Lloyd-Williams et al., 2017). The current conceptualization of nursing staff needs draws largely upon findings from studies conducted in long-term care facilities. Nonetheless, the article concerning home care did not appear to differ substantially in terms of themes (Smith et al., 2016). Thus, nursing staff working in long-term care facilities and home care may face similar challenges in their daily work, underpinned by similar fundamental needs. Similarities and differences in the particular needs perceived by nursing home staff compared to home care staff requires further study.

Lastly, nursing staff needs in providing care for families have not been studied extensively, inducing the need for future research. Starting early in the dementia process when still receiving care at home, providing support for families of people with dementia continues to be an important element of palliative care after admission to long-term care (Brodaty and Donkin, 2009; van der Steen et al., 2014). Upon admission to a long-term care facility, individuals may already have advanced dementia, limiting opportunities for nursing staff to become acquainted with the person (Koppitz et al., 2016). This highlights the importance of involving family.

4.1. Strengths and limitations

The current scoping review has several strengths, including its focus on recent research, as the landscape of palliative dementia care is subject to rapid change. Three researchers evaluated the methodological quality of studies, addressing weaknesses that may require attention in future studies. It should be noted that initially there was only 'fair' interrater agreement observed from the quality assessment tool, indicating proneness to bias. Two authors carried out the screening of titles and abstracts, and full-text articles for a random selection and after reaching agreement one author continued. The coding of texts from articles and classifying of codes into themes was performed by one author and may therefore have been prone to researcher bias. However, written memos and triangulation by discussing and fine-tuning interpretations with all authors increased objectivity and reduced the influence of the researcher's personal viewpoint. Moreover, relevant information may have been overlooked as studies were only included if they were written in English or Dutch, and grey literature was not searched for. Lastly, a limitation of the included articles is that none addressed cultural or gender differences that may influence nursing staff needs. Future research may consider these factors.

5. Conclusions and implications

This review provides an overview and comprehensive summary of primary research findings concerning nursing staff needs in providing palliative care for people with dementia at home or in long-term care facilities. A conceptualization of these findings shows the interdependency of nursing staff needs, occurring within an organizational context. Reaching the primary goal of the overarching DEDICATED project (Academische Werkplaats Ouderenzorg, 2017) to improve palliative care for people with dementia and their loved ones, may require addressing educational and organizational issues to support daily caregiving. Areas recommended for further research on nursing staff needs in palliative care for people with dementia include home care settings, psychosocial and spiritual domains, advance care planning, and family involvement. An integrated understanding of nursing staff needs in providing palliative care for people with dementia may support integration of tailored and feasible interventions in everyday nursing practice, increasing competences to improve quality of care and quality of life of people with dementia.

Conflicts of interest

None declared

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