

Nutrition and hydration for people living with dementia near the end of life: A qualitative systematic review

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Abstract

Aims: To synthesize the qualitative evidence of the views and experiences of people living with dementia, family carers, and practitioners on practice related to nutrition and hydration of people living with dementia who are nearing end of life.

Design: Systematic review and narrative synthesis of qualitative studies.

Data sources: MEDLINE, Embase, PsycINFO, CINAHL.

Review methods: Databases were searched for qualitative studies from January 2000–February 2020. Quantitative studies, or studies reporting on biological mechanisms, assessments, scales or diagnostic tools were excluded. Results were synthesized using a narrative synthesis approach with thematic analysis.

Results: Twenty studies were included; 15 explored the views of practitioners working with people living with dementia in long-term care settings or in hospitals. Four themes were developed: challenges of supporting nutrition and hydration; balancing the views of all parties involved with 'the right thing to do'; national context and sociocultural influences; and strategies to support nutrition and hydration near the end of life in dementia.

Conclusion: The complexity of supporting nutrition and hydration near the end of life for someone living with dementia relates to national context, lack of knowledge, and limited planning while the person can communicate.

Impact: This review summarizes practitioners and families' experiences and highlights the need to include people living with dementia in studies to help understand their views and preferences about nutrition and hydration near the end of life; and those of their families supporting them in the community. The review findings are relevant to multidisciplinary teams who can learn from strategies to help with nutrition and hydration decisions and support.

KEYWORDS

artificial nutrition and hydration, carers, dementia, end of life, experiences, nurse, nutrition and hydration, practitioners, qualitative, systematic review

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1 | INTRODUCTION

It is estimated that 47 million people were living with dementia in 2015, expected to increase to 132 million by 2050 worldwide (WHO, 2017). Difficulties with eating and drinking affecting nutrition and hydration are common among people living with dementia and might develop at different times depending on the type and progression of dementia (Cipriani et al., 2016; Ikeda et al., 2002). In the earlier stages of dementia an individual may sometimes forget to eat and drink and experience changes in perceptions of food, including altered taste and smell (Sandilyan, 2011). As dementia develops, apraxia or a lack of attention might develop, making it difficult for the person to feed themselves (Sampson et al., 2009; Volkert et al., 2015). Some might struggle to recognize food, reject food, or not feel hungry (Harwood, 2014).

1.1 | Background

As someone living with dementia approaches end of life, their symptoms may worsen and new difficulties can emerge, such as swallowing problems (Sampson et al., 2017) which affect over 80% of those nearing the end of life (Baijens et al., 2016). Swallowing problems, or dysphagia, together with the symptoms associated to the progression of dementia (e.g., apraxia) may lead to malnutrition, dehydration, weight loss, aspiration and pneumonia (Alagiakrishnan et al., 2013; Arcand, 2015; Guigoz et al., 2006; Neuberger, 2013; White et al., 1996). These problems often lead to a dilemma among practitioners and families over what is best for the person living with dementia (Watt et al., 2019).

The use of Artificial Nutrition and Hydration (ANH) is sometimes considered. Despite a lack of evidence to support the use of ANH for people living with dementia (Sampson et al., 2009), it is unclear to what extent this knowledge reaches family carers and practitioners working with people living with dementia near the end of life. There is reported to be a lack of understanding of how best to manage nutrition and hydration difficulties (Alagiakrishnan et al., 2013; Nell et al., 2016) and what strategies to use to support intake (Ball et al., 2015).

2 | THE REVIEW

2.1 | Aims

This review aims to synthesize the qualitative evidence of the views and experiences of people living with dementia, family carers, and practitioners on practice related to nutrition and hydration of people living with dementia near the end of life. An inclusive approach to defining end of life was chosen by using the term “near the end of life” and including research referring to palliative care, the later, advanced, severe or end of life stages of dementia conducted in any setting.

While the aim of the review was broad we were also guided by, but not limited to more specific questions including: (a) What is the

level of knowledge and understanding of nutrition and hydration near the end of life?; (b) What strategies do family carers and practitioners (including nurses, doctors, healthcare assistants and other staff in the community, hospitals or long-term care settings) use to support nutrition and hydration for a person living with dementia near the end of life?; (c) What help is needed to better support nutrition and hydration for the person living with dementia near the end of life?; and (d) What are the views and experiences about provision of artificial nutrition and hydration for people with dementia near the end of life?

2.2 | Design

A systematic review of qualitative studies following the guidelines from the Centre for Reviews and Dissemination (2009) and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Statement (Moher et al., 2009). The protocol for the review was registered and published with PROSPERO (CRD42019134299). Papers were included or excluded following the criteria summarized in Table 1.

2.3 | Search methods

We searched MEDLINE, CINAHL, Embase, and PsycINFO for articles published between January 2000-25 February 2020. Keywords used were dementia, nutrition, hydration, palliative care and qualitative. Initial scoping searches were conducted to identify relevant search terms including index terms (Medical Subject Headings) and a comprehensive list of synonyms. An example search strategy from PsycINFO is provided in Supplementary Material A. Citations were tracked using Google Scholar and reference lists of all relevant papers were screened to identify any additional studies.

TABLE 1 Inclusion and exclusion criteria

Papers were included if they	Papers were excluded if they
<ol style="list-style-type: none"> Used qualitative research methods (including primary research using qualitative research alone or alongside quantitative methods, if qualitative evidence in form of quotes was provided); Were published in a peer-reviewed journal; Focused on nutrition and hydration in dementia near the end of life or in the severe stages of dementia; Focused on the views and experiences of practitioners, family carers, and/or people living with dementia. 	<ol style="list-style-type: none"> Reported quantitative research only; Were conference proceedings, commentaries or opinion pieces; Focused on biological mechanisms or on reporting assessments, scales or diagnostic tools.

2.4 | Search outcome and selection procedure

Duplicates were removed and titles and abstracts were screened by one reviewer (YBM or LH) against the inclusion and exclusion criteria. A second reviewer screened a random 20% of the titles and abstracts (either YBM or LH). Articles that were potentially eligible were read in full by one reviewer (YBM or LH). A second reviewer screened a random 20% of the excluded full texts (either YBM or LH). Both reviewers read all included articles (YBM and LH). Any disagreements regarding inclusion between the two reviewers were resolved through discussion with a third reviewer (ND). Disagreement between both reviewers was rare and only lead to the exclusion of

further papers at the title and abstract screening stage. Non-English articles were rapidly appraised using English abstracts to check relevance. Experts in the field were contacted to identify any additional papers. Figure 1 shows the PRISMA flowchart.

2.5 | Quality appraisal

Quality of the included studies was appraised using the Critical Appraisal Skill Programme (CASP) qualitative checklist (2018) by LH and YBM. No studies were excluded based on quality, but the CASP checklist was used as a way to discuss the included papers and

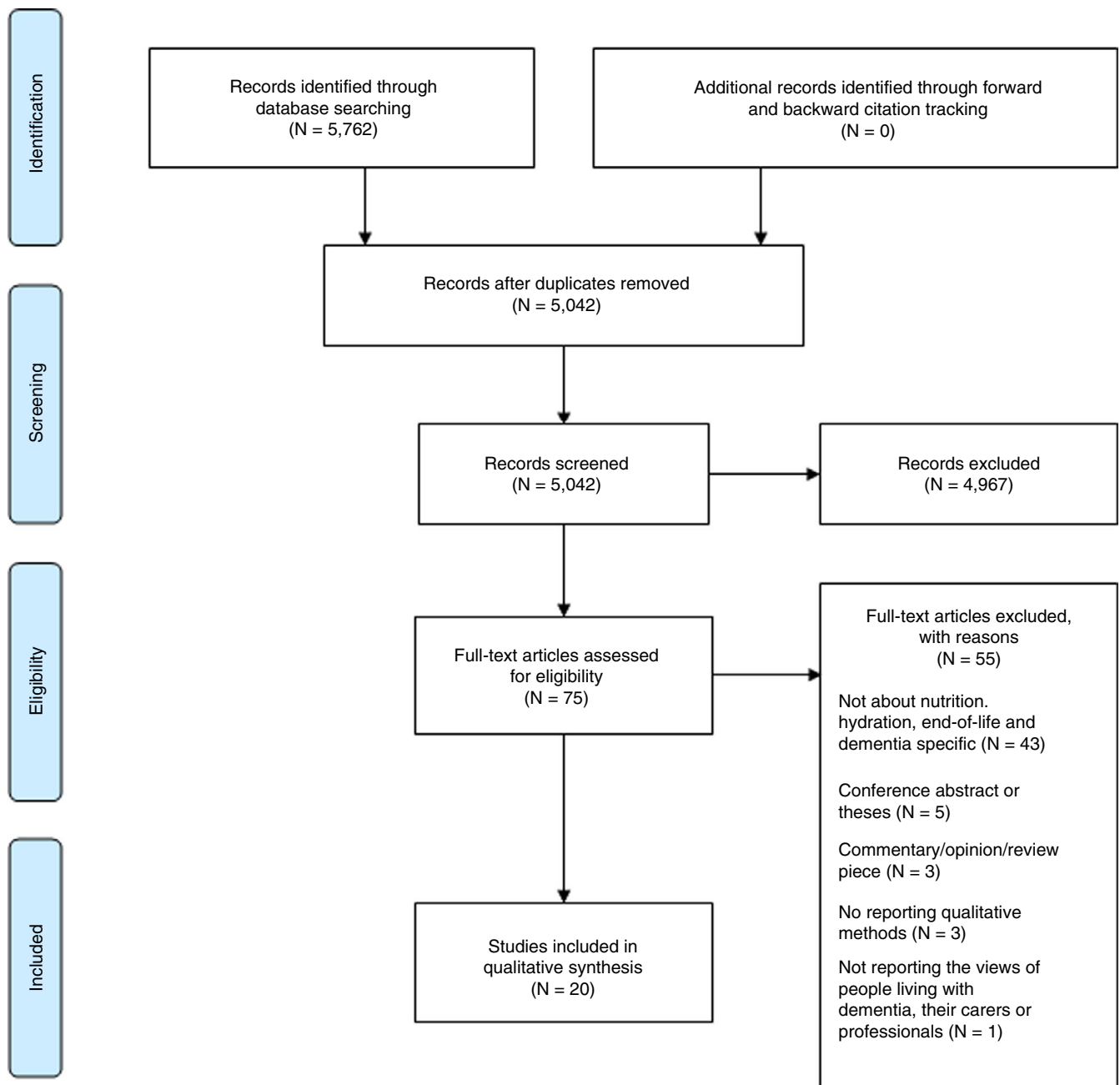


FIGURE 1 PRISMA Flow diagram summarizing the screening process [Colour figure can be viewed at wileyonlinelibrary.com]

consider quality when weighting findings and the discussion. The CASP checklist does not provide cut offs for high and low quality in a dichotomous form so we have not classified studies as high or low quality but presented them in Table 4.

2.6 | Data extraction and synthesis

We extracted the following data: author(s), year of publication, country of study, aims, study participants, sample size, study setting, methods, key findings, and conclusions. Data were extracted by YBM or LH and later crosschecked by each other. Any discrepancy was discussed and any disagreement discussed with a third reviewer (ND).

A narrative synthesis was used following guidance from the Economic and Social Research Council (ESRC) methods programme (Popay et al., 2006), using tabulation and thematic analysis methods. Analysis followed an inductive approach, two reviewers (YBM & LH) independently coded three papers to produce a coding

frame. The two reviewers met to discuss their coding and agree a coding framework to be applied to all papers. The refined coding frame was applied to all papers by YBM with meetings throughout the coding process to discuss and amend the framework. Coding of all papers was shared with a third reviewer (ND) and the team met to discuss and explore relationships and hierarchies between codes, devising themes across the data. Preliminary themes were shared and discussed with all authors for further discussion and refinement.

3 | RESULTS

3.1 | Characteristics of included studies

Twenty papers were included (Table 2 for characteristics). These 20 papers related to 15 different research projects. An overview of included papers is provided in Table 3.

TABLE 2 Characteristics of the included studies

Characteristics	Papers
Year of publication	Six papers were published between 2000 and 2009 (Aita et al., 2007; Gessert et al., 2006; Pasman et al., 2003, 2004; The et al., 2002), and 14 between 2010 and 2020 (Austbo Holteng et al., 2017; Berkman et al., 2019; Bryon et al., 2012a; Bryon et al., 2010, 2012b; Buiting et al., 2011; Gil et al., 2018; Kuven & Giske, 2015; Lopez & Amella, 2011; Lopez, Amella, Mitchell, et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Smith et al., 2016; Snyder et al., 2013; Volicer & Stets, 2016).
Study country	Most of these studies were based in the USA ($N = 8$) (Berkman et al., 2019; Gessert et al., 2006; Lopez & Amella, 2011; Lopez, Amella, Mitchell, et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Smith et al., 2016; Snyder et al., 2013; Volicer & Stets, 2016) and The Netherlands ($N = 4$) (Buiting et al., 2011; Pasman et al., 2003, 2004; Volicer & Stets, 2016), followed by Belgium ($N = 3$) (Bryon et al., 2012; Bryon et al., 2010, 2012), Norway ($N = 2$) (Austbo Holteng et al., 2017; Kuven & Giske, 2015), Australia ($N = 1$) (Buiting et al., 2011), Israel ($N = 1$) (Gil et al., 2018), UK ($N = 1$) (Wilmot et al., 2002) and Japan ($N = 1$) (Aita et al., 2007).
Methods used	Studies used interview methods ($N = 13$) (Aita et al., 2007; Bryon et al., 2012a; Bryon et al., 2010, 2012; Buiting et al., 2011; Gil et al., 2018; Lopez & Amella, 2011; Lopez, Amella, Mitchell, et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2003, 2004; Snyder et al., 2013; The et al., 2002), focus group methods ($N = 6$) (Austbo Holteng et al., 2017; Gessert et al., 2006; Kuven & Giske, 2015; Smith et al., 2016; Volicer & Stets, 2016; Wilmot et al., 2002), observational/ethnographic methods ($N = 5$) (Gil et al., 2018; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2003, 2004; The et al., 2002) and open-ended survey questions ($N = 1$) (Berkman et al., 2019).
Setting	Most studies reported data collected from long-term care facilities (care homes or nursing homes) ($N = 11$) (Austbo Holteng et al., 2017; Berkman et al., 2019; Gessert et al., 2006; Gil et al., 2018; Lopez & Amella, 2011; Lopez, Amella, Mitchell, et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2003, 2004; Snyder et al., 2013; The et al., 2002), followed by medical settings or hospitals ($N = 9$) (Aita et al., 2007; Berkman et al., 2019; Bryon et al., 2012a; Bryon et al., 2010, 2012; Buiting et al., 2011; Kuven & Giske, 2015; Volicer & Stets, 2016; Wilmot et al., 2002), and community settings ($N = 4$) (Berkman et al., 2019; Buiting et al., 2011; Lopez & Amella, 2011; Smith et al., 2016).
Participants	The majority of participants in these studies were practitioners (including nurses, doctors, healthcare assistants and other practitioners in hospitals or long-term care settings) ($N = 15$) (Aita et al., 2007; Austbo Holteng et al., 2017; Berkman et al., 2019; Bryon et al., 2012a; Bryon et al., 2010, 2012b; Buiting et al., 2011; Kuven & Giske, 2015; Lopez, Amella, Mitchell, et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2003, 2004; Smith et al., 2016; The et al., 2002; Wilmot et al., 2002), followed by family carers ($N = 7$) (Gessert et al., 2006; Gil et al., 2018; Lopez & Amella, 2011; Pasman et al., 2004; Snyder et al., 2013; The et al., 2002; Volicer & Stets, 2016) and people living with dementia ($N = 3$) (Pasman et al., 2003, 2004; The et al., 2002). People living with dementia were only included in observational studies (Pasman et al., 2003, 2004; The et al., 2002).
Central topic	Eleven studies focused on the use of ANH in dementia care, focusing on different practitioners' perceptions and communication between practitioners involved in the decision making or implementation of ANH (Aita et al., 2007; Bryon et al., 2012a; Bryon et al., 2010, 2012b; Buiting et al., 2011; Gil et al., 2018; Lopez, Amella, Mitchell, et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2004; Smith et al., 2016; The et al., 2002). The other nine studies focused broadly on nutrition and hydration in people with dementia (Austbo Holteng et al., 2017; Berkman et al., 2019; Gessert et al., 2006; Kuven & Giske, 2015; Pasman et al., 2003; Snyder et al., 2013; Volicer & Stets, 2016; Wilmot et al., 2002), however, two also addressed ANH (Snyder et al., 2013; Wilmot et al., 2002).

TABLE 3 Overview of included studies

First author, year of publication and country	Aims	Methods	Sample size, population and location	Key findings and conclusions
Aita et al. (2007) Japan	To identify and analyse factors related to the decision to provide ANH ^a through PEG ^b in older Japanese adults with severe cognitive impairment.	Retrospective, in-depth interviews.	30 doctors and nurses in the Tokyo metropolitan area.	<ul style="list-style-type: none"> Five factors influence Japanese physicians' decisions to provide ANH through PEG tubes: National health insurance system that allows elderly patients to become long-term hospital in-patients; Legal barriers with regard to limiting treatment; Emotional barriers, especially abhorrence of death by 'starvation'; Cultural values that promote family-oriented end-of-life decision making; and Reimbursement-related factors involved in the choice of PEG. Majority of informants stated that they would not want PEG tubes themselves if they were in the same situation as their patients.
Austbo Holteng et al. (2017) Norway	To investigate the experiences of care staff when providing nutritional care for people with dysphagia and dementia using texture modified food (TMF ^c).	Semi-structured focus groups.	12 professional 'carers' in a care home.	<ul style="list-style-type: none"> Textured modified food (TMF) is perceived by staff as useful to improve the nutritional care of people living with dementia and dysphagia. A lack of clear guidance and support for staff in improving nutritional care of people living with dementia and dysphagia. Authors argue staff would need training to feel confident in providing good quality nutritional care.
Berkman et al. (2019) USA	To describe the circumstances under which SLPs ^d (Speech and Language Pathologists) recommend oral nutritional intake for these patients.	One open-ended question within a survey.	509 SLPs working in general medical hospital, nursing home, or home-health agency responded to the open-ended question in the survey.	<p>Speech and Language Pathologists recommend oral nutritional intake even when people living with dementia are at high risk of aspiration when:</p> <ol style="list-style-type: none"> The patient's wishes are known through an advanced directive or family carers/surrogate decision-makers; The quality of life of the patient with dementia is expected to be better (e.g., in terms of comfort and pleasure) by promoting oral intake in the context of a poor prognosis/near the end of life; The aspiration risk can be mitigated by the patient being alert or mobile, having carers available to support good oral hygiene, who can provide a close supervision and implement safe swallowing strategies and who can follow the recommendations suggested by SLP in terms of food consistencies and feeding techniques; The recommendation made by the physician; The aspiration risk is well documented and families have signed a waiver; and The SLP are aware of the latest evidence base that does not recommend the use of tube feeding in advanced dementia.
Bryon et al. (2010) Belgium	To explore and describe how nurses are involved in the care that surrounds decisions concerning ANH in hospitalized patients with dementia.	Semi-structured interviews.	21 hospital nurses in Flanders.	<ul style="list-style-type: none"> Nurses are closely involved in the care that surrounds decisions concerning ANH in hospitalized patients with advanced dementia. Opinions between nurses differed as to whether the enjoyment of food was more important than the gaining of calories. If nurses disagreed with the physician's decision to initiate ANH, they would sometimes liaise with the family to indirectly influence their decision. Nurses looked for creative ways to postpone the ANH decision by adapting what, how, and when food was offered.

(Continues)

TABLE 3 (Continued)

First author, year of publication and country	Aims	Methods	Sample size, population and location	Key findings and conclusions
Bryon et al. (2012a) Belgium	To explore and describe how Flemish nurses experience their involvement in the care of hospitalized patients with dementia, particularly in relation to ANH.	Same as Bryon et al. 2010 Belgium (Bryon et al., 2010)	Same as Bryon et al. 2010 Belgium (Bryon et al., 2010)	<ul style="list-style-type: none"> • Nurses were moved by the vulnerability of the hospitalized patient with dementia. • Nurses' involvement in ANH decision-making processes that concern patients with dementia is a difficult and ethically sensitive experience. Nurses have to be supported as they carry out this ethically sensitive assignment.
Bryon et al. (2012) Belgium	To explore nurses' experiences of nurse-physician communication during ANH decision-making in hospitalised patients with dementia.	Same as Bryon et al. 2010 Belgium (Bryon et al., 2010)	Same as Bryon et al. 2010 Belgium (Bryon et al., 2010)	<ul style="list-style-type: none"> • Nurses felt they formed a bond with patients and came to understand what the patient wanted/ what was in their best interests. • Nurse-physician communication was the most important factor determining whether nurses succeeded or failed to advocate for the patient during ANH decision-making.
Buiting et al. (2011) Australia and The Netherlands	To investigate how Dutch and Australian doctors decide about the use of ANH in patients with advanced dementia, and under what circumstances its use is considered appropriate or inappropriate.	Interviews with open-ended questions.	31 hospital and community doctors.	<ul style="list-style-type: none"> • Different understandings of ANH – ranging from spoon feeding to PEG. • Doctors are generally reluctant to provide ANH to patients with advanced dementia, though are willing in some situations (especially artificial hydration for short time periods). • Disparities between the Dutch and Australian doctors are related to the process of decision-making (i.e., them making the decision versus involving families or taking advance directives into account).
Gessert et al. (2006) USA	To describe and understand rural-urban differences in attitudes toward death and in end-of-life decision making.	Focus groups.	38 family members of people with severe cognitive impairment in a residential or nursing home.	<ul style="list-style-type: none"> • Rural respondents perceived death as a result of the 'natural forces', whereas urban tended to be more resistant to the approach of death and opted for aggressive medical care in advanced dementia. • Urban responders were more likely to feel that they had to fight against medical practitioners for active treatment of their relative, whereas their rural counterparts felt that they had to limit the influence and medicalisation imposed by doctors.
Gil et al. (2018) Israel	To probe the considerations underlying the decision for gastrostomy, despite the data and the recommendations.	Participant observation at the clinic and in-depth interviews with guardians.	17 guardians of patients with advanced dementia most of whom were nursing home residents.	<ul style="list-style-type: none"> • Communication regarding end-of-life decisions is absent among Israeli families; no patients had advance care plans. • Palliative approach is perceived as a death sentence, and percutaneous endoscopic gastrostomy (PEG) as the last resort. • Religious beliefs and socio-economic considerations influence the decision-making process regarding tube feeding. • Guardians did not realise the terminal nature of dementia; felt that they had to continue feeding the person with dementia (including via PEG). • Most interviewees would not want the same treatment (i.e., ANH).

(Continues)

TABLE 3 (Continued)

First author, year of publication and country	Aims	Methods	Sample size, population and location	Key findings and conclusions
Kuven and Giske (2015) Norway	To explore the ethical dilemmas faced by nurses in hospitals when taking care of malnourished people living with dementia.	Focus groups.	15 hospital nurses.	<ul style="list-style-type: none"> There are areas where nurses think ethical dilemmas might need further exploration (i.e., when to keep pressing the patient to eat versus respecting their lack of interest/food rejection). It is important to have the support of diverse members of the healthcare team to make decisions. Ethical dilemmas led to different sources of pressure for nurses, depending on the individual generating them.
Lopez, Amella, Mitchell, et al. (2010) USA	To understand nursing beliefs, knowledge and roles in (ANH) feeding decisions for nursing home residents with advanced dementia.	Semi-structured interviews.	11 nurses working in 2 nursing homes.	<ul style="list-style-type: none"> Most nurses were not aware of the most recent research regarding ANH, and this led them to overestimate the benefits of feeding tubes and underestimating its risks. Nurses perceived their role as reporting observations to = doctors and facilitate communication between doctors and family, but not advise or influence families.
Lopez, Amella, Strumpf, et al. (2010) USA	To better understand how nursing home characteristics influence the practice of tube feeding in patients with advanced cognitive impairment.	Observation (80 hr) and semi-structured interviews.	30 practitioners in 2 nursing homes (including social workers, nurses, speech and language pathologists, and diet technicians).	<ul style="list-style-type: none"> Several differences were reported between the two nursing homes studied (one with low and the other high rate of ANH use). The nursing home with low ANH use had a home-like environment, promoted enjoyment of feeding, used verbal and social cues around meals. This nursing home had also a higher ratio of staff per resident to support feeding and practitioners were aware of the challenges and strategies to use.
Lopez and Amella (2011) USA	To explore the perspective of community and nursing home family caregivers' experience of assisting a family member with advanced dementia.	In-depth interviews.	16 family carers of people living with advanced dementia at home or living in a nursing home.	<ul style="list-style-type: none"> Carers seem not to be clearly in favour or against the use of artificial feeding, but different carers have different opinions. They reflect on the ethical difficulties of making this decision and some carers seem to be against the use of artificial feeding.
Pasman et al. (2003) The Netherlands	To describe the nature of problems nurses face when feeding nursing home patients with severe dementia, and how they manage these problems.	Participant observation (and interviews).	Observed: 106 participants; 60 patients with feeding problems [and severe dementia] and 46 nurses in 2 nursing homes. Unclear how many people were interviewed.	<ul style="list-style-type: none"> Nurses suggested a series of strategies to promote patients' nutrition and explained how they felt responsible if a patient would not eat. They found different reasons (i.e., swallowing difficulties or not recognizing food) to explain patients' aversions to food, and different interpretations led to different reactions (i.e., stop or continue feeding the patient).

(Continues)

TABLE 3 (Continued)

First author, year of publication and country	Aims	Methods	Sample size, population and location	Key findings and conclusions
Pasman et al. (2004) The Netherlands	To determine the role and influence of different participants in the decision-making process of starting or withholding ANH in people living with dementia in nursing homes.	Participant observation (and interviews)	Observed 83; 8 nursing home physicians, 32 families, and 43 nurses. Unclear how many people were interviewed.	<ul style="list-style-type: none"> Nursing home physicians tended not to recommend artificial feeding, and sometimes did not even mention this option to families. Sometimes, tube-feeding was not totally withdrawn but was reduced (to an amount that would not be sufficient to keep the patient alive), if it was hard for the patient to tolerate but the patient's family could not accept that they were not getting enough food. Family carers during decision-making meetings had different emotional reactions, including not accepting that their loved ones were approaching the end of life, experiencing conflicting feelings and doubts (between what was 'logical' and their emotions) or not willing to take 'responsibility of representing the patient'. Some families had an opinion and demanded it, whereas others left the decision to the physician as the 'expert'. Despite having their own views, family members were mostly prepared to accept the best interest decision for the patient, taking advice from the physician.
The et al. (2002) The Netherlands	To clarify the practice of withholding the artificial administration of fluids and food from elderly patients with dementia in nursing homes.	Participant observation (and interviews).	Observed: 118; 35 patients on 10 wards, and 8 nursing home physicians, 32 families, and 43 nurses. Unclear how many people were interviewed.	<ul style="list-style-type: none"> Decisions about artificial nutrition and hydration vary depending on the situation of the individual and if dehydration was the result of the dementia progression or due to an acute illness. Staff considered living wills and written agreements, current expressions of willingness or unwillingness to live (verbal or non-verbal) as well as patients' reactions to ANH and families' emotional responses. Doctors face uncertainties due to unexpected health fluctuations and patients' living wills.
Smith et al. (2016) USA	To explore perceptions of home healthcare nurses related to suffering, artificial nutrition and hydration in people with late-stage dementia.	Focus groups.	17 home-health nurses working in a home-care setting.	<ul style="list-style-type: none"> Staff reported how difficult it was to assess a patient's pain and needing to consider body language and facial grimacing to decipher whether the patient was in pain. Staff also mentioned ANH as something that would increase patient suffering as an invasive intervention (and sometimes only used to comfort the family), and which would lead to a series of consequences.
Snyder et al. (2013) USA	To describe surrogates' baseline perceptions of the advantages and disadvantages of feeding options in dementia; and assess the impact of using a decision aid.	Interviews.	126 surrogate decision makers for nursing home residents with advanced dementia.	<ul style="list-style-type: none"> Advantages of eating by mouth included the enjoyment of food and drink, health and nutrition, and effectiveness. Disadvantages of eating by mouth included a loss of independence by being assisted to eat, the risk of choking and the uncertainty of the appropriate amount of food or drink. Surrogates named three main advantages of tube-feeding: complete nutrition, prolonged survival, and less time-consuming. Disadvantages of tube-feeding they identified: health complications associated to the use of tube-feeding, prolonging life in a context were might not be indicated, loss of enjoyment or pleasure associated with eating, and not respecting prior wishes of the person with dementia. Surrogates' views did not necessarily match with existing evidence, but their knowledge increased through the use of a decision aid.

(Continues)

TABLE 3 (Continued)

First author, year of publication and country	Aims	Methods	Sample size, population and location	Key findings and conclusions
Volicer and Stets (2016) USA	To explore the acceptability of an advance directive that includes discontinuation of feeding at certain stage of dementia for relatives of persons who died with dementia.	Focus groups.	15 relatives of patients with dementia who died between 6 and 12 months ago in a hospice	<ul style="list-style-type: none"> The study findings suggested that: advance directives which specified withdrawal of food would be acceptable to individuals whose family member was dying with advanced dementia. Participants accepted this directive as far as the person with dementia could be provided with food or drink should they ask or indicate non-verbally wanting food/drink, in case of a change of mind. This advance directive did not interfere with participants' religious beliefs.
Wilmut et al. (2002) UK	To explore how nursing and health care assistant staff apply ethical principles in feeding the person living with dementia, how they manage conflicts between those principles, and what they think influences their views on these issues.	Focus groups.	12 nursing and health care assistant staff in a psychiatric hospital.	<ul style="list-style-type: none"> Healthcare staff perceived that patients relying on ANH were less likely to enjoy mealtimes, including the associated social engagement, and experienced a reduced quality of life. It might therefore be necessary to accept the risks of oral feeding to preserve quality of life. Choking was an important factor in decision-making. Staff were 'ambiguous' in defining if 'force feeding' was wrong. Most staff perceived an important part of their role was to prevent self-starvation and interpreted patients' refusal as a result of their cognitive decline and not as an expression of their wishes. Authors argue that good feeding practice might result from a joint team and organizational approach instead of a 'code of conduct'.

^aArtificial Nutrition and Hydration.

^bPercutaneous Endoscopic Gastrostomy.

^cTexture Modified Food.

^dSpeech and Language Pathologists.

TABLE 4 Quality appraisal of included papers

Paper	Clear aims of research	Appropriateness of qualitative research	Appropriate research design	Appropriateness of the recruitment strategy	Data collected addressed the research issue	Adequate consideration of the relationship between researcher and participants	Considered ethical issues	Rigorous data analysis	Clear statement of findings
Aita et al. (2007)	✓	✓	✓	✓	✓				✓
Austbo Holteng et al. (2017)	✓	✓	✓		✓		✓		✓
Berkman et al. (2019)	✓	✓	✓	✓			✓		✓
Bryon et al. (2010)	✓	✓	✓		✓		✓		✓
Bryon De et al. (2012a)	✓	✓	✓		✓		✓		✓
Bryon et al. (2012)	✓	✓	✓		✓		✓		✓
Buiting et al. (2011)	✓	✓	✓	✓	✓				✓
Gessert et al. (2006)	✓	✓	✓	✓	✓		✓		✓
Gil et al. (2018)	✓	✓					✓		✓
Kuven and Giske (2015)	✓	✓	✓	✓	✓				✓
Lopez and Amella (2011)	✓	✓					✓		✓
Lopez, Amella, Mitchell, et al. (2010)	✓	✓	✓		✓				✓
Lopez, Amella, Strumpf, et al. (2010)	✓	✓	✓	✓	✓	✓	✓		✓
Pasman et al. (2004)	✓	✓				✓	✓		✓
Pasman et al. (2003)	✓	✓	✓				✓		✓
Smith et al. (2016)	✓	✓	✓	✓	✓		✓		✓
Snyder et al. (2013)	✓	✓	✓	✓	✓		✓		✓
The et al. (2002)	✓	✓	✓			✓	✓		✓
Vollicer and Stets (2016)	✓	✓	✓				✓		✓
Wilmot et al. (2002)	✓	✓	✓	✓	✓		✓		✓

Note: Ticked boxes represent "yes." White boxes represent "no/can't tell."

3.2 | Quality assessment

The quality of the 20 included papers varied (see Table 4 for various quality criteria). All papers provided an explanation of their aims and justified their use of qualitative methods, reflected on the ethical issues taken into consideration in their study and explicitly reported their findings.

The recruitment process was less frequently reported in detail as the way data were collected (e.g., using topic guides) and the description of data saturation. Rarely was the relationship between the researcher and the participant reported and description of the data analysis process was often brief.

3.3 | Themes

We developed four main themes from the papers: (a) Challenges of supporting nutrition and hydration; (b) Balancing the views of all parties involved with “the right thing to do”; (c) National context and socio-cultural influences; and (d) Strategies to support nutrition and hydration.

3.3.1 | Challenges of supporting nutrition and hydration

Challenges around nutrition and hydration near the end of life were commonly discussed, including:

Communication difficulties

Verbal communication was often diminished in the later stages of dementia and practitioners relied on non-verbal communication from the person living with dementia, such as facial expressions (Bryon et al., 2010, 2012a; Buiting et al., 2011; Pasman et al., 2003, 2004; Smith et al., 2016; The et al., 2002; Wilmot et al., 2002). However, staff differed in how they interpreted these expressions and hence led to different responses for the same expression by different staff (Pasman et al., 2003).

Lack of preparation and validity of advance care plans (ACP)

Papers often used the terms ACP, advance directives and living wills interchangeably (Berkman et al., 2019; Buiting et al., 2011). Many observed that planning was not completed routinely (Bryon et al., 2012a; Buiting et al., 2011; Lopez et al., 2010; Pasman et al., 2004) and existing plans, often did not mention nutrition and hydration (Volicer & Stets, 2016). A lack of discussion and reporting of wishes regarding eating and drinking sometimes led to families thinking ANH could be used to avoid ‘killing’ the individual (Aita et al., 2007; Gil et al., 2018). However, many felt decisions should be dependent on the current situation, context and individuals’ latest wishes, which meant care plans would always be outdated and irrelevant (Bryon et al., 2012a; Buiting et al., 2011; Pasman et al., 2004; The et al., 2002; Volicer & Stets, 2016).

Strain on carers and practitioners

Helping someone to eat and remain hydrated while balancing risks of choking and aspiration requires skill, giving rise to not just practical challenges for family carers and practitioners but also emotional challenges. Helping someone with dementia to eat was a time-consuming process which meant families were not able to focus on other aspects of care (Lopez & Amella, 2011). Staff had to prioritize tasks around mealtimes and it significantly reduced their ability to care for other patients in settings where there were often already staff shortages (Austbo Holteng et al., 2017; Kuven & Giske, 2015). Practitioners experienced guilt when they felt they had not met their duty to support adequate nutrition (Austbo Holteng et al., 2017; Kuven & Giske, 2015) and for many family carers the heightened level of need highlighted the progression of the dementia and that their relative may be near the end of their life (Bryon et al., 2010; Lopez & Amella, 2011; Pasman et al., 2004).

Information and understanding

Throughout studies there was limited understanding of the natural progression of dementia (The et al., 2002) and the dying process (Gessert et al., 2006; Kuven & Giske, 2015; Lopez, Amella, Strumpf, et al., 2010; Volicer & Stets, 2016). Practitioners saw understanding of these principles as crucial to support families (Smith et al., 2016; The et al., 2002). However, nurses in the USA in particular appeared to lack confidence supporting families (Lopez et al., 2010; Pasman et al., 2004; Smith et al., 2016).

This broad lack of understanding about death and dying, coupled with lack of knowledge about the evidence base of using ANH among family carers (Gil et al., 2018; Pasman et al., 2004; Snyder et al., 2013) and practitioners meant some still favoured using ANH. Some practitioners and families perceived benefits of ANH, including the ability to extend life, maintain weight and avoiding starvation (Aita et al., 2007; Gessert et al., 2006; Gil et al., 2018; Pasman et al., 2004; Snyder et al., 2013). Some also felt ANH provided hope and comfort to the person living with dementia (Smith et al., 2016; Snyder et al., 2013). However, with greater knowledge of the evidence and understanding of their role, practitioners were strongly opposed to the use of ANH (Bryon et al., 2010). Likewise, increased knowledge among family carers reduced the use of ANH (Aita et al., 2007; Berkman et al., 2019; Buiting et al., 2011; Kuven & Giske, 2015; Smith et al., 2016; Snyder et al., 2013). However, some families resisted withholding ANH when they felt that it was their duty to protect the person living with dementia's right to life, or if they perceived comfort feeding or palliative care to be synonymous with euthanasia (Gessert et al., 2006; Gil et al., 2018).

3.3.2 | Balancing the views of all parties involved with ‘the right thing to do’

The decision-making process was complex, practitioners were not only constantly managing fluctuations in the health of the individual (The et al., 2002), but they also had to consider the wishes and

beliefs of the individual, their quality of life (Berkman et al., 2019), the views of families and also their own views (Bryon et al., 2012a; Bryon et al., 2010; Buiting et al., 2011; Gil et al., 2018; Lopez, Amella, Mitchell, et al., 2010; Pasman et al., 2003, 2004; Smith et al., 2016). This created the difficulty of balancing the views of all parties involved with 'the right thing to do' clinically, reflected in the sub-themes below.

Disagreement and conflict

Some papers discussed disagreements between friends and family, which increased as the numbers of people involved rose (Lopez & Amella, 2011; Pasman et al., 2004). The complexity of the decision, together with lack of knowledge around end of life and/or different views among third parties (e.g., extended family), created further emotional distress for some family carers (Lopez & Amella, 2011; Pasman et al., 2004).

Internal conflict was discussed by nurses or healthcare practitioners who reported having their own views about what was right for the individual which sometimes conflicted with their idea of what was right for the family (Bryon et al., 2010; Gessert et al., 2006; Kuven & Giske, 2015; Lopez & Amella, 2011; Pasman et al., 2004). This conflict occasionally manifested into disagreement with colleagues (Bryon et al., 2010, 2012a, 2012b; Pasman et al., 2004; The et al., 2002). Despite disagreements, it was accepted that doctors were responsible for making the ultimate decision on the type of treatment to be used near the end of life, but a shared decision was best practice (Bryon et al., 2010; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2004; The et al., 2002).

Ethical concerns and considerations

Ethical dilemmas for practitioners and family were common mainly concerning problems of decision-making, capacity, and communication (Lopez & Amella, 2011; Pasman et al., 2003, 2004; Snyder et al., 2013; Wilmot et al., 2002).

Staff in hospitals and nursing homes reflected on the dilemmas they faced when applying the principles of minimizing or doing no harm, autonomy, and preservation of life. They discussed the challenges of following these principles when they were superimposed, or when the person living with dementia was unable to verbally communicate (Kuken & Giske, 2015; Wilmot et al., 2002). Those in a nursing home reported finding themselves balancing what they were expected to do with what they thought was right. This included respecting the views of the individual and stopping assisting them with eating versus using lure and tricks to sustain eating (Kuken & Giske, 2015).

Ethical issues were particularly prevalent in the literature discussing ANH. Some practitioners reflected on the difference between withholding (or 'avoiding inappropriate care') and withdrawing ANH (Buiting et al., 2011). Family members also experienced ethical conflicts when having to decide on stopping ANH (Lopez & Amella, 2011; Snyder et al., 2013). At one end of the spectrum family carers and practitioners discussed the idea of not using ANH (a lack of

intervention) as feeling like they would be taking someone's life. ANH was considered as a 'basic' element of care (Aita et al., 2007; Pasman et al., 2004) and not the same as life support used to keep people alive. Not providing ANH was 'killing' the person with dementia and 'giving up' (Aita et al., 2007; Gessert et al., 2006; Gil et al., 2018; Lopez & Amella, 2011). Some practitioners who felt ANH was futile, still could not 'do nothing' (Aita et al., 2007; Gil et al., 2018).

Prognosis

The approach to nutrition and hydration appeared to be influenced by prognosis. For example, the use of ANH together with antibiotics for acute episodes was justified if it was expected that this would cure the infection and increase quality of life (Buiting et al., 2011; The et al., 2002).

Unexpected fluctuations in the patient's condition made decisions difficult and sometimes altered previous agreements (Pasman et al., 2004; The et al., 2002; Wilmot et al., 2002). Doctors stated they mainly focused on their assessment of the current well-being (including prognosis) and patient's quality of life (Buiting et al., 2011; Pasman et al., 2004; The et al., 2002).

3.3.3 | National context and sociocultural influences

National and sociocultural factors influenced supporting eating and drinking, particularly the use of ANH; however, they did not explicitly lead to withholding ANH (Aita et al., 2007; Gessert et al., 2006; Gil et al., 2018; Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2004). At a national level financial factors were seen to be influential on implementation of ANH in some countries; for example; lack of staff and resources in Israel (Gil et al., 2018), generous reimbursement for use of PEG in Japan (Aita et al., 2007) and healthcare regulations around weight monitoring in US care homes penalising weight loss (Lopez, Amella, Strumpf, et al., 2010)). Fear of legal action by some led to the use of ANH, particularly in countries like Japan where there was a lack of clear legislation and guidance (Aita et al., 2007).

Cultural values were also relevant. For example, in Japan, greater emphasis was placed on the wishes and happiness of families than the individual patient (Aita et al., 2007). Sub-groups and populations within countries, for example African Americans and urban residents, appeared to be favourable to the use of ANH (Gessert et al., 2006; Lopez, Amella, Strumpf, et al., 2010). Finally, religious beliefs (or religious interpretations) were also identified as a factor influencing support; however its influence was mixed across studies (Gil et al., 2018; Pasman et al., 2004; Snyder et al., 2013).

3.3.4 | Strategies to support nutrition and hydration near the end of life in dementia

Only a few papers reported on strategies to support nutrition and hydration in people nearing the end of life including:

Getting to know the person and their preferences

Needs and preferences of the individual may change continuously (Austbo Holteng et al., 2017), studies suggested offering food at various times and exploring individual's needs through involving families to learn about their food preferences (Bryon et al., 2010). These approaches were important to family carers who reported the importance of the enjoyment of food and drink (Snyder et al., 2013).

Enriching food

Practitioners and family carers reported altering food to ensure high caloric intake through enriching food with cream for example or offering more caloric food, such as two desserts (Kuken & Giske, 2015; Lopez & Amella, 2011; Pasman et al., 2003).

Texture modified diet

Adapting food according to the individual's needs, such as modifying food consistency by blending or choosing softer food and using 'baby' food (Volicer & Stets, 2016). Texture modified food increased care staff confidence by reducing the risk of choking, better meeting the needs of people living with dementia and enhanced the individual's independence by enabling them to feed themselves (Austbo Holteng et al., 2017).

Assisted techniques to encourage eating

Family carers felt preserving the individual's dignity was one of the advantages of eating by mouth as opposed to tube feeding (Snyder et al., 2013). Practitioners reported this could be done via several techniques including: stimulating the swallowing reflex by gently touching the individual's lips with a napkin and gently pushing them to eat softly (Pasman et al., 2003); maintaining visual contact, providing physical support, and using verbal encouragement (Lopez, Amella, Strumpf, et al., 2010). These techniques enabled the human connection and preserved dignity. Speech and language pathologists highlighted the need for the individual to be alert and carers had to be able to provide adequate oral hygiene and use strategies to reduce aspiration risk (Berkman et al., 2019). However, family carers raised concerns these techniques encouraged the loss of independent eating, the risk of choking and overfeeding (Snyder et al., 2013). Occasionally, practitioners also reported situations where they pushed the person living with dementia forcefully or held their hands in a restrictive way (Pasman et al., 2003).

Environmental and contextual modifications

Modification of the environment and the use of routines, reminiscence (e.g. recreating family celebrations) and involvement of familiar faces played an important role in facilitating nutrition and hydration as reported by practitioners and family carers (Kuken & Giske, 2015; Lopez & Amella, 2011). Environmental modifications creating a more home-like environment in care homes or encouraging a quieter environment, were considered to lead to a better quality of care overall, focused on the pleasure and enjoyment of nutrition and hydration and to fewer residents receiving ANH (Lopez, Amella, Strumpf, et al., 2010; Pasman et al., 2003). Other approaches to nutrition and

hydration were also discussed, ranging from small steps of adapting cutlery, cups, and plates that may also enhance the individual's autonomy around eating, through to more substantial changes of increasing time allocation for mealtimes (Bryon et al., 2010; Lopez, Amella, Strumpf, et al., 2010).

4 | DISCUSSION

Four main themes were identified: challenges of supporting nutrition and hydration; balancing the views of all parties involved with 'the right thing to do'; the national context and sociocultural influences; strategies to support nutrition and hydration near the end of life in dementia. Most studies focused on practitioners' views, rather than family carers'. No studies reported the views of people living with mild dementia, reinforcing that little is known about people living with dementia's wishes in respect of nutrition and hydration.

Studies focused on the use of ANH and the process of decision-making, including contextual factors influencing these processes. Few focused on alternative strategies to ANH to support and manage nutrition and hydration. This might be related to studies' focus on practitioners' perspectives in long-term care or medicalized settings rather than those of family carers. Notably, most of the family members in the included studies were supporting their relative with dementia in care home or nursing homes settings, with few studies including carers supporting someone living at home (Gil et al., 2018; Lopez & Amella, 2011).

Whilst every possible scenario cannot be planned, advance care planning (ACP) is often seen as 'the solution' to ensure a good death. However, this review highlights that some practitioners may question the 'validity' of ACP. This helps to understand previous findings that under 40% of physicians surveyed in The Netherlands agreed that an advance directive should always be followed (Rurup et al., 2006). This leads to questions of why undertake ACP, if it is seen as immediately outdated. If policy is to continue to encourage the use of ACP, more work is needed on the use of discretion in interpreting the validity and utility of ACP. Importantly, if the use of ACP is questioned and discussion is needed, it is important to include the views of people living with dementia in end of life research so we have a better understanding of what the priorities at the end of life are from their perspective to inform practice. This review has revealed a lack of research with people living with dementia focusing on nutrition and hydration and this mirrors the wider field of end of life care research more generally. This will ensure their views and experiences around important topics such as nutrition and hydration near the end of life are better respected.

Latest evidence continues to report the lack of effectiveness of ANH interventions near the end of life of people living with dementia (De & Thomas, 2019; Sampson et al., 2009). However, this review suggests that practitioners in some countries (e.g., US, Japan, Israel) have not necessarily been applying the latest evidence to their clinical practice. A multitude of factors appear to affect decision-making

going beyond the individuals involved and including both national and sociocultural factors, such as; staff and financial imperatives, weight control policies and lack of clear legislation. These findings are aligned with those of a previous systematic review on the decision-making process around the use of ANH among people lacking capacity, where the basis for its use was the belief that ANH could prolong life (Clarke et al., 2013) despite not corresponding with current evidence (Davies et al., 2019; Sampson et al., 2009). In contrast, living in rural areas and some religious interpretations led to the withholding of ANH near the end of life of the person living with dementia. The role of religious beliefs seems unclear, however, as two papers identified religious beliefs would lead to the use of ANH while another paper reported the opposite. This could point towards religious interpretations (in different groups or locations) and more broadly culture not just religious beliefs having an impact on decision-making (Chakraborty et al., 2017).

Strategies to support nutrition and hydration near the end of life were identified and included, however, findings suggest that strategies to support nutrition near the end of life in the context of dementia are rarely explored in depth. Hence, there is a need for studies exploring how carers and practitioners manage such difficulties, what support they need and how people living with dementia would like to be looked after at life's end.

4.1 | Strengths and weaknesses

This review used a systematic and rigorous approach to our search strategies and screening by multiple reviewers. The review was conducted by a large multi-disciplinary team consisting of backgrounds in psychology, speech and language therapy, social work, psychiatry, and general practice. This enabled a variety of perspectives to understand and interpret the findings and address the implications for practice and research.

This review only included qualitative studies, which may mean we have omitted an important part of the story from quantitative studies; however, we are aware of other ongoing reviews investigating quantitative literature. A strength of this review is the wide time frame searched (20 years). Including studies published in the past 20 years allowed us to reflect on both the growing interest in end of life research but also the limited inclusion of people living with dementia's views and the slow translation of research into practice (e.g., regarding the use of ANH).

We only included studies where it was clearly mentioned that carers and practitioners were caring for the person living with dementia nearing the end of life, at an advanced or later stage of dementia. Thus, some qualitative papers were excluded as they did not refer to the stage of dementia. This highlights the importance for qualitative researchers to clearly report participant characteristics.

Finally, when making international comparisons we should be mindful of the variety of terms used to discuss staff. In some studies, it appeared that the term nurses might be being applied to both certificated and non-certificated staff and was not necessarily being

applied to registered nurses. This may have implications for the interview data and observations and the nurses' communications with medical personnel.

4.2 | Implications for research and practice

The use of ACP to inform decision-making differs between countries (Harrison Dening et al., 2019). In our review, some studies noted that some practitioners raised issues regarding the validity of ACP, since these cannot account for every contingency. Existing research is focused on developing resources to support ACP and exploring how we conduct ACP and engage in discussions. However, reluctance to complete ACP and issues around validity are important and should be explored further. In particular, there is a lack of research to explore directly the views of people living with dementia regarding their preferences near the end of life and approach towards advance care planning.

Even when ANH decisions take place in national or sociocultural contexts where ANH use is considered as the default option, learning about ANH and guidance might help reduce its use without unwarranted consequences for physicians and others involved.

Finally, our understanding of challenges is well-developed but ways of supporting nutrition and hydration near the end of life, particularly at home, remain largely unexplored. This is an important gap. The difficulties and the successful approaches undertaken by carers and practitioners of people living with dementia at home are important to understand as we see an increasing shift of emphasis of formal care services providing care, to family carers providing care at home. Increasing this understanding would enable us to understand what further support family carers need at home and how.

5 | CONCLUSION

This review points towards the complexity of supporting nutrition and hydration for the person living with dementia near end of life. Lack of awareness of evidence, limited prior discussions and care planning with the person living with dementia and the national and sociocultural context, all further increased this challenge. Exploration of how families are successfully supporting nutrition and hydration at home near the end of life is needed, focusing on situations when ANH is not used. Furthermore, the inclusion of diverse groups of people living with dementia is needed in qualitative work to understand their views and lived experience about nutrition and hydration near the end of their lives.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1. substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
2. drafting the article or revising it critically for important intellectual content.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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Additional supporting information may be found online in the Supporting Information section.

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