

## REVIEW

# A qualitative systematic review of family caregivers' experiences of artificial nutrition and hydration at home: A meta-ethnography

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## Abstract

**Background:** Artificial nutrition and hydration (AN&H) may be provided to individuals in the home environment, and family caregivers are often involved in the management of this intervention. This experience can have multiple consequences for families.

**Aims:** The aim of this meta-ethnography is to explore and synthesize the personal experiences of family caregivers providing care to a person receiving home AN&H.

**Methods & Procedures:** A comprehensive search of the literature was conducted without any time limitations applied. Seven stages of meta-ethnography were followed. Public and patient involvement was incorporated into the development of the line of argument synthesis in this review. This review is reported following the eMERGe guidelines and it was registered in PROSPERO.

**Main Contribution:** A total of 22 studies were included representing the experiences of 336 family caregivers. Two main themes emerged: (1) sink or swim, being thrown in at the deep end; and (2) professional support as a bedrock. The first theme represents the experiences from the very start of home AN&H when the family caregivers may be overwhelmed with the level of skills they have to acquire. With time, family caregivers perceived the benefits, but also the challenges, associated with managing home AN&H. If a person receiving home AN&H was able to continue with some oral intake, it had a positive impact on family caregivers' experiences. The second theme represents the influence of professional support on the lived experience of family caregivers managing home AN&H. This support should be individualized, comprehensive, and co-created with the family caregiver and the person receiving home AN&H.

**Conclusions & Implications:** This review concluded that caring for a person receiving home AN&H can be very challenging for family caregivers. Family

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caregivers require personalized support from a multidisciplinary team of health-care professionals to acquire skills, competence and confidence in this new role. Speech and language therapists are important members of this multidisciplinary team because they can facilitate a continuation of oral intake as appropriate.

#### KEYWORDS

artificial feeding, enteral feeding, family caregivers, meta-ethnography, systematic review, tube feeding

#### WHAT THIS PAPER ADDS

##### *What is already known on the subject*

- AN&H has an impact not only on the person receiving it but also on the wider family and family caregivers. Healthcare professionals have a role in supporting people living with AN&H.

##### *What this paper adds to existing knowledge*

- This review presents a rigorous qualitative evidence synthesis that adheres fully to the eMERGe guidance for reporting of meta-ethnography. Within this meta-ethnography a current caregiver was consulted during the creation of the line of argument synthesis to provide a unique perspective to the review process. This review synthesized the current body of evidence that explores the lived experience of home AN&H (any type) for family caregivers, identifies where professional support is required and highlights current gaps.

##### *What are the potential or actual clinical implications of this work?*

- Family caregivers require personalized support from a multidisciplinary team of healthcare professionals to adjust to living with home AN&H. This support assists people living with home AN&H in perceiving benefits and developing more positive experiences. Speech and language therapists are important members of the multidisciplinary team supporting individuals with home AN&H and their family caregivers as they can facilitate a continuation of oral intake as appropriate.

## INTRODUCTION

Nutrition and hydration are essential for living, and individuals who cannot adequately receive food and fluids orally may require artificial nutrition and hydration (AN&H). The types of AN&H include enteral nutrition (EN) and parenteral nutrition (PN). EN means that nutrition is delivered via a feeding tube into the stomach or bowel to bypass the mouth and pharynx. EN requires a functional gastrointestinal tract and may assist in maintaining the integrity of the gut barrier (Altintas et al., 2011; King et al., 1999; Kyle et al., 2006). EN is suitable for some

populations, but not all. For example, critically ill people may develop significant side effects (Lewis et al., 2018). PN is introduced to bypass the gastrointestinal tract as nutrition is delivered intravenously. PN may be supplemental to EN when EN alone is inadequate (Singer et al., 2011).

Some countries and cultures consider AN&H as medical interventions that aim to improve life expectancy or quality of life (QOL), while others perceive them as means to facilitate the basic needs of an individual (Cardenas, 2021). The meaning of nutrition for humans extends beyond satisfying hunger and sustaining life, and has been of interest to

sociologists (how we choose, prepare and share food) and anthropologists (often investigating the relation between food and cultures) (Aktas-Polat & Polat, 2020). The recent ESPEN guideline on home EN highlights how this allows the individual to return home to a familiar environment in which support can be provided by the individual, family, friends or professional carers (Bischoff et al., 2020). The family members of people dependent on home AN&H often become informal caregivers and are obligated to partake in many duties related to AN&H, such as cleaning and administration of formula and medications (Silver & Wellman, 2002). These family caregivers (FCs) may have limited knowledge and training when compared with professional caregivers, such as nurses (Alsaeed et al., 2018; Silver et al., 2004) and caring at home provides a different dynamic than hospital care, or that of care homes (Alsaeed et al., 2018). This presents various challenges for FCs and although some describe the experience as positive, highlighting their dedication, pride and satisfaction with the role (Bjuresäter et al., 2012; Jukic et al., 2017; Smith et al., 1991), others have found it burdensome and difficult (Bjuresäter et al., 2012).

People living with AN&H, as well as their FCs, have identified positive outcomes from AN&H and weight management is noted as one of the main benefits (Mayre-Chilton et al., 2011). The provision of AN&H can reduce FCs' anxiety about the risk of choking among loved ones (Brotherton et al., 2006; Green et al., 2019a; Halliday et al., 2017; Stavroulakis et al., 2016; Wilson, 1993) and its initiation can be associated with a sense of relief and security for FCs (Orrevall et al., 2005). However, the role of FCs managing older adults receiving home AN&H is time and task intensive, requiring constant care (Jukic et al., 2017; Silver et al., 2004). Many FCs experience stress and fatigue (Lim et al., 2018) as well as a significant impact on their own QOL (Jukic et al., 2017). Although changes in lifestyle and QOL are noted among FCs of individuals on AN&H, Jukic et al. (2017) conclude that this is influenced by the impact of the frailty and underlying disease of the family member receiving AN&H, and related to the level of social support provided by other family members or formal caregivers (Jukic et al., 2017).

In light of the significant impact on personal and family life, the ESPEN guidelines on home PN make specific recommendations (Bischoff et al., 2020). It is proposed that psychologists and social workers should be part of the multidisciplinary team supporting individuals with AN&H, alongside physician specialists with a background in surgery and gastroenterology, specialized nurses, dietitians and pharmacists (Pironi et al., 2020). The ESPEN guidelines on home enteral feeding recognize the role of speech and language therapists (SLTs) for optimal management (Bischoff et al., 2020).

A recent systematic review aimed to identify and synthesize the available evidence exploring the experiences of home EN caregivers and included 10 studies published since 2012 on this topic (Mou et al., 2021). While the review methods employed by Mou et al. (2021) present some limitations in terms of comprehensiveness of their review process, their findings may provide some potential insight into this phenomenon. They note that FCs take on new roles and responsibilities which result in changes in daily care routines, lifestyles and relationships. The authors also conclude the FCs are not adequately supported and recommend further research exploring specific interventions and supports for FCs (Mou et al., 2021). In light of the limitations regarding the methods of this recent review, a gap remains with respect to the systematic synthesis of the current evidence exploring FCs' experiences of AN&H at home.

The aim of this meta-ethnography is to explore the personal experiences of FCs providing care to a person receiving home AN&H. Qualitative syntheses may generate more comprehensive theory, add further depth to existing systematic reviews of effectiveness of an intervention, or provide insights into reasons why interventions succeed or fail (Atkins et al., 2008). Meta-ethnography is a commonly used method of qualitative synthesis that draws together data from multiple studies, thus enriching our understanding of personal experiences and helping to inform health policy (Cahill et al., 2018). This review will synthesize the available evidence related to FCs' experiences of home AN&H and propose a new line of argument synthesis in order to inform clinical practice and identify research gaps in relation to FCs' experience of AN&H.

## METHODS

This review employed a meta-ethnographic approach (Noblit & Hare, 1988) which is a qualitative evidence synthesis methodology frequently used within healthcare professions (Cahill et al., 2018; Campbell et al., 2011; Grose et al., 2013). Meta-ethnography is a seven-phase process (Noblit & Hare, 1988) which allows for rigorous synthesis of qualitative data (Cahill et al., 2018; France et al., 2019). This article follows the eMERGe meta-ethnography reporting guidance (France et al., 2019), detailed in Table 1. This review was registered on PROSPERO (CRD42020221925). Patient and public involvement (PPI) is an important element of empirical health research and considered as advantageous by the Cochrane Consumer Network for the production of relevant and accessible reviews (Park et al., 2020). Although reported as infrequent in published meta-ethnographic studies (Park et al., 2020), the benefits of PPI have been noted in a recent meta-ethnographic review



TABLE 1 Summary of eMERGe reporting guidance

Phase	Article headings	Reporting criteria
Phase 1: Selecting meta-ethnography and getting started	Introduction	1. Rationale and context
		2. Aims
		3. Focus
		4. Rationale
Phase 2: Deciding what is relevant	Methods	5. Search strategy
		6. Search processes
		7. Selecting primary studies
Phase 3: Reading included studies	Findings	8. Outcome of study selection
	Methods	9. Reading and data extraction approach
Phase 4: Determining how studies are related	Findings	10. Presenting characteristic of included studies
	Methods	11. Process for determining how studies are related
Phase 5: Translating studies into one another	Findings	12. Outcome of relating studies
	Methods	13. Process of translating studies
Phase 6: Synthesizing translations	Findings	14. Outcome of translation
	Methods	15. Synthesis process
Phase 7: Expressing the synthesis	Discussion	16. Outcome of synthesis process
		17. Summary of findings
		18. Strengths, limitation and reflexivity
		19. Recommendations and conclusions

Source: France et al. (2019).

exploring the personal experiences of gastrostomy tube in neurodegenerative diseases (Lisiecka et al., 2021). This current review also incorporated PPI to allow for multi-perspectival interpretation of findings. A current FC was briefed on the findings emerging from the studies included in this review and invited to provide their own contribution to the line of argument synthesis based on personal experiences of AN&H.

## Search strategy

With support from an academic librarian, the initial search strategy was developed by D.L. and A.K., in conjunction A.B. A systematic search of eight databases was completed in November 2020 and a follow-up search was completed in October 2021, with two new studies included in the review. The following databases were searched, Academic Search Complete, APA PsychArticles, APA Psychinfo, CINAHL, Medline, Pubmed, Embase and Cochrane Library using a combination of keywords and Boolean terms, as outlined in Table 2.

## Screening process

The search results were imported into the web application Rayyan (<https://rayyan.qcri.org/>) (Ouzzani et al.,

2016) and two authors (D.L. and A.K.) performed independent reviews of titles and abstracts. Following this initial screening process, both authors then read all articles identified for full text review to determine if the studies met the inclusion criteria. Any disagreements were discussed until a consensus was reached. The reference list of any related review articles were also screened to identify any potentially relevant studies for inclusion. Where full-text articles were not available, authors were contacted to request a full text. Figure 1 presents the identification, screening and inclusion process.

## Eligibility criteria

Qualitative and mixed-methods study designs were included if they focused on the lived experiences, thoughts or perspectives of FCs who were caring for adults over 18 years of age, living at home and receiving home AN&H. There was no restriction in relation to the type and regime of AN&H. Studies including experiences of individuals with AN&H only, health professionals or formal (paid) caregivers, along with findings limited to quantitative results were excluded. Studies investigating the experiences of FC and people living at home with AN&H were excluded if it was not possible to extract the data from FC in the findings. The care recipient's illness and their relationship to the caregiver (whether spouse, child, friend)

TABLE 2 Boolean operator terms

Boolean operator terms		
S1	S2	S3
<b>Population (family caregivers)</b>	<b>Exposure (non-oral feeding)</b>	<b>Outcome (experience)</b>
Spouse OR parent OR famil* OR carer OR caregiv* OR wife OR husband OR next of kin OR partner	Artificial feeding OR Artificial nutrition OR Enteral feeding OR Enteral nutrition OR Feeding tube OR NG OR Nasogastric OR Parenteral nutrition OR Parenteral feeding OR PEG OR PIG OR PEJ OR Tube feeding OR non-oral feeding OR Gastrostomy	Understanding OR perspective OR views OR feelings OR World experience OR Lived experience Or qualitative OR phenomenology
Language	English	
Time limits	None	
Type of studies	Qualitative studies reporting experiences of informal adult caregivers of adults living with non-oral feeding (both must be over 18 years of age). All types and reasons for non-oral feeding will be included. No restrictions in relation to the duration of caregiving experience	
Exclusion	Quantitative studies, large-scale surveys which include some qualitative data through open questions. Participants < 18 years old Studies where the focus is not on the caregiver' perspective (e.g., those focusing on the patient's experience or health professional experience of delivering interventions). Studies with carers as well as people receiving home AN&H where it was not possible to extract the findings from the caregivers. Studies where persons with AN&H were in acute or long-term institution	

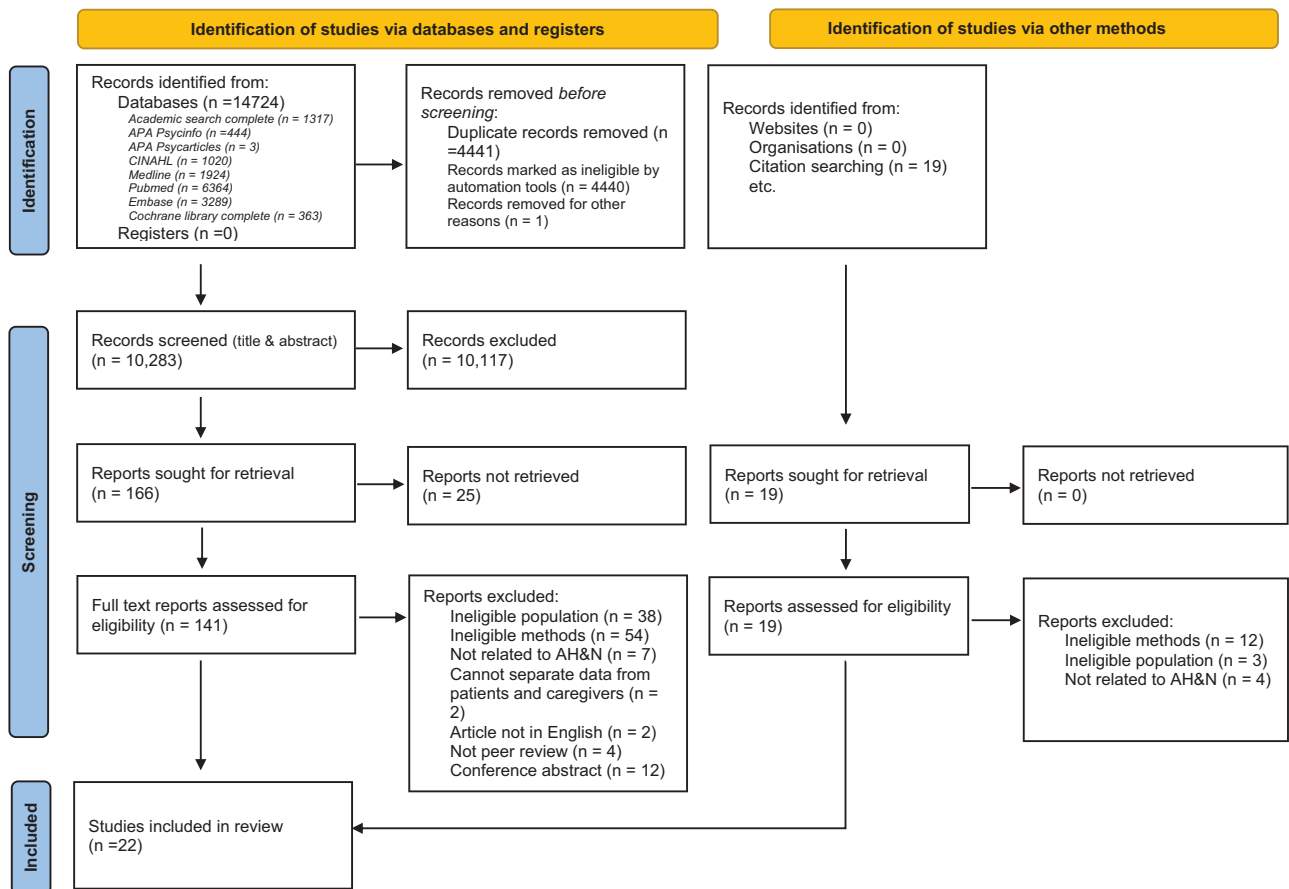


FIGURE 1 PRISMA [Colour figure can be viewed at wileyonlinelibrary.com]





were not stipulated. No time limit was applied, however, only studies published in English were considered for inclusion.

## Quality appraisal

Two authors (D.L. and A.K.) independently used the critical appraisal skills programme tool (CASP) to assess the quality and rigour of each of the included articles (Cahill et al., 2018; Chenail, 2011) (see the additional [supporting information 1](#)). Any disagreements were discussed and studies were reviewed collaboratively until a consensus was reached. The results of the CASP tool are not easily translated into classification from 'low' to 'high', so a 'deciding criteria' can be useful to determine relative study quality and its importance for the review (Long et al., 2020). The deciding criteria for inclusion in this review was the presence of qualitative data from participants who were acting in the capacity of FCs for adults receiving home AN&H.

## Translating and synthesizing studies

The studies deemed eligible for inclusion were imported into NVivo 12. Study characteristics and key contextual information were extracted from each article. Data collection and analysis was carried out systematically and independently by D.L. and A.K. The initial step of data collection included extracting first-order data (participants' quotations, mainly from the result section) from each study within NVivo12 where coding was completed. The emerging themes were established. These themes represented close reflections of the original data. Subsequently, the same process was followed for second-order data. Here data was extracted from authors' interpretations of first-order data, mainly presented in the discussion section of the articles and within the authors' summaries of the first-order data when reporting the findings. Regular meetings took place to agree the themes emerging from the first- and second-order data and in order to ensure they adequately represent each study. Next, D.L. and A.K. developed new theories (third-order themes), by interpreting first- and second-order themes across all 22 studies. A.B. was available to resolve any disagreements throughout the above process. During the process of reciprocal and refutational translation of data from all studies, new theories were developed and synthesized into third order themes. For a visual representation of this process, see the additional [supporting information 2](#).

Following the process of reciprocal and refutational translation, initially within each study and subsequently

across all 22 studies, the new theories (third-order themes) were developed. A line of argument synthesis provides a novel interpretation going further than translation, placing any similarities and dissimilarities into a new interpretive context (France et al., 2019; Noblit & Hare, 1988). The line of argument synthesis was created from the third-order themes, which we discussed, merged and expressed as our interpretative creation. A current caregiver was consulted during this process; this facilitated the provision and consideration of a unique perspective. Following the caregiver's feedback, the final line of argument synthesis was generated and the associated diagram was developed (Figure 2).

## FINDINGS

### Selected studies

Following the systematic search, 14,724 articles were identified through electronic databases and a further 19 through screening of reference lists. After a systematic elimination process (Figure 1), 22 articles were selected for inclusion in this meta-ethnography.

The 22 studies included in this review were published over a 30-year period. The majority (19/22) of studies employed a qualitative design (Ang et al., 2019; Asiedu et al., 2018; Bjuresäter et al., 2012; Brotherton et al., 2006; Cohen et al., 2012; Green et al., 2019a, 2019b; Halliday et al., 2017; Jukic et al., 2017; Mayre-Chilton et al., 2011; Mori et al., 2019; Orrevall et al., 2005; Penner et al., 2012; Rickman, 1998; Sezer et al., 2020; Smith et al., 1993; Sowerbutts et al., 2020; Stavroulakis et al., 2016; Xue et al., 2021) and three were mixed methods (Fuhr & Ciachi, 2019; Kurien et al., 2017; Rickman, 1998). Data were collected predominantly through interviews (19/22) (Ang et al., 2019; Asiedu et al., 2018; Bjuresäter et al., 2012; Brotherton et al., 2006; Cohen et al., 2012; Fuhr & Ciachi, 2019; Green et al., 2019a, 2019b; Halliday et al., 2017; Kurien et al., 2017; Orrevall et al., 2005; Penner et al., 2012; Rickman, 1998; Sezer et al., 2020; Smith et al., 1991; 1993; Sowerbutts et al., 2020; Stavroulakis et al., 2016; Xue et al., 2021) and focus groups (3/22) (Jukic et al., 2017; Mayre-Chilton et al., 2011; Mori et al., 2019). One study used a photo-elicitation interviewing method (Asiedu et al., 2018), and one supplemented interviews with observations of Percutaneous Endoscopic Gastrostomy (PEG) feeding practices (Sezer et al., 2020). Studies represented a wide geographical location including the UK (Brotherton et al., 2006; Green et al., 2019a, 2019b; Halliday et al., 2017; Kurien et al., 2017; Mayre-Chilton et al., 2011; Sowerbutts et al., 2020; Stavroulakis et al., 2016), United States (Asiedu et al., 2018; Cohen et al., 2012; Smith et al., 1991; 1993), Sweden (Bjuresäter

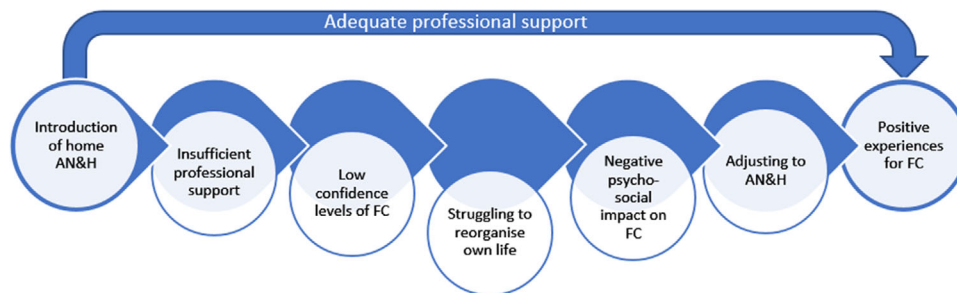


FIGURE 2 Line of argument synthesis [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

et al., 2012; Orrevall et al., 2005), Canada (Penner et al., 2012), Brazil (Fuhr & Ciachi, 2019), Singapore (Ang et al., 2019), Japan (Mori et al., 2019), China (Xue et al., 2021), Turkey (Sezer et al., 2020) and Italy (Jukic et al., 2017). One study did not specify the location of participants, but the authors' affiliations were in the UK (Rickman, 1998). Sample size ranged from three (Mayre-Chilton et al., 2011) to 84 (Cohen et al., 2012) participants, and in total 336 FCs were included in the meta-synthesis. Where reported, their age ranged from 18 (Cohen et al., 2012) to 94 years (Bjuresäter et al., 2012). Gender was reported in 16 studies, and the majority were female (75%). There was no reference to socio-economic status in any of the studies, and only five reported data on participants' employment (Mayre-Chilton et al., 2011; Mori et al., 2019; Sezer et al., 2020; Smith et al., 1991; Sowerbutts et al., 2020). Ethnicity was reported in seven studies only (Ang et al., 2019; Asiedu et al., 2018; Cohen et al., 2012; Halliday et al., 2017; Jukic et al., 2017; Kurien et al., 2017; Sowerbutts et al., 2020), and the majority were white. With regard to the relationship with the care recipient approximately half ( $n = 155$ ) were spouses. These data were not reported for six studies (Ang et al., 2019; Fuhr & Ciachi, 2019; Jukic et al., 2017; Rickman, 1998; Stavroulakis et al., 2016) or could not be extracted (Sowerbutts et al., 2020). Where reported, cancer (Ang et al., 2019; Asiedu et al., 2018; Bjuresäter et al., 2012; Brotherton et al., 2006; Cohen et al., 2012; Halliday et al., 2017; Kurien et al., 2017; Mayre-Chilton et al., 2011; Orrevall et al., 2005; Penner et al., 2012; Rickman, 1998; Sezer et al., 2020; Smith et al., 1991, 1993) and neurological conditions (Ang et al., 2019; Asiedu et al., 2018; Bjuresäter et al., 2012; Brotherton et al., 2006; Jukic et al., 2017; Mori et al., 2019; Rickman, 1998; Sezer et al., 2020; Stavroulakis et al., 2016) were the most prominent diagnosis for the care recipients. One study reported the experiences of patients with short bowel syndrome intestinal failure (SBS-IF) and their FC (Sowerbutts et al., 2020). A variety of AN&H types were used (see Table 3 for further characteristic of individual studies).

## Synthesizing translations

New theories, which were developed during the process of reciprocal and refutational translation of data from all studies, were synthesized into two third-order themes: (1) sink or swim and (2) professional support as a bedrock. These are presented below. Participants' quotations (first-order data) are underlined and in italics, authors' quotations are in italics only. Additional supporting information 2 provides an overview of the first- and second-order themes, their subthemes, and a supporting quotation, along with their connection to the third-order themes.

### Theme 1: Sink or swim, being thrown in at the deep end

The commencement of home AN&H generally emerged as a difficult time, as FCs had to cope with this new intervention on top of other demands associated with the underlying illness of the care recipient. For some, the initial reaction to AN&H was *'very strong and negative'* (Jukic et al., 2017). FCs often perceived finding themselves in an *'inescapable'* (Bjuresäter et al., 2012) situation where they had not been given any choice (Bjuresäter et al., 2012; Penner et al., 2012; Smith et al., 1991, 1993): *'The roles we're in right now are not roles we would choose to be in'* (Penner et al., 2012).

FCs had to quickly learn new skills required to manage AN&H (Smith et al., 1991), which sometimes had to be achieved with little assistance from professionals (Smith et al., 1993; Xue et al., 2021). Handling equipment related to AN&H was challenging, in some cases due to FCs' decreased fine motor skills or fragility of the equipment parts (Stavroulakis et al., 2013). Some FCs felt forced to take on new responsibilities (Bjuresäter et al., 2012). Some felt insecure when managing home AN&H as they were worried about *'making a mistake and leaving something out'* (Jukic et al., 2017). Uncertainty and ambivalence were most frequently mentioned feelings in one study: *'We don't*



TABLE 3 Characteristic of included studies

Author	Year	Country	Study aim	Smith et al. (1993)	Rickman (1998)	Orrevall et al. (2005)	Brotherston et al. (2006)	Mayre-Chilton et al. (2011)	Bjuresäter et al. (2012)	Cohen et al. (2012)	Penner et al. (2012)	Stavroulakis et al. (2016)	Halliday et al. (2017)	Jukic et al. (2017)	Kurien et al. (2017)	Asiedu et al. (2018)	Ang et al. (2019)	Green et al. (2019a)	Green et al. (2019b)	Führ et al. (2019)	Mori et al. (2019)	Sezer et al. (2020)	Sowerbutts et al. (2020)	Xue et al. (2021)
USA		USA	To assist in understanding the experiences of families and face in adapting to either short-or long-term dependence on technology	To explore the psychological effects of PEG feeding on both patients and carers	To investigate the experiences of HPN from the perspective of advanced cancer patients and their family members	To explore how feeding impacts the daily lives of adult patients, from the perspective of patients' and carers' families	To explore the impact of the daily lives of adult patients, from the perspective of patients' and carers' families	To explore what it means to be a relative of a person dependent on home enteral tube feeding (HETF) and how they can manage this situation	To describe the meaning of hydration for terminally ill cancer patients in home hospice care and their primary caregivers	To explicate the lived experience of caring for a relative with advanced head and neck cancer	To explore the experience of gastrostomy insertion perspective of the patients and their informal carers	To explore how patients and their informal carers experience care-giving with a JFT in the first months following surgery	To comprehend and describe the views, experiences and adaptations of caregivers who assist older patients treated with Home Enteral Nutrition	To determine how gastrostomy affects health-related quality of life in recipients and caregivers	To examine the material artefacts involved in the delivery of HEN and to explore patient and caregiver experiences around HEN	To explore patients' and home carers' experiences and perceptions of different modalities of enteral feeding	To gain an understanding of the experiences of people with ETs and carers concerning hospital admission for ET-related issues and to explore their views of services that could support the management of ETs at home and avoid hospital admission	To present one major theme, 'Living with a tube', which explores people's experiences of living with an ET and managing associated problems	To analyse the possibilities, limitations and challenges of oral intake of home enteral nutrition	To explore the impact of patient's slight and recovery of oral intake because of swallowing and lowering rehabilitation on Public Health Care long-term care of Iguaçu County living with a PEG tube nutritional profile of patients subjected to this post-hospital discharge therapy	To identify the post-discharge problems and PEG living with a holistic approach	To explore the patient's family experience of living with SBS-IF and caring for patients with NGT, in China	To gain an understanding of the experience of the family experience of FCs, caring for patients with living PEG and SBS-IF by taking a holistic approach	

(Continued)





TABLE 3 (Continued)

Author	Smith et al. (1991)	Smith et al. (1993)	Rickman et al. (1998)	Orrevall et al. (2005)	Brother-ton et al. (2006)	Mayre-Chilton et al. (2011)	Bjuresäter et al. (2012)	Cohen et al. (2012)	Penner et al. (2012)	Stavroulakis (2016)	Halliday et al. (2017)	Jukic et al. (2017)	Kurien et al. (2017)	Asiedu et al. (2018)	Ang et al. (2019)	Green et al. (2019a)	Green et al. (2019b)	Führ et al. (2019)	Mori et al. (2019)	Sezer et al. (2020)	Sower-butts et al. (2020)	Xue et al. (2021)	
Study type	Mixed methods qualitative study (pilot)	Qualitative study	Mainly qualitative phenomenological study	Explorative qualitative study	Cross-sectional qualitative design	Qualitative grounded theory	Grounded theory	Hermeneutic phenomenological logical	Phenomenological	Descriptive	Retrospective qualitative exploration	Qualitative inductive thematic inquiry	Grounded theory	Mixed prospective study	Qualitative socio-material approach	Qualitative inductive descriptive design	Mixed methods descriptive design	Mixed methods descriptive design	Qualitative thematic approach	Qualitative thematic logical design	Qualitative thematic logical design	Qualitative thematic design study	
Methods of data collection	Interviews and questionnaires	Semi-structured interviews	Semi-structured interviews using a carer questionnaire as prompts	Semi-structured interviews	Semi-structured interviews	Focus groups	Open interviews	Phenomenological interviews	Interviews on two occasions	Interviews on semi-structured interviews	Semi-structured interviews	Focus groups	Semi-structured interviews	Photovoice method	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Focus groups	Interviews and observations of PEG practices	Semi-structured interviews	Semi-structured interviews	
Methods of data analysis	n.r.	Content analysis	n.r.	Constant comparative analysis	Data were analysed descriptively and thematically	Thematic analysis	Grounded theory (simultaneous sampling, data collection, analysis, constant comparison)	Phenomenological analysis	Phenomenological approach (intuitive, phenomenological, logical, analysing, and constant describing)	Thematic analysis	Thematic analysis	Thematic interpretive analysis	Thematic interpretive analysis	Layered approach	Inductive content analysis approach	Thematic analysis	Thematic analysis	Content analysis	Content analysis	Constant comparative analysis	Content analysis	Thematic analysis	Inductive content analysis approach
Sample size (FCs)	5	20	8	11	19	3	12	84	6	8	8	22	10	8	9	15	15	12	22	21	5	13	
Sample age (years)	57-76	30-76	n.r.	n.r.	n.r.	40-70	23-94 (median = 58)	18-90 (mean = 56)	49-64	n.r.	n.r.	45-84 (mean = 61.1)	Unable to extract	n.r.	44-74 (mean = 55)	22-77 (mean = 51)	22-77 (mean = 51)	39.67 (with follow-up) and 37.83 (no follow-up)	31 to > 65.53.8 (32-69) (mean = 60.5)	31 to > 65.53.8 (32-69) (mean = 51.1)	31 to > 65.53.8 (32-69) (mean = 51.1)	31 to > 65.53.8 (32-69) (mean = 51.1)	

(Continued)



TABLE 3 (Continued)

Author	Year	Sample	Smith et al. (1993)	Rickman (1998)	Orrevall et al. (2005)	Brother-ton et al. (2006)	Chilton et al. (2011)	Mayre-säter (2012)	Cohen et al. (2012)	Penner et al. (2012)	Stavroulakis (2016)	Halliday et al. (2017)	Jukic et al. (2017)	Kurrien et al. (2017)	Asiedu et al. (2018)	Ang et al. (2019)	Green et al. (2019a)	Green et al. (2019b)	Führ et al. (2019)	Mori et al. (2019)	Sezer et al. (2020)	Xue et al. (2021)	
Socio-economic status	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	
Ethnicity	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	52 (62%) white, 19 (23%) African American, 11 (13%) Latino, 2 (2%) Asian	n.r.	n.r.	All white British	100% Italians	Majority was white	All white non-Hispanic	7 Chinese, 1 Malay, 1 Indian	13 F, 2 M	13 F, 2 M	7 F, 5 M	21 F, 1 M	15 F, 6 M	2 F, 3 M	7 F, 6 M
Employ	n.r.	6 retired, 6 full-time and 6 part-time employment outside the home. Employment data were not reported for 2 care-givers	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	1/15 was paid to support the person with the tube	1/15 was paid to support the person with the tube	n.r.	20 unem-ployed, 2 employ as a result of SBI-IF, 2 retired, 1 other	n.r.	n.r.	n.r.
Living arrangements between FC and CR	n.r.	Unable to extract	n.r.	n.r.	Daughters were the only family members inter-viewed who did not permanently reside with the patient	n.r.	n.r.	All spouses and 1 sibling lived together with the patients and all other close relatives lived separately from the patient	n.r.	4/6 lived in the same household	n.r.	n.r.	All lived with the CR	65.2% lived with CR	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	17/21 living with CR	n.r.	Unable to extract

(Continued)



TABLE 3 (Continued)

Author	Year	Study	Family	Medical	Genetic	Other	Pathology	Diagnosis	Outcome												
Smith et al. (1991)	1991	Smith et al. (1993)	Smith et al. (1998)	Orreval et al. (2005)	Brother-Chilton et al. (2006)	Mayre-Bjuresäter et al. (2012)	Cohen et al. (2012)	Penner et al. (2012)	Stavroulakis et al. (2016)	Halliday et al. (2017)	Jukic et al. (2017)	Kurien et al. (2017)	Asiedu et al. (2018)	Ang et al. (2019)	Green et al. (2019a)	Green et al. (2019b)	Führ et al. (2019)	Mori et al. (2019)	Sezer et al. (2020)	Xue et al. (2021)	
Relation to CR	4 spouses, 16 spouses, n.r.	1 sister, and 2 parents of adult children	5 wives, 4 husbands and 2 daughters; 1 husband	5 wives, 4 husbands, 1 partner, 3 mothers, 1 daughter	5 spouses, 244 daughters, 22 siblings, 17 other, 1 daughter-in-law	7 spouses, 244 daughters, 22 siblings, 17 other, 1 daughter-in-law	244 spouses, 22 children, 17 other, 1 missing daughter-in-law	4 spouses, 4 siblings	2 n.r.	6 wives, 1 partner, 1 daughter	6 wives, 1 partner, 1 daughter	n.r.	6 partners, 2 children, 2 siblings	1 mother, 2 daughters, 5 spouses	2 n.r.	5 mothers, 2 fathers, 1 sister, 6 wives /partners	5 mothers, 2 fathers, 1 sister, 6 wives /partners	13 spouses, 2 mothers, 4 daughters, 1 cousin	8 spouses, 8 children, 7 partners, 1 cousin	8 spouses, 8 children, 7 partners, 1 cousin	6 spouses, 3 parents, 3 adult children, 1 sibling
CR diag-nosis	Colitis with severe diarrhoea plus severe perianal break-down; advanced gastric cancer; metastatic carcinoma of the colon; carcinoma of the lung with metastasis to the brain; carcinoma of the colon with liver metastasis	gastrointestinal disorders, such as Crohn's disease or ischemic bowel disease; 5 head and neck cancer; malignancy associated with radiation enteritis; removed	chronic neurological disease, 7 had malignancy disease in the neck areas, 1 had had malignancy disease removed	Advanced cancer	Oesophageal cancer, pituitary tumour, benign oesophageal stricture, CVA (stroke), cerebral palsy, motor neuron disease, multiple sclerosis, cardiac disease, irritable bowel syndrome, drome, meningococcal septicaemia, unexplained dysphagia, rare neurological disorder	Head and neck cancer, neurological intestinal disease	Advanced cancer	Advanced head and neck cancer, cancer of the oral cavity, oropharynx, or neck (1/6 stage III, 5/6 stage IV)	Motor neuron disease	Esophageal cancer	97% with neurological disorders, 67% with comorbidities; mostly cardiac insufficiency and DM2. Older people, 100% bedridden	6 progressive neurological disease, 3 oropharyngeal cancer, 1 CVA	5 malignant amyotrophic lateral sclerosis, 1 diabetes, Parkinson's disease	5 malignant functional decline, 2 son's disease, 1 CVA	n.r.	n.r.	n.r.	17 CVA, traumatic brain injury, oncological, 1 dysphagia	neurological disease, 4	neurological disease, 4	n.r.

(Continued)



TABLE 3 (Continued)

Author	Smith et al. (1991)	Rickman et al. (1998)	Orrevall et al. (2005)	Brotherton et al. (2006)	Mayre-Chilton et al. (2011)	Bjuresäter et al. (2012)	Cohen et al. (2012)	Penner et al. (2012)	Stavroulakis et al. (2016)	Halliday et al. (2017)	Jukic et al. (2017)	Kurien et al. (2017)	Asiedu et al. (2018)	Ang et al. (2019)	Green et al. (2019a)	Green et al. (2019b)	Führ et al. (2019)	Mori et al. (2019)	Sezer et al. (2020)	Soverbutts et al. (2020)	Xue et al. (2021)
CR's age (years)	58–78	n.r.	32–78	n.r.	4 M average = 55 (range = 51–60) years, 2 F average = 64 (range = 27–92)	n.r.	38–91 (mean = 67)	47–74 (mean = 67)	42–91 (mean = 67.1)	67 (range = 52–74)	Average = 86.7 ± 8.1	n.r.	58.9 (range = 30–85)	n.r.	3–83 (mean = 41; SD = 27)	3–83 (mean = 41; SD = 27)	Unable to extract	10/21	were 21–64, 11/21 were > 65	Unable to extract	n.r.
Type of AN&H as reported in each study	HTPN	TPN (n = 9)	PEG	HPN, most of the patients could eat orally; many had HPN-free weeks-ends	PEG (n = 6)	Nasogastric tube, PEG, or a button	Parenteral hydration	Tube feeding	Gastrostomy Tube (PTG or PEG)	Jejunostomy feeding tube (overnight)	HEN	GT (55% PEG, 45% RIG)	HEN (likely PEG)	n = 6 PEG, n = 3 NG	RIG 7, PEG 2, tube with JEG with JEG extension 3	RIG 7, PEG 2, tube with JEG with JEG extension 3	HEN	PEG	PEG	Parenteral nutrition at night	NGT feeding
Length of AN&H	of 2 weeks–3 months	1 month–8 years	Majority for < 4 years	One patient had been treated for 8 years and the man caring for himself for 6 years	Minimum = 3 months (range = 2 months–9 months)	2.5 years (median = 5.5 months)	n.r.	n.r.	3 months approximately	Median = 42 days (range = 0–104 days)	Duration of caregiving for HEN: median = 28.5 months; minimum = 6 months, maximum = 100 months)	Within the first 6 weeks	Within the first 6 weeks	n.r.	2–240 months (mean = 76)	2–240 months (mean = 76)	n.r.	> 1 year, median = 41.5 months	≥ 3 months to > 49 months	> 1 year	Mean = 7.1 months

(Continued)



TABLE 3 (Continued)

Author	Year	Funding	Smith et al.	Smith (1993)	Rickman et al.	Orrevall et al.	Brotherton et al.	Chilton et al.	Mayre-Bjuresäter et al.	Cohen et al.	Penner et al.	Stavroulakis et al.	Halliday et al.	Jukic et al.	Kurien et al.	Asiedu et al.	Ang et al.	Green et al.	Green et al.	Führ et al.	Mori et al.	Sezer et al.	Sowerbutts et al.	Xue et al.		
Smith et al.	(1991)	n.i.	n.i.	n.i.	n.i.	Swedish Cancer Society and Fre-senius Kabi AB Sweden	Lancashire Teaching Hospital NHS Trust	Teaching declared	No funding.n.i.	National Institutes of Health, National Cancer Institute	National Cancer Institute of Canada Sociobehavioural Cancer Research Network; Manitoba HealthResearch Council; Canadian Institutes of Health Research New Emerging Team Grant in Palliative Care:	National Cancer Institute of Canada Sociobehavioural Cancer Research Network; Manitoba HealthResearch Council; Canadian Institutes of Health Research	Motor Disease Association (MINDA) and Sheffield Institute for Translational Neuroscience (SITraN)	n.i.	n.i.	The Bardhan Research and Education Trust of Rotherham	The Care Experience Program with Mayo Clinic's Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery	n.i.	National Institute for Health Research and Health Education England	n.i.	n.i.	n.i.	n.i.	n.i.	Supported by NPS Pharma	Department of Science and Technology in Shandong Province (grant/award number: 2019GSF108068)

Note : CVA, Cerebrovascular accident; CR, care recipient; ET, Enteral Tube; FC, family caregivers; HTN, Home Total Parenteral Nutrition; HTPN, Home Parenteral Nutrition; JFT, Jejunostomy; JET, Jejunostomy; JFT, Jejunostomy Feeding; NG, Nasogastric; NGT, Nasogastric Tube; n.i., not reported; PIG, Per-oral Image-guided Gastrostomy; PEG, Percutaneous endoscopic gastrostomy; RIG, Radiologically Inserted Gastrostomy; SBS-IF, short bowel syndrome intestinal failure.



*know anything about how long this tube is going to last, and when we can feed him (the patient) through his mouth'* (Xue et al., 2021). Managing AN&H was reported as 'struggling in an inescapable life situation' (Bjuresäter et al., 2012), 'time consuming' (Kurien et al., 2017) or an 'inconvenience' (Green et al., 2019b). Many FCs reported experiencing significant challenges as their life had changed (Bjuresäter et al., 2012; Fuhr & Ciachi, 2019; Green et al., 2019b; Jukic et al., 2017; Penner et al., 2012; Sowerbutts et al., 2020; Stavroulakis et al., 2016; Xue et al., 2021) and they had to plan their days around feeding times (Stavroulakis et al., 2013). 'Juggling' all tasks and duties became necessary, as 'life happened between feedings' (Penner et al., 2012). 'I can be strong but, you know, it's hard to be strong...' (Penner et al., 2012). AN&H restricted freedom (Bjuresäter et al., 2012; Green et al., 2019a, 2019b; Sowerbutts et al., 2020): 'Living with that it's like having a ball and chain right. It ruins your life' (Green et al., 2019a). Feeding routines were restrictive for the FCs: 'Everything about his regimen restricts my life. He's feeding during the day now and it is stopping us from going out. I'm quite bitter about it because he hasn't got that long to live' (Brotherton et al., 2006).

All studies reported that home AN&H had an evident impact on the FCs. For some, it brought a change of relationships, responsibilities and roles within families (Bajens et al., 2020; Penner et al., 2012; Smith et al., 1993; Xue et al., 2021). Psychological burden of AN&H was frequently reported, with FCs feeling lonely and socially isolated (Bjuresäter et al., 2012; Green et al., 2019b; Jukic et al., 2017; Mori et al., 2019; Penner et al., 2012; Sezer et al., 2020; Smith et al., 1991; Xue et al., 2021), anxious (Ang et al., 2019; Fuhr & Ciachi, 2019; Green et al., 2019b; Kurien et al., 2017; Penner et al., 2012; Smith et al., 1991) and depressed (Bjuresäter et al., 2012; Smith et al., 1991). FCs' sleep was affected (Green et al., 2019b; Halliday et al., 2017; Penner et al., 2012), for example, due to altered sleep position or noises from the feeding pump (Halliday et al., 2017). Some FCs neglected their own needs to provide the best care for their relative (Sezer et al., 2020; Xue et al., 2021), and for some the burden of managing home AN&H overshadowed the benefits of it (Bjuresäter et al., 2012).

FCs experienced loneliness and loss of togetherness during meals, which was difficult for them (Green et al., 2019b; Mori et al., 2019; Stavroulakis et al., 2016). Mealtimes were now stressful for FCs, who often felt guilty (Bjuresäter et al., 2012; Penner et al., 2012): 'It was painful that only I ate but you could not eat at all' (Mori et al., 2019). Some FC avoided eating in front of the person with AN&H or chose to cook bland food without any strong aroma (Penner et al., 2012). FCs greatly appreciated if a care recipient was able to take even minimal amounts of oral diet (Green et al., 2019b; Mori et al., 2019) as this reduced their burden and social isolation, allowing the whole family to sit

at the table for meals: 'My husband himself did not want to meet visitors. If his friends leave his room to drink tea, the purpose of visiting the patient cannot be fulfilled. This situation changed completely and dramatically when he was able to eat or drink a little bit from the tip of a spoon' (Mori et al., 2019). Sometimes oral diet was given, despite professional advice and clinical risk, to improve QOL (Green et al., 2019b; Mori et al., 2019).

The impact of AN&H on the recipient's and FC's QOL was not straightforward. In addition to AN&H, QOL was also influenced by the underlying illness (Brotherton et al., 2006). One study reported that QOL of the participants (patients and FCs) was preserved, but not improved following AN&H insertion (Kurien et al., 2017). One FC reported that AN&H resolved the issue of relative's chest infections leading to 'acceptable but boring [QOL] because of the loss of enjoyment of food' (Brotherton et al., 2006). In this study which explored both patients' and FCs' perspectives, it emerged that FCs' perceptions of care recipients' QOL may differ from the care recipient's self-perceived QOL. FCs perceived that the QOL of the person with AN&H was less acceptable than the perception of the person with AN&H. People with home AN&H viewed their QOL much more positively than their FCs (Brotherton et al., 2006).

The relationship between FCs and care recipients was reciprocal and the success of managing AN&H well is a 'shared accomplishment' (Asiedu et al., 2018). Some FCs reported social and psychological benefits related to AN&H and stated that the perceived benefits can outweigh problems associated with managing AN&H at home (Orrevall et al., 2005; Stavroulakis et al., 2013, 2016). Parenteral hydration was well received by FCs of relatives nearing the end of life, as it lessened their pain, improved appetite, sleep and energy levels (Cohen et al., 2012). It emerged that FCs required time to adapt and adjust to living with home AN&H and to see benefits of it (Ang et al., 2019; Bjuresäter et al., 2012; Green et al., 2019a; Kurien et al., 2017; Mayre-Chilton et al., 2011; Smith et al., 1993; Sowerbutts et al., 2020; Xue et al., 2021), 'In the beginning, the situation was experienced as chaotic, but as time went by, things settled down', but others perceived themselves as being 'forced to adjust their own daily living to the tube feeding' (Bjuresäter et al., 2012). In one study, most FCs required 3 months to perceive expected benefits of home AN&H (Kurien et al., 2017). Despite significant psychosocial impact of AN&H on FCs, the adaptation process was generally positive once FCs mastered the technology (Smith et al., 1993). Some FCs, who reported benefits from home AN&H, perceived this intervention to be 'convenient' (Green et al., 2019b), a 'peace of mind' (Asiedu et al., 2018) and an 'enormous relief' (Orrevall et al., 2005) that an alternative route for nutrition, hydration and medication had been established (Asiedu et al.,

2018; Orrevall et al., 2005). AN&H saved the time previously required to prepare meals, and it reduced an anxiety associated with an oral diet (Green et al., 2019a, 2019b). Managing AN&H united some families and provided them with a sense of success in caring for their loved-one (Smith et al., 1993). Finding a new purpose in life, sense of pride and achievement extending beyond care-related activities was reported: *'You really have a sense of accomplishment when you seethat everything is going well. My relatives and neighbours respect me, and they think what I am doing is great'* (Xue et al., 2021).

## Theme 2: Professional support as a bedrock

Professional support was generally perceived as beneficial (Halliday et al., 2017; Mayre-Chilton et al., 2011). FCs highly valued professional training and advice (Smith et al., 1991) but the professionals should be able to provide both clinical and psychological support: *'The sole psychological support of people, without clinical competencies, wouldn't be of use'* (Jukic et al., 2017). Some FCs perceived lack of sufficient professional support (Bjuresäter et al., 2012; Green et al., 2019a, 2019b; Xue et al., 2021), while others were satisfied with the training and support received (Ang et al., 2019; Halliday et al., 2017; Rickman, 1998). Home visits from professionals provided a sense of security (Orrevall et al., 2005), but also felt like *'an examination that I have to pass each month'* (Jukic et al., 2017). Some FCs perceived to be left *'a bit in the dark, we were struggling... I had no knowledge of what I had to do to keep the thing clean or to even put a feed through'* (Stavroulakis et al., 2013), or they were not given adequate time to learn the skills required to manage home AN&H (Green et al., 2019a; Sezer et al., 2020; Xue et al., 2021). Having follow-up services was referred to as *'the best thing'*, but not everyone was offered this service (Fuhr & Ciachi, 2019; Xue et al., 2021). FCs were reluctant to bring their family member to a hospital in case of out of hours problems with AN&H due to previous negative experiences and prolonged waiting time in the emergency department (Green et al., 2019a). FCs were observed to make serious mistakes and find their own solutions in the absence of professional support, which can undermine the safety of the person receiving home AN&H (Sezer et al., 2020). A conflict between FCs and physicians was reported regarding differences in perceptions of the risk versus benefit of oral diet. In one study physicians wished to stop any oral diet due to the risk of aspiration and death, whereas for FCs even a slight amount of oral diet was associated with many positive experiences (Mori et al., 2019).

FCs required comprehensive emotional, psychological and clinical support at the time of making decision

and ongoing after AN&H insertion (Asiedu et al., 2018; Bjuresäter et al., 2012; Fuhr & Ciachi, 2019; Green et al., 2019a; Jukic et al., 2017; Kurien et al., 2017; Mayre-Chilton et al., 2011; Penner et al., 2012; Rickman, 1998; Stavroulakis et al., 2016; Xue et al., 2021). This support must include adequately tailored education (Stavroulakis et al., 2016) where cultural values are addressed (Ang et al., 2019). Professionals' support needs to be well coordinated (Brotherton et al., 2006) and individualized (Orrevall et al., 2005). There may be a discrepancy between a FC's and care recipient's needs, perceptions and expectations, therefore the professional supports must be tailored to each person (Brotherton et al., 2006; Mayre-Chilton et al., 2011). The management of home AN&H should be *'a joint process'* between FCs and professionals (Smith et al., 1991) in which professionals should ensure a flexible approach (Orrevall et al., 2005; Penner et al., 2012). Peer support may be beneficial, especially to alleviate the initial fear of managing AN&H (Asiedu et al., 2018). Appropriate community support can reduce the need of hospital admissions and should offer out-of-hours services to manage emergencies (Green et al., 2019a).

## Line of argument

This review identified that commencement of home AN&H often has a profound impact on the lives of FCs. This impact starts when FCs are expected to manage home AN&H, in many cases with insufficient education and guidance from professionals. FCs may have little confidence in their own ability to manage home AN&H, for example due to their advanced age, decreased motor skills, or other commitments in their family and professional lives. When home AN&H is introduced, FCs seem to be expected to reinvent their lives and find the time to provide adequate support. Living with home AN&H can become easier with time and especially when the condition of the care recipient improves. However, many FCs may feel forced into this role and perceive no other choice but to adapt to home AN&H, despite feeling overwhelmed and unable to take on all duties related to the management of AN&H. Psycho-social consequences for FCs are multiple and can be long lasting. Professional support can be a bedrock for FCs, but it has to be individualized, comprehensive, and co-created with FCs and the person receiving home AN&H to ensure all their needs are adequately considered. Professional support is crucial during the decision-making process (this may start in a hospital) and throughout living with AN&H, especially during the first 3 months post insertion. Professionals should not assume that every FC is capable of managing home AN&H without a careful assessment and open



discussion. All potential consequences of living with AN&H should be discussed, beyond expected medical benefits. Oral intake, even minimal and provided for pleasure and not nutritional value, should be supported as it can minimize the burden of care, improve mealtime experiences, and reduce social isolation for FCs. SLTs, as part of a MDT, may play an important role in supporting oral intake for individuals living with AN&H and their FCs. If a FC is unable to manage home AN&H, alternative arrangement should be in place to support the person requiring AN&H. With the right professional support, FCs may gain confidence more quickly in their own ability to manage home AN&H, perceive the benefits of this intervention, and ultimately experience less psycho-social challenges (Figure 2).

## DISCUSSION

### Summary of the findings

This article systematically analysed and synthesized the available qualitative literature on FCs' experiences of home AN&H. A total of 22 studies were included in this meta-ethnography representing the experiences of 336 FCs of different ages and from a variety of geographical locations. The majority of studies were published in the last 10 years, which seems in line with the growing prevalence of AN&H globally (Bischoff et al., 2020). Cancer and neurological conditions were the most frequent underlying conditions of care recipients. The role of FCs of people with cancer (Wang et al., 2021) and progressive neurological diseases, such as motor neurone disease (Pagnini et al., 2010), has been recognized as critical in ensuring transfer and continuity of care between the clinical and the home environment. The impact of caregiving can cause significant psychological distress in FCs of people with progressive neurological conditions (Aoun et al., 2013; Galvin et al., 2018; McCabe et al., 2009) and cancer (Kim & Schulz, 2008; Longacre et al., 2014; Northouse et al., 2012). In a recent systematic review, psychological, social, and informational needs of FCs of people with head and neck cancer have been identified as three main needs for this population, with the psychological needs being 'highly unmet' (Wang et al., 2021). It is recognized that psychological strain in FCs can also be increased due to a high burden of physical duties (Patterson et al., 2013; Wang et al., 2021).

The findings of our review indicate that for many FCs home AN&H has a significant impact on their psychological well-being with anxiety, depression and social isolation being reported. It must be acknowledged that these FCs face a 'double burden' of care, as they may be already managing other symptoms related to the underlying condition

of the family member when the AN&H is introduced (Santarpia & Bozzetti, 2018).

Swallowing difficulties have been shown to disrupt the lives of FCs of people with cancer (Arai, 2006; Nund et al., 2014; Patterson et al., 2013) and progressive neurological diseases (Lisiecka et al., 2020). In head and neck cancer, the presence of swallowing impairment and AN&H has been identified as resulting in higher stress than other caregiving duties (Patterson et al., 2013). In our review, relatively little reference was made to the AN&H recipient's swallowing ability. AN&H was predominantly perceived by FCs as a tool to improve nutrition and hydration, rather than to minimize the risk of aspiration and choking. This appears in line with the underlying conditions of people receiving home AN&H in our review; malnutrition commonly affects people with cancer (Muscaritoli et al., 2021) and neurological conditions (Burgos et al., 2018), and adequate nutrition is considered as an important prognostic factor in these groups (Haskins et al., 2020; Jawaid et al., 2010; Körner et al., 2013; Limousin et al., 2010). If a care recipient was able to eat orally it lessened the burden on FCs even if the oral diet was minimal (for example tastes only) (Green et al., 2019b; Mori et al., 2019). Receiving nutrition and hydration exclusively through enteral tube can have a negative psycho-social impact on people with AN&H (Lisiecka et al., 2019) while continuation of oral diet may lead to a more positive experience (Lisiecka et al., 2021). Food has been recognized as having a much wider role than sustaining life, including emotional, cultural and traditional meaning (Aktas-Polat & Polat, 2020). When food is no longer a part of life, significant loss can be experienced by both the person with home AN&H and the FC. This impact must be recognized and considered by professionals.

The complexity of AN&H has been recognized in the literature, and ethical guidelines have been developed (Druml et al., 2016). Although these guidelines consider the involvement of FCs at the time of decision-making to commence or withdraw AN&H, little consideration is made regarding the FC's burden of everyday living with AN&H. The recently published ESPEN guideline on home EN seems to address this gap (Bischoff et al., 2020). It recommends good forward planning considering the impact of AN&H on everyday life, establishing who will take care of administering feeds, including FCs in discussions, ensuring appropriate communication between professionals, patient and family and providing well-coordinated care (Bischoff et al., 2020). This guideline recognizes the physical, social and psychological impact of AN&H on patients and their caregivers. It recommends periodical assessments of QOL and provision of regular support which could improve the QOL for patients and FCs (Bischoff et al., 2020).

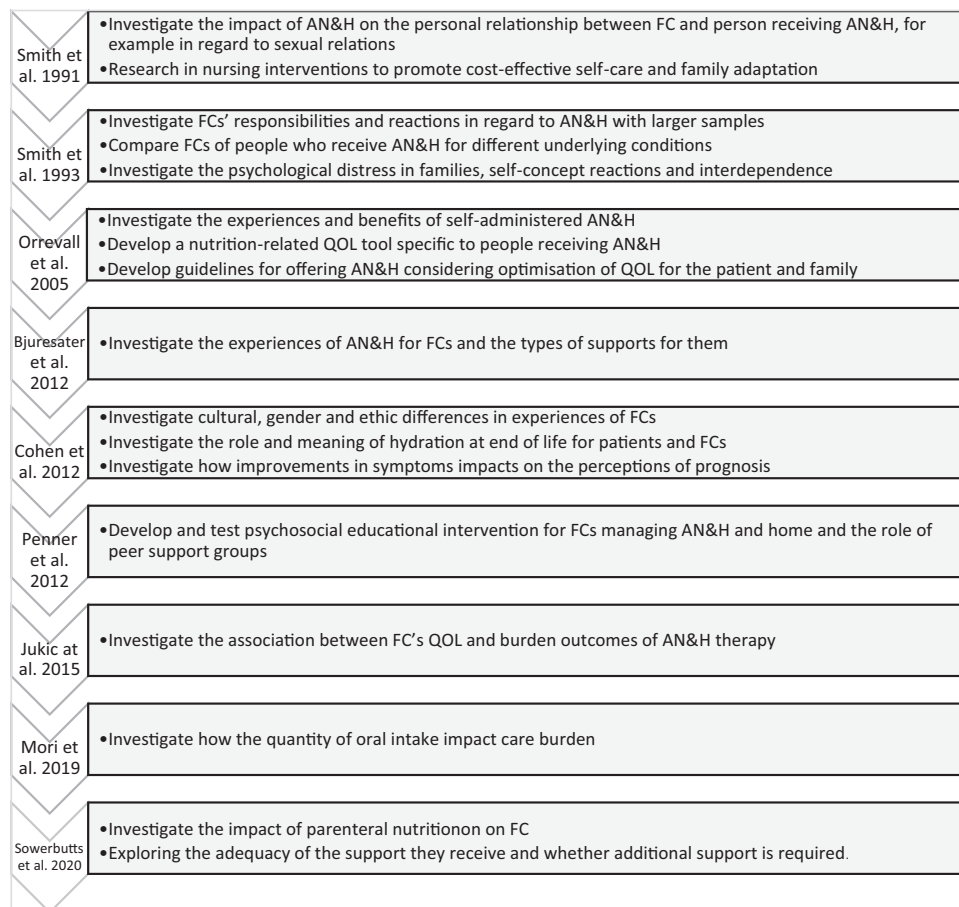


FIGURE 3 Research priorities identified by studies in this review

## Direction for future research

Directions for future research were specified in some studies included in this meta-ethnography (Bjuresäter et al., 2012; Cohen et al., 2012; Jukic et al., 2017; Mori et al., 2019; Orrevall et al., 2005; Penner et al., 2012; Smith et al., 1991, 1993; Sowerbutts et al., 2020) and Figure 3 presents these data in chronological order. Although there seems to be no consensus and consistency across the research recommendations in above studies, the discrepancies in research priorities can indicate the complexity of this topic. As FCs present with individualized needs, future research should be context specific to provide adequate understanding of their experience, recognize their unmet needs, and identify appropriate professional support.

## Strengths, limitation and reflexivity

This review was conducted with a great degree of rigor and is reported following the eMERGe guidelines (France

et al., 2019). No time limits were applied. All studies had a clear aim relevant to the topic of this review. No distinction was made between different types and regimes of home AN&H which may have influenced the findings. Our systematic search was limited to the English language only and supplementary searches, such as forward citation searching and hand searching of relevant journal contents lists, were not carried out due to resource constraints.

The three authors are qualified SLTs. Two of them represent academic institutions and have over 10 years of experience in supporting families of people with dysphagia and AN&H as well as prior experience of qualitative research methodologies. The authors acknowledge their professional background and personal experiences may have influenced their interpretations of findings. However, all interpretations were carefully discussed and checked against the original data. As none of the authors has first-hand experience of living with AN&H, a current FC was consulted to discuss and provide feedback on and insight to the line of argument synthesis.



## RECOMMENDATIONS AND CONCLUSIONS

The findings of our review indicated that the lived experience of home AN&H is complex and individualized for FCs. There are gaps in support offered by the health-care professionals in relation to education, clinical and psychological supports when AN&H is managed in the home environment. This support provision is essential, but it is challenging because of the individualized needs of FCs. Healthcare professionals, as part of an MDT, should continue to make an effort to adequately prepare FCs for all tasks related to managing home AN&H and provide psycho-social support throughout the entire experience of AN&H. SLTs, as part of a MDT, should facilitate a continuation of oral intake as this may improve QOL for the person receiving AN&H and the FCs. It is important to ensure effective and regular communication between the professionals and FCs and create a supportive environment where FCs do not feel intimidated to ask for help.

Having to manage home AN&H evoked multiple negative experiences and emotions for FCs and they required time to adjust and accept AN&H. Perceived improvement in the care recipient's status or some recovery of oral intake were associated with more positive perceptions of home AN&H.

Although research on the topic of caregiving and AN&H has increased recently, ongoing research is needed to influence organizational structure, clinical practice, and improve the everyday experiences in the management of home AN&H for individuals and their FCs. Future studies should be context sensitive and investigate differences in FCs' experiences of managing AN&H at home taking into account demographic characteristic, cultural influences, as well as differences in the underlying illnesses of the care recipients. Further development of specific education and support interventions for FCs is required.

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### CONFLICT OF INTEREST

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article and its additional supporting information.

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## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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