

REVIEW

Experiences of food and mealtime from the perspective of patients with chronic life-limiting disease: A mixed-method systematic review

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Abstract

Aim: To describe and synthesise experiences of food and mealtimes from the perspective of patients with chronic life-limiting disease.

Design: A mixed-method systematic review.

Data Sources: The databases Academic Search Complete, CINAHL, Nursing and Allied Health Database, PsycINFO, PubMed, Soc Index and Web of Science Core Collection were searched (January 2000 to March 2019).

Review Methods: Out of 3151 identified articles, 24 were included for appraisal and synthesis, using a data based convergent design.

Results: Four themes were derived: 'understanding hampered eating—perhaps it is best to let nature run its course'; 'food and meals evoke distress—reducing joy, testing interim ways'; 'struggling with food and meals—eating to please others and to postpone death'; and 'food and meals as caring and love—flanked by social disconnecting'.

Conclusion: For patients with chronic life-limiting disease, food entailed potential to remain healthy, improve well-being and prolong life. Meanwhile, eating difficulties were experienced as fundamentally affecting social life and interactions; consequently, joy around food and meals was lost.

KEYWORDS

chronic disease, eating problems, end-of-life, nursing, nutrition, patient perspectives, systematic review

1 | INTRODUCTION

Eating and drinking are important parts of our daily lives (Louge, 2014), where food and nutrients both can contribute to developing disease (Grosso et al., 2017; Kivimäki et al., 2017), as well as promoting or regaining health (Fleming et al., 2019). Food and nutrients have a fundamental role in physiological well-being, however, are also affected by illness and cancer (Arends et al., 2017; Tan & Fearon, 2008). With the worldwide trajectory of ageing populations, many with chronic life-limiting disease

live longer (Cristea et al., 2020), resulting in an increased need for supportive healthcare interventions around food and meals.

2 | BACKGROUND

Food and eating have multiple meanings in people's lives and is conferred with symbolic value (Louge, 2014), since healthy eating habits are symbols of healthy living (McCarthy et al., 2017).

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Furthermore, food and eating are embedded in everyday life, and mealtimes are fundamental daily activities providing both structure and opportunity to socialise (Castelo et al., 2021). Mealtimes and food choices are found to be ritualised in the sociocultural context of family and other social groupings in a broad spectrum of traditions (Ares et al., 2016).

Living with chronic life-limiting disease will, at some point during the illness trajectory, comprise eating patterns in everyday life that differ from those before the illness (Cooper et al., 2015; Oberholzer et al., 2013). Chronic life-limiting disease includes chronic conditions where death is the likely outcome (International Association for Hospice & Palliative Care, 2019). The illness trajectories include a chronic phase that lasts a year or more, followed by a palliative (terminal) phase, with either episodic functional decline in the last year, or marked functional decline in the last three months of life (Lunney et al., 2003). Irrespective of medical diagnoses, patients living with chronic life-limiting disease often experience eating deficiencies, i.e., illness-related symptoms and signs of hampered eating (Wallin et al., 2014), affecting appetite and intake of food (Solheim et al., 2014). Given the central role that food and eating play in everyday life, issues related to patient eating and weight loss pose significant distress for patients' informal caregivers (Wheelwright et al., 2016). Anger, fear, guilt, helplessness and worry are examples of difficult emotions related to patient rejection of food, that carers must contend with, both as a direct result of being in conflict with the patient or other constraints related to caregiving.

Nursing originating in patients' needs and experiences enhances satisfaction and increases well-being (Park et al., 2018). Supporting food intake is an integral aspect of nursing (Druml et al., 2016), and when patients with chronic life-limiting disease were asked to name a healthcare professional involved in their care, they chose an advanced practice nurse (Kobleder et al., 2017). The importance of nutritional support is recurrently stressed in scientific literature (Cederholm et al., 2017; Hudson et al., 2018). From healthcare professionals' perspectives, questions about food and meals can be loaded and cause ethical dilemmas (Bryon et al., 2008; Fetherston et al., 2018). Healthcare professionals find that nutrition-related problems trigger frustration and uncertainty about supportive interventions (Millar et al., 2013).

Chronic life-limiting disease means facing changed eating habits, e.g., ability to eat and to fulfil nutritional needs during mealtimes. Food and meals are linked to experiences of well-being both for patients and informal caregivers. Expectations are that healthcare professionals meet care needs around food and meals. Especially registered nurses have a central role in instigating nutritional support and promoting well-being for patients with chronic life-limiting disease. To the best of our knowledge, systematic reviews about food and meals in end-of-life care have predominantly focused on cancer and family perspectives (Pettifer et al., 2019; Wheelwright et al., 2016), families and patients (Del Rio et al., 2012), or families, patients and healthcare professionals (Cooper et al., 2015; Oberholzer et al., 2013). Studies describing patients' experiences

What problem did the study address?

- Food and meals in chronic life-limiting disease are associated with distress and comprise an area for improvement in end-of-life care.
- Knowledge of patients' experiences of food and meals is required for care interventions to relieve suffering and promote well-being in chronic life-limiting disease.

What were the main findings?

- Patients' experiences of food and meals in chronic life-limiting disease revealed physical, psychological, social and existential aspects crucial to patients' experiences of suffering, health and well-being.

Where and on whom will the research have an impact?

- The present review contributes to increasing healthcare professionals' understanding of patients' needs and highlight foci for intervention studies regarding food and meals, including development of clinical guidelines for end-of-life care.

have yet to be systematically reviewed and synthesised. Therefore, a mixed-method systematic review was performed to address the aims below.

3 | THE REVIEW

3.1 | Aim

The overall aim was to describe and synthesise experiences of food and mealtimes from the perspective of patients with chronic life-limiting disease. A secondary aim was to explore implications of these experiences in everyday life.

3.2 | Design

A mixed-method systematic review, with an integrated data-based convergent synthesis design, was used. The design was selected to allow findings from a diverse range of research methods and to provide a breadth of perspectives with comprehensive understanding of the studied phenomenon (Noyes et al., 2019). The method comprised data searching, screening, extraction and synthesising quantitative and qualitative results. To ensure rigour and stringency, at least two authors were involved in each stage of the review process. The Centre of Dissemination and Research Guidelines for Systematic Reviews in Healthcare (Centre for Reviews and Dissemination, 2009) were used to guide the structure and process of the review.

Throughout, guidelines and transparency in line with ENTREQ informed the review process (Tong et al., 2012). Since ENTREQ is for qualitative studies, PRISMA guidelines (Moher et al., 2009) were used in parallel to identify guideline items specific to quantitative studies.

3.3 | Search methods

The PROSPERO protocol database at York University was initially searched for systematic reviews close to aim and area of interest. None were found, subsequently a protocol for the present review was constructed and registered in the PROSPERO database [CRD42020134290] (National Institute for Health Research, 2019). Databases were chosen to cover a broad area for suitable articles aligned with the aim. Published studies were searched for in the following databases: Academic Search Complete, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Nursing and Allied Health Database, PsycINFO, Soc Index, PubMed, and Web of Science Core Collection. The databases were searched with search strings comprising: (I) patients living with chronic life-limiting disease, (II) experiences OR perceptions and (III) food OR eating. Search terms used were Subject Headings. Peer reviewed papers in English, published between January 2000 and March 2019 were searched. This time frame was chosen to focus on more recent findings from the 21st century. Inclusion criteria were studies examining experiences of food or mealtimes for adult patients with chronic life-limiting disease. Empirical studies, original quantitative, qualitative and mixed methods research studies, as well as multiple case studies were considered for inclusion.

3.4 | Search outcomes

The literature search resulted in 3151 identified articles. These were imported into Rayyan software (Ouzzani et al., 2016) for continued screening and data evaluation of titles and abstracts. After duplicates were removed ($n = 374$) by the first author, 2777 remained, and these were independently screened and evaluated by two authors (first and last or first and second). For articles with relevant titles, abstracts were read, and if suitable, full length articles were assessed. Ensuing disagreements were subsequently discussed in a meeting with all authors for consensus. Articles presenting both patients' and informal caregivers' perspectives were included if results were separable. When articles were included for full-text screening and evaluation ($n = 61$), two authors, first and last ($n = 50$) or first and third ($n = 11$), independently screened and evaluated articles, which again were discussed in the research team. Reference lists were hand searched, and suitable articles included. See the flow diagram, Figure 1 for a flow diagram of the inclusion process. In total, 24 articles were included, 19 from database searches, and 5 from hand searches.

3.5 | Quality appraisal

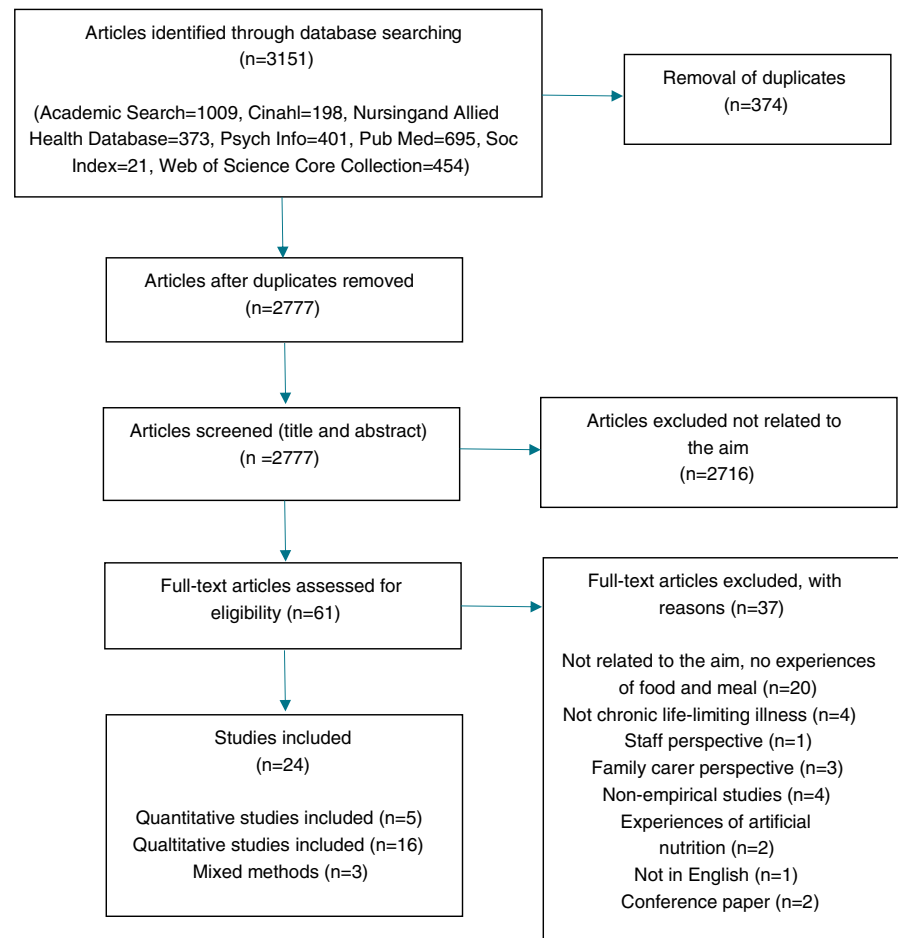
Quality appraisal was conducted independently by two authors (first and last author) and systematically evaluated based on the Critical Appraisal Skills Programme checklists (CASP, 2021); see supplemental files, Appendices S1 and S2. Quality ranged from medium (3) to high (5). In addition, methodological limitations were noted for each study. In two qualitative studies (Mahmoud et al., 2011; Wallin et al., 2015), recruitment of participants was conducted by nurses, possibly based on subjective assessments of suitability, thereby introducing selection bias. In three studies (Johnston Taylor, 2016; Keller et al., 2010; Souter, 2005), interviews were conducted in dyads with patients and informal caregivers, possibly influencing interview candour. Two mixed-methods studies did not report analysis proceedings (Luchesi & Silveira, 2018; Mahmoud et al., 2011), making assessment of trustworthiness challenging. In five quantitative studies (Amano et al., 2016; Hawkins, 2000; Hopkinson et al., 2006; Mahmoud et al., 2011; Strasser et al., 2007), questionnaires were not validated, making inferences difficult. Response rate was not reported in one mixed-methods study (Mahmoud et al., 2011). One quantitative study collected data simultaneously in family dyads (Hawkins, 2000), possibly introducing bias. Quality was not used to exclude studies, rather for focus and transparency regarding possible inferences and to allow assessment of the trustworthiness of review findings.

3.6 | Data abstraction

Results from included articles were extracted according to the aims and coded independently by first and last authors. This entailed including relevant parts of the article results, i.e., data or themes corresponding to the aim, into a data extraction template; see supplemental online file, Appendix S2. Results of the extraction were discussed and confirmed in the research group, and a matrix comprising an overview of included studies was constructed. Please refer to the online supplemental file for a more comprehensive overview of included studies, Appendix S3.

3.7 | Synthesis

Data were synthesised using a data based convergent design; i.e., extracted results were analysed using the same methods, meaning that quantitative data was transformed and qualited into words, by two authors (VW, AK) independently. Next, data were compared, analysed and synthesised using thematic analysis identifying similarities, differences and patterns (Sandelowski & Leeman, 2012). The extracted data were separated in units and given labels to summarise the experiences described in the text units, for example, 'physical impediments', 'distress', 'social', 'guilt', 'existential' and 'survival'. All authors read the full-text articles in combination with detailed summaries, participated in data display, and development of themes.

FIGURE 1 Flow diagram of the inclusion process

The thematic analysis process required approaching and displaying data in different ways to allow shifting perspectives and ensuring robust analyses. Similar labels were grouped together, discussed, and themes were created from formed clusters. This iterative process required movement from being close to data in individual articles, to aiming for the emerging bigger picture by looking at the whole, i.e., merged results from articles. The analysis process entailed independent reading, re-reading, written communications with reflections, and analysis meetings with all researchers for verifying findings and drawing conclusions.

4 | RESULTS

Twenty-four studies were included in the review: 16 (67%) employed qualitative methods (Gwilliam & Bailey, 2001; Hopkinson, 2007; Hopkinson & Corner, 2006; Johnston Taylor, 2016; Keller et al., 2010; McClement et al., 2003; McQuestion et al., 2011; Monturo & Strump, 2014; Odencrants et al., 2005; Orrevall et al., 2004, 2005; Reid et al., 2009; Shragge et al., 2007; Souter, 2005; Van der Riet et al., 2006; Wallin et al., 2015). Five (21%) articles were based on quantitative research methods (Amano et al., 2016; Chai et al., 2014; Chan & Pang, 2007; Hawkins, 2000; Hopkinson, 2007), while three (13%) described their study design as mixed methods (Luchesi &

Silveira, 2018; Mahmoud et al., 2011; Strasser et al., 2007). See Table 1 for an overview of included studies.

Studies were conducted in twelve different geographical locations, with a clear majority in developed countries. Numbers of study participants ranged from 4 to 287, and in total, 1013 participants were included. Two sets of participants appeared twice, although with different aims: Orrevall et al. (2004) and Orrevall et al. (2005), as well as Hopkinson and Corner (2006) and Hopkinson (2007). Gender was not presented in three articles (Gwilliam & Bailey, 2001; Hopkinson et al., 2006; Souter, 2005), and two had only male participants (Monturo & Strump, 2014; Strasser et al., 2007). Considering this, 427 (42%) participants were men and 224 (22%) were women, whereas the gender of 362 (36%) participants was unknown. Participants' ages ranged between 21 and 97 years; however, in three studies, ages were not presented (Hawkins, 2000; Keller et al., 2010; Reid et al., 2009). The context in the majority of articles ($n = 20$, 83%) was described as palliative care, and most of the participants were diagnosed with advanced cancer, predominantly in home care; see Table 2.

4.1 | Synthesis

For patients with chronic life-limiting disease, food entailed potential to remain healthy, to improve well-being and to prolong life,

TABLE 1 Overview of included studies

Authors (year) Country	Methods
Amano et al. (2016) Japan	Design: Quantitative cross-sectional descriptive survey Sample: 60 patients with advanced cancer Analysis: Descriptive statistics
Chan and Pang (2007) China	Design: Quantitative cross-sectional comparative survey Sample: 287 older people in long-term care facilities Analysis: Descriptive and analytic statistics
Chai et al. (2014) Singapore	Design: Quantitative cross-sectional comparative survey Sample: 38 palliative care patients Analysis: Descriptive statistics
Gwilliam and Bailey (2001) UK	Design: Qualitative explorative study, phenomenological approach Sample: 10 patients with terminal malignant bowel obstruction Analysis: Content analysis
Hawkins (2000) UK	Design: Quantitative cross-sectional comparative survey Sample: 145 patients with advanced cancer Analysis: Descriptive and analytic statistics
Hopkinson (2007) UK	Design: Qualitative explorative study, hermeneutic phenomenological approach Sample: 30 patients with advanced cancer Analysis: Content analysis
Hopkinson and Corner (2006) UK	Design: Qualitative explorative study Sample: 30 patients with advanced cancer Analysis: Content analysis
Hopkinson et al. (2006) UK	Design: Quantitative cross-sectional comparative survey Sample: 199 patients with advanced cancer Design: Descriptive and analytic statistics
Johnston Taylor (2016) New Zealand	Design: Qualitative study phenomenological approach Sample: 13 patients with cancer or motor neuron disease Analysis: Content analysis
Keller et al. (2010) Canada	Design: Qualitative explorative study, grounded theory approach Sample: 27 persons with dementia Analysis: Grounded theory
Luchesi and Silveira (2018) Brazil	Design: Mixed methods, explorative multiple case study Sample: 4 persons with ALS Analysis: Descriptive analysis of both quantitative and qualitative data
Mahmoud et al. (2011) USA	Design: Mixed methods, explorative, multiple case study Sample: 15 persons with cancer Analysis: Descriptive and analytic statistics
McClement et al. (2003) Canada	Design: Qualitative study, grounded theory approach Sample: 13 patients with cancer Analysis: Grounded theory
McQuestion et al. (2011) Canada	Design: Qualitative descriptive study Sample: 17 patients with cancer Analysis: Content analysis
Monturo and Strump (2014) USA	Design: Qualitative descriptive study Sample: 20 patients with terminal or advanced progressive illness Analysis: Content analysis
Odenrants et al. (2005) Sweden	Design: Qualitative descriptive study Sample: 13 patients with chronic obstructive pulmonary disease Analysis: Content analysis
Orrevall et al. (2005) Sweden	Design: Qualitative descriptive study Sample: 13 patients with advanced cancer Analysis: Content analysis

(Continues)

TABLE 1 (Continued)

Authors (year) Country	Methods
Orrevall et al. (2004) Sweden	Design: Qualitative descriptive study Sample: 13 patients with advanced cancer Analysis: Content analysis
Reid et al. (2009) UK	Design: Qualitative study, phenomenological approach Sample: 15 patients with advanced cancer Analysis: Content analysis
Shragge et al. (2007) Canada	Design: Qualitative explorative study Sample: 9 patients with advanced cancer Analysis: Grounded theory
Strasser et al. (2007) Switzerland	Design: Mixed methods explorative study Sample: 19 male patients with advanced cancer Analysis: Grounded theory, and comparative analytic statistics
Souter (2005) UK	Design: Qualitative study, phenomenological approach Sample: 7 patients with cancer Analysis: Hermeneutical analysis
Van der Riet et al. (2006) Australia	Design: Qualitative descriptive longitudinal study Sample: 5 patients with advanced cancer Analysis: Grounded theory
Wallin et al. (2015) Sweden	Design: Qualitative descriptive study Sample: 12 patients with advanced cancer or neurological disease Analysis: Content analysis

furthermore, that an impaired ability to eat was a natural part of the illness trajectory. Having eating difficulties was experienced as fundamentally affecting social life and interactions, and the joy around food and meals was lost, in struggles to find interim ways. Food and eating affected relationships and stirred emotions. Forcing oneself to eat was experienced as something done to please others and to survive. Four themes were derived: 'understanding hampered eating—perhaps it is best to let nature run its course', 'food and meals evoke distress—reducing joy, testing interim ways', 'struggling with food and meals—eating to please others and to postpone death' and 'food and meals as caring and love—flanked by social disconnecting'; see Table 3. Not surprisingly, some findings within themes contradict each other, representing simultaneous, multifaceted aspects of living with chronic life-limiting disease. They are presented accordingly, as they appear in the included studies.

4.2 | Understanding hampered eating—Perhaps it is best to let nature run its course

Living with chronic life-limiting disease meant various physical impediments that hampered eating; see Table 4 for physical symptoms. Patients tried to understand their unpredictable bodily changes, and one way of seeing this was as a natural part of progressing illness.

Patients struggled to understand their hampered eating and found that loss of appetite was unpredictable and rapid (Souter, 2005; Strasser et al., 2007). Sometimes causes for hampered eating were related to other symptoms (Johnston Taylor, 2016; Odencrants et al., 2005; Souter, 2005; Strasser et al., 2007). Physical explanations were biological processes, natural in relation to the

disease (Hopkinson & Corner, 2006; McClement et al., 2003; Van der Riet et al., 2006). When expected former body functioning was lost, this was experienced as a bodily loss (Gwilliam & Bailey, 2001; McQuestion et al., 2011) or the body failing them (Keller et al., 2010; McQuestion et al., 2011). Letting nature run its course, entailed acceptance of living with eating deficiencies and trust in one's body to be self-regulatory (Hopkinson & Corner, 2006). Tension around food and meals conflicted with the approach of letting nature run its course (McClement et al., 2003). Lost interest in eating (Van der Riet et al., 2006) or just being unable to eat was described (Gwilliam & Bailey, 2001). For some, not eating, or just eating a little was described as not worrying (Amano et al., 2016; McClement et al., 2003; Souter, 2005; Van der Riet et al., 2006). The gradually decreasing intake could be accepted, experiencing no hunger nor thirst was recognised as death approaching, and food would not help (Van der Riet et al., 2006).

4.3 | Food and meals evoke distress—Reducing joy, testing interim ways

Living with chronic life-limiting disease and eating deficiencies influenced patients' everyday lives and was described as stressful. Former routines around food and eating were disrupted, and joy was reduced or lost. Patients tried to find interim ways to handle food and meals along the disease trajectory.

Distress from eating deficiencies was often profound (Amano et al., 2016; Chan & Pang, 2007; Gwilliam & Bailey, 2001; Hawkins, 2000; Hopkinson et al., 2006; Johnston Taylor, 2016; McQuestion et al., 2011; Odencrants et al., 2005; Orrevall

TABLE 2 Care contexts, diagnoses and settings

Care context n (%)	Diagnoses n (%)	Author/authors, years and settings
Palliative care 20 (83)	Advanced cancer 16 (67)	Amano et al. (2016) ^a Chai et al. (2014) ^a Gwilliam and Bailey (2001) ^b Hawkins (2000) ^c Hopkinson (2007) ^a Hopkinson and Corner (2006) ^a Hopkinson et al. (2006) ^a Mahmoud et al. (2011) ^b McClement et al. (2003) ^b Orrevall et al. (2005) ^a Orrevall et al. (2004) ^a Reid et al. (2009) ^a Shragge et al. (2007) ^a Strasser et al. (2007) ^a Souter (2005) ^a Van der Riet et al. (2006) ^b
	Advanced cancer or muscle degenerative disease 2 (8)	Johnston Taylor (2016) ^b Wallin et al. (2015) ^a
	Muscle degenerative disease 1 (4)	Luchesi and Silveira (2018) ^d
	Not specified 1 (4)	Monturo and Strump (2014) ^a
Health care, not described as palliative 4 (17)	Cancer diagnosis and receiving radiation treatment 1 (4)	McQuestion et al. (2011) ^e
	Chronic obstructive pulmonary disease 1 (4)	Odencrants et al. (2005) ^f
	Dementia 1 (4)	Keller et al. (2010) ^g
	Not specified 1 (4)	Chan and Pang (2007) ^h

^aPalliative homecare.^bHospice clinic.^cHospice clinic or community care.^dNeurological clinic.^eReceiving radiation at hospital.^fPrimary care.^gCommunity care.^hLong-term care.

et al., 2004; Souter, 2005; Strasser et al., 2007; Wallin et al., 2015). Having eating deficiencies influenced well-being, this was emphasized and considered more important than physical impairment (Gwilliam & Bailey, 2001; Souter, 2005). Eating-related distress among younger individuals was more pronounced; however, reasons were not specified (Hawkins, 2000; Hopkinson et al., 2006). Food-related worries were connected to whether the patient could derive enjoyment from food or not (Amano et al., 2016). Aspects of mealtime as enjoyment could not be substituted with artificial nutrition (Orrevall et al., 2005). The stressful situation included feelings like self-blame, being incapable and being responsible for causing the disease (Hopkinson & Corner, 2006), or feeling sad and weak due to an inability to eat like before (Hopkinson, 2007). Grief was experienced due to the loss of pleasure in food (Johnston Taylor, 2016).

Living with eating deficiencies meant loss of joy around food and eating (Hopkinson, 2007; Hopkinson & Corner, 2006; McQuestion et al., 2011; Monturo & Strump, 2014; Odencrants et al., 2005;

Strasser et al., 2007; Van der Riet et al., 2006). Food and mealtimes were experienced as gradually changing from something taken for granted, pleasant and enjoyable, to a stressful task, often burdensome and difficult to deal with (Strasser et al., 2007; Wallin et al., 2015). Due to these changes, patients did not look forward to eating (Van der Riet et al., 2006). Patients struggled to find interim ways to prepare food and to eat. Eating and cooking turned into a chore, and not enjoyable as before (Hopkinson, 2007; Odencrants et al., 2005). The distress and lost joy of food and meals was associated with concern in families (Keller et al., 2010; Souter, 2005). Cooking and sharing meals were experienced as a creative process where interim ways were found, i.e., when trying new foods or new places to eat (Keller et al., 2010; McQuestion et al., 2011). Finding new ways could bring joy (Keller et al., 2010; Wallin et al., 2015) or feelings of control (Hopkinson, 2007). Humour was helpful for handling demanding situations around food and eating (Hopkinson, 2007). Maintaining oral intake was emphasised even when eating was impaired (Luchesi

TABLE 3 Themes in relation to included articles

Understanding hampered eating—perhaps it is best to let nature run its course	Amano et al. (2016); Gwilliam and Bailey (2001); Hopkinson and Corner (2006); Johnston Taylor (2016); Keller et al. (2010); Luchesi and Silveira (2018); Mahmoud et al. (2011); McClement et al. (2003); McQuestion et al. (2011); Monturo and Strump (2014); Odencrants et al. (2005); Shragge et al. (2007); Strasser et al. (2007); Souter (2005); Van der Riet et al. (2006)
Food and meals evoke distress—reducing joy, testing interim ways	Amano et al. (2016); Chan and Pang (2007); Gwilliam and Bailey (2001); Hawkins (2000); Hopkinson (2007); Hopkinson and Corner (2006); Hopkinson et al. (2006); Johnston Taylor (2016); Keller et al. (2010); Luchesi and Silveira (2018); McQuestion et al. (2011); Monturo and Strump (2014); Odencrants et al. (2005); Orrevall et al. (2005); Orrevall et al. (2004); Strasser et al. (2007); Souter (2005); Van der Riet et al. (2006); Wallin et al. (2015)
Struggling with food and meals—eating to please others and to postpone death	Amano et al. (2016); Chai et al. (2014); Hopkinson (2007); Hopkinson and Corner (2006); Johnston Taylor (2016); Keller et al. (2010); Luchesi and Silveira (2018); McQuestion et al. (2011); Monturo and Strump (2014); Odencrants et al. (2005); Orrevall et al. (2005); Reid et al. (2009); Shragge et al. (2007); Strasser et al. (2007); Souter (2005); Wallin et al. (2015)
Food and meals as caring and love—flanked by social disconnecting	Amano et al. (2016); Chai et al. (2014); Gwilliam and Bailey (2001); Hopkinson (2007); Hopkinson and Corner (2006); Johnston Taylor (2016); Keller et al. (2010); Luchesi and Silveira (2018); McQuestion et al. (2011); Monturo and Strump (2014); Odencrants et al. (2005); Orrevall et al. (2005); Orrevall et al. (2004); Reid et al. (2009); Souter (2005); Wallin et al. (2015)

& Silveira, 2018; Orrevall et al., 2005). When having difficulties eating, holding food in the mouth for enjoyment could be important (Luchesi & Silveira, 2018).

4.4 | Struggling with food and meals—Eating to please others and to postpone death

Eating was regarded fundamental and patients forced themselves to eat both to please others, to ease the stress of family and friends and also to postpone death. Food was experienced as having the potential to improve well-being and to maintain life. Being able to eat promoted satisfaction and a sense of victory, when resisting death.

Patients forced themselves to eat (Hopkinson, 2007; Strasser et al., 2007), hoping to stop weight loss and dying (Reid et al., 2009; Strasser et al., 2007). Eating was perceived as influencing other persons' emotions (McQuestion et al., 2011; Wallin et al., 2015). Awareness of the distress friends and family experienced was described (Orrevall et al., 2005; Wallin et al., 2015). Patients forced themselves to eat food they did not want, just to please others (Johnston Taylor, 2016; McQuestion et al., 2011; Reid et al., 2009), and patients ate more when eating with others (Hopkinson & Corner, 2006; Odencrants et al., 2005). Eating meant signalling a will to fight (Johnston Taylor, 2016), as food and eating were a way to maintain health and bodily functions (Amano et al., 2016; Hopkinson & Corner, 2006; Luchesi & Silveira, 2018). Patients also talked about improving well-being by eating more food, since eating led to strength and energy to be physically active (Shragge et al., 2007; Wallin et al., 2015). Objectives of eating were reframed to slowing disease progression and bodily deterioration (Shragge et al., 2007). Weight was considered closely linked to eating and weight loss a bad sign, indicating uncontrolled illness (McQuestion et al., 2011;

Strasser et al., 2007), and that death was closing in (Johnston Taylor, 2016; Shragge et al., 2007). Death by starvation would ensue if patients did not remain determined to maintain an adequate intake (Orrevall et al., 2005; Shragge et al., 2007; Souter, 2005; Strasser et al., 2007). Eating took on the meaning of resisting death, and patients struggled to stay alive (Johnston Taylor, 2016; Monturo & Strump, 2014; Shragge et al., 2007; Souter, 2005; Strasser et al., 2007). Food had high symbolic value, and eating was a source of hope (Chai et al., 2014; Souter, 2005; Strasser et al., 2007).

4.5 | Food and meals as caring and love—Flanked by social disconnecting

Preparing food and eating together, caring for each other and expressing love, was experienced as positive aspects of food and mealtimes. In social gatherings, the decreased ability to take part in meal preparations and eating comprised barriers to inclusion and partaking on the same terms as others. Social loss and being undeniably confronted with a looming social disconnect (death) was experienced.

Food and meals were experienced as socially significant, even though the illness trajectory disrupted situations around food and mealtimes (Gwilliam & Bailey, 2001; Keller et al., 2010; Luchesi & Silveira, 2018; McQuestion et al., 2011; Monturo & Strump, 2014; Orrevall et al., 2005; Souter, 2005; Wallin et al., 2015). Preparing food and eating together was experienced as caring for each other (Chai et al., 2014; Johnston Taylor, 2016; Keller et al., 2010). Eating together comprised valued opportunities for social interactions and community (Gwilliam & Bailey, 2001; Keller et al., 2010; Wallin et al., 2015), with food tying people together (Keller et al., 2010; Monturo & Strump, 2014), and food given or received was a

TABLE 4 Physical impediments hampering eating in articles

Experienced bodily impediments	Articles
Decreasing appetite	Amano et al. (2016); Gwilliam and Bailey (2001); Hawkins (2000); Hopkinson and Corner (2006); Hopkinson (2007); Hopkinson et al. (2006); Johnston Taylor (2016); McClement et al. (2003); McQuestion et al. (2011); Monturo and Strump (2014); Orrevall et al. (2005); Orrevall et al. (2004); Reid et al. (2009); Shragge et al. (2007); Souter (2005); Strasser et al. (2007); Van der Riet et al. (2006)
Feeling full/early satiety	Hopkinson and Corner (2006); Hopkinson (2007); Johnston Taylor (2016); Mahmoud et al. (2011); McQuestion et al. (2011); Odencrants et al. (2005); Reid et al. (2009); Souter (2005); Van der Riet et al. (2006)
Oral symptoms, e.g., dry mouth, sores, candida	Hopkinson and Corner (2006); Hopkinson (2007); Johnston Taylor (2016); Luchesi and Silveira (2018); Mahmoud et al. (2011); McQuestion et al. (2011); Odencrants et al. (2005); Orrevall et al. (2005); Orrevall et al. (2004); Shragge et al. (2007); Strasser et al. (2007)
Intolerance of smells	Johnston Taylor (2016); Odencrants et al. (2005); Orrevall et al. (2005); Orrevall et al. (2004); Souter (2005); Strasser et al. (2007)
Difficulties swallowing	Hopkinson and Corner (2006); Hopkinson (2007); Johnston Taylor (2016); Luchesi and Silveira (2018); McQuestion et al. (2011); Monturo and Strump (2014); Orrevall et al. (2005); Orrevall et al. (2004); Shragge et al. (2007); Strasser et al. (2007)
Coughing	Odencrants et al. (2005); Strasser et al. (2007)
Nausea, emesis	Johnston Taylor (2016); Orrevall et al. (2005); Orrevall et al. (2004); Shragge et al. (2007); Souter (2005)
Bowel symptoms as obstruction, bloating, constipation, diarrhea	Gwilliam and Bailey (2001); Orrevall et al. (2005); Orrevall et al. (2004); Souter (2005); Strasser et al. (2007)
Taste changes	Hopkinson and Corner (2006); Hopkinson (2007); Mahmoud et al. (2011); McQuestion et al. (2011); Odencrants et al. (2005); Van der Riet et al. (2006); Souter (2005); Strasser et al. (2007)
Food aversion	Hopkinson and Corner (2006); Hopkinson (2007); Johnston Taylor (2016); Mahmoud et al. (2011); McQuestion et al. (2011); Strasser et al. (2007)
Cravings	McQuestion et al. (2011); Strasser et al. (2007)
Tiredness	Odencrants et al. (2005); Van der Riet et al. (2006)
<i>Physical impediments not described in detail</i>	Chai et al. (2014); Chan and Pang (2007); Wallin et al. (2015)

metaphor for love (Johnston Taylor, 2016). Despite having problems eating, some patients continued to cook for family to express caring and love (Orrevall et al., 2005), and cooking for others was an incentive for making an effort despite limited strength (Odencrants et al., 2005). Gratefulness for help around food and eating was described (Odencrants et al., 2005; Orrevall et al., 2004), however, when eating was difficult patients felt that they disrespected the kindness of others (Amano et al., 2016; Johnston Taylor, 2016).

Not cooking nor eating together as before was experienced as a social loss and a disconnect (Gwilliam & Bailey, 2001; McQuestion et al., 2011; Orrevall et al., 2005); however, eating together with others could also add to the stress (Keller et al., 2010; Odencrants

et al., 2005; Orrevall et al., 2004). Social relationships were changed, and food became a cause of tension, when informal caregivers tried to compel participants to eat (Hopkinson, 2007; Hopkinson & Corner, 2006; Johnston Taylor, 2016; Keller et al., 2010; McQuestion et al., 2011). Patients expressed being angry and upset (McQuestion et al., 2011), embarrassed (Souter, 2005), frustrated (Keller et al., 2010) or feeling observed when eating in social situations (Odencrants et al., 2005). Sometimes avoidance of social gatherings around meals was preferred (McQuestion et al., 2011; Odencrants et al., 2005; Reid et al., 2009; Souter, 2005), even though avoidance was experienced as a social loss (McQuestion et al., 2011; Wallin et al., 2015).

Food-related memories were a reminder of the people they used to be (Monturo & Strump, 2014). Role changes and being dependent, when unable to shop or prepare food, were experienced (Odencrants et al., 2005; Orrevall et al., 2004). Not participating in food-related activities made patients feel inadequate and displaced within the family (Gwilliam & Bailey, 2001), as well as feeling different or odd in social gatherings (Hopkinson, 2007; Wallin et al., 2015).

5 | DISCUSSION

This review focused on experiences of food and mealtimes from the perspective of patients with chronic life-limiting disease, such as neurological diseases or cancer, near the end of life. The results revealed existential distress, and social gatherings around mealtimes instigated detachment, and familiar routines and considerations based on love and care for others were disrupted. Everyday life included physical, psychological, social and existential challenges, irrespective of medical diagnoses and care settings.

Neither life nor health is static, rather an ongoing process, and from the lens of caring sciences, health processes for individuals encompass well-being and suffering (Arman et al., 2015; Eriksson, 2007). Since people are unique and inviolable, health originates in individuals' own wishes and processes. The results revealed a variation of experiences, which provide an overview and foci of care interventions for registered nurses. Patients' care needs are intertwined with experiences of suffering and well-being, in a constant fluid movement, and thus, care needs are more than separate needs as they constitute parts of a whole (Eriksson, 2007). According to the ontological perspective of caring sciences, health is understood as 'doing', 'being' and 'becoming', a movement towards deeper wholeness (Eriksson, 2007; Lindström et al., 2014). This study showed that patients strived to understand the cause of their eating deficiencies and that signs of hampered eating were interpreted as both natural and as something to confront. Dialogue is emphasised as a useful strategy for exploring patients' true care needs (Arman et al., 2015), and dialogue in itself can be a nursing intervention. Building on basic assumptions that both health, suffering and well-being are natural parts of living and that suffering and health are not mutually exclusive (Eriksson, 2007), the possibility to share experiences about hampered eating ('health by doing'), with someone can create a sense of connectedness and alleviate suffering that is perceived as helpful in itself, thus, ultimately finding interim ways of being together around mealtime ('being health') and adapting with the illness trajectory. Suffering can be integrated with well-being, as in our results pertaining to letting nature run its course and finding ways to endure and to experience health in extenuating circumstances ('health by becoming'). Communication skills are crucial for registered nurses to allow sensitivity and accommodation of patients' evolving needs throughout their health journeys; health as *doing*, *being* and *becoming*, perhaps especially challenging in circumstances of chronic life-limiting disease.

In this review, food and eating were interconnected with love and care. Hamburg et al. (2014) described similar results and that supporting food intake demonstrates love, for both the provider and the receiver. These results coincide with stressful situations around food in families with an individual struggling with eating deficiencies (Barrado-Martín et al., 2020; Lize et al., 2020). We suggest including social and existential dimensions when communicating about food and mealtimes. In our results, mealtimes as triggers of memories, both of one's identity and of social structures, contributed to experiences of distress. Registered nurses have a key role in caring for patients with chronic life-limiting disease, and integration of a 'palliative approach' to reduce suffering has been suggested (Reimer-Kirkham et al., 2016). The International Council for Nurses (2012) emphasise that nursing encompasses care of patients alongside with health promotion. Integrating a palliative approach in care contexts outside specialist palliative care may be beneficial as experiences of food and meals for patients with chronic life-limiting disease affected multiple dimensions (Amano et al., 2019). Principles of palliative care, focusing on patients' well-being instead of the disease, are crucial (Reimer-Kirkham et al., 2016). Hopkinson et al. (2010) highlighted that eating-related distress could be met by recognising patients' strengths and strategies as a starting point, instead of focusing on problem-identifying and prescribing solutions. Ultimately, letting the experiences of each unique patient guide healthcare interventions has potential for meeting needs. Avoiding paternalistic approaches are imperative (Lepore et al., 2018), to meet physical, psychological, social and existential challenges around food and meals for patients with chronic life-limiting disease.

5.1 | Limitations

This review comprehensively explored experiences of food and meals as perceived by patients with chronic life-limiting disease. A mixed-method systematic review with integrated design is a broad research review, enabling inclusion of studies with different methods. The research group adhered to existing guidelines for undertaking a systematic mixed-method review with integrated design (CASP, 2021; Flemming et al., 2018; Noyes et al., 2019), striving for a systematic and transparent approach to enable readers to assess study credibility and trustworthiness (Hopia et al., 2016). A strength of this systematic review was following a structured research protocol to reduce bias throughout the research process. The research approach comprised being informed by two separate guidelines for reporting qualitative (ENTREQ) (Tong et al., 2012) and quantitative (PRISMA) (Moher et al., 2009) research, supported by methodological guidance described by Noyes et al. (2019). Consolidated reporting guidelines for mixed-method systematic reviews would be helpful for stringency throughout the research process. Quality of included articles varied, as displayed in the supplemental files. Nonetheless, we have assessed and reported limitations of individual studies in a transparent way, to allow readers to independently appraise and evaluate findings as well as possible implications.

Gathering findings from studies, both qualitative and quantitative, always involves a degree of subjectivity and interpretation. In our study, at least two authors conducted each step independently. In the inclusion and extraction processes, there was movement between blinding and transparency to ensure quality. All steps comprised at least two researchers, and conflicts were discussed for negotiated consensus (McGreevy et al., 2013). Included articles are from developed countries; thus, the results may not be transferable to other regions.

Finding articles focusing on the perspectives of food and mealtimes when living with chronic life-limiting disease was challenging. Our effort was on finding articles beyond the field of palliative care and cancer; however, most of the articles included cancer diagnoses and palliative care contexts. This may be a result in itself; this is where the majority of research in the area of food and mealtimes is conducted. Future research should target areas outside oncology care.

6 | CONCLUSION

For patients with chronic life-limiting disease, food entailed potential to remain healthy, to improve well-being and to prolong life. At the same time, having eating difficulties was experienced as fundamentally affecting social life and interactions, and the joy around food and meals was lost. Food and eating affected relationships and stirred emotions. Forcing oneself to eat was experienced as something done to please others and to survive. When caring for patients with chronic life-limiting disease, registered nurses can be instrumental in leading care processes and healthcare interventions focusing on well-being and care satisfaction, embracing holistic perspectives of multiple dimensions of human existence. Awareness and knowledge about how food and meals relate to social, psychological and existential dimensions may guide registered nurses in shaping interventions to promote well-being for patients with chronic life-limiting disease. We recommend further research outside oncology care, along with developing clinical guidelines regarding issues of food and mealtimes at the end-of-life. The present mixed-method systematic review contributes to the evidence base of patients' needs concerning food and meals at the end-of-life. This knowledge assists healthcare professionals' understanding of patients' healthcare needs and highlights foci for intervention studies regarding food and meals.

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CONFLICT OF INTEREST

No conflicts of interest have been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors designed the study, contributed to the protocol and designed the search strategy. Searches were performed by VW; VW,

AK and EM performed screening and data extraction. All authors contributed to analyses and forming themes. The manuscript was drafted by VW and AK. All authors read, contributed and approved the final manuscript.

PEER REVIEW

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

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

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