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The experiences of family members witnessing the diminishing drinking of a dying relative: An adapted meta-narrative literature review

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Abstract

Background: Addressing the concerns of family members is an important aspect of palliative and end of life care. One aspect that commonly causes family caregivers concern is the decline of patients' oral fluid intake in the last few days of life.

Aim: To map the narratives in which family members' experiences of witnessing the diminishing drinking of a dying relative have been researched, review the findings within each narrative and consider directions for future research.

Design: An adapted meta-narrative review approach.

Data Sources: The Cumulative Index of Nursing and Applied Health Literature (CINAHL), Medline, PsycINFO, Psycharticles and Scopus databases were searched for relevant research published between January 1982 and December 2017. Quality was assessed using the Quality Assessment and Review Instrument.

Results: Twenty-two papers met the inclusion criteria. No study focused specifically on the experiences of family members when witnessing the diminishing drinking of dying relatives. However, research about diminishing drinking was identified within studies broadly focusing on cancer cachexia, clinical decision-making about hydration and/or nutrition and support in a hospice context. The research indicates that family members' experiences of diminishing drinking vary with their views about the significance of drinking, dying well and their expectations of themselves and healthcare professionals.

Conclusion: While some understanding of the topic can be inferred from research in related areas, there is a paucity of information specifically about family members' experiences when witnessing the diminishing drinking of a dying relative.

Keywords

Palliative care; terminal care; family; caregiver; drinking; dehydration; hydration; meta-narrative review

Key statements

What is already known about the topic?

- Family members are concerned about diminishing drinking and the clinical management of dehydration at the end of life.
- Both family members and professionals regard issues surrounding hydration at the end of life as a research priority.

What this paper adds

- A systematic review of current research knowledge of family members' experiences of witnessing the diminishing drinking of dying patients.
- These experiences have not been researched explicitly but have been considered within wider research narratives.
- The experiences of family members vary with their views about the significance of drinking, patient characteristics, the care environment and their expectations of care by themselves and professionals.

Implications for practice, theory or policy

- A broad range of approaches, including tailored communication, is required to support family members.
- Further research that specifically explores the experiences of family members witnessing diminishing drinking of dying patients is required to develop supportive interventions.

Introduction

Rationale for review

As patients with advanced, life-limiting conditions enter the last few days of their lives, their everyday drinking of fluids normally diminishes and may eventually cease.^{1, 2} Family members may be concerned by this process, the dehydration it causes and the clinical management of it. For example, in the United Kingdom, most of the concerns reported to the Independent Review of the Liverpool Care Pathway for the dying patient by bereaved family members related to hydration and nutrition, and the review found that it was the diminishment and cessation of drinking, rather than lack of nutrition, which concerned family members most.³ Issues regarding hydration were also recently identified as a research priority in end of life care by both carers and professionals.⁴ Support for families is integral to palliative care;⁵ however, as yet no systematic review of family members' experiences of diminishing drinking at the end of life has been undertaken.

Objectives and focus of review

This adapted meta-narrative review aims to identify, map and analyse the existing narratives about the experiences of family members witnessing diminishing drinking of dying relatives. It will appraise the limitations of existing knowledge and identify future research to enhance the support of family members.

The review question is:

How have the experiences of family members witnessing the diminishing drinking of a dying relative been researched and what is known about these experiences?

For the purpose of this review, 'family members' are defined as those people who are significant to patients at the end of their lives, whether related to them or not. The term 'relative' refers to the dying relative of the family member. 'Witnessing' is defined as being aware of their relatives' diminishing drinking. 'Dying' and the related expressions 'end of life' and 'last few days of life' are defined as the time when death is imminent, usually a few days.

Methods

Rationale for a meta-narrative review approach

Meta-narrative review, developed by Greenhalgh et al.,⁶ was selected as the most appropriate method. It draws on Thomas Kuhn's concept of scientific 'paradigms' as frameworks of agreed concepts and methodologies within which scientific endeavour proliferates. Kuhn argues that, as scientific knowledge develops, it will inevitably stretch the integrity of the paradigm in which it was formed to breaking point^{7, 8} so eventually a new paradigm will be needed.⁹ Meta-narrative review seeks to identify, map and analyse the paradigms or narratives in which research has been developed and to consider their usefulness.

Meta-narrative review is most appropriate because it takes a historical and plural approach to knowledge development. It seeks to integrate and learn from diverse, heterogeneous evidence developed over time.⁸ Initial scoping of the topic found research dating from 1982, which was heterogeneous in two regards: it was conceptualised within the research literature as part of broad concepts such as cancer cachexia rather than a discrete concept in its own right, and was undertaken using a range of research methodologies. Meta-narrative review is also appropriate because it intends to open up new possibilities for understanding rather than answer a question definitively⁶ and this is congruent with the stated aims of this review with regard to identifying future research.

Changes to the meta-narrative review process

The meta-narrative review process was adapted to take account of the resource constraints of having a single reviewer. Normally, experts, stakeholders and peers collaborate to map the existing narratives within the field and might act as a consultative group throughout the review process.¹⁰ However, a single researcher, consulting with two experts acting in a supervisory capacity, undertook this review. Furthermore, non-research papers such as influential discursive literature are usually included in meta-narrative reviews.¹⁰

Unfortunately, this was not feasible within the resources available so the scope of this review was limited to research only. Despite these limitations, the fundamental focus on how an issue has been researched and understood within different narrative traditions over time⁶ has remained intact.

Scoping the literature

Initially, the research traditions or narratives within which family members' experiences of diminishing drinking has been studied were by scoped using the pre-existing knowledge of the reviewer and by browsing literature reviews and seminal texts. The following three narratives were identified:

Narrative A: The experiences of family members witnessing the diminishing drinking of a dying relative.

Narrative B: The experiences of family members regarding intervention for diminishing drinking and its consequences.

Narrative C: The professional support for family members of dying people whose drinking is diminishing.

Searching process

The Cumulative Index to Nursing and Allied Health (CINAHL), Medline, PsycINFO, Psycharticles, Scopus, EPPI-centre Database of Systematic Reviews and Cochrane Collaborative Database of Systematic Reviews were selected as suitable for searching on the advice of a subject specialist librarian and searched from January 1982 to December 2017.

The researcher and the specialist librarian identified three key search areas using the acronym ProPheT, which denotes problem (Pro), phenomenon (Phe) and time (T). They listed free-text search terms in each area. Synonyms and additional relevant search terms were found from keywords in retrieved papers. The free-text terms and synonyms were truncated where possible and then searched in combination using the Boolean term OR as shown in Table 1 below.

Table 1. Free-text search terms of each question area.

Element of ProPheT	Key area of the review question	Free-text search terms used
Problem	Diminishing drinking	drink* OR hydrat* OR dehydrate*OR 'oral intake' NOT sedat* NOT alcohol
Phenomenon	The experiences of family members	family OR families OR relative OR relatives* OR carer* OR caregiver*
Time	When a relative is dying	dying OR 'end of life' OR palliat* OR terminal* OR hospic* NOT 'vegetative state'

Titles and abstracts of the literature were searched for the identified free-text search term. The literature retrieved in each of the three areas was then combined using the Boolean term AND to identify literature considering all three areas. Literature containing the free-text terms 'sedat*' AND 'vegetative state' in the title or abstract was excluded since it relates to the management of diminishing drinking caused by sedation and/or by persistent vegetative state rather than through the process of dying per se. Similarly, literature containing the free-text term 'alcohol' was excluded as it relates to a different meaning of the word 'drinking' from that in this review. Limiters were applied to reflect the inclusion and exclusion criteria.

Wherever possible, free-text terms were mapped to the relevant subject headings or MeSH terms of each database. Subject heading and MeSH terms were exploded to retrieve all relevant titles from the subject tree. Titles, abstracts and keywords of papers were searched for subject headings and MeSH terms using Boolean logic which mirrored the free-text searches.

Database searching alone is not considered optimal for meta-narrative reviews because of their broad, complex scope and their focus on understanding the paradigms or contexts in which research has been undertaken.¹¹ Tracking the citations of seminal papers is recommended in order to find additional papers within the paradigms.¹¹ The literature reviews identified through the database searches were chosen for tracking because they articulate the established knowledge in their chosen area. The prospective citations and references of the literature reviews were tracked wherever possible.

Selection and appraisal of documents

The scope of this meta-narrative review was broad in order to capture the multiple sources of knowledge relevant to the research question.

The scope included studies which:

- considered any aspect of family members' experiences of diminishing drinking in the last few days of life as a substantial theme;
- conceptualised and defined diminishing drinking in any way;
- were published between January 1982 and December 2017 (these dates were set to include the earliest discussion found within the field as undertaken in 1983¹² and to continue until the date the review was undertaken);
- were from any ontological or epistemological perspective;
- generated qualitative and/or quantitative data; and
- were available in English but conducted anywhere within the world.

The scope excluded studies which:

- excluded consideration of the last few days of life;
- were position papers, literature reviews or policy guidelines;
- considered family members' experiences of diminishing drinking only as a finding; or
- considered voluntary refusal of drinking.

Analysis and synthesis processes

The papers that met the inclusion criteria were analysed and synthesised using the process described below.

Quality appraisal

The quality of the papers was judged using the Quality Assessment and Review Instrument (QARI) critical appraisal tool.¹³ Although QARI has been designed for qualitative research appraisal, the researcher judged its prompts flexible enough to facilitate appraisal across both qualitative and quantitative data. Poor quality papers were not excluded but the appraisals were used to inform the synthesis.¹¹

Data extraction

Relevant data were extracted from the retrieved papers using a modified version of the British Psychological Society data extraction tool.¹⁴ The modifications were made to categorise the research into the three narratives identified in the scoping phase; place the data in chronological order; and highlight significant aspects of how the narrative has been conceptualised and studied, such as whether diminishing drinking was considered separately from diminishing oral intake of any kind.

The analysis and synthesis

The studies researched within each narrative were read in detail and the following elements analysed:

- the chronological, conceptual and methodological development of each narrative;
- the knowledge generated within each narrative; and
- the limitations of each narrative.

The individual narratives were compared and contrasted. The limitations of the existing knowledge as a whole were appraised, and the potential use of the knowledge for healthcare professionals supporting family members was considered. The review has been reported in accordance with the RAMESES publication standards for meta-narrative reviews.

Results

The results of the search are shown in Figure 1 below.

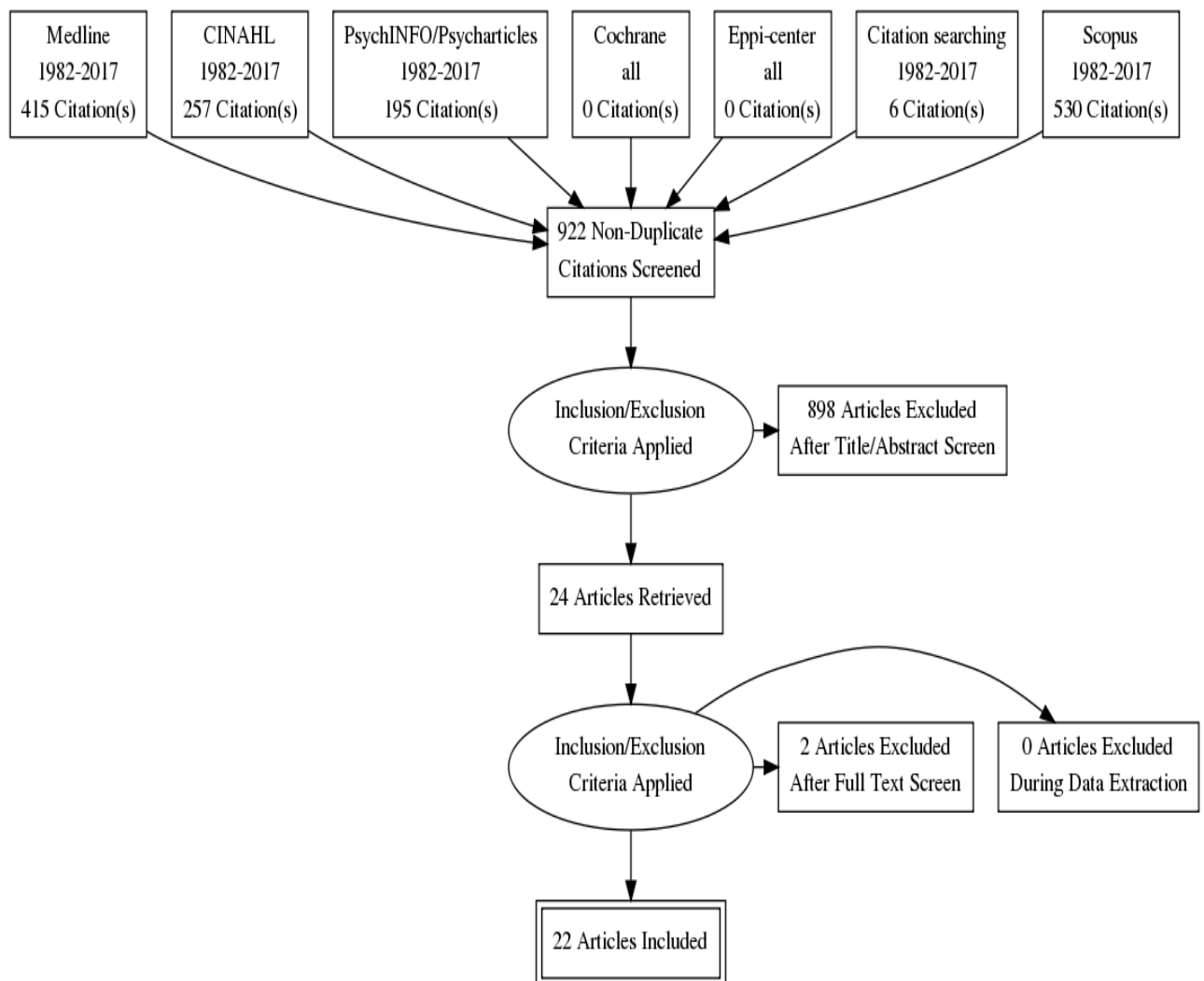


Figure 1. PRISMA chart.

Document characteristics

Twenty-two papers met the inclusion criteria. Two other papers were considered but were excluded after full text screening because they did not include consideration of diminishing drinking at the end of life. Five included papers were concerned with the experiences of family members witnessing the diminishing drinking of their dying relatives (narrative A).¹⁵⁻¹⁹ Eight were concerned with the experiences, opinions or views of family members regarding intervention given to their dying relatives to address diminishing drinking (narrative B family).²⁰⁻²⁷ Two of these papers had collected data from both family members and professionals.^{20, 24} Eight papers reported research that had collected data from doctors, nurses or both regarding the concerns of family members about intervention for diminishing

drinking at the end of life (narrative B, professionals).²⁸⁻³⁵ A single paper focused on supportive care (narrative C).³⁶

Main findings

The significant identifying features of research in narratives A, B and C are presented in Table 2.

Table 2. Significant identifying features of data in each narrative.

(Acronym: Clinically assisted hydration (CAH))

Author(s) and Date	Narrative	Separate to eating?	Separate to Clinically Assisted Hydration (CAH) or Artificial Nutrition and Hydration?	The reported point of dying trajectory on which the research was focused
Meares, 1997 ¹⁵	A	No	Yes	Bereaved family members reflecting on period in which a dying patient's oral intake decreased 'below levels required to sustain life'.
McClement, Degner and Harlos, 2004 ¹⁷	A	No	Yes	Included family members of patients within 2-6 weeks of death at time of interview, and bereaved relatives who recalled declining oral intake.
McClement and Harlos, 2008 ¹⁸	A	No	Yes	Patients within 2-6 weeks of death at time of interview and bereaved relatives recalling declining oral intake.
Yamagishi et al., 2010 ¹⁶	A	No	Yes	Bereaved family members reflecting on experiences of cancer patient unable to eat or drink at 'end of life' (undefined).
Raijmakers et al., 2013 ¹⁹	A	No	Yes	Bereaved family members recalling their perception of food and fluid intake during last month of life.
Musgrave, Bartal and Opstad, 1996 ²⁰	B (family)	Yes	No	All family of patients with prognosis of 10 days or less.
Parkash and Burge, 1997 ²¹	B (family)	Yes	No	When patients were unable to drink orally.
Morita et al., 1999 ²²	B (family)	Yes	No	The family members of cancer patients with a prognosis of less than 6 months and unable to maintain 'satisfactory' oral intake.

Morita et al., 2006 ²³	B (family)	No	No	Bereaved family members recalling 'end of life'. This period included death but the point when it started was not defined.
Rurup et al., 2006 ²⁴	B (family)	Yes	No	Family members of advanced dementia patients assessed as unable to drink sufficient fluids to sustain life.
Cohen et al., 2012 ²⁵	B (family)	Yes	No	Family members of advanced cancer patients receiving hospice care focusing on prospective views of CAH in last weeks of life (undefined).
Torres-Vigil et al., 2012 ²⁷	B (family)	Yes	No	Family members of advanced cancer patients receiving hospice care in last weeks of life (undefined).
Bükki et al., 2014 ²⁶	B (family)	No	No	Family members of symptomatic advanced cancer patients focusing on prospective views and preferences at end of life (undefined).
Chambaere et al., 2014 ²⁸	B (professionals)	No	No	Retrospective consideration of decisions made at end of life (undefined).
Critchlow and Bauer-Wu, 2002 ³⁴	B (professionals)	Yes	No	Retrospective consideration of decisions when a long-term care patient was dying (undefined).
Ke et al., 2008 ²⁹	B (professionals)	No	No	Consideration of decisions that might be made about care of cancer patients with prognosis less than one month.
van der Riet et al., 2008 ³¹	B (professionals)	No	No	When terminally ill patients were unable to eat and drink.
van der Riet et al. 2009 ³⁰	B (professionals)	No	No	Consideration of care at 'end of life' (undefined).
Good et al., 2011 ³⁵	B (professionals)	Yes	No	Doctors reflecting on dying patients (undefined).
Higgins et al., 2014 ³²	B (professionals)	No	No	Nurses' reflections about patients who were imminently dying.
Cabañero-Martínez et al., 2016 ³³	B (professionals)	Yes	No	Palliative care professionals' perceptions of hydration at end of life care (undefined).
Clark et al., 2017 ³⁶	C	No	Yes	Towards end of life (undefined).

The key descriptive data extracted from research in narratives A, B and C are presented in table form in supplementary information 1, 2 and 3 respectively. These are available within supporting documents. The findings within each narrative are discussed as follows.

Narrative A: The experiences of family members witnessing the diminishing drinking of a dying relative

Four studies, reported in five papers, consider the self-expressed experiences of family members witnessing the diminishing drinking of dying patients as part of reducing oral intake in patients with cancer.¹⁵⁻¹⁹ Two papers report different findings from the same study.^{17,18} The studies are from different countries in North America,^{15, 17, 18} Asia¹⁶ and Australia.¹⁹ Three studies used different qualitative designs to generate in-depth data in specialist palliative care settings^{15, 17-19} and one analysed secondary data from a nationwide cross-sectional survey of the bereaved family members of cancer patients to quantify their distress and to shape care provision.¹⁶

Studies within this narrative are largely positioned within wider research about cancer cachexia-anorexia, although one study included a small number of patients with non-malignant disease.¹⁹

The findings of the studies demonstrate the significance of diminishing drinking to family members.^{16,19} In Japan, most (80%) bereaved family members of cancer patients had witnessed dying relatives becoming unable to eat and drink and almost three quarters of these (71%) had been distressed by it.¹⁶ The studies draw different conclusions about the source of this distress. Yamagishi et al. report family members felt helplessness and guilt because they believed their relative was distressed by dehydration¹⁶. The authors of the qualitative studies report that the responses of family members varied. Some family members accepted the reducing intake of food and drink as a normal part of the dying process^{17,19} but others viewed it as part of a battle against the disease.^{15,18,19} The response of family members corresponded with their feelings about the decline and with their expectations of themselves as carers. Those who were accepting of the diminishing drinking found ways of showing care that did not involve hydration, such as protecting their relative from pressure to drink. However, others persevered in encouraging their relative to eat and drink and wanted healthcare professionals to do likewise.

The studies in this narrative discuss the potential of communication strategies to support family members and make recommendations for practice. Recommendations include

anticipating the concerns of family members,^{15,17} giving guidance and information prior to family members becoming concerned,^{15,16} initiating discussions,¹⁵ assessing expectations, considering a range of different supportive approaches¹⁵⁻¹⁸ and encouraging family involvement with practical care.^{16,18} However, these strategies may not be widely employed. Raijmakers found that relatives of patients referred to a specialist palliative care service in New Zealand recalled few detailed discussions about diminishing nourishment with professionals and those that occurred focused on information rather than on assessment or wider support.¹⁹

In summary, knowledge generated within this narrative illuminates a plethora of emotions and responses by family members to the diminishing drinking of their dying relative and recommends a wide range of communication strategies to support them.

The limitations of this narrative stem from its focus on the reduced oral intake of predominantly cancer patients. Findings relating to the experiences of family members concerning a dying relative's diminishing drinking cannot be reliably disaggregated from those relating to reducing oral intake in palliative care patients in general. This limits the utility of this narrative in understanding family members' experiences of diminishing drinking at the end of life more widely.

Narrative B: The experiences of family members regarding intervention for diminishing drinking and its consequences

The literature review found 16 studies about the experiences of family members regarding interventions given to their dying relatives to address diminishing drinking and its consequences.²⁰⁻³⁵ All 16 studies focused on the medical intervention of clinically assisted hydration and/or nutrition. The studies did not explore any other supportive interventions, such as mouth care or sipping small amounts of fluid in depth, although these emerged within the findings of one study.³¹

Eight studies presented data generated directly from family members.²⁰⁻²⁷ Two of these also collected data from professionals^{20,24} and four also collected data from patients.^{20,22,25,26} With the exception of Morita et al.²³ whose participants were bereaved family members,

most studies included participants whose dying relatives' life expectancy far exceeded a few days. Methodologically, they include both qualitative^{20,21,25}, and quantitative^{22,23,25-27} designs. They were undertaken within North America^{21,25,27,34} and Europe.^{20,24,26,28}

Studies in this narrative can be largely positioned within wider research exploring the views of family members about clinically assisted hydration at the end of life. Indeed two pieces of research are sub-studies of randomised controlled trials about the efficacy of hydration.^{25,27} The research reflects the specific legal and cultural context of decision-making about clinically assisted hydration at the end of life within the country in which the research was undertaken. For example, Morita et al. explored participants' understanding of legal options regarding end of life care in Japan.²³

The findings within this narrative demonstrate that family members hold a range of views about clinically assisted hydration stemming from their underpinning beliefs about the effects of hydration and dehydration, expectations of themselves as carers and expectations of professionals. Most family members had positive views of clinically assisted hydration and one study found family members to be more positive towards it than dying patients.²⁶ Reasons for these positive views included beliefs that it can reduce the symptom burden of dying patients,^{21-23,25,26} support food intake,²⁰ increase energy levels²⁵ and extend life.²⁵ However, a few family members viewed it negatively considering that it might extend dying patients' suffering^{21,22,25} and dependency²² by prolonging their lives.

There is some evidence that attitudes towards clinically assisted hydration are rooted in cultural and religious beliefs. Torres-Virgil et al. found family members from ethnic minority populations of 'Latinos' and 'Asians' in Texas were more likely to view fluid as having a nutritional role than European Americans.²⁷ As a result, they may perceive fluid provision to be a basic human need and clinical assistance to receive fluids as fundamental to care. Similarly, in Japan Morita et al. found that half of family members of people in palliative care units held the view that clinically assisted hydration was fundamental to care²² so its non-provision could be viewed as inhumane. Clinically assisted hydration is similarly imperative within cultures that emphasise the preservation of life at all costs. This view is dominant in

the Jewish culture²⁰ and was also identified in some participants within a 'white middle-class' Canadian culture.²¹

The research in Europe suggests that family members' attitudes to clinically assisted hydration are also influenced by the age and diagnosis of the dying person and their own expectations of care.^{24,26} The reasons for the influence of age and diagnosis were not identified in the studies but may reflect societal notions of age appropriate death. For example, Rurup et al. found that most family members in the Netherlands were supportive of assisted hydration and nutrition being withheld from their older relatives with advanced dementia, particularly if they had increased pain and discomfort at the time.²⁴ In these cases, most family members perceived not drinking as the patients' autonomous choice, which should be respected; however, those with religious beliefs were less likely to favour autonomous decision-making.²⁴ Family members' expectations of themselves and of professionals were also important in their attitudes. Some family members perceived that clinically assisted hydration was a sign of caring but others did not, particularly if the withholding of fluids was medically justified.²¹

Eight papers reported on research that had collected data from doctors, nurses or a combination of both regarding the concerns of family members.²⁸⁻³⁵ These were also methodically and geographically diverse and with qualitative and quantitative designs from across North America,³⁴ Europe,^{28,33} Australasia³⁰⁻³⁵ and Asia.²⁹ This narrative of research with professionals about family members shows a shift in focus over time. It starts with the exploration of professional attitudes towards the clinical state of terminal dehydration,³⁴ shifts to the exploration of attitudes towards clinically assisted hydration^{29,32,35} and later, considers its withholding.²⁸

In contrast to studies directly reporting family members' predominately positive views of intervention, most studies of professionals found they regarded clinically assisted hydration as having a detrimental effect on the comfort of dying patients due to the potential for fluid overload and the impact of giving sets.²⁹⁻³¹ However, this varied with the time of the research, with more professionals being supportive of it in earlier studies than in later ones.^{20,34}

A cluster of Australian studies has explored the contrasts between family members' and professionals' views of clinically assisted hydration in some depth^{30-32,35} and some used the term 'contesting discourses' to describe the different stances of family members and professionals.^{30,31} Professionals postulate that dehydration decreases the suffering of patients but also recognise that family members may be distressed if clinical nutrition and hydration is not provided. These contesting discourses reflect wider struggles concerning the optimal care of dying patients and differences in the foci of acute care and palliative care settings.^{30-32,35}

Tensions about the management of dehydration also exist between different professionals.^{32,35} Good et al. found that doctors working in acute care settings had conflicting and confusing views about the effect of being dehydrated, with some believing it to be uncomfortable while others believing it was not.³⁵ Some doctors associated clinically assisted hydration with cure, hope, life and caring and associated its discontinuation or withholding with hopelessness and abandonment. They recognised that their associations were culturally rooted in both themselves and the family members in their care. Two papers suggested that the tensions between different discourses were exacerbated by uncertainty about the dying trajectory.^{32,35}

Several studies in this narrative discuss the potential of communication to support families concerned with clinically assisted hydration.^{21,26-28,31,35} Two studies found that relatives preferred verbal communication with doctors to written guidelines,^{21,26} and one found a correlation between family members' involvement in decision-making and satisfaction with communication about clinically assisted hydration.²⁶ However, it would appear that such communication can be limited in practice since Good et al. found doctors delayed or avoided discussing decision-making about clinically assisted hydration with family members in order to protect themselves from the difficult emotions associated with it.³⁵

In summary, knowledge generated about intervention for diminishing drinking and its consequences suggests that family members and professionals have a range of views about the effects of dehydration and potential benefits of clinically assisted hydration. Their views

reflect wider approaches to the care of dying people within the cultural contexts of individual studies. The views of family members and professionals are often culturally determined and can conflict.

There are limitations to the knowledge within this narrative. While direct perspectives of family members are present, much of the research in this narrative has come vicariously from healthcare professionals. While the validity of professionals' knowledge of family members' perspectives can be questioned, the research shows some commensurability in that professionals are aware of the divergence between the views of family members and their own. Furthermore, the utility of this is strongly compromised by its focus on decision-making about clinically assisted hydration AH and nutrition for dying patient with limited consideration of any more comfort-orientated measures such as mouth care or sipping low volumes of fluids.

Narrative C: Professional support for family members of patients with diminishing drinking

The sole study within this narrative aimed to consider how healthcare professionals might support family members and address their needs.³⁶ This was a qualitative thematic analysis of interviews about declining oral intake with 10 experienced palliative care specialists working in a hospice. It describes professional support for family members delivered through communication between healthcare professionals, patients and family members working within specialist palliative care.

The findings contrast with those of the earlier study by Critchlow and Bauer-Wu³⁴ within narrative B, which was undertaken in a hospital setting and focused on nurses' perceptions of dehydration. Critchlow and Bauer-Wu found that nurses working in long-term care lacked the knowledge and skills to support family members. This contrast may reflect differences within the two care groups³⁴ and raises questions about how the supportive strategies might be used beyond specialist palliative care.

Research exploring professional support for family members of patients with diminishing drinking is an emerging and new narrative, thus far limited to a single study of specialist

practice. This was undertaken as part of research on diminishing oral intake, including both eating and drinking.

Narratives A, B, and C compared

The tradition, findings and limitations of each of the three narratives informing knowledge of the experiences of family members witnessing the diminishing drinking of a dying relative are summarised and presented alongside each other in Table 3. The commonalities and differences between them are discussed below.

Table 3. The tradition, key findings and limitations of each narrative

Acronym: Clinically assisted hydration (CAH)

Narrative	Key findings	Narrative tradition	Key limitations
Narrative A The experiences of family members witnessing the diminishing drinking of a dying relative	Most family members who experience diminishing drinking are distressed by it. They may have feelings of helplessness, guilt and acceptance and may interpret diminishing drinking as a battle with disease. They respond in a range of ways from protecting patients from pressure to drink to exerting pressure on them to drink.	Narrative from cancer cachexia.	Knowledge about diminishing drinking cannot be disaggregated from diminishing eating.
Narrative B The experiences of family members regarding intervention for diminishing drinking and its consequences (Family members)	Views of family members and professionals concerning best management of diminishing drinking and subsequent dehydration may conflict. Attitudes towards clinically assisted hydration (CAH) are rooted in diverging cultural, philosophical and religious values and beliefs.	From research concerned with decision-making regarding CAH and nutrition of diminishing drinking.	Studies of family members' experiences of intervention have exclusively focused on CAH and nutrition for dehydration. Much of the in-depth research has been undertaken in oncology and specialist palliative care settings: it may not transfer to more general contexts.
Narrative B	The research shows a chronological shift of	From research	As above but in addition, the knowledge has

<p>The experiences of family members regarding intervention for diminishing drinking and its consequences (Professionals)</p>	<p>professional concern from the clinical state of terminal dehydration to attitudes towards CAH and later, consideration of its withholding. Professionals consider that dehydration decreases patient suffering and CAH has a detrimental effect but also recognise that family members are distressed at the non-provision of CAH.</p>	<p>concerned with decision-making around CAH and nutrition for diminishing drinking and/or resulting dehydration.</p>	<p>been gained through professionals. The research reflects the specific legal and cultural context of decision-making about CAH at the end of life within the country in which the research has been undertaken and may not be generalisable beyond this.</p>
<p>Narrative C Professional support for family members of patients with diminishing drinking</p>	<p>Palliative care professionals view declining intake as part of the dying process. They recognise significance of this change to patients and relatives and focus on support, enjoyment and safety. Communication with relatives is important to professionals.</p>	<p>Emerging narrative about supporting family members.</p>	<p>The single study was undertaken with specialist palliative care professionals. Its findings may not be applicable to other contexts. Findings about diminishing drinking cannot be disaggregated from diminishing oral intake.</p>

Diminishing drinking has been researched from different perspectives which reflect the many ways it impacts palliative care endeavour. However, the findings of the three narratives are interrelated and augment each other. Arguably, the findings within narrative A are most directly relevant to the research question since they explore relatives' experiences, albeit of relatives dying from cancer; however, much can also be inferred from family members' beliefs about dehydration at the end of life from narrative B, and narrative C points to potential areas for helpful interventions.

Discussion

Summary of main findings

All three narratives point to the significance of diminishing drinking for family members and the challenges for professionals seeking to support them. Family members usually find the diminishing drinking of dying patients distressing.^{16,19} Their experiences vary with their diverging cultural, religious and philosophical values and their beliefs. The experiences of family members are shaped by notions of the significance of fluids and drinking to life, what constitutes dying well and the concomitant nature of caring by both family members and professionals. These values and beliefs shape the experiences of both family members and professionals. They also shape the approach professionals take to caring for dying patients with diminishing drinking and to supporting their family members.

Discussion of communication strategies that may support family members is common to all narratives and there is some evidence that family members value consultation with healthcare professionals. Many studies recommend that professionals enhance their communication about clinically assisted hydration with family members.^{21,23,26} It would appear that professionals are well aware that this is a challenging area and are likely to find it useful to have more knowledge of family members' experiences. Although research into supportive intervention is emerging, the single study discussed here was undertaken in a specialist palliative care settings so may not easily transfer to more general care contexts where uncertainty and conflicting demands are heightened.³⁷

Strengths and limitations of the review

The strength of this review methodology lies in the capability of meta-narrative review to illuminate the strengths and weaknesses in diverse knowledge. However, the adaptations to the process used here to meet the resource constraints have limited the scope to empirical research only. The inclusion of discursive and policy literature may have provided further insight regarding how the experiences of family members witnessing diminishing drinking of a dying relative have been studied. The processes of searching and reviewing were undertaken by a single reviewer and involved judgements about the search process and suitability and synthesis of the identified research. The inherent subjectivity of this process was reduced by expert supervision of the reviewer and advice from a subject specific librarian, although the use of multiple reviewers would have been preferable had resources allowed.

The knowledge the research has yielded has limitations. Family members' experiences when witnessing diminishing drinking of dying patients has been researched only as part of a wider subject. Definitions of 'end of life' have varied from consideration of the last few days of life to longer periods that are not always quantified. Many studies have researched the experiences of family members alongside those of professionals, presenting the findings collectively. This has meant that the perspective of each group is not always distinguishable.^{18,24} Research endeavour has focused predominantly on the experiences of clinically assisted hydration as an intervention addressing the diminishing drinking of dying patients and has responded to the imperative to involve family members in clinical decision-making about such interventions. Only five of the 22 included studies were concerned with understanding the experiences of family members regarding diminishing drinking and none of these papers disaggregate diminishing drinking from diminishing oral intake of any kind. The narrative exploring more support-orientated care is even smaller.

What this review adds

The findings of this meta-narrative review suggest that family members' experiences of witnessing the diminishing drinking of dying patients are varied and therefore family members will have differing needs for support from healthcare professionals. This implies that detailed assessment of the views and expectations of individual family members concerned about diminishing drinking is likely to be central to understanding their

experiences. Furthermore, supportive communication, tailored to individuals' experiences, is likely to be key to offering support.

Research that considers diminishing drinking separately from diminishing nutrition and decision-making about clinically assisted hydration and is focused on the last few days of life is needed to fully understand the experiences of family members at this time. Research is particularly required beyond a specialist palliative care setting and across diverse cultural groups. Furthermore, research is required that develops assessment and a range of therapeutic interventions that could be tailored to support individual family members appropriately.

Conclusion

This review set out to map, analyse and synthesise what is known about the experiences of family members witnessing diminishing drinking of a dying relative. These experiences have not been discretely conceptualised and explored but knowledge of these areas exists within three distinct but related narratives: family members' experiences of witnessing diminishing drinking (narrative A), their experiences regarding intervention (narrative B) and professional support for family members in this situation (narrative C). This review found that each narrative has previously been predominantly studied from a particular focus so their specific relevance to the experiences of family members witnessing the diminishing drinking of a dying relative is limited. However, it is clear that many family members are concerned and distressed about it and their experiences appear related to their personal beliefs and expectations. Taken as a whole, the research suggests communication based on individual assessment may be central to supporting families concerned about diminishing drinking. Discrete exploration of the experiences of family members witnessing diminishing drinking of a dying relative may add to current knowledge and assist in the development of assessment and supportive care strategies.

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Data management and sharing

No primary data was gathered. All of the papers included in this review are publicly available.

Declaration of conflicts of interest

The authors declare there is no conflict of interest.

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Supplemental material

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