

Key extracted data within narrative A: The experiences of family members witnessing the diminishing drinking of a dying relative

Acronyms used: Artificial nutrition and hydration (ANH). Clinically assisted hydration (CAH)

Style Definition: references: Space Before: Auto, After: Auto, Line spacing: single

Citation and location	Aim	Care setting	Participants	Methodology	Data collection	Data analysis	Key relevant findings	Relevant recommendations
Mearns 1997, USA ¹	To explore the meaning of gradual cessation of eating and drinking described by women caregivers.	Adult in-home hospice patients	12 women, bereaved family members and primary caregivers of cancer patients who had died at home	Phenomenology	Interviews	Line-by-line coding and thematic analysis	Seven key themes were identified. These were the meaning of food, caregiver as sustainer, current losses, personal responses, ceasing to be-starved to death, being bereaved—the meaning now and paradox.	Each situation needs individual assessment and clarification of the values of family members. Nurses may need to open discussions proactively and initiate them early. Further research might include consideration of ethical decision-making and diverse cultural and disease contexts.
McClement, Degner and Harlos 2004, Canada ²	To report on a sub-theme of wider research entitled 'fighting back: It's best to eat.	Specialist palliative care in-patient unit	13 adult in-patients, mostly with cancer, 13 family members, 10 bereaved family members, 11 professionals	Grounded theory	Participant observation and interviews	Grounded theory	The strategies family members used to encourage food and fluid intake were targeting the patient, food manipulation and the health care provider. Efforts to increase fluid intake comprised auditing care, blaming healthcare providers and petitioning for remedial intervention. These strategies can be emotionally difficult for professionals.	Healthcare providers need to anticipate, acknowledge and assess concerns and elicit the expectations of family members regarding care. More research needed for non-malignant groups.

McClement, and Harlos 2008, Canada ³	To report on a sub-theme of wider research entitled 'letting nature take its course: it's best not to eat'.	Specialist palliative care in-patient unit	13 in-patients, mostly with cancer, 13 family members, 10 bereaved family members, 11 professionals	Grounded theory	Participant observation and interviews	Grounded theory	The strategies family members who accepted declining intake as a 'normal' part of dying involved 'finding other ways to care'. These included participating in physical care, being present and protecting.	More research needed to test the findings, explore the issue in differing cultural contexts and investigate complexities of nutritional care.
Yamagishi et al. 2010, Japan ⁴	To clarify the levels and determinants of family members' distress about patients' cessation of oral nourishment.	Bereaved relatives of cancer patients who had died in palliative care units	452 bereaved family members	Nationwide cross-sectional survey	Piloted questionnaire	Univariate and logistic regression analysis using SPSS	71% found a relative becoming unable to drink very distressing or distressing; 60% felt a need for much, some or considerable improvement in professional practice; 69% reported helplessness and guilt; 60% had believed dehydration causes distress and 58% believed CAH is a minimum standard of care. 68% perceived professionals paid enough attention to their concerns.	Health professionals should relieve family members' helplessness and guilt, provide appropriate information, understand family concerns and provide emotional support.
Raijmakers et al. 2013, New Zealand ⁵	To understand family members' concerns about decreasing oral intake of dying patients.	Specialist palliative care service including in-patient, community and hospital team	Bereaved relatives of people who had died under specialist palliative care service	Qualitative (cit)	One-to-one semi-structure interviews	Thematic analysis	Oral intake at end of life was meaningful for relatives due to its nutritional value, enjoyment, social function, daily rhythm and expression of caring and love. It was distressing when the intake of patients declined. Some viewed decreasing intake as	Healthcare professionals should be aware of broader meaning of declining intake to family members and that many aspects of the concerns of family members about decreasing intake cannot be addressed by artificial nutrition and

							<p>a normal part of process of dying but others viewed it as the patient's choice to 'give up'. This left some family members feeling helpless and others relieved of the imperative to feed. Some felt caught in a vicious circle in which both patient and family did not want each other to worry. Participants recalled little communication with health professionals.</p>	<p>nutrition (ANH). Conversations with family members are needed.</p>
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Key extracted data within Narrative B: The experiences of family members regarding intervention for diminishing drinking and its consequences. (Family members' perspective)								
Acronyms used: Artificial nutrition and hydration (ANH). Clinically assisted hydration (CAH)								
Citation and location	Aim	Care setting	Participants	Methodology	Data collection	Data analysis	Key relevant findings	Relevant recommendations
Musgrave, Bartal and Opstad 1996, Israel ⁶	To identify the attitudes of patients, doctors, nurses and family members towards intravenous fluids in dying patients and their involvement in decision-making.	Adult oncology unit of a hospital	Convenience sample of 33 patients, 32 family members and 35 professionals	Pilot survey	Structured interviews	Responses categorised as positive, negative or neutral and statistically described	81% of families were positive towards intravenous fluids for administration of medication, and symptom control. Doctors usually initiated decisions, with 13% involving family. Findings were considered contextual to Israeli community.	Wider research needed focusing on reasons for starting fluids.

Parkash and Burge 1997, Canada ⁷	To describe the issues of family caregivers when making decisions regarding CAH for dying patients.	Home support and in-patient palliative care programme with a medical centre	7 family members: white, middle-class Canadian of British or Irish origin	Qualitative (cit)	Semi-structure interviews	Categorised under a priori themes	The factors influencing caregivers were concerns about symptom distress and positive and negative effects of rehydration on this, ethics, emotional considerations, information exchange, decision-making and culture. Caregivers' perceptions of the benefits of CAH are varied and are central to their decision-making.	More timely discussions about hydration issues to consider patients' wishes, to increase provision of information and to elicit concerns of family.
Morita, et al. 1999, Japan ⁸	To clarify patients' and family members' perceptions about CAH and identify factors in their decision-making about it.	In-patient hospice	62 hospice in-patients with cancer and 119 family members	Prospective survey	Structured interview Recording of potential contributing factors	Multiple logistic regression analysis	85% of family members believed patient could not get appropriate nutrition without CAH. 56% believed that dehydration hastens death.	More research including development of a tool to assess family members' concerns.
Morita, T. et al. 2006, Japan ⁹	'To clarify knowledge and beliefs of a general population regarding CAH (and other aspects of end of life care).	General population and palliative care units	2548 general population subjects and 513 bereaved family members of people with cancer	Survey	Piloted questionnaire	Analysis of variance	33-50% of participants believed ANH should be continued as minimum standard until death and 15%-31% agreed ANH relieved patient symptoms. No significant differences between those recruited from palliative care units and others.	Good practice in palliative care should reduce inaccurate beliefs.

Rurup et al. 2006, Netherlands ¹⁰	To investigate the attitudes of physicians, nurses and relatives towards medical decisions about patients with dementia at the end of life.	39 nursing homes	190 patients with advanced dementia, 75 physicians, 136 family members, 178 nurses	Survey	Piloted questionnaire	Descriptive statistical analysis	65% of family members agreed more than disagreed or fully agreed that decisions of patients who refuse to drink should be respected. Family members agreed with this more than nurses or physicians, particularly if they thought relative had more pain and discomfort at time of decision. Physicians are more confident of peaceful death in the absence of CAH than either nurses or families.	More open discussion of likelihood of CAH influencing peaceful death. Greater cognisance of different perspectives.
Cohen et al. 2012, USA ¹¹	To describe the meaning of CAH for terminally ill cancer patients and their caregivers.	Hospice home care	85 cancer patients, 84 family caregivers	Hermeneutic phenomenology Part of larger randomised control trial	Interviews on day 1 and then 4 of the trial	Thematic hermeneutic analysis	Two themes emerged: hope – fluids were considered essential for survival, healing and staying healthy by family members; comfort – hydration was considered important for reducing pain, enhancing medication effectiveness, nourishing body, mind and spirit, and enhancing breathing and quality of life.	Need for individualised care. Recommends future research into meaning of dehydration and parenteral hydration and also consider cultural and gender preferences for it.

Torres-Vigil et al., 2012, Texas, USA ¹²	To identify whether patients with advanced cancer and their caregivers view CAH as food or medicine.	Hospice home care	54 cancer patients, 68 family caregivers	Optional and additional qualitative part of randomised control trial	Asked a single question during interview	Chi squared analysis for correlation using SPSS	38% of participants felt fluid was more like food, 34% felt it was more like medicine and 14% as both. Ethnic minority participants more likely to view fluid as food (66%) compared with white participants (42%) but no other significant differences.	Professionals need to ask patients and caregivers about their perceptions to enhance communication and culturally appropriate care.
Bükki et al. 2014, Germany ¹³	To evaluate the needs, concerns, preferences and experiences of patients and caregivers regarding decisions about ANH at end of life.	Hospital wards providing cancer care	39 patients and 30 caregivers	Prospective, cross-sectional survey	Modified questionnaire	Descriptive statistics and correlation between ordinal variables assessed using SPSS.	Family members were more positive about assisted fluids and nutrition than patients when deciding on behalf of patients. No association with religiosity but advancing age was a factor in desire to forgo ANH in family and patients. Information did not change decision but did change confidence of relatives. Family concerned about pain, thirst and agitation. Family preferred detailed information from doctors; moderate satisfaction with current communication.	Early discussions focusing on addressing concerns. Research about cross-cultural differences. Assessments of level of knowledge of non-malignant groups.

Studies within Narrative B: The experiences of family members regarding intervention for diminishing drinking and its consequences. (Professionals' perspective)

Acronyms used: Artificial nutrition and hydration (ANH). Clinically assisted hydration (CAH)

Citation	Aim	Care setting	Participants	Methodology	Data collection	Data analysis	Key findings	Recommendations
Critchlow and Bauer, 2002, USA ¹⁴	To explore how nurses working with elderly people view terminal dehydration.	Long-term care	64 registered nurses and licensed practical nurses	Survey	Modified Questionnaire	Descriptive analysis, correlated to demographic variables	Age and experiences of nurses was associated with positive perceptions of terminal hydration; however, there was considerable diversity of views.	Recommendations for improvements in nurse education including how nurses can support decision-making with families.
Ke et al., 2008, Taiwan ¹⁵	To explore the knowledge, attitudes and behavioural intentions of nurses providing ANH for terminal cancer patients.	General hospital in Taiwan. Largely Buddhist or Taoist population	197 general and intensivist nurses	Survey	Self-developed structured questionnaire	Mean values and standard deviations calculated using SPSS	Nurses had reasonable general knowledge about palliative care but less knowledge of the effects of ANH. Difficulties of communicating about ANH with families and identified as one factor which influenced its provision.	Greater education regarding ANH is needed to support nurses to communicate effectively.
van der Riet et al. 2008, Australia ¹⁶	To explore the issue of family members' desire to feed patients despite them being unable to eat and drink with health care professionals.	2 palliative care units	15 nurses and doctors	Discourse analysis	2 focus groups and 4 interviews	Discourse analysis	Three discourses were identified: family members' distress at non-provision of CAH; professionals' belief that dehydration decreases suffering and polarisation between acute and palliative care settings.	Recommends communication, education and team approach. Staff need more information about pathophysiology of dying and clinical guidelines need to be developed.
van der Riet	To report on the	2 palliative	15 nurses and	Discourse	2 focus groups	Discourse	The main theme identified	Recommends exploration of

et al. 2009 Australia ¹⁷	discourses of palliative care nurses and doctors regarding the management of nutrition and hydration at the end of life in patients with severe brain injury and patients with cancer.	care units	4 doctors	analysis	and 4 interviews	analysis	was 'blurring boundaries'. It refers to difficulties when decisions are complex because there is a tension between actions that promote quality of life before death but may also prolong suffering. This is particularly difficult if dying is protracted and unpredictable.	mixed management approach involving both curatively and palliative focused care including consideration of ethics and impact on professionals and families.
Good et al. 2011, Australia ¹⁸	To explore the perceptions of doctors regarding CAH for dying patients.	Medicine, haematology and oncology units	8 medical officers	Qualitative descriptive study	Face-to-face interviews	Discourse analysis	Professionals experience tensions surrounding uncertainty about the transition from curative to palliative care; communication with patient and family about dying; cultural expectations; conflicting views about effects of dehydration; technology and the media; hydration as being symbolic of hope; uncertainty as a battleground; and the futility of treatment. Negotiating transition from curative to palliative care is challenging for doctors, and decision-making re CAH is reflective of this.	More education of doctors regarding the effect of dehydration. Research regarding the impact of reducing intake of dying patients is needed.

Higgins et al. 2014, Australia ¹⁹	To explore the perceptions of nurses regarding the provision and non-provision of ANH for dying patients.	Medical, oncology and haematology units	Acute care nurses	Qualitative, descriptive design	Focus groups	Thematic analysis	The main theme identified was the tensions of nursing dying patients. These tensions were nurses' limited involvement in decision-making, the balancing of treatment which could comfort or cause discomfort to patients and families, managing uncertainty and considering the potential advantages of withdrawing treatment.	Palliative approach to care needed in acute care. Exploration of ethical issues nurses face in acute hospitals. Education for nurses on the effect of hydration and dehydration.
Chambaere, et al. 2014, Belgium ²⁰	To explore decisions to withhold ANH.	All care settings	Doctors of deceased patients	Postal survey	Questionnaire	Descriptive analysis then multivariate logistic regression analysis	Family often involved in decision-making (76%). Decisions to forgo assisted fluids and nutrition vary with patient characteristics: more likely for females, when dying in care home or hospital and when suffering from cancer or neurological disease.	Call for improved advance care planning. Need for early communication to promote autonomy.
Cabañero-Martínez, et al. 2016, Spain ²¹	To explore the perceptions, attitudes and opinions of health professionals regarding subcutaneous hydration of dying patients.	Specialist palliative care units registered in one of two regions of Spain.	Doctors and nurses working in specialist palliative care	Qualitative	2 with nurse focus groups and 2 focus groups with doctors	Content analysis	The relationship of the professional team and the family was important in addressing family members' emotional and informational needs. Early intentional communication focusing on emotional and informational needs is essential.	Authors recommend impact on protocols and guidelines for health management practices. A consistent approach is needed.

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

Acronyms used: Artificial nutrition and hydration (ANH). Clinically assisted hydration (CAH)

Citation and location	Study aims	Study setting	Sample	Methodology	Data collection	Data Analysis	Findings	Recommendations
Clark et al., 2017 New Zealand ²²	To explore specialist palliative care practice regarding decreasing oral intake of dying patients.	Specialist palliative care including in-patient, community and hospital team	2 doctors, 8 nurses	Qualitative	One-to-one interviews	Thematic analysis	Three themes emerged. Palliative care professionals see declining intake as part of dying process. They recognise significance of this change and respond empathically, focusing on support, enjoyment and safety. Communication with family is important to professionals.	Future research into conversations of professionals and care recipients to develop care strategies and support communication.

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