

Medical communication and decision-making about assisted hydration in the last days of life: A qualitative study of doctors experienced with end of life care

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Arjun Kingdon , Anna Spathis, Bárbara Antunes 
and Stephen Barclay

Abstract

Background: The impact of assisted hydration on symptoms and survival at the end of life is unclear. Little is known about optimal strategies for communicating and decision-making about this ethically complex topic. Hydration near end of life is known to be an important topic for family members, but conversations about assisted hydration occur infrequently despite guidance suggesting these should occur with all dying people.

Aim: To explore the views and experiences of doctors experienced in end-of-life care regarding communicating with patients and families and making decisions about assisted hydration at the end of life.

Design: Qualitative study involving framework analysis of data from semi-structured interviews.

Setting/participants: Sixteen UK-based Geriatrics and Palliative Medicine doctors were recruited from hospitals, hospices and community services from October 2019 to October 2020.

Results: Participants reported clinical, practical and ethical challenges associated with this topic. The hospital setting provides barriers to high-quality communication with dying patients and their families about assisted hydration, which may contribute to the low incidence of documented assisted hydration-related conversations. Workplace culture in some hospices may make truly individualised decision-making about this topic more difficult. Lack of inclusion of patients in decision-making about assisted hydration appears to be common practice.

Conclusions: Proactive, routine discussion with dying people about hydration-related issues is indicated in all cases. There is room for debate regarding the limits of shared decision-making and the benefits of routine discussion of assisted hydration with all dying people. Clinicians have to navigate multiple barriers as they strive to provide individualised care.

Keywords

Decision making, shared, communication, terminal care, death, fluid therapy

What is already known about the topic?

- The impact of assisted hydration on symptoms or survival in the last days of life is unclear.
- Hydration-related conversations near the end of life are important, but the frequency of such conversations appears to be low.
- Some studies have explored hydration-related communication strategies but few have examined decision-making processes and influences, or cultural considerations.

Corresponding author:

Arjun Kingdon, Department of Public Health and Primary Care, University of Cambridge, East Forvie Site, Cambridge Biomedical Campus, Hills Road, Cambridge CB2 0SR, UK.
Email: adnk2@medschl.cam.ac.uk

What this paper adds

- Several barriers exist to the effective individualisation of hydration-related practice at the end of life, including the formation of rigid workplace cultures.
- This area of practice is challenging even for senior clinicians with experience in end of life care, given clinical uncertainties, discrepancies of opinion between patients, families and medical teams, and ethical quandaries.
- Current practice may not be commensurate with shared decision-making principles.

Implications for practice, theory or policy

- A debate is required regarding the inclusion of dying people in conversations about hydration-related aspects of their care.
- Education for undergraduate and postgraduate medical professionals could usefully address individualisation of care in practice as well as in theory.
- Future research needs to examine the perspectives of dying people and their family carers on assisted hydration.

Introduction

There is at present a limited evidence base regarding the impact of clinically assisted hydration on symptoms or survival of people approaching the last days of life.¹ Despite this uncertainty, healthcare professionals are regularly faced with communicating with patients and those close to them and making decisions about this important and emotive area of clinical care.² The prevalence of provision of assisted hydration for people near to or in the last days of life varies considerably between countries³ and between organisations such as hospitals and hospices,⁴ indicating a lack of consensus about best practice.^{5,6} Factors such as organisational cultures and the beliefs and values of clinicians, patients and families may play important roles in decision-making.⁷⁻⁹

Given the lack of available evidence, few countries have produced guidelines with specific recommendations about the use of assisted hydration towards the end of life. In Japan, a clinical guideline gives detailed recommendations for the use of assisted hydration for patients with cancer experiencing a range of symptoms in the last weeks of life.¹⁰ In the UK, National Institute for Health and Care Excellence (NICE)¹¹ guidelines avoid in-depth statements about benefits and risks, instead encouraging healthcare professionals to discuss issues relating to assisted hydration with all dying people and those close to them (henceforth 'family'). However, UK audit data suggests that conversations about assisted hydration are only documented with dying people and families in 9% and 30% of cases respectively, well below the prevalence of other important conversations often held as death approaches.¹² It is not known why assisted hydration-related conversations occur so infrequently: the discrepancy between guidelines and practice suggests either that current practice is suboptimal,¹³ or that existing guidelines are unrealistic or in need of revision. In the UK, the Review of the Liverpool Care Pathway made recommendations highlighting the

need for training in the appropriate use of assisted hydration, how to discuss assisted hydration, and the need for specialist services to develop assisted hydration-related education and training,¹⁴ which have not been actioned widely to date. This review, and the fallout accompanying the withdrawal of the Liverpool Care Pathway, demonstrated that the topic of hydration near the end of life is of great importance to families, and that poor communication or decision-making about hydration can result in drastically negative consequences.

A recent literature review included studies that explored some potential hydration-related communication strategies and acknowledged the multiple meanings that hydration may hold.^{15,16} A small number of studies have examined healthcare professionals' decision-making processes and influences.¹⁷⁻¹⁹ However, there is little understanding of the optimum timing of such discussions; the extent to which shared decision-making is practiced; and the extent to which hydration is incorporated into advance care planning discussions. This research has been designed to develop a more comprehensive understanding of assisted hydration-related communication and decision-making. This is needed to support healthcare professionals in challenging situations,¹³ and to understand the antecedents of current practice, in order that future education and interventions may be effectively designed.

Aims

Regarding doctors experienced in the provision of end of life care, this study aims to gain greater understanding of their views and experiences of:

- Providing or withholding assisted hydration
- Communicating with dying patients and families about assisted hydration
- Decision-making about assisted hydration

Box 1. Eligibility criteria for study recruitment.

- Currently practising qualified doctor working in Palliative Medicine or Medicine for Older People
- Employed by one (or more if working cross-site) of the participating organisations
- Practising at current level of seniority (but not necessarily current place of work) for over 6 months at time of interview

Methods*Design*

This research is situated within a constructivist paradigm, that is, the researchers take the position that reality is socially constructed and that knowledge is co-created between interviewer and participant.²⁰ This position led to the choice of a semi-structured interview approach for this study, which allows for a dialectic between interviewer and participant, and for the generation of rich insights into participants' subjective experiences.

Setting

Interviewees were drawn from two tertiary hospitals, one district general hospital and six hospices/community palliative care services serving a wide geographical area and socio-economically diverse populations.

Population

Participants were doctors working as speciality trainees, staff grade doctors or consultants in the fields of Palliative Medicine and Medicine for Older People. Doctors working in these two specialties were chosen as they are frequently involved in end-of-life hydration decisions and discussions. Restrictions imposed by the COVID-19 pandemic limited our ability to include a wider range of participants including general practitioners, non-specialist providers of palliative care and nursing colleagues. We plan to undertake future research with these groups. Full eligibility criteria are outlined in Box 1.

Sampling

Interviewees were purposively selected on parameters of age, gender, ethnicity, level of seniority and site of work, to ensure a diverse sample of participants and to maximise variety and depth of insight.

Recruitment

Study information was sent to administrators at participating sites for dissemination to potentially eligible participants. Those who wished to take part contacted AK;

thus, no data are available concerning numbers who did not wish to participate. If the sample had been less representative, we would have selected participants from under-represented groups; however, this was not necessary and all who showed interest were interviewed. Demographic data were collected and written consent was gained at interview onset. Participants were made aware of the availability of counselling services should the interview cause any distress. There were no inducements for participation. No participants withdrew having showed initial interest.

Data collection

AK, at the time working as an Academic Clinical Fellow and Specialty Trainee in Palliative Medicine, conducted semi-structured interviews with participants. Interviews lasted up to 1 h (range 35–59 min). From October to December 2019, interviews 1–10 were conducted in person at the participant's place of work; interviews 11–16 were conducted via video call from July to October 2020. The hiatus, and altered approach to data collection, relate to the effects of the COVID-19 pandemic.

The interview schedule (Supplemental Appendix 1) was developed by the research team and was piloted by AK before interviews commenced (no changes made following pilot). Topics included: an invitation to recall recent or memorable cases that had involved assisted hydration; questions about participants' experiences and usual approaches to communication and decision-making; and participants' perceptions of current practice and how it may be improved. Interviews were audio-recorded, then transcribed verbatim by a confidential professional service. Transcripts were checked and anonymised by AK.

Data analysis

Analysis was inductive and undertaken concurrently with data collection to permit investigation of emergent issues in subsequent interviews, using a framework analysis approach as described by Gale et al.²¹ After familiarisation with the transcripts, AK and BA dual-coded the first five interviews using NVivo-12 software. At this point, initial coding was discussed (no a priori codes were used) and a working analytical framework developed. AK coded the remaining interviews, iteratively updating the analytical framework as the study progressed. Following coding of all transcripts, the framework was finalised and data were analysed within and across cases, resulting in inductive development of themes and subthemes. AK kept a reflexive research diary throughout this process. COREQ criteria were utilised during manuscript preparation.²²

Data saturation was judged to have been reached after eight interviews with primarily hospice-based professionals, using Guest et al.'s²³ thematic saturation assessment

Box 2. Themes and subthemes.

Themes	Subthemes
1. How decisions are made about assisted hydration	(a) Harms and benefits of assisted hydration: perceptions and evidence (b) Factors that influence decision-making (c) 'Treating the family' and ethical considerations (d) Assisted hydration provision in different care settings
2. The building blocks and strategies of the hydration conversation	(a) Techniques: normalising, listening, reassuring, involving (b) Values: open-mindedness, patient-centredness
3. The 'meta-conversation': what is and isn't discussed, when and with whom	(a) Timing: proactivity and advance care planning (b) Discussing with patient or family (c) Discussing assisted hydration or just hydration
4. Society, workplace culture and education: contextual factors affecting assisted hydration practice	(a) Cultural factors influencing views about assisted hydration (b) Changing practice over time: the legacy of the Liverpool Care Pathway (c) Not a simple conversation (d) Educating healthcare professionals: a difficult topic to teach well

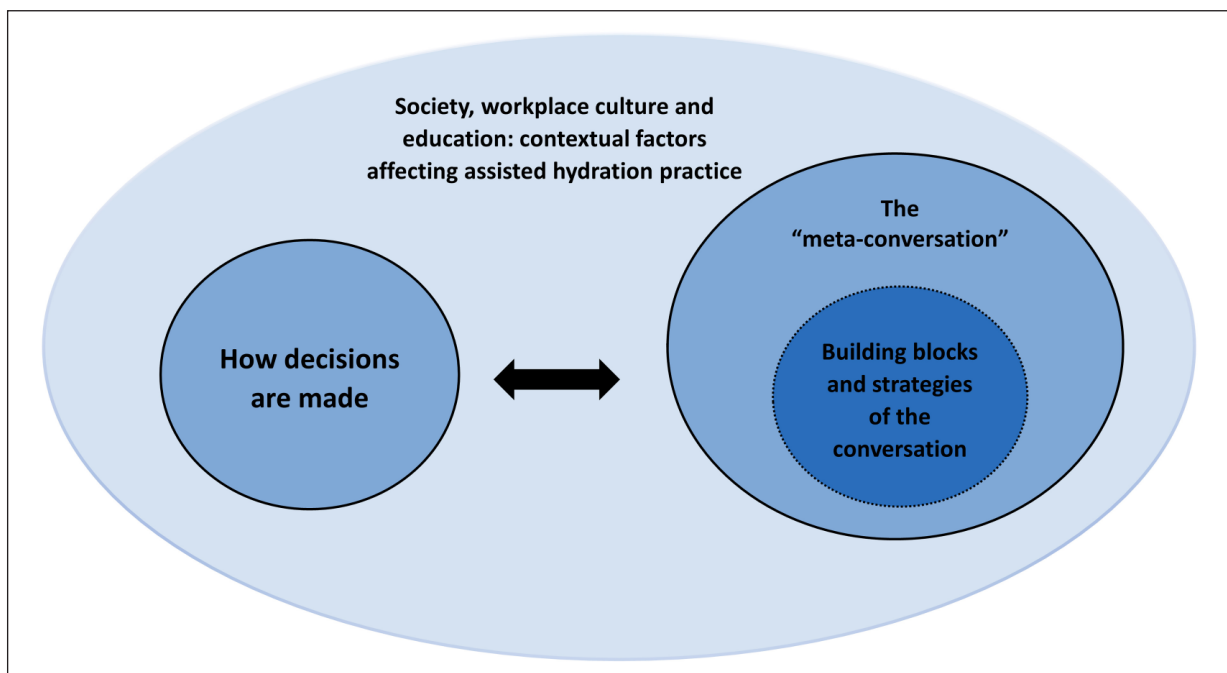


Figure 1. The relationships between the four themes.

method; two additional interviews were conducted in this setting, then six additional interviews were conducted with hospital-based professionals in anticipation of new information from this group. Complementing this approach, the concept of 'information power' was also utilised in determination of optimal sample size, taking into consideration principles suggested by Malterud et al²⁴ such as this work's dense sample specificity and strong interview dialogues.

Ethics

The study protocol was approved by the University of Cambridge Psychology Research Ethics Committee (PRE.2019.063, August 2019).

Results

Analysis of the transcripts identified four main themes relating to doctors' views and experiences of assisted hydration at the end of life (Box 2). Figure 1 demonstrates how themes interrelate. 'Building blocks' and communication strategies are influenced by contextual communication-related factors (the 'meta-conversation'); these communication-related themes interact reciprocally with decision-making, and all these three are influenced broadly by wider contextual considerations including medical education, organisational cultures, and societal attitudes to hydration, death and dying. In the following account, 'most participants' refers to 50% or more; 'many'

Table 1. Participants' details.

		Number of participants	
Gender	Female	11	
	Male	5	
Seniority	Palliative Medicine consultant	7	
	Medicine for Older People consultant	4	
	Palliative Medicine speciality doctor	3	
	Palliative Medicine specialist registrar	1	
	Medicine for Older People specialist registrar	1	
Ethnicity	White British	12	
	Asian British	3	
	Irish	1	
Site of work	Palliative Medicine consultants	Hospital liaison work	1
		Hospice/hospital/community	6
	Medicine for Older People consultants	Hospital wards and clinics	4
		Inpatient hospice work	3
	Palliative Medicine speciality doctors	Hospice/hospital/community	1
	Palliative Medicine specialist registrars	Hospital wards and clinics	1

refers to five or more participants; 'some' refers to three or more participants.

Participants were mostly consultant grade with a median of 9 years' experience in their current speciality (range 2–16 years), principally working in an inpatient setting. Demographic details of the sixteen participants are displayed in Table 1.

Theme 1: How decisions are made about assisted hydration

Harms and benefits of assisted hydration: Perceptions and evidence

Participants perceived more potential harms of assisted hydration than benefits. Participants expressed concerns about the development of oedema, respiratory distress and secretions, prolongation of dying, and the 'burden' of the intervention (P8). By comparison, some thought assisted hydration might ameliorate thirst on occasion, while others felt it 'makes them feel someone is doing something' (P2). Some participants referenced specific recent studies that had influenced their practice; many stated that they knew of little firm evidence. There were discrepancies of opinion regarding specific side effects.

P11 [Medicine for Older People consultant, male]: *I know there's not strong evidence for this, but I tend to say that giving hydration, particularly intravenously, increases the risks of secretions, respiratory secretions which can make a patient uncomfortable.*

P13 [Medicine for Older People consultant, male]: *I don't think I really believe that about the airway secretions and fluids making that worse, I think that's probably an old wives' tale.*

Factors that influence decision making

A large number of factors that impact on decision-making were discussed by participants, summarised in Table 2.

'Treating the family' and ethical considerations

All participants had encountered situations in which family requested assisted hydration provision, but where participants felt clinical benefit from assisted hydration was unlikely. All but one described that unless they had concerns regarding particular risk of specific harms, and if family were implacable, they would commence a trial of assisted hydration, with careful communication about monitoring and cessation of the trial if no improvement was seen, as expected by participants. Some expressed that this use of assisted hydration 'buys time' (P15) for adjustment to the dying process.

P16 [Medicine for Older People specialist registrar, female]:

At that stage we all recognise we're treating the relatives and not the patient. . . best interests does include some reference to your sort of family and cultural background, but the primary driver is generally accepted to be what actually is going to be of benefit, or not, to the patient. . . It's not going to do a massive harm, but it's certainly not going to do anything particularly good. And so it's just that reticence to hook people up to bags of fluid that are probably pointless.

One participant described using the smallest amount of fluid possible for fear of prolonging dying, and how in this setting assisted hydration is 'for show. . . a trick from the medical profession' (P13). While participants omitted mentioning fear of complaints as an influence on practice, almost all remembered challenging cases in

Table 2. Factors participants discussed as influencing whether assisted hydration is used in the last days of life.

	Factors favouring provision of assisted hydration	Factors favouring no provision of assisted hydration
Patient factors	Unresolved thirst not responding to mouth care Dying person still conscious Prolonged dying process Hypercalcaemia Unsafe swallow and no alternative route* Dying person's wish to have assisted hydration	Conditions predisposing to pulmonary oedema, for example, congestive cardiac failure Conditions resulting in risk of or actual raised intracranial pressure Existing fluid overload Conditions where gastrointestinal secretions have been a problem and may be worsened, for example, bowel obstruction Explicit wish expressed by patient to avoid assisted hydration or invasive treatments in general
Family factors	Family request plus perceived high bereavement risk Concerns regarding possible complaints**	Family recognises and accepts that their relative is dying
Situational factors	Lack of prognostic certainty Buying time, for example, if a family member is travelling from a distance Preferred place of death is home or hospice and assisted hydration is used as a bridge to improve chances of the dying person achieving discharge	Provision of assisted hydration is opposed by members of the team Greater clinical certainty that death is imminent within days
System factors	(If assisted hydration is already being provided:) Understaffing and/or lack of continuity in clinical team Lack of trust or rapport with dying person or family Late recognition of dying process Conversations about hydration not being held Hospital setting	Lack of organisational support or processes for assisted hydration provision in the community Nurses' competences in hospice and community settings Skilled communication

*A number of participants described an important cohort of patients who are weeks from death but may benefit from provision of assisted hydration up to and into the last days of life: those who have no oral route, who are too unwell for placing of enteral tubes, whose prognosis is short enough that parenteral nutrition would be inappropriate, but long enough that they would die from dehydration rather than underlying illness if fluid was not provided; and who are still conscious and thirsty – for example, patients with certain strokes, or head and neck tumours. Participants described that this cohort of patients were among the few for whom assisted hydration provision in a community setting may be helpful.

**By inference.

which assisted hydration-related complaints occurred or were felt to be a risk. Several identified that it can be unhelpful to treat dying person and family separately in end-of-life decision-making.

Assisted hydration provision in different care settings

Decision-making is influenced by the setting and available resources. Use of assisted hydration in the community was described as exceptional; only few participants described having organised this, in highly unusual cases. Participants described barriers including access to equipment, lack of clarity about processes and medical responsibility, and concerns over monitoring; they thus tend to avoid proactive discussion about assisted hydration in community settings. Some expressed a view that while it may be rarely used, there are circumstances where it would be ideal to have assisted hydration in the

community as an option. In a hospice setting, some described that logistical concerns could affect their willingness to use assisted hydration.

P10 [Palliative Medicine consultant, female]: Here [hospice] one of the drivers is if that cannula goes in the middle of the night our out-of-hours doctor isn't going to come in and re-site it. . . Arguably that shouldn't form part of the decision-making process but it does.

Theme 2: The building blocks and strategies of the hydration conversation

Techniques: normalising, listening, reassuring, involving

Many participants emphasised 'making sure that everyone is on the same page' (P8) (i.e. aware of the context of the patient's declining health and the likelihood of further decline and death) before proceeding to discuss assisted

hydration with dying people and/or families. Hospice-based participants discussed communicating the normalcy of diminishing oral intake towards end of life; this narrative was not prominent in hospital-based participants' responses. This may relate to a greater diversity of trajectories and points of recognition of dying in a hospital setting.

P1 [Palliative Medicine specialty doctor, female]: *I'll explain to people that we try and assess whether their loved one is thirsty or not, and explain the difference between thirst and a dry mouth, and the possibility of giving people fluids by sponge. . . and I very often explain that people's feeling of hunger and thirst diminishes in the dying period.*

Many discussed using the technique of normalising as reassurance, conveying the idea that most dying people appear comfortable without assisted hydration. Most discussed encouraging family involvement in mouth care. Participants discussed explaining [their perceptions of] harms and benefits of assisted hydration, typically focusing on harms. Some felt that hydration is an emotive topic, connected with symbolism of life, hope and caregiving, and discussed acknowledging this and the impulse to help a loved one to stay hydrated.

P3 [Palliative Medicine consultant, female]: *I say to everybody, food and drink is the essence of life, why would you not question "why can't I have something additional if I'm not eating and drinking so much?". . . it's really important to listen to someone and ask why is it that you think that you need intravenous fluids?*

When reflecting on 'difficult' cases (signified by a discrepancy in preferred outcomes between medical team and patient or family), many felt that if families are disquieted by non-provision of assisted hydration, this may herald other unaddressed concerns. Some discussed needing to 'unpick' these concerns (P7); others were inclined to take requests for assisted hydration at face value. Some discussed encouraging patients to articulate their feelings with family present:

P10 [Palliative Medicine consultant, female]: *It's not usually the patient themselves driving for stuff, it's usually their relatives, and once you enable someone to voice that "I don't really want it", then that is I think the most helpful thing, anything said in the patient's voice.*

Values: Open-mindedness, patient-centredness, and individualised care

Many participants discussed using what they considered to be good general communication skills, including taking time to build rapport and trust, and listening rather than launching into prepared explanations. Many felt that

remaining open-minded is important; as several participants had views about assisted hydration being unhelpful, the term 'open-mindedness' may refer to being prepared to consider the use of assisted hydration despite doubts about efficacy. Individualisation of care was seen as overwhelmingly important; most emphasised that while they feel assisted hydration is rarely clinically beneficial for dying people, blanket decisions must be avoided. The conversation is seen as one where there is 'real potential to upset the person you're talking to' (P8).

P14 [Palliative Medicine consultant, female]: *It's like all difficult conversations. If you go into them task focused, I'm coming to have a conversation about resuscitation, about IV [intravenous] fluids. . . then you miss the clues from the patient and the family, whereas if you go in with a, "I'm going to have a conversation . . . about how they think things are going and what needs to happen next," then you go in with a much more broad angled lens and that way you pick things up.*

Theme 3: The 'meta-conversation': what is and isn't discussed, when and with whom

Timing: Proactivity and advance care planning

Participants agreed that proactively raising the topic of hydration or assisted hydration is helpful. Some felt that if eventual impaired swallowing is foreseeable, hydration should be discussed as part of advance care planning. Hospice-based doctors spoke about normalising ideas relating to reduced intake and reduced thirst while patients are still conscious, thus involving them, and preparing families to be more accepting of non-provision of assisted hydration later on. This strategy relies on early recognition of short prognosis.

P8 [Palliative Medicine consultant, male]: *If it's never been thought of or discussed at any point and then you're going in the day someone's dying . . . and having that conversation for the first time, that's always going to be difficult.*

Discussing with patient and/or family

Most stated they do not routinely discuss assisted hydration with dying people ahead of them losing capacity; the topic is commonly raised with family when the patient is obtunded and recognition of last days of life has occurred. Some were concerned about patients' non-involvement in these decisions and advocated for more routine assisted hydration discussions with patients. Others defended this approach, feeling that decisions about assisted hydration are not suited to being planned in advance.

P14 [Palliative Medicine consultant, female]: *There are so many situations where it would be good symptom control to*

give them IV fluids. . . I don't think it's very helpful to have someone to say, "I definitely don't want to ever have IV fluids", because I don't think you can really give them all the scenarios in which case that treatment might be appropriate.

Discussing assisted hydration or just hydration

Many participants differentiated between discussing assisted hydration and discussing hydration in general terms, without mentioning parenteral fluids. For hospice-based participants whose patients rarely receive assisted hydration, the goal was described as achieving a shared understanding of a focus on comfort. Discussing assisted hydration was felt to be potentially undesirable in cases where it is clinically inappropriate, or where the discussion could be burdensome. All felt that regardless of if assisted hydration is mentioned, it is important to discuss hydration in all cases, to avoid misunderstandings and assumptions.

P5 [Palliative Medicine consultant, female]: *I think you might choose to talk about it [assisted hydration] pre-emptively with some people, but you could individualise it. Whereas if you bring it up with everybody, you might be bringing it up only to immediately shoot the idea down. Basically, making it like resuscitation is.*

Theme 4: Society, workplace culture and education: Contextual factors affecting assisted hydration practice

Cultural factors influencing views about AH

Participants discussed how societal factors impact on their practices and attitudes, as well as those of patients and families. Some participants noted that the concept of terminal dehydration may be perceived as undignified and barbaric, and how this impacts on the nature of the discussion required. Some referenced long-term societal shifts in place of death, and how these shifts have impacted on people's experiences and expectations of dying, resulting in assisted hydration-related issues taking on greater significance. Some noted that people from certain cultural or religious backgrounds may attach (even) more importance than others to issues of nutrition and hydration, including maintenance of hydration up to the end of life. One participant reflected on their own cultural background and its influence on their practice:

P3 [Palliative Medicine consultant, female]: *In Asian culture everything centres around food and drink. . . it underpins all of the social norms and it's how people show that they love somebody or appreciate somebody. . . it's analogous to, you know, you have a relative that's constantly trying to feed somebody when they're dying, it's because that's their way of expressing love.*

Changing practice over time: the legacy of the Liverpool Care Pathway

Some hospice-based participants felt their organisations' practices have changed in recent years, becoming more open to considering assisted hydration, although provision remains rare in this setting. Many felt that some attitudes remain overly fixed regarding assisted hydration being inappropriate for all dying people; many related episodes describing assisted hydration provision being opposed strongly by hospice staff. Some participants' narratives equated the concept of a 'good death' with the non-provision of assisted hydration.

P5 [Palliative Medicine consultant, female]: *Because there is this, I don't know, this old adage that if the nurses don't want them to have the subcut fluids, they'll just say they're pooling and then, and then, oh, well, what do you know. . . we can't do that anymore. . . somebody said that to me, like you only really get subcut fluids if the nurses are on board with the plan, otherwise barriers will appear. . .*

Not a simple conversation

In the hospital setting, participants noted how in some cases patients' and families' mistrust of the medical establishment and doctors' motives can result in more challenging conversations. Trust was seen as harder to generate in hospitals, due to increased likelihood of previous negative experiences, less continuity of care, and more difficult prognostication. Most felt that while discussing assisted hydration became easier with experience, it remains a particularly challenging topic for junior or generalist clinicians. Many felt that junior doctors avoid starting assisted hydration-related conversations due to fears about incorrectly predicting prognosis, or about whether families are ready for cessation of assisted hydration.

P12 [Medicine for Older People consultant, male]: *It was seen as a very simple thing for a trainee who was busy and on-call, this person's deteriorating, right, red lights, hand over notes, LCP [Liverpool Care Pathway], sign the paperwork, job done. Not communicated with the family. We've perhaps swung the other way. . . it's so open now, it's quite a complex situation for trainees to be in. . . people are shying away more from these discussions, junior nurses and junior doctors.*

Educating healthcare professionals: A difficult topic to teach

Many participants felt that communicating and decision-making about assisted hydration at end of life are difficult topics to teach. Role-modelling of individualised conversations was identified as a useful technique. Some felt junior doctors prefer protocols and can be overly rigid about assisted hydration provision for dying people being

universally incorrect and felt teaching resources should address this. One recalled personal experiences of engaging with teaching material:

P8 [Palliative Medicine consultant, male]: *My interview to get into palliative care. . . the books I read or things I looked up was almost giving you pointers on how to explain effectively and sensitively why these things [assisted hydration] wouldn't be in the person's best interests. I guess in the back of my head was . . . if I haven't convinced sort of the family that they shouldn't be advocating for sort of fluids, then I've not done well at the station.*

Discussion

Main findings

Geriatricians and palliative care doctors reflected on clinical, practical, and ethical challenges associated with making decisions and communicating about assisted hydration at end of life, and about the wider social and cultural climate that influences these decisions and conversations. A tension was apparent between participants' aspirations to provide individualised assisted hydration-related care, and barriers that can make this aspiration difficult to achieve.

Strengths and Limitations

AK has worked clinically with some participants as a trainee, potentially affecting the dynamic and content of some interviews. AK kept a reflexive diary and took field notes to mitigate this eventuality. The sample size was small and represents a single region of the UK; while this region's population is economically diverse, the comparative lack of population ethnic diversity may have impacted on participants' experiences and may reduce the transferability of these findings.²⁵ The sample would have included other medical specialties to provide greater breadth of opinion from generalist providers of end-of-life care; recruitment proved challenging in the context of the COVID-19 pandemic. Assisted hydration practice varies across the globe³ and findings from the UK may not translate closely to countries with different cultural and legal frameworks. Nevertheless, this research aims to highlight points of practice that are applicable to all settings.

In sampling medical experts who routinely deliver palliative care, this research provides a snapshot of their current practice, much of which may be worthy of emulation. Greater understanding of this group's practices and opinions may result in transferable learning that is useful to other clinicians and in the development of undergraduate and postgraduate medical education materials. However, this selection omits several narratives: those of clinical nurse specialists, and of generalist physicians and junior doctors, whose experiences may help with developing

understanding of the educational needs of non-specialist providers of palliative care. Most importantly, the perspectives of dying people and their relatives remain poorly understood. This research focuses on how doctors say they communicate and make decisions; further studies could usefully explore how such interactions take place in reality.

What this study adds

The lack of inclusion of patients in decision-making about assisted hydration at end of life appears to be standard practice. This is incommensurate with NICE guidance¹¹ and shared decision-making principles. Dying people should be involved in decisions to the extent that they choose,²⁶ which entails asking them their preferences, and doctors perform poorly when estimating patients' preferred roles in decision-making.²⁷ However, participants indicated that when patients have limited energy and days to live, raising questions about assisted hydration may be burdensome and may relate more to the clinician's agenda. Patients may not find assisted hydration as burdensome as clinicians seem to expect.²⁸ Careful, individualised reflection is required regarding whether the exclusion of patients from hydration-related decision-making is a conscious choice with the aim of reducing burden, or whether this exclusion relates to time pressure, discomfort with these conversations, or the extra conversational and associated emotional work required. For these conversations to include patients while shared decision-making is still possible, professionals and systems need to be equipped to recognise dying at an earlier stage than occurs in current hospital-based clinical practice.¹²

Practitioners will draw their own conclusions regarding the extent to which 'treating the family' is acceptable. Classic models of shared decision-making uphold Western ideas about autonomy by focussing on doctor-patient dyads²⁹; however, some evidence suggests that patients do wish for families to be included in decision-making.^{30,31} Participants' described practices suggest that as patients approach end of life, doctors are more likely to deviate from strict interpretations of best-interests decision-making, and involve family in decision-making. It may be helpful for clinicians to view interactions with dying patients and their families through the lens of relational autonomy.^{32,33}

Many communication strategies outlined above echo those set out in existing research³⁴ and in the Cambridge-Calgary model of clinical communication.³⁵ Assumptions must be avoided regarding whether the approaches described by participants constitute best practice. Results largely confirm previous findings that demonstrated discourses of uncertainty and suggest that doctors sometimes avoid discussions for 'protection' of family – or themselves.² In carefully selected circumstances, it seems reasonable not to specifically discuss *assisted* hydration,

as long as *hydration* has definitely been discussed, patient and family understand what to expect regarding fluid intake and have had opportunity to express their views. When communicating, clarity about whether assisted hydration is being discussed or offered is essential (as with discussions about cardiopulmonary resuscitation).³⁶

Participants described several barriers to high-quality communication in the hospital setting. Moreover, families may have more difficulty trusting what they hear, and are more often asked to reconcile themselves to assisted hydration ceasing, rather than not starting. Although some ethicists may deny a distinction between acts and omissions,³⁷ participants suggested that they, patients and families find cessation of assisted hydration harder to process^{38,39}; the widely-used time-limited trial of assisted hydration is a practical solution.⁴⁰ The number and quality of hospital-based discussions about assisted hydration are unlikely to improve unless resources are less thinly stretched, and unless clinicians observe practice and receive education that engenders comfort with uncertainty and avoids dichotomous right-vs-wrong viewpoints.

Challenges are often different in a hospice environment, where non-provision of assisted hydration is highly normative.⁴ 'Hospice philosophy' may predispose to a reified conception of good death as one which is as 'natural' and de-medicalised as possible.⁴¹ Hospital-based practitioners may need reminding that active treatment until death is not always the right course of action; hospice-based professionals may need reminding that it is not always wrong. Individualisation of care is always essential – but entrenched workplace cultures can stymie attempts to individualise. Clinicians can challenge inflexible viewpoints and contribute to culture change.

Participants felt that non-specialist junior doctors on a Palliative Medicine rotation tended to be inconfident with assisted hydration-related conversations at the start of the placement, needing specific pointers in order to develop independence. It is unclear whether existing UK-based programmes of undergraduate and postgraduate education effectively address communication and decision-making about assisted hydration, although 'understanding' of the topic is referenced in the 2014 Association for Palliative Medicine curriculum for undergraduate medical education.⁴² Approaches that explore how individualised care can be provided in practice may be helpful, alongside existing approaches explaining why this is necessary.

Conclusion

This research indicates the benefits of routine proactive discussion of hydration in all cases; clinicians face difficult decisions about timing and what exactly to include,

including whether it is necessary to mention assisted hydration in every case. Although the Liverpool Care Pathway has been withdrawn, the 'one size fits all' mentality for which it was blamed may still linger. Clinicians must actively oppose this in education and in practice, and strive to provide individualised care, while navigating the plethora of challenges involved in conversing and making decisions about assisted hydration.

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Author contributions

AK conducted the study and wrote the manuscript. SB and AS helped to conceptualise the study and provided supervisory input. BA dual-coded the first five interviews. All authors have read and approved the manuscript.

Data sharing

Data relating to this review can be obtained by contacting the lead author at adnk2@medschl.cam.ac.uk, or by post at the Department of Public Health and Primary Care, Cambridge Institute of Public Health, University of Cambridge School of Clinical Medicine, Forvie Site, Cambridge Biomedical Campus, Cambridge CB2 0SR.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics

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ORCID iDs

Arjun Kingdon  <https://orcid.org/0000-0002-2914-082X>

Bárbara Antunes  <https://orcid.org/0000-0003-1655-7391>

Supplemental material

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