

Original Article

What Influences Patients' Decisions on Artificial Hydration at the End of Life? A Q-Methodology Study

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Abstract

Context. Artificial hydration (AH) is used to palliate patients with reduced fluid intake at the end of life but is a controversial practice. Patients' involvement in decision making varies, and little is known about patients' understanding of the benefits and burdens of AH.

Objectives. To identify the factors that patients consider most important when making decisions regarding AH at the end of life.

Methods. Interview study using Q-sort methodology conducted with 20 patients with advanced diseases recruited from inpatient and outpatient palliative care services.

Results. Several domains appear to influence a decision about AH: the patient's understanding of AH, their philosophical position on end-of-life care, the process of discussion, and who makes the final decision. Patients generally based their decision on whether AH would improve quality of life, although prolonging life was important for some. Hydration was not considered a burden, and many would want a trial of AH in the event that they could no longer drink. Patients wanted to be guided by medical opinion, although some wanted to make the decision on their own. All patients welcomed the opportunity to discuss AH.

Conclusion. Patients view AH as an important issue and are keen to be involved in decision making. Health care professionals may withhold AH at the end of life because they perceive it as a burden on patients and on their interactions with family, although this view is not shared by patients. Some patients lack understanding regarding the likely benefits of AH. Research examining the impact of clinical information regarding AH on patients' decision making is now needed. *J Pain Symptom Manage* 2011;42:192–201. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Artificial hydration, decision making, palliative care

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Introduction

Reduced fluid intake is common in patients with advanced disease and can be caused by nausea, physical obstruction, loss of appetite, or anorexia-cachexia syndrome. As death

approaches, fluid intake diminishes further because of extreme weakness and, eventually, consciousness decreases. The provision of fluid to quench thirst is a powerful symbol of caring, and questions often arise from patients at the end of life and their families regarding the provision of artificial hydration (AH).

AH refers to the methods used to provide hydration to patients who are unable to take such provision by mouth or swallow, most commonly via intravenous or subcutaneous administration. The use of AH in palliative care is a complex, emotive, and sometimes controversial topic, with great variation in practice.^{1,2} Decisions regarding whether to initiate AH are based often on anecdotal rather than scientific evidence, frequently influenced by the attitudes of those involved in decision making.^{3,4}

A recent Cochrane review revealed a lack of sufficiently good quality studies to make any recommendations for practice on the effects of AH in palliative care patients.⁵ Existing evidence suggested that AH may have some benefit in terms of improving sedation, myoclonus, and a perception of overall benefit, but adverse effects such as fluid retention also were apparent.

Involving patients in decision making is central to palliative care philosophy and necessary when hydration issues are to be discussed.⁶ In the United Kingdom, the National Council for Palliative Care advises that patients with capacity should always be helped to participate in discussions if AH is being considered.⁷ Despite these recommendations, patients' involvement in decision making varies, and little is known about patients' understanding of the benefits and burdens of AH, although evidence suggests that knowledge is poor.⁸

Previous studies conducted outside the United Kingdom indicate that many palliative care patients have a positive attitude toward AH, perceiving it to be of clinical benefit although the futile nature of AH was stressed and respondents agreed that AH might worsen suffering.^{4,9–11} This perception was strongly held, with respondents feeling that withholding AH would cause premature death.⁹ Explanations for such strongly held views include religiosity, fear of death and dying, or a desire to carry on living regardless of the circumstances.

These views are not held universally, however. One study found that 73% of patients did not want treatment if the chance of survival was poor.¹²

Cultural factors can influence patients' beliefs about end-of-life care in general and AH in particular. Issues such as the Jewish principle of prioritizing the sanctity of life have been cited as influencing decisions relating to AH, as well as the cultural and spiritual significance relating to provision of fluids and nutrients.^{4,10} Different ethnic groups also traditionally practice different models for the process of decision making in end-of-life care. For example, it is common practice in some cultures not to disclose the truth about a poor prognosis to a dying patient on the basis of nonmaleficence.¹⁰

As clinicians managing patients with advanced disease, we wanted to improve our discussions with patients regarding AH and understand how their preferences are formed. This is part of a larger program of work called Attitudes to Rehydration in the Dying (ARID). For this study, we aimed to identify the factors that patients consider most important when deciding whether they wish to receive AH.

Methods

Participants and Setting

We recruited 20 patients with advanced disease who were either inpatients or outpatients at a large U.K. hospice. The aim of sampling was to gain a range of attitudes about AH, and so we included male and female patients of different ages and performance status. Participants provided written consent, and ethical approval was provided by the King's College Research Ethics Committee (CREC/07/08-194).

Q-Methodology

Developed in the 1930s, Q-methodology provides a means of exploring beliefs, attitudes, and subjectivity. Participants in a Q-methodology study are presented with a sample of statements or propositions that represent a full spectrum of views and values about the topic in question. This set of statements is known as the Q-set. Respondents are asked to rank order the statements according to the

sheet and a score attached to it (-4 to $+4$), forming the individual's Q-sort. The interviewer asked the participants to explain their placement of the statements on the grid, and the patients' comments about the items were documented by the researcher and read back to each participant at the end of the sorting process. These notes were later used to aid the interpretation of factors identified.

Data Analysis

Data from the completed Q-sorts of each patient were then entered into the dedicated software package PQ Method (free software from www.qmethod.org). Data analysis in Q-methodology involves the sequential application of three sets of statistical procedures: correlation, factor analysis, and the computation of factor scores.¹⁵ First, the correlation matrix of all Q-sorts is calculated. This shows all possible pairwise correlations between patients. Next, the correlation matrix is subjected to factor analysis to identify the number of natural groupings of Q-sorts according to their being similar or dissimilar to each other. People significantly associated with a given factor will share similar views on the subject in question.¹⁶ Rotating the factors enables the researcher to examine factors from

different angles and maximizes the amount of variance explained by the extracted factors.¹⁷ Each resulting final factor signifies a group of individual points of view that are highly correlated with each other and uncorrelated with others.¹⁴ Eigenvalues reflect the amount of variation accounted for by the corresponding factor. A standard requirement is to select only those factors with an eigenvalue in excess of 1, but use of this method alone may result in too many factors being retained.¹⁷ To adjust for this, a scree plot was created, and factors were retained that lay to the left of the point where the scree line flattens.

Finally, factor scores are calculated. A statement's factor score is the normalized weighted average statement score (z-score) of respondents that define that factor.¹⁸ These scores can be used to form a summary Q-sort that characterizes the set of responses to statements that are held by respondents with that particular viewpoint, illustrated in Fig. 2.¹⁶

Validity and Reliability. Validity of a Q-study is evaluated by content, face, and Q-sorting validity.¹⁹ Content validity was assessed via triangulation of the findings of the extensive literature search, along with expert opinion



Fig. 2. Example of summary Q-sort responses characterizing Factor 3.

from the clinicians taking part in focus groups, who were used as domain experts. Content validity also was checked via extensive piloting of the methodology. Using exact wording from the original source wherever possible on the Q-set statements assures their face validity.²⁰ Reliability of Q-sorting has been demonstrated in several studies using a test-retest procedure. Administering the same Q-set to the same individuals at two different points in time produced correlation coefficients of 0.80 or higher.^{18,19}

Results

Recruited Patients

Twenty participants consented to take part in the study over a 10-week period. Of these, 17 participants completed the Q-sort process; three withdrew before completion because of drowsiness, fatigue, and the unexpected arrival of visitors. Mean age of patients was 66.1 years (range 38–84 years); 13 patients were of white British ethnicity, three patients were of black British or Caribbean ethnicity, and one was Southeast Asian. Most had advanced cancer, but three had end-stage respiratory disease. All patients had had previous experience with AH but were not receiving AH at the time of interview. Mean Karnofsky performance status was 45.5 (range 20–60).

Factor Analysis and Discriminating Statements

Eight factors were identified, and five of these had eigenvalues greater than 1. Following scree plot analysis, three factors were retained in the final model, which accounted for 54% of the total variance. We examined the statements that loaded differentially across each of the three factors (i.e., discriminating statements where some patients agreed and others disagreed) and used these to characterize the factor (Table 1).

Factor 1—“Quantity of Life at all Costs.” Factor 1 accounted for 28% of the variance within the model, and the Q-sorts of six patients characterized this factor. Patients defining this factor agreed strongly that provision of AH was likely to prolong their life and they were willing to try any measure that would extend it. Comments

made included “*I would try owt (anything) to keep alive*” and “*A drip is an alternative way of feeding. I see it like oxygen, which I need to keep me alive.*”

This grouping included all three non-cancer patients, and all participants had lived with their illness for several years. Some had received repeated infusions of AH and intravenous medication such as antibiotics. Factor 1 patients were not keen to be in control of decision making. Although they wanted AH to be discussed with them while they were well enough to express their wishes, this group wanted medical staff to make decisions about AH on their behalf. The group demonstrated faith in the knowledge and expertise of medical staff: “*Doctors are the best people to advise. I can’t possibly know all about it, they are much more experienced than me.*” This faith may have been misguided at times: “*The doctors wouldn’t suggest it, if it didn’t provide nutrients.*”

Patients defining Factor 1 were not influenced by their family’s opinion nor did they want their families to make decisions on their behalf. Although faith was important to some of the patients, it did not influence their beliefs regarding AH.

Factor 2—“Passive Decision Maker Influenced by Others.” Factor 2 accounted for 14% of the variance, and the Q-sorts of five patients characterized this factor. Participants defining this factor did not wish to be in control of decision making. Instead, they looked for guidance from several influencing powers, including relatives, medical staff, and, in particular, their religious faith. This group agreed that they would wish for information about AH and that this should be discussed with them. Ultimately, however, they were willing for medical staff to actually make a treatment decision for them and, to a lesser extent, their family. These patients trusted the knowledge and expertise of medical staff and appeared to believe that while in medical care they should follow medical advice. This was illustrated by several comments: “*Why go to the doctors if you are not going to follow their advice?*” and “*Doctors know best. They have more experience and deal with this every day.*”

Patients defining this factor accepted their terminal illness and were keen that life was not prolonged if it lacked quality. As a result,

Table 1
Item Scores for Each Statement by Factor

No.	Statement	Factor Arrays		
		1	2	3
1.	Being attached to a drip disturbs my sleep	-3	-2	1
2.	Being attached to a drip would be a burden	-4	-2	0
3.	A drip might make me more alert	1	0	-1
4.	A drip might cause me problems	-1	-1	0
5.	I would wish for a drip if it would relieve my thirst	1	0	0
6.	If I were unable to drink, having a drip would make me feel something was being done for me	3	-1	-1
7.	I would be content to have regular mouth care if this alleviated a dry mouth	-1	0	0
8.	I would wish for medical staff to make decisions on my behalf	1	3	-4
9.	I would like to know I had a choice in whether to have a drip or not	0	0	3
10.	A drip might provide me with nutrients	0	-1	1
11.	Having a drip may improve my energy levels	2	1	0
12.	If I couldn't drink, I would worry about my fluid intake	1	1	0
13.	Having a drip may prolong my life	4	-1	2
14.	Having a drip is uncomfortable	-2	-3	1
15.	I would want information about the benefits and burdens of drip treatments	0	2	2
16.	I would only want a drip if it improved my quality of life	1	3	4
17.	I have no strong feelings about drip treatments	-1	1	-2
18.	Being attached to a drip reduces quality of life	-4	-2	-1
19.	I would try anything that extended my life	3	-3	-3
20.	I am influenced by information I read on the internet or see on TV	-2	-4	-1
21.	Having a drip would give me hope	0	-2	-3
22.	A drip should be used until the end of life if a patient is too unwell to drink	2	-4	-2
23.	I would feel happy for my family to make decisions on my behalf	-2	1	0
24.	Drip treatments should be discussed along with other important decisions such as resuscitation	2	2	3
25.	Previous experience of having a drip would influence my decisions about drip treatments	-1	-1	-2
26.	Having a drip means I cannot get close to friends or family	-3	-1	-2
27.	My family's opinion would be important to me	-1	3	-1
28.	My faith influences my thoughts about drip treatments	-3	2	-4
29.	I would feel confident to raise the issue of a drip with my doctor	0	0	2
30.	I would like a trial of drip therapy if I couldn't drink	1	1	1
31.	I feel I have enough knowledge about the use of drip treatments	0	0	-1
32.	Being attached to a drip would make me feel more dependent on nursing staff	0	-3	1
33.	The provision of fluid is a basic necessity	4	2	2
34.	I would want to be at home. If a drip prevented this, I would not want a drip	-2	0	-3
35.	Having different tastes/flavors in my mouth would be important to me even if I could only sip small amounts	-1	1	4
36.	I would want doctors to discuss drip treatments with me while I was well enough to discuss my wishes	2	4	3
37.	I would be guided by what my doctor suggests	3	4	1

The consensus was apparent for 10 statements (defined as all patients agreeing or all patients disagreeing with the statement), highlighted in bold.

they wished for a drip only if it were to improve quality of life and strongly disagreed with statement 22: "A drip should be used until the end of life if a patient is too unwell to drink."

Factor 3—“Autonomous Information Seeker Who Values Quality Rather Than Quantity of Life.” Factor 3 accounted for 12% of the variance, and Q-sorts of four participants defined this factor, illustrated in Fig. 2. Patients in this group were keen to be involved in decision making regarding AH and felt strongly that hydration should be discussed with them in advance, at a time when they were fit enough

to be involved in decision making. They wanted information about benefits and burdens of AH to make an informed decision: "Good information is very important. This would need to be in advance as I might not be fit enough to be involved when the time comes." These patients wanted to make independent decisions and were not likely to be influenced by faith, the media, or family. They strongly disagreed about medical staff making decisions on their behalf, for example, "The doctor suggested I should have a drip earlier this week. I wanted to make my own decision and decided to try and drink more."

Participants who defined Factor 3 wished for quality of life over quantity at all costs. Although agreeing that having a drip may prolong life, these patients only wished for AH if it were likely to improve their quality of life. Factor 3 patients were concerned about the experience of being attached to a drip and indicated weak agreement that AH may be uncomfortable or disturb sleep, although they did not agree that it would be a burden. Other factors such as enjoying different tastes and flavors, which may improve quality of life, were important to this group. *"I have a very dry mouth. The nurses have been giving me different types of fruit juice. I find it refreshing. It is important to keep having different flavors."*

Factor 3 participants disagreed that they were willing to try any measure that might extend their lives. This was illustrated in comments such as *"I wouldn't go to drastic actions. I believe when your time is up, your time is up"* and *"If it isn't doing you any good, what is the point?"*

Consensus Statements

Consensus was apparent for 10 statements (defined as all patients agreeing or all patients disagreeing with the statement), highlighted in bold in Table 1. All patients agreed that provision of fluid was a basic necessity and so they would want AH if they could no longer drink, but only if it improved quality of life. Patients also agreed that this decision was important and should be discussed with medical staff while they were well enough to do so. All patients would be guided by what medical staff suggested, although for patients defining Factor 3, this did not mean that medical staff should make the decision.

Responses also demonstrated that patients were not influenced by information from the Internet or television and disagreed that AH reduces quality of life or separates a patient from friends or family. No patient agreed with the statement that AH would cause him or her problems.

Discussion

Decision-Making Domains

We found that patients had strongly held opinions regarding AH at the end of life. Several domains appear to influence a decision

about AH: the patient's understanding of AH, their philosophical position on end-of-life care, the process of discussion, and who makes the final decision. We identified three distinct decision-making styles reflecting convergent or divergent views across these domains.

Understanding of AH. Faced with not being able to drink, some patients would worry and all patients would want a trial of AH. They did not appear to be content with mouth care as a substitute for this. Factor 1 patients regarded AH as providing hope and that it should be used routinely until death, although these views were not shared by the other two decision styles.

There were no strongly held views on the benefits of AH, with only ambivalence or weak agreement regarding the effect of AH on energy levels and alertness. This finding probably reveals a lack of knowledge but could suggest that these benefits are not particularly valued although these outcomes are supported by better evidence.⁵ Previous studies demonstrate a negative correlation between knowledge about AH and desire for AH, with those patients who are better informed being less likely to want AH.¹⁰

More interestingly, patients did not perceive that AH was a burden nor that it would cause problems or reduce quality of life, common reasons cited by staff for withholding AH.²¹ This may reflect the reality of patients' previous experience of AH: *"It's only a piece of tubing."* In some cases (Factor 1), statements highlighted an acceptance of putting up with practical limitations of being attached to a drip in order for perceived benefit: *"I've got used to having drips, I'm pretty adaptable."* Participants did not agree with the perception that AH would prevent them being close to their family, and given the choice of AH as an inpatient or being at home without it, they would choose the former.

Philosophical Position of End-of-Life Care. The attitude toward end-of-life care differentiated patients' decision-making styles most. For some patients, prolonging life was the most important influence on their decision (Factor 1). Although AH is unlikely to influence prognosis in patients at the end of life, this group

considered AH necessary to stay alive. It has been suggested that many requests for such futile treatment reveal that patients are not ready to let go and die.²²

Others strongly disagreed with this view in relation to AH. Factors 2 and 3 participants recognized that there may come a time when their prognosis would not be affected by medical intervention and at this point would only wish for AH to provide comfort. Certain patients appeared to feel that their life lacked any quality and thus would not wish for it to be prolonged even if AH was likely to do so.

Process of Discussion. There was a strong consensus that AH was an important issue, and the benefits and burdens should be discussed with patients when they are able to take part in a discussion. This is consistent with the U.K. End of Life Care Strategy.²³ However, health care professionals have been shown to influence decision making toward their own preferred outcome through selective presentation of information.²⁴ Such a “framing effect” can bias both the perception of the problem and the way it is processed by the patient.

Who Makes the Final Decision? Patients were consistent in their willingness to be guided by doctors, and many would be happy for doctors to make the final decision. However, for some patients (Factor 3), autonomy was paramount, and they wanted to make the decision themselves. These findings reflect earlier studies indicating that although patients typically express a high degree of interest in learning about their illness and treatment, their preference for actual participation in treatment decision making is highly variable.^{25–27}

In general, the influence of family was minimal, and although religious faith was important for some in making a decision, many of the patients interviewed rejected its influence. Interviews with family caregivers have shown that they were concerned that withholding fluids would shorten life, and many had received no information about AH, did not understand the benefits or burdens, and were misinformed; caregivers had rarely discussed AH with the patient.²⁸ Decisions regarding AH are frequently left until a point when patient involvement may be limited by fatigue or impaired cognition.¹ The fact that most of

these patients did not wish for their family to make decisions for them and yet are willing to be influenced by medical staff highlights the need for timely communication among patient, family, and health care providers.

Study Limitations

This study has potential limitations. We recruited from one U.K. hospice, and most patients were of white British ethnicity, although we recruited four patients who were not from this ethnic group. Although it is recognized that cultural factors influence attitudes regarding AH, this study was small and only included patients able to read and speak English. In addition, we did not evaluate mood or perceived quality of life of recruited patients, and these may have influenced attitudes toward AH at the end of life.

The researcher was present with each participant during the Q-sort process. This was necessary, as many participants needed physical assistance to pick up or place cards. The presence of the researcher may have unconsciously influenced participants’ responses.²⁹

This study aimed to explore diversity in attitudes regarding AH at the end of life. Although three statistically independent factors were identified (representing distinct decision-making styles), and a number of consensus statements revealed, it is not claimed that these factors represent all possible views nor that results can be generalized to the wider population. Q-sample sizes are typically smaller than those of a regular survey. Replication in other centers or with a different sample including those for whom English is not a first language would be valuable and may reveal additional factors. Similarly, replication within larger samples of cancer and noncancer patients would be important.

Bias also may occur in the interpretation of the research data. Although factors can be analyzed statistically, these results require human interpretation. We took measures to reduce bias: One of us (C. M.) identified factors, whereas the other (M. I. B.) acted as domain expert. We agreed on the final three factors for inclusion and their defining characteristics.

Implications for Clinical Practice

Clinicians should discuss AH with patients at the end of life as part of advance care planning

discussions. Although clinicians may feel uncomfortable discussing such sensitive topics, this study indicated that interviewed patients welcomed the opportunity to explore their feelings about AH. Many of these patients would be guided by medical opinion, but some patients will want to make this decision on their own. Although the decision regarding AH is usually based on whether it improves quality of life, for some patients, AH will be seen as life prolonging. Involving family carers in these discussions is likely to be helpful.

We have shown that Q-sort methodology is feasible in a palliative care population for exploring ethically challenging issues, and this could be used in clinical practice to clarify patient attitudes' regarding AH and tailor subsequent discussions. This approach has been used in oncology clinics to screen patients for appropriate interventions relating to fatigue.³⁰

There is a risk that health care professionals may withhold AH because they perceive it as a burden on patients and on their interactions with family. Our findings indicate, however, that these patients would wish for a trial of AH and do not see this intervention as a burden or likely to reduce their quality of life. Interestingly, the recently revised Liverpool Care Pathway for the Dying now places greater emphasis on the assessment and management of hydration at the end of life.³¹ Finally, the impact on patients' decisions of evidence-based information regarding the physiological benefits and burdens of AH needs to be tested in a clinical trial.³²

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