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The Meaning of Parenteral Hydration to Family Caregivers and Patients with Advanced Cancer Receiving Hospice Care

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Abstract

Context—In the U.S., patients with advanced cancer who are dehydrated or have decreased oral intake virtually always receive parenteral hydration in acute care facilities but rarely in the hospice setting.

Objectives—To describe the meaning of hydration for terminally ill cancer patients in home hospice care and for their primary caregivers.

Methods—Phenomenological interviews were conducted at two time points with 85 patients and 84 caregivers enrolled in a randomized, double-blind, controlled trial examining the efficacy of parenteral hydration in patients with advanced cancer receiving hospice care in the southern U.S. Transcripts were analyzed hermeneutically by the interdisciplinary research team until consensus on the theme labels was reached.

Results—Patients and their family caregivers both saw hydration as meaning hope and comfort. Hope was the view that hydration might prolong a life of dignity and enhance quality of life by reducing symptoms such as fatigue and increasing patients' alertness. Patients and caregivers also described hydration as improving patients' comfort by reducing pain, enhancing the effectiveness of pain medication, and nourishing the body, mind and spirit.

Conclusion—These findings differ from traditional hospice beliefs that dehydration enhances patient comfort given that patients and their families in the study viewed fluids as enhancing comfort, dignity and quality of life. Discussion with patients and families about their preferences for hydration may help tailor care plans to meet specific patient needs.

Keywords

Parenteral hydration; advanced cancer; hospice; qualitative; caregivers

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Disclosures

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Introduction

The controversy regarding whether to administer hydration during patients' last weeks of life has generated intense debate in the media and the medical literature for over 20 years (1–5). In some countries, such as the U.S., patients with advanced cancer who are dehydrated or have decreased oral intake almost always receive parenteral hydration in acute care facilities but almost never in the hospice setting (6–7). These marked differences in practice patterns occur across practice settings in the U.S., and internationally. Indeed, reported frequencies of providing artificial hydration to cancer patients in the last week of life ranged from 10% to 88% (8). However, what is less clear is if and/or how these divergent practice patterns are influenced by the preferences of patients and their families.

Central to the deliberations occurring across medical, ethical, and legal communities is the question of whether parenteral hydration at the end of life represents the medicalization of death and dying or the fulfillment of a basic human care/need and comfort to patients and their families. Among clinicians, ethicists and the courts, parenteral hydration at the end of life has largely been understood as a *medical treatment* that patients or their proxies may choose based on the potential benefits and risks, and the religious and cultural beliefs of the patients or proxies (9). However, patients and family caregivers may attribute a much different meaning and value to parenteral hydration and equate fluids to food, nurturing, love, warmth, compassion, caring, and comfort. Indeed, the limited number of studies assessing the attitudes of terminal patients and relatives regarding artificial hydration suggests that they tend to hold more positive attitudes towards hydration in the last week of life and often perceive it as clinically useful standard care at the end of life (10–13). Thus, understanding patient and family attitudes, beliefs and preferences regarding difficult end-of-life decisions such as hydrating patients during their last weeks of life becomes central to providing optimal patient- and family-centered care (14).

The controversy surrounding the potential benefits and disadvantages of parenteral hydration remains (15). The arguments in favor and against parenteral hydration in terminally ill patients have been previously summarized (12, 16–17). Arguments in favor of parenteral hydration in advanced cancer patients are: dehydration can cause confusion, restlessness, and neuromuscular irritability; oral hydration is given to dying patients reporting thirst and, therefore, parenteral hydration should also be administered; parenteral hydration is the minimum standard of care in the acute care setting, and withholding parenteral fluid from dying patients may result in withholding therapies from other compromised patient groups; and dying patients have poor quality of life. Therefore, parenteral hydration should be given to reduce dehydration-associated symptoms, resulting in improved comfort and quality of life. Arguments against parenteral hydration in patients with advanced cancer are: comatose patients do not experience symptom distress; less urine results in a reduced need to void or use catheters; dehydration results in less gastrointestinal fluid, nausea and vomiting and respiratory tract problems, and in a decreased frequency and severity of edema and ascites; dehydration may act as a natural anesthetic for the central nervous system; and parenteral hydration is uncomfortable and limits patients' mobility.

A limited number of studies have been published that explore patient and caregiver beliefs concerning parenteral hydration. One Italian survey assessing cancer patients' and family members' perceptions of subcutaneous and intravenous modes of providing hydration at the end of life found that patients and caregivers alike believed that hydration improved both the quality of life and clinical well-being of patients. Both patients and caregivers expressed willingness to continue with parenteral hydration in the home, if it were needed (12). A large population-based survey conducted in Japan with the general population and 866 bereaved

family members of cancer patients who died in palliative care units found that 33% to 50% of the respondents believed "artificial hydration should be continued as the minimum standard until death," and 15–31% agreed that "artificial hydration relieves patient symptoms" (13). A study of 197 terminal cancer patients admitted to a palliative care unit in Taiwan found that the patients related the symbolic nature of food and fluid as an integral component to end-of-life care and 75% of the sample identified a preference for receipt of artificial nutrition and hydration compared to palliative care without artificial nutrition and hydration (11). Another study conducted with 121 Japanese cancer hospice inpatients experiencing insufficient oral intake and their family members identified the following determinants of physician recommendations to hydrate: level of patient distress, presence of denial, recommendation of the physician, and the belief of family members that the presence of parenteral hydration would cause a worsening of the patient's condition (10). A recent small qualitative study of family members of terminally ill patients who had dealt with or would soon deal with issues of hydration in a palliative care program in Halifax, Nova Scotia reported caregiver concerns regarding withholding parenteral hydration and perceptions that it was a viable treatment for weakness, improved the removal of wastes, and was an effective method to reduce pain. Some caregivers reported parenteral hydration was a means to relieve suffering, and other caregivers thought it prolongs suffering. Caregivers also reported the level of patient distress, ethical and moral considerations, dialogue with the health care provider and others, and culture as factors influencing parenteral hydration decisions at the end of life (18).

Research suggests that health care professionals who are aware of the patients' perspective may be less likely to ignore important concerns or to respond in inappropriate ways (19). Therefore, knowledge of patient and caregiver perspectives could provide a more effective basis for clinical interactions and decision making. Thus, the purpose of this study was to understand and describe the meaning of hydration for hospice patients with advanced cancer and their family caregivers.

Methods

Patients and caregivers in the study were participants in a randomized, double-blind, controlled trial that examined the efficacy of parenteral hydration compared with placebo in patients with advanced cancer receiving hospice care. All patients enrolled in the trial were persons with advanced cancer with decreased oral intake (less than 1,000 mL/day, as determined by clinical assessment) and evidence of mild or moderate dehydration. Patients in the trial were randomly assigned to receive 1,000 mL of normal saline (the hydration group) or 100 mL of normal saline (the placebo group) over four hours daily, and were enrolled in the study for a minimum of four days and a maximum of 14 days.

The portion of the study reported here was guided by hermeneutic phenomenological, descriptive and interpretive research methods (19). These research methods are based on phenomenological philosophy, and they are used to determine how people interpret their lives and make meaning of what they experience. The phenomenological approach was used because its purpose is to understand the meaning of an experience from the perspective of the persons who have had that experience (19).

After patients and caregivers signed informed consent forms, they were interviewed separately in phenomenological interviews as close together in time as possible, so that patients and their caregivers did not have the opportunity to discuss their interviews with each other before both sets were completed. We conducted the interviews at baseline (Day 1) and Day 4, resulting in 222 interviews with 85 patients and 84 family caregivers.

Patients were asked to tell us about their experience with being hydrated. Caregivers were asked to describe what it was like for them to have their loved one hydrated. The interviewer used open-ended questions to ensure that the person being interviewed, rather than the interviewer, determined the content discussed. We asked both patients and their caregivers for specific examples to illustrate general statements and encouraged them to discuss their experiences fully. The goal was to help them verbalize — that is, to clarify their own meaning and to ensure that the meaning of their experiences was clearly understood.

As is usual with hermeneutic phenomenological designs (19), data analysis began during data collection. Interviews were audiotaped and transcribed verbatim, and the accuracy of the transcription was verified by a member of the research team. Phenomenological analysis was performed by four investigators, one of who had extensive experience using this type of analysis. The investigators began the analysis by reading each transcript several times to get a sense of each interview as a whole. In the hermeneutic circle, the researcher starts uncovering a tentative notion of the meaning of an experience using reflective awareness. This awareness leads to dialectical examination of parts of the data to better understand the whole. When the whole is understood, different data or the same parts of the data are examined at a deeper level. Then the analysis is repeated. The process helps the researcher to understand the statements in relation to the larger context of the individual's experience. Four of the authors identified the themes in each transcript by examining it line by line and underlining and labeling passages with tentative theme labels. Passages from interview text and labels, or theme labels, for each interview were compared with passages and themes among and between all other interviews with both patients and family caregivers (19).

Procedures to ensure scientific rigor included having the analysis conducted by four researchers, and validation of the themes with members of the research team. All co-authors of the paper reviewed the theme labels and passages, and consensus was reached. Although verification of the theme labels with patients and family members would have been ideal, most patients were no longer alive by the time analysis was completed. Interviews were conducted until data saturation was reached (that is, until no new themes emerged), meeting the standard criterion used in qualitative research (19).

Results

From a total of 85 patients and 84 family caregivers, 222 interviews were analyzed phenomenologically. Patients ranged in age from 38 to 91 years of age, with a mean of 67 years. Among these, 46 (54%) were female, 52 (61%) were white, 18 (21%) African American, 13 (16%) Latino, and two (2%) Asian. Caregivers ranged in age from 18 to 90 of age, with a mean of 56 years. Among these, 66 (79%) were female, 52 (62%) were white, 19 (23%) African American, 11 (13%) Latino, and two (2%) were Asian. More detailed demographics are presented in Table 1.

Hydration was viewed as hope for prolonging dignity and enhancing quality of life by reducing fatigue and increasing patients' alertness and energy. Hydration also was described as enhancing comfort through reducing pain and improving the effectiveness of pain medication. Table 2 outlines the themes and subthemes. Further description of both themes and subthemes follows.

Hope

Two of the caregivers captured the way these participants perceived hydration as providing hope:

My hope is that it means improving her quality of life, that's my biggest hope.

It's been ... a little bit a ray of hope. To prolong her life of dignity... hopefully... to sustain to give her back a little bit of nourishment and put fluids in her body to help her along... with her medication ... cause don't see her vomiting in the time that she's been taking it [hydration].

Life Sustaining: Essential for Survival—Both patients and caregivers viewed hydration as essential for survival. As a patient noted:

I suppose they are giving me part of nutritional values that I need in order to survive... as a person realizes that nothing has change(d) for any better... hoping that's what was causing the problem... not getting enough energy...just need a little more time.

Caregivers also viewed hydration as essential to survival:

A couple of times I thought he was just going to die from the dehydration and the side effects of that... So my hope was that he would get good hydration and that would make his energy better ... help his appetite, the pain control, all that... my understanding is that it helps keep your electrolytes balanced and all the other various chemicals in your body functioning the way they should... you can die sooner without water than you can without food.

Healing/Staying Healthy—The final subtheme in the theme of hope was the perception that fluids had a healing quality. As one patient said, “[It is like medicine] cause it's supposed to help me get better.” Another patient noted, “[It is medicine because] it's something that I have to take ... to stay healthy... It's not that it's enjoyable, food is enjoyable.”

Caregivers talked about many benefits they perceived from hydration, including improved physical and mental health. They were less explicit than patients in viewing the fluids as helping patients to get better or stay healthy, but did view fluids as prolonging life, and helping patients to feel better.

That he does have it [fluids], because if not, then he probably would be hospitalized or pass away sooner without that. ...[fluids] help you and at the same time it does give you, it's like having electrolytes. It is giving you intake, what your body does need, fluids.

Additional comments:

She doesn't eat the way she should eat, and the little strength that she has, I only see the physical aspect of it coming from that which y'all are giving her [fluids].

Finally, a caregiver noted: “The fluids perked him up, he felt a lot better.”

Comfort

The second major theme was comfort. Both patients and caregivers saw hydration as keeping patients comfortable mentally and physically. As a patient noted, “To me it's something that I need to have to feel comfortable.”

Caregivers also described comfort:

He's just been more comfortable overall, and more satisfied ... he has known he was dehydrated and he wanted fluids and so that has helped him...mentally and physically.

Another caregiver described the necessity of hydration:

Your body is made up of water... so it's necessary to keep hydration in your body... nourishment for the body... and if it helps the medicines work that's another plus. What's important is for him to be comfortable, to ease pains in any way possible... and to have his body function as normally as possible, for as long as possible... comfort, I think is the most important thing.

Reducing Pain—Reducing pain was an aspect of comfort patients and caregivers attributed to hydration. A patient said, “They [fluids] are supposed to help with the pain because when you're hydrated your pain is better.”

A caregiver had similar views:

She's not had the pain that she had...at the hospital... with this, we only had pain just two or three times in the last couple of days...and it's only been on maybe on two or three levels, it's not been very high... She's been alert and she's been talking ...she's had a great day.

Enhancing Medication Effectiveness—Patients and caregivers also described fluids as enhancing comfort by making medication more effective. As a patient noted, fluids were “helping the medication do its job.”

Caregivers expressed similar ideas:

It's almost like [a] plant drying up...and as far as medications goes, without the fluids, medication wouldn't work, she needs more fluids for the medication to circulate and do its thing.

Another caregiver summed up the idea of fluids helping medication:

She doesn't really eat enough, so I think it's important to keep hydrated. I don't think that the medicines she is taking really works well without some fluid in her body...So in that case it's kind of a medicine helper if you will.

A final description by a caregiver summarized how some caregivers perceived hydration:

When my mother went into hospice care, I was very concerned that they said that they do not keep fluids coming in on a[n] ongoing basis, and they told me I did not need to encourage her to drink or eat because it was a very natural function, that this be part of the process, it would be abandoned and it sort of the slowing down of her body. We grow up always knowing eat and drink are central to keeping you going. I noticed, she came out of the hospital after a week of being on fluids...the pain wasn't necessarily being managed... it's mixture of different components acting on her, but I'm finding, like now we're not seeing the hallucination that she had additionally when she switched drugs. She's able to sleep better. I'm finding that she's more communicative, she's talking, she's expressing herself as a person rather than as an invalid, she also ate much better this morning. So at this point I'm very encouraged by the results.

Nourishing: Replenish Body, Mind and Spirit—Patients and caregivers also perceived comfort from the hydration replenishing patients in a very holistic way. A patient noted:

I didn't feel so winded and I even felt like maybe I could eat a little bit... it seemed to help replenish my system... give me what my body needs...Makes me feel overall better.

Another patient elaborated:

Almost within the first thirty minutes, I just felt like a different person, I had more energy, I was more alert. ... It kind of replenishes your body...takes away headaches.

One patient considered the fluid as medicine from a spiritual perspective: “I think the water is medicine because that’s why Jesus gives us to drink.”

Caregivers also discussed patients being replenished:

Trying to just keep the situation under control and calm so knowing that there’s going up and that’s just part of it... and what do I do about the worst of it all is the... hallucinations, the terror, that extreme fear that she has, is just horrible. It’s terrible... for a person having it and the person trying to... calm them down ... The weakness... that’s bad but that’s more acceptable than...seeing someone in such extreme fear and... not being rational..... I think of fluids as... nourishing your body... just like you have to have water.

Two additional caregivers talked about the effect of fluids on patients’ mental states:

Because it gives her stuff that apparently that she needs, that she’s not getting from other stuff. Because when she’s on the fluids at the hospital, she’s fine and perky ... just eating, it’s not enough for her. I didn’t expect to see a big difference, but I did expect to see something. But I guess it is working a little...

A second caregiver added:

When she got dehydrated, she seemed to be incoherent and kind of spaced out but when they gave her the fluids, she seems to come back to herself. It may be more than medicine because water has a great importance in the structure of the human cell... the fluid adds nourishment to the cell and the cell adds energy to the body... she seems to be calmer...than she was when you first started... because without the fluids her body wouldn’t be functional because ... our body is made up a large percent of water so if we don’t have the water we can’t function... cells dry up and mental capacity is not what it’s supposed to be.

Enhancing Breathing, Energy and Quality of Life—Fluids were also seen as increasing energy. A patient noted:

I feel that it’s making a new life for me... to have energy to feel better... Now with the new treatment I gain energy, I gain... a good mood.

Another patient noted:

It made me get better...Walk, shave myself, ... go to the living room and watch TV in the den, move around ... a lot more mobile. I felt that severe problems were evident; possibly even death, because it was leading to shortness of breath. Loss, loss of breath is a big problem...Voice cleared up and everything. It’s nutrition for the body. They are the elements that we need to keep the body going... more energy, more appetite, sleeping better...having less anxiety...The fluid reminds me that it’s time to eat if I’m hungry, and the medicine part is if I feel better with the anxiety and without looking for extra air that it’s helping me.

Caregivers also saw fluids enhancing patients’ energy:

I think that there’s a noticeable change. She stays awake a lot more, where as she was sleeping all the time. And she’s more alert and can talk. So I think if that’s due to this, it’s helped her... it’s changed her attitude and activity level...it’s changed her.

A second caregiver added:

Basically, they helped him feel better. Gave him enough hydration to get him over the point of just falling into that sleep stage and not being able to eat and drink for himself. To me, it was like medication, because it helped him to be able to handle the food and drink that he needed... It was not something that he was depending upon... It helped him feel better to where he felt like eating....He's much more alert. He's definitely sleeping very soundly.I mean he's spending the evenings watching movies and not just sleeping around the clock. ... He's eating so much better and still drinking. ...where he had been very lethargic ... when you would try to arouse him he didn't always make a lot of sense....Now, you know, you can get a much quicker response.

Caregivers noted that energy came with improved appearance:

When he got those fluids, he was good to go for the next time, you know, he was perked up. You could tell the difference. Well, the fluid was more like energy builder. ... It was like he ate better, his skin color was better, his lips wasn't as dark.

Strength and mood were both improved:

Because she was more laying and weeping... she started having strength after the IV.... she talks more.

Caregivers hoped for improved quality of life but not a cure or a permanent fix:

We realized it's not anything that's gonna cure. It should help his wellbeing as far as feeling better. ... The doctor told me that the fluids are not gonna take the place of him eating ...they're just gonna help him become hydrated rather than being so dehydrated.

Discussion

To our knowledge, this is the first study conducted with advanced cancer patients and caregivers in the U.S. describing the meaning of hydration in the context of hospice care. The major themes that emerged were hope and comfort. Patients and caregivers hoped for improved symptoms, quality of life, and dignity -- not for a cure or prolongation of life. Caregivers reported that pain management improved with hydration. This is consistent with the findings of Morita et al. (13) regarding the perceptions by caregivers of the importance of hydration in cancer pain relief. Caregivers in this study also felt that the patients had more energy, a better appetite, and better sleeping habits. Caregivers noted patients had a healthier physical appearance, with healthier skin, and were more alert and lucid. The relationship between physical and psychological well-being is manifested through notions of dignity and a "good death." Thus, notions of "hope" and "staying healthy" referred primarily to issues related to improved quality of life and comfort.

Similar to the findings of Parkash and Burge (18), patients and caregivers perceived hydration to be life sustaining. Subsequently, some viewed the lack of hydration as life limiting. Many were concerned that lack of fluids would rapidly increase health deterioration. Both patients and caregivers expressed views that suggest hydration may fulfill a basic human need for water. They conveyed this as a universal need, not just for the ill, and spoke of water/hydration as "central for life." Some felt that hydration is not only necessary to keep one's body functioning to its best capacity, but also could be necessary for the body to function at all. Moreover, many implied that comfort itself is also a basic human need.

No gender or ethnic differences emerged from the narrative. Members of all ethnic groups and both genders discussed both themes and all subthemes. Patients and their family caregivers alike described hydration as providing both hope and comfort. This lack of differences perhaps reflects a common, fundamental, overall meaning attributed to hydration at the end of life, one which transcends ethnic, gender or other subgroup differences. Yet, although this overall meaning seemingly common to the human experience emerged from the present study design, it is possible that a more deductive approach based on the quantitative analysis of categories and labels given to the meaning of hydration would yield significant cultural or group differences. More research is needed in this area.

The findings suggest that patients and family members perceived that parenteral hydration administered to dehydrated persons with advanced cancer in the home setting during the last weeks of life is ethically appropriate, technically feasible and very well received. They saw hydration as important and necessary. Water, many felt, fulfills a basic human need. Patients and their caregivers alike noted that it is essential since our bodies are made up largely of fluids. Fluids, they felt, improved many end-of-life symptoms and thus prolonged dignity and enhanced their quality of life. In addition, they perceived that fluids were necessary to enhance the effectiveness of pain medications and provide comfort.

Limitations

The study had several limitations. One limitation relates to potential selection bias. All the study participants were enrolled in a hydration study and, therefore, open to the possibility of receiving fluids at the end of life. It may be that persons who participated were more likely to have positive attitudes, beliefs and perhaps past experiences related to parenteral hydration than those who refused participation. However, it is difficult to ascertain whether persons who refused held different perceptions regarding parenteral hydration as this information was not collected from them. To minimize bias, all study personnel took part in a standardized and rigorous training program to ensure consistency in recruitment, obtaining of informed consent (which included the study's purpose and description, the investigational nature of the study, potential risk, side effects and benefits) and protocol implementation. Among patients and caregivers who were eligible and approached to participate in this research, 105 refused to participate. Most gave no reason for refusing, but reasons provided included not wanting to participate in research, and not wanting to receive the placebo.

Some of the positive perspectives conveyed by participants may be attributable to patient and caregiver satisfaction with the research staff members' presence and attention. This may have minimized feelings experienced by hospice patients and caregivers related to "abandonment" by the medical system. On a related note, the overwhelmingly positive patient and caregiver perceptions regarding parenteral hydration during their participation in the clinical trial included persons in both the intervention and control groups of the study. This finding may reflect a type of placebo effect or perhaps the social meaning this group of participants attached to water. Another possible reason for the virtual lack of negative perceptions communicated in the study was the timing of the interviews that were conducted on Days 1 and 4 of the trial. It is possible that interviews conducted at a later date may detect negative perceptions not discovered in the current study.

Generalizing the study findings to other countries, cultures, or clinical contexts is cautioned. It is quite possible that meanings attributed to dehydration and artificial hydration may vary across cultures and nations. Generalizing these findings to all hospice patients is also cautioned since the timing of referral to hospice care can vary greatly (20). Our study, conducted in a major urban city of the U.S., only enrolled patients with very advanced disease with decreased oral intake and evidence of dehydration. Hence, the study's findings should be interpreted in the context of its design and objective.

Future Research and Practice

Some patients and caregivers expressed perceptions that fluids had a healing quality, helped patients feel better, were necessary for getting better or staying healthy, and even could prolong life. This study is one of the first to capture important patient and caregiver *perceptions* regarding the meaning of hydration at the end of life. Although some may argue that these perceptions reflect a “sense of false hope,” findings from a recent, well-designed longitudinal study of lung cancer patients suggest that certain levels of denial in cancer patients may have a protective effect on social and emotional outcomes, including role functioning, social functioning, anxiety and depression (21). Patient-rated physical outcomes, such as improved overall perception of health and physical functioning, decreased fatigue, nausea and vomiting, appetite loss, dysphagia and pain also were detected among cancer patients with higher levels of denial (22). Recent studies also suggest that the role of denial in cancer patients may vary by gender and across ethnic groups (22–24). Thus, denial in these populations of cancer patients, it is argued, may reflect an adaptive or coping mechanism that clinicians may need to respect (22, 25). In addition, the meaning of symptoms has been found to alter both patients’ reports of symptoms and limit treatment options that patients find acceptable. Research with persons who reported little or no pain but were overwhelmed with other symptoms such as fatigue and who had significantly diminished quality of life (26) found that they were reluctant to take pain medications. Instead of pain, they described what they felt as a new experience (they were “never sick”), had other ways to deal with the pain (e.g., distraction), or labeled their experiences as something other than pain (e.g., “I notice my joints hurt, felt heavy, I don’t want to say pain.”). All these meanings that they attributed to their feelings left them reluctant to take pain medications.

Recent studies also suggest that palliative care not only improves quality of life, but may also increase survival among lung cancer patients (27). Findings such as these underscore the importance and value of understanding patient perceptions – particularly around issues such as comfort and hope.

More research about the role of hydration in care is needed to better characterize the meaning of dehydration and parenteral hydration at the end of life among patients and their caregivers. Future studies also should examine cultural and gender differences regarding preferences and decision making related to parenteral hydration, as well as the possible role of denial among end-of-life cancer patients receiving artificial hydration and their family caregivers. Furthermore, more research is needed to determine whether improvements in symptoms among persons with advanced cancer may result in “misperceptions” regarding their prognosis, and if so, what types of effects result from these “misperceptions.”

The Liverpool Care Pathway for the dying patient (LCP) has historically considered progressive loss of oral intake and dehydration as part of the normal process of dying and has recommended restricting parenteral hydration in dying patients (28–30). These guidelines were initially premised on the belief that parenteral hydration is harmful and that dehydration produces natural and wanted effects, such as anesthesia, and thus enhances comfort. However, newer versions of these guidelines state, “A blanket policy of clinically assisted (artificial) nutrition or hydration, or of no clinically assisted (artificial) hydration, is ethically indefensible and, in patients lacking capacity, prohibited under the Mental Capacity Act (2005)” (31). Such modifications clearly strengthen the consideration of clinically assisted (artificial) hydration and recommendation that the decision to administer fluids be individualized to patient needs by the treating team. Obtaining a better understanding of individual patients’ and caregivers’ perceptions through improved communication between health professionals, patients and families will be vital to decision making about providing

hydration at end of life and individualizing treatment decisions to best meet specific patient needs.

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References

1. Craig GM. On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? *J Med Ethics*. 1994; 20(3):139–143. discussion 144–145. [PubMed: 7527863]
2. Mion L, O’Connell A. Parenteral hydration and nutrition in the geriatric patient: clinical and ethical issues. *J Infus Nurs*. 2003; 26(3):144–152. [PubMed: 12792372]
3. Lanuke K, Fainsinger RL, DeMoissac D. Hydration management at the end of life. *J Palliat Med*. 2004; 7(2):257–263. [PubMed: 15130203]
4. Derse AR. Limitation of treatment at the end-of-life: withholding and withdrawal. *Clin Geriatr Med*. 2005; 21(1):223–238. xi. [PubMed: 15639048]
5. Hampson LA, Emanuel EJ. The prognosis for changes in end-of-life care after the Schiavo case. *Health Aff (Millwood)*. 2005; 24(4):972–975. [PubMed: 16012137]
6. MacDonald, N.; Fainsinger, R. Indications and ethical considerations in the hydration of patients with advanced cancer. In: Bruera, E.; Higginson, I., editors. *Cachexia-anorexia in cancer patients*. New York: Oxford University Press; 1996. p. 94–109.
7. Bruera E, Belzile M, Watanabe S, Fainsinger RL. Volume of hydration in terminal cancer patients. *Support Care Cancer*. 1996; 4(2):147–150. [PubMed: 8673352]
8. Raijmakers NJ, van Zuylen L, Costantini M, et al. Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects. *Ann Oncol*. 2011; 22(7):1478–1486. [PubMed: 21199887]
9. Casarett D, Kapo J, Caplan A. Appropriate use of artificial nutrition and hydration—fundamental principles and recommendations. *N Engl J Med*. 2005; 353(24):2607–2612. [PubMed: 16354899]
10. Morita T, Tsunoda J, Inoue S, Chihara S. Perceptions and decision-making on rehydration of terminally ill cancer patients and family members. *Am J Hosp Palliat Care*. 1999; 16:509–516. [PubMed: 10661058]
11. Chiu TY, Hu WY, Chuang RB, et al. Terminal cancer patients' wishes and influencing factors toward the provision of artificial nutrition and hydration in Taiwan. *J Pain Symptom Manage*. 2004; 27(3):206–214. [PubMed: 15010099]
12. Mercadante S, Ferrera P, Girelli D, Casuccio A. Patients' and relatives' perceptions about intravenous and subcutaneous hydration. *J Pain Symptom Manage*. 2005; 30(4):354–358. [PubMed: 16256899]
13. Morita T, Miyashita M, Shibagaki M, et al. Knowledge and beliefs about end-of-life care and the effects of specialized palliative care: a population-based survey in Japan. *J Pain Symptom Manage*. 2006; 31(4):306–316. [PubMed: 16632078]
14. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. Washington DC: National Academy Press; 2001.
15. Bruera E, Sala R, Rico MA, et al. Effects of parenteral hydration in terminally ill cancer patients: a preliminary study. *J Clin Oncol*. 2005; 23:2366–2371. [PubMed: 15800328]
16. Fainsinger RL, Bruera E. When to treat dehydration in a terminally ill patient? *Support Care Cancer*. 1997; 5(3):205–211. [PubMed: 9176966]

17. Dalal S, Del Fabbro E, Bruera E. Is there a role for hydration at the end of life? *Curr Opin Support Palliat Care*. 2009; 3(1):72–78. [PubMed: 19365165]
18. Parkash R, Burge F. The family's perspective on issues of hydration in terminal care. *J Palliat Care*. 1997; 13:23–27. [PubMed: 9447808]
19. Cohen, MZ.; Kahn, D.; Steeves, R. *Hermeneutic phenomenology research: a practical guide for nurse researchers*. Thousand Oaks, CA: Sage Publications; 2000.
20. Johnson KS, Kuchibhatla M, Tulsky JA. Racial differences in location before hospice enrollment and association with hospice length of stay. *J Am Geriatr Soc*. 2011; 59(4):732–737. [PubMed: 21410443]
21. Vos MS, Putter H, van Houwelingen HC, de Haes HC. Denial and social and emotional outcomes in lung cancer patients: The protective effect of denial. *Lung Cancer*. 2011; 72(1):119–124. E. [PubMed: 20705356]
22. Vos MS, Putter H, van Houwelingen HC, de Haes HC. Denial and physical outcomes in lung cancer patients, a longitudinal study. *Lung Cancer*. 2010; 67(2):237–243. [PubMed: 19423181]
23. Vos MS, de Haes JC. Denial in cancer patients, an explorative review. *Psychooncology*. 2007; 16(1):12–25. [PubMed: 16868929]
24. Roy R, Symonds RP, Kumar DM, et al. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer*. 2005; 92(8):1393–1397. [PubMed: 15812548]
25. Rabinowitz T, Peirson R. "Nothing is wrong, doctor": understanding and managing denial in patients with cancer. *Cancer Invest*. 2006; 24(1):68–76. [PubMed: 16466995]
26. Cohen MZ, Williams L, Knight P, et al. Symptom masquerade: understanding the meaning of symptoms. *Support Care Cancer*. 2004; 12(3):184–190. [PubMed: 14735337]
27. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010; 363(8):733–742. [PubMed: 20818875]
28. Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Symptom Manage*. 1995; 10(3):192–197. [PubMed: 7629413]
29. Ellershaw, JE.; Wilkinson, S., editors. *Care of the dying: A pathway to excellence*. Oxford: Oxford University Press; 2003.
30. Ellershaw, JE.; Flockton, R.; Murphy, D., et al. *Changing gear: managing the last days of life in adults*. London: National Council for Palliative Care; 2006.
31. Liverpool Care Pathway for the Dying Patient (LCP) supporting care in the last hours or days of life. LCP generic version 12 [Internet]. Marie Curie Palliative Care Institute Liverpool; 2009. Available from [http://www.mcpcil.org.uk/liverpoolcarepathway/Updated%20LCP%20pdfs/LCP_V12_Core_Documentation_FINAL_\(Example\).pdf](http://www.mcpcil.org.uk/liverpoolcarepathway/Updated%20LCP%20pdfs/LCP_V12_Core_Documentation_FINAL_(Example).pdf)

Table 1Sample Characteristics of the Participants ($n=169$)

Variable	Patient $n=85$ (%)	Caregiver $n=84$ (%)	Total $n=169$ (%)
Gender			
Male	39 (46)	18 (21)	57 (34)
Female	46 (54)	66 (79)	112 (66)
Age, mean (range)	67 years (38–91)	56 years (18–90)	62 years (18–91)
Ethnicity			
White	52 (61)	52 (62)	104(61)
Black	18 (21)	19 (23)	37 (22)
Latino	13 (16)	11 (13)	24 (14)
Asian	2 (2)	2 (2)	4 (3)
Relationship to patient^a			
Spouse		44 (53)	44 (53)
Child		22 (27)	22 (27)
Other		17 (20)	17 (20)
Missing		1 (1)	1 (1)
Cancer Diagnosis^b			
Gastrointestinal	38 (44)		38 (44)
Lung	16 (19)		16 (19)
Breast	7 (8)		7 (8)
Ovarian	6 (7)		6 (7)
Urological	3 (4)		3 (4)
Head and Neck	3 (4)		3 (4)
Other	12 (14)		12 (14)

^aCaregivers only.^bPatients only.

Table 2

Themes and Subthemes

Hope

Life sustaining: Essential for survival

Healing/Staying healthy

Comfort

Reducing pain

Enhancing medication effectiveness

Nourishing: replenish body, mind and spirit

Enhancing breathing, energy and quality of life
