Published in final edited form as:

BMJ Support Palliat Care. 2012 September 1; 2(3): 276–279. doi:10.1136/bmjspcare-2012-000205.

Food or Medicine: Ethnic Variations in Perceptions of Advanced Cancer Patients and their Caregivers Regarding Artificial Hydration During the Last Weeks of Life

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Abstract

Purpose—To identify whether advanced cancer patients receiving home hospice care and their primary caregivers view artificial hydration (AH) as food or medicine and the demographic and clinical factors influencing these perceptions.

Methods—Participants were enrolled in a randomized, double-blind controlled trial examining the efficacy of AH in cancer hospice patients. In-depth interviews at days 1 and 4 of study enrollment explored the meanings attributed to AH at the end-of-life. Responses to the question, “Are these fluids more like food or more like medicine?” were categorized as “food”, “medicine”, “both” or “other”. Chi-square analyses were conducted with data from 122 interviews (54 patients and 68 caregivers) to identify differences between patients and caregivers, and by gender, age, ethnicity and caregiver relationship. Predictors of perceptions were identified using logistic regression analysis.

Results—Overall, 47 participants (38%) understood the fluids to be more like food, 41 (34%) as medicine, 17 (14%) as both and 17 (14%) as “other”. Ethnic minority participants (N = 34, 66%) were significantly more likely than Non-Hispanic European Americans (N = 30, 42%) to view AH as food, or both as food and medicine ($P = 0.034$). Ethnic differences persisted in the final regression model (odds ratio [OR] 2.7; 95% CI 1.3–5.7, $P = 0.010$). No significant differences were detected between patients and caregivers, or across gender, age, caregivers’ relationship to the patients, group assignment, disease severity or cancer type.

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Competing Interest: None declared.

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Conclusions—AH was perceived as food/nutrition by many cancer patients and caregivers in the study, particularly among ethnic minorities. This perception may lead to greater distress if fluids are discontinued or withheld. Asking patients/caregivers about their AH perceptions may enhance patient/provider communication and culturally appropriate end-of-life care.

Keywords

parenteral hydration; advanced cancer; hospice; caregivers; decision-making; minorities; health disparities

INTRODUCTION

Artificial hydration (AH) for patients with advanced cancer is a controversial therapy commonly employed during in-patient treatment but generally withheld from patients receiving hospice care.[1] The decision of whether to provide AH to patients during their last weeks of life may be complex and is influenced by ethical, legal, sociocultural, physical considerations, as well as patient and family preferences and emotions.[2]

The symbolic nature of water, fluids and drinking and hydration has been described in the sociological, bioethical and qualitative literature.[3–5] Withholding fluids at the end-of-life, indeed, is believed by some to hasten death and to be morally abhorrent [4, 6] as water and fluids are frequently equated to human rights.[7] On the other hand, traditional hospice philosophy recommended restricting AH believing that dehydration enhances comfort as part of the normal dying process and that AH may lead to unwanted symptoms, prolonged suffering and an overly medicalized death.[8, 9]

The limited number of studies exploring patient and caregiver perceptions regarding AH at the end-of-life have reported generally positive attitudes and support for AH.[2, 10–14] For instance, most palliative cancer patients and their caregivers in one Italian study believed that AH was an effective, useful and desirable medical treatment that is able to provide some nutrition.[13] These researchers argued for greater assessments of patient and family preferences regarding AH given that the choice is challenging from a clinical perspective. [13]

Research regarding whether patients and caregivers view AH more as a medical procedure or as food and nutrition has been limited. Examining perceptions related to this fundamental dichotomy among patients and caregivers is needed to facilitate decision-making regarding AH at end-of-life and to inform the development of appropriate end-of-life communication strategies and care. The purpose of the study was to identify whether advanced cancer patients receiving home hospice care and their primary caregivers view AH as food or medicine and the demographic and clinical factors associated with these perceptions.

MATERIALS AND METHODS

Participants

Cancer patients and primary caregivers in the study were participants in a larger randomized, double-blind controlled trial examining the efficacy of subcutaneous AH as compared to placebo in hospice cancer patients. This study was approved by the Institutional Review Board of The University of Texas MD Anderson Cancer Center. All participants signed informed consent forms. In-depth separate interviews with patients and caregivers at baseline (day 1) and day 4 of their participation explored the meanings attributed to hydration at the end-of-life. The interview was an additional and optional component of the larger trial and interviews were not conducted with patients and in many cases with

caregivers, if the patient was severely ill and non-responsive. Due to the advanced status of their disease, a large proportion of patients and/or caregivers were unable to complete the interviews. The qualitative findings from these interviews are currently in press.[15] Participants and caregivers were also asked if they believed hydration to be more like food or medicine. Fifty-four of the 131 cancer patients and 68 of the 131 caregivers enrolled in the trial were able to answer the question on either day 1 or day 4 ($N = 70$), or both days ($N = 52$). For all participants, we evaluated only their first-time responses to ensure comparability across respondents since not all respondents were able to answer the questions on both days. We therefore report on a total of 122 responses from 122 participants.

Statistical analysis

We examined the responses to the question, “Are these fluids more like food or more like medicine?” Answers were categorized as: a) food, b) medicine, c) both, or d) other. Chi-square analyses were conducted to determine whether patients and caregivers responded differently to the question, and if responses varied across gender, age and ethnicity. The potential influence the caregiver’s relationship to the patient may have had on their responses was also investigated, as was the participants’ group assignment (i.e., enrollment in the intervention vs. control group of the trial). We also examined if cancer type and disease severity (measured by survival time between dates of interview and death) influenced AH perceptions among interviewees. Additionally, we assessed non-response bias by comparing respondent and nonrespondent distributions of all independent variables. Finally, predictors of perceptions were identified using logistic regression analysis and adjusted for age and gender based on prior research.[10, 14] All statistical analyses were conducted using SPSS release 16.01 (SPSS Inc., Chicago, Illinois, 2007). For all analyses, significance was set at $p < .05$ (two tailed).

RESULTS

Table 1 details the characteristics of the study participants and displays the bivariate association between the category ascribed to hydration by participants and their characteristics ($N=122$). Overall, 47 participants (38%) understood the fluids to be more like food, 41 (34%) as medicine, 17 (14%) as both and 17 (14%) as “other” (e.g., “vitamins”, “just saline”). Ethnic minority participants ($N = 34$, or 66%) were significantly more likely than Non-Hispanic European Americans ($N = 30$, or 42%) to view parenteral fluids as food, or both as food and medicine ($P = 0.034$). However, we found no significant differences in responses between patients and caregivers or across gender, age, caregivers’ relationship to the patients, group assignment, disease severity or cancer type. The ethnic differences persisted after adjusting for age and gender (odds ratio [OR] 2.7; 95% CI 1.3–5.7, $P = 0.010$). Finally, participants who were unable to respond were significantly older than those who responded (63% over age 60, vs. 45% respectively, $P = 0.006$), as well as more infirm than responders (mean survival of 24 days vs. 39 days respectively, $P = 0.005$).

DISCUSSION

Our findings suggest that over half of the participants believed that AH has some nutritional role. Consequently, these patients and caregivers may experience greater distress if fluids (understood as basic sustenance) are withheld or discontinued due to the symbolic significance of nourishment/food and drink and the associated emotions.[4, 5] Thus, this perception of AH may reflect an ethical position in which the withholding of AH is considered inhumane and a denial of patients’ rights to basic care.[16] Notions of AH as medicine (or a medical treatment), however, have different ethical implications, since medical treatments are carefully guided by clinical assessments of the potential benefits and

burdens. Since these participants were enrolled in a clinical trial of the effects of hydration, these findings may not be representative of the overall cancer population, or other types of patients and more research is needed to assess patient and caregiver perceptions in a representative hospice population.

The provision of AH has been largely regarded by health care professionals as a medical treatment and not as basic care.[7, 16] In a previous manuscript, our team reported findings from a qualitative study describing the meaning of hydration for terminally ill cancer patients in home hospice care and their primary caregivers enrolled in the clinical trial examining the efficacy of parenteral hydration compared with placebo. The overarching themes that emerged from the phenomenological interviews were “hope” and “comfort” – hope for improved symptoms, quality of life, and dignity and comfort associated with the control of pain and shortness of breath, for instance. However, ethnic differences related to the meaning of hydration did not emanate from the phenomenological interviews; rather the universal themes of hope and comfort emerged, transcending salient constructs such as ethnicity.[15] Nevertheless, culture, understood as the compilation of shared meanings, values, rituals, and modes of interacting with others that inform how people view and understand the world, may strongly influence attitudes and preferences related to end-of-life care.[17] Consequently, we investigated this hypothesis further quantitatively by analyzing responses to the specific question, “Are these fluids more like food or more like medicine?” An important finding was that ethnic minorities in this study (66%) were more likely to equate AH to food when compared to Non-Hispanic European Americans (42%).

Ethnic and cultural differences have been well documented regarding other end-of-life issues such as hospice use, attitudes, beliefs and use of advance directives, disclosure of diagnostic and prognostic information preferences, end-of-life treatment and decision making preferences, place of death and notions of a good death.[17] However, this is the first study to investigate ethnic differences in perceptions of AH at the end-of-life. One study limitation was the use of the umbrella terms “Latinos” and “Asians” as measures of ethnicity since neither group is monolithic; each comprised of subgroups with varied cultural belief systems that may influence their views of AH at the end-of-life. Nonetheless, identifying some of the beliefs and barriers regarding the decision making process in this challenging area may provide *preliminary* evidence for culturally appropriate end-of-life communication strategies and care that incorporates individual assessments of the pros and cons of hydrating in each particular context. Indeed, AH may be one more area where it is crucial to better tailor clinical encounters to meet the diverse, multicultural needs and expectations of patients and families in our society. More research is therefore needed to better characterize the meaning of hydration in larger, culturally well-defined, diverse samples of patients and caregivers.

Notably, while ethnicity was associated with patient and caregiver perceptions of AH in the study, other demographic characteristics examined were not. Unfortunately, data on the participants’ education, religiosity and spirituality were not available. It is possible that some of these variables might influence perceptions of AH at the end-of-life, as well as interact with ethnicity, and should be investigated in future studies.

Patients who were unable to complete these interviews were older and more infirm (or were the caregivers of the severely ill) than those who completed the interviews. This is one of the challenges commonly faced in palliative care research and we were unable to ascertain whether persons who could not or did not answer the questions, held different views regarding AH than those who responded. However, future research should anticipate this challenge and continue to attempt to capture these perceptions among the older and more infirm populations. Our study did not allow for multiple assessments of the primary research

question since an insufficient proportion of participants answered the question on both days. Further research is needed as well to prospectively assess the stability of patient and caregiver perceptions over time.

Decisions about hydration can be emotionally and ethically challenging issues in end-of-life care. Our findings identified a significant discrepancy between how many patients/caregivers and health care professionals perceive AH. In instances where advanced cancer patients begin to decrease their oral intake of fluids and/or when the discontinuation of AH is being considered, health care professionals should ask patients and/or their caregivers about their perceptions regarding the role of AH. This would create important opportunities for assessing individual needs and preferences and providing counseling and education as needed in cases of severe distress or difficult decision making situations, addressing the appropriateness of providing or withholding AH to patients who are near the end of their lives. This preliminary study has generated an important hypothesis regarding possible ethnic differences in AH perceptions that should be carefully tested in subsequent studies.

Acknowledgments

Drs. Isabel Torres-Vigil and Marlene Z. Cohen had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Data used in the manuscript resulted from "Parenteral Hydration in Advanced Cancer Patients: A Randomized Controlled Trial", funded by the National Institutes of Health/ National Cancer Institute, R01CA122292. Dr. Torres-Vigil was supported in part by the National Cancer Institute (3R01CA122292-03S1 and 1K01CA151785-01). Dr. Marlene Z. Cohen was supported in part by the National Institutes of Health (R01CA122292-01 and R01NR010162-01A). Dr. Eduardo Bruera was supported in part by the National Institutes of Health (R01CA122292-01, R01NR010162-01A, and R01CA124481-01). The funders had no specific role in the conduct of the study or the development of the submission.

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Table 1

Sample description and the category ascribed to AH by participant characteristics (N=122)

Variable	Food (%)	Medicine(%)	Both (%)	Other(%)	Total (%)	P value
Participants						
Total	47 (38)	41 (34)	17 (14)	17 (14)	122 (100)	N/A
Patient	20 (37)	21 (39)	6 (11)	7 (13)	54 (44)	.687
Caregiver	27 (40)	20 (29)	11 (16)	10 (15)	68 (56)	
Gender						
Male	16 (38)	14 (33)	7 (17)	5 (12)	42 (34)	.911
Female	31 (39)	27 (34)	10 (12)	12 (15)	80 (66)	
Ethnicity^a						
Non-Hispanic European-American	24 (34) ^b	28 (39) ^c	6 (9) ^d	13 (18) ^e	71 (58)	.034
African American	11 (41)	8 (30)	6 (22)	2 (7)	27 (22)	
Latino	12 (52)	4 (17)	5 (22)	2 (9)	23 (19)	
Asian American	0 (0)	1 (100)	0 (0)	0 (0)	1 (1)	
Age						
18–60	25 (37)	20 (30)	12 (18)	10 (15)	67 (55)	.481
61–93	22 (40)	21 (38)	5 (9)	7 (13)	55 (45)	
Relationship to patient^f						
Spouse	15 (43)	12 (34)	5 (14)	3 (9)	35 (52)	.418
Child	7 (50)	2 (14)	3 (22)	2 (14)	14 (21)	
Other	5 (28)	6 (33)	2 (11)	5 (28)	18 (27)	
Cancer Type^g						
Gastrointestinal	8 (33)	7 (29)	5 (21)	4 (17)	24 (44)	.815
Lung	4 (40)	4 (40)	0 (0)	2 (20)	10 (19)	
Urological	2 (33)	4 (67)	0 (0)	0 (0)	6 (11)	
Ovarian	2 (50)	1 (25)	0 (0)	1 (25)	4 (7)	
Head and Neck	1 (33)	1 (33)	1 (33)	0 (0)	3 (6)	
Breast	1 (50)	1 (50)	0 (0)	0 (0)	2 (4)	

Variable	Food (%)	Medicine(%)	Both (%)	Other(%)	Total (%)	P value
Other	2 (40)	3 (60)	0 (0)	0 (0)	5 (9)	

^a Comparisons based on Non-Hispanic European-American vs. African American, Latino and Asian American

^b Food; 34%, Standard error (SE) = 28 – 40 vs. 66%, SE = 59 – 73

^c Medicine; 39%, SE = 33 – 45 vs. 61%, SE = 54 – 68

^d Both; 9%, SE = 0 – 20% vs. 42%, SE = 38 – 46

^e Other; 18%, SE = 13 – 23 vs. 82%, SE = 77 – 87

^f Caregivers only;

^g Patients only