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Nutrition and hydration for terminal cancer patients in Taiwan

Published online: 18 September 2002
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Abstract Many medical professionals are still confused when facing the reduction of food or fluid intake in terminal cancer patients. The aim of this study was to assess the frequency and causes of the inability of eating or drinking in terminal cancer patients and to investigate the use of artificial nutrition and hydration (ANH); the frequency, type, and the extent to which staff found ANH to be ethically justified. Three hundred forty-four consecutive patients with terminal cancer admitted to a palliative care unit in Taiwan were recruited. A structured data collection form was used daily to evaluate clinical conditions, which were analyzed at the time of admission, 1 week after admission and 48 h before death. One hundred thirty-three (38.7%) of the 344 patients were unable to take water or food orally on admission; the leading cause was GI tract disturbances (58.6%). This impaired ability to eat or drink had become worse 1 week after admission (39.1%, $P<0.01$) and again 48 h before death (60.1%, $P<0.001$). The total rate of ANH use declined significantly, from 57.0% to 46.9% 1 week after admission ($P<0.001$), but rose again to the same level as at admission in

the 48 h before death (53.1%, $P=0.169$). Parenteral hydration could be reduced significantly 1 week after admission ($P<0.05$), but no reduction was possible in the 48 h before death; nor was it possible to reduce the nutrition administered. Multiple Cox regression analysis shows that the administration of ANH, either at admission or 2 days before death, did not have any significant influence on the patients' survival (HR: 0.88, 95% CI: 0.58–1.07; HR: 1.03, 95% CI: 0.76–1.38). In conclusion, sensitive care and continuous communication will probably lessen the use of ANH in terminal cancer patients. We have found it easier to reduce artificial hydration than artificial nutrition, which corresponds to local cultural practice. Whether or not ANH was used did not influence survival in this study. Thus, the goals of care for terminal cancer patients should be refocused on the promotion of quality of life and preparation for death, rather than in simply making every effort to improve the status of hydration and nutrition.

Keywords Nutrition · Hydration · Terminal cancer · Survival · Ethics

Introduction

The reduction of food or water intake and the use of artificial nutrition and hydration (ANH) in terminal cancer

patients are confusing and troubling issues for the medical staff involved in the care of these patients. Otherwise, the symptoms related to malnutrition or dehydration, such as asthenia, anorexia, and nausea/vomiting,

which usually appear as part of the natural process of dying and are often difficult to manage, are also severely distressing the patients, their families and the medical staff caring for them [2, 5, 8, 21]. Many medical professionals still lack expertise in managing these issues properly and comfortably [12, 15].

Early studies suggested that aggressive nutritional therapy could improve the response to antineoplastic treatments or reduce the incidence and/or severity of complications in these patients [3, 18]. However, later randomized controlled studies have suggested that aggressive nutritional therapy has no impact on tumor response, toxicity, or survival [1, 9]. Moreover, one animal study showed that aggressive nutritional therapy could significantly increase tumor growth [20]. It is widely recognized that the outcome measures of aggressive nutritional therapy for patients with advanced cancer should also include the patients' overall quality of life [14]. Unfortunately, there is currently no evidence that aggressive nutrition therapy can improve such patients' quality of life [10, 14, 16, 19, 22, 23].

In Taiwan, the decision to use or forgo artificial nutrition and hydration (ANH) remains a perplexing and emotional issue in the care of terminally cancer patients. A previous study in Taiwan, conducted in 1998, showed that about one quarter of palliative care patients have encountered the ethical conflicts of using nutrition and hydration during their stay in hospital [7]. We felt that in the interests of providing better communication and appropriate support for nutrition and hydration, an exploration of the current use of nutrition and hydration in these terminally ill patients would be helpful.

The aims of this study were to assess the frequency and causes of inability to eat or drink in terminal cancer patients. In addition, an investigation of the use of ANH, including its frequency and type and the extent to which staff found ANH to be ethically justified, should also be carried out. The results suggest improvements which may promote the local quality of terminal care.

Patients and methods

Patients

Three hundred forty-four consecutive patients with advanced cancer who were admitted to the hospice and palliative care unit of National Taiwan University Hospital between January 2000 and the end of February 2001, were enrolled in the study. Patients whose cancers were not responsive to curative treatment were identified in an initial assessment performed by members of the admissions committee. The selection of patients and design of this study were approved both by the National Science Council in Taiwan and by the ethical committee in the hospital. By the end of the study period, 319 (92.7%) of the patients had died.

Instrument

The assessment tool used was a recording form designed after a careful scrutiny of the literature in this area by the investigators. The form was tested for content validity with a panel comprising physicians, a nursing supervisor, senior nurses and a dietitian, all of whom were experienced specialists in the care of terminal cancer patients. In addition, a pilot study was conducted for 1 month in the same unit. The pilot study further confirmed the instrument's content validity and ease of application. The instrument recorded demographic data (gender, age), clinical oncological conditions (primary cancer sites, metastases, outcome, and survival time), hydration and nutrition status, conditions of nutrient intake (route of intake, type of nutrients), causes of any inability to eat or drink (consciousness disturbance, head/neck cancer, esophageal obstruction, gastrointestinal tract disturbances, fatigue/anorexia due to underlying pathology, and emotional factors), the use of ANH [frequency, type (tube feeding and parenteral hydration and nutrition)] and the extent to which staff found ANH to be ethically justified (appropriate, only acceptable, or inappropriate to the decision to use ANH).

Impaired eating or drinking was defined in the study as the inability to take water or food by mouth. When the patient becomes unable to take water or food orally, the care problems and ethical conflicts arise very easily. Patients who could take even a little water by mouth were not considered impaired as defined in this study.

Methods

Conditions of water and nutrient intake, prevalence of common symptoms, and the use of artificial nutrition and hydration were recorded daily by the same members of staff. Data were assessed and subsequently analyzed at the time of admission, 1 week after admission, and 48 h before death (retrospectively) in a weekly team meeting. All of the 344 patients admitted, including 243 patients whose stay in the hospice extended to longer than 1 week and 273 patients who had died in the hospice, were completely assessed. Moreover, we analyzed the clinical circumstances of each case and investigated the conflicts among patients, families and medical staff in decision-making relating to the use of ANH on the basis of moral discussions in the 60 weekly team meetings held during the study period.

The use of ANH at the time of admission was usually dependent on a previous prescription issued by the referring physicians, despite the fact that the amount of ANH was always rapidly reduced to less than 1 l of fluid after admission on the basis of the patient's condition. The decision to use ANH 1 week after admission was always made on the basis of consultation among medical staff, patients and families, indicating the effectiveness of such communication.

Statistical analysis

Data management and statistical analysis were performed using SPSS 8.0 statistical software (SPSS, Chicago, Ill.). Frequency distributions were used to describe the demographic data and the distribution of each variable. Mean values and standard deviation were used to analyze the severity of each symptom. The McNemar test was used to compare the changes between frequency of the capability of oral intake and the use of ANH. A paired *t*-test was used to compare the differences in fluid amounts at different times. Afterward, multiple Cox regression analysis was used to examine the influence of the following factors on survival: gender, age, primary cancer sites, common symptoms in the study patients (fatigue, pain, and confusion), the capability of oral intake, and the use of ANH. A *P*-value less than 0.05 was considered statistically significant.

Table 1 Demographic characteristics of patients

Variables	<i>n</i>	%
Sex		
Male	188	54.7
Female	156	45.3
Age group		
=18	5	1.4
19–35	15	4.4
36–50	64	18.6
51–64	77	22.4
=65	183	53.2
Mean±SD	62.18±15.81	
Primary sites of cancer		
Lung	74	21.5
Liver	59	17.2
Colorectal	39	11.3
Stomach	26	7.6
Head and neck	25	7.3
Pancreas	21	6.1
Cervical/uterine	14	4.1
Breast	10	2.9
Uncertain	9	2.6
Esophagus	8	2.3
Others	59	17.1
Outcome		
Discharge	79	23.0
Death	265	77.0
Survival days		
=3	46	13.4
4 to 7	58	16.9
8 to 30	140	40.7
=31	75	21.8
Mean±S.D.	23.94 ± 30.39	
Alive still	17	4.9
Referred to other cities	8	2.3
Total	344	100.0

Results

The primary cancer sites in these patients were lung (21.5%), liver (17.2%), colon/rectum (11.3%) and stomach (7.6%); 274 patients (79.7%) already had metastases. Around a third of the patients (30.3%) died within 1 week of admission, and mean survival was 23.94 days. The demographic characteristics are displayed in Table 1.

Table 2 shows the prevalence and causes of the inability to take water or food by mouth. One hundred thirty-three patients (38.7%) were unable to eat or drink at the time of admission, for which the main causes in the opinion of the medical staff were gastrointestinal tract disturbances (58.6%), systemic disorders including fatigue or anorexia due to the underlying pathology (42.9%), disturbed consciousness (33.8%), and emotional factors (8.3%). Two hundred eleven patients (61.3%) were capable of taking water or food orally on admission, but 143 of them (67.8%) needed help from caregivers. One week after admission, the percentage of the remaining 243 patients who were incapable of eating or drinking was significantly higher than on admission (39.1% vs 32.1%, $P<0.001$). The percentage worsened to 60.1% 2 days before death, with significant differences from the situation in the same 273 patients at the time of admission (41.4%, $P<0.001$), when systemic disorders, including fatigue and anorexia due to the underlying pathology, became the leading cause of inability to eat or drink (43.3%). One hundred nine patients (39.9%) were still able to take some water or food by mouth 2 days before death, but nearly all ($n=108$, 99.1%) of them need help from their caregivers.

As seen in Table 3, 196 (57.0%) of the 344 patients received ANH on admission, with its prevalence signifi-

Table 2 Frequency and causes of inability to eat or drink in terminal cancer

	Admission		One week after admission		Two days before to death	
	No.	%	No.	%	No.	%
Unable to eat or drink orally?						
Unable to	133	38.7	95	39.1*	164	60.1**
Able to	211	61.3	148	60.9	109	39.9
Total patients	344	100.0	243	100.0	273	100.0
Main causes of inability to eat and drink by mouth (multiple choices)						
Consciousness disturbance	45	33.8	32	33.7	56	34.1
Head/neck tumor	34	25.6	26	27.4	27	16.5
Esophageal obstruction	15	11.3	13	13.7	11	6.7
GI disturbances	78	58.6	53	55.8	69	42.1
Systemic disorders including fatigue or anorexia	57	42.9	37	38.9	71	43.3
Emotional factors	11	8.3	8	8.4	9	5.5
Total impaired patients	133		95		164	

* $P<0.01$: the ability decreased compared to the same patients ($n=243$) at the time of admission; ** $P<0.001$: the ability decreased compared to the same patients ($n=273$) at the time of admission

Table 3 Use of artificial nutrition and hydration (ANH) in terminal cancer patients

	Admission		One week after admission		Two days before death	
	No.	%	No.	%	No.	%
Using ANH?						
Using	196	57.0	114	46.9*	145	53.1
Not using	148	43.0	129	53.1	128	46.9
Total	344	100.0	243	100.0	273	100.0
Types of ANH (multiple choices)						
Tube feeding	44	12.8	31	12.8	35	12.8
Parenteral						
1) Hydration and electrolyte	153	44.5	90	37.0**	118	43.2
2) Glucose	127	36.9	77	31.7	106	38.8
3) Other nutrients (albumin, amino acid, intrafat,.. etc)	66	19.2	37	15.2	50	18.3
Mean amount (ml) of i.v. fluid	862±618		714±528*		637±420***	
Total	344		243		273	

* $P<0.001$: decreased compared with the condition of the same patients ($n=243$) at the time of admission; ** $P<0.05$: decreased compared to the condition of the same patients ($n=243$) at the time of

admission; *** $P<0.001$: decreased compared to the condition of the same patients ($n=273$) at the time of admission

Table 4 Effects perceived by patients subjectively and ethical acceptability of medical staff toward the use of ANH

	Admission		One week after admission		Two days before death	
	No.	%	No.	%	No.	%
Effects perceived by patients who used ANH (only for patients using ANH)						
Discomfort	5	2.5	2	1.8	9	6.2
Not changed	149	76.0	76	66.6	109	75.2
More comfort	42	21.5	36	31.6	27	18.6
Medical staff's acceptance of use of ANH in the patients from moral viewpoint						
Appropriate	158	80.6	97	85.1	123	84.8
Only acceptable	38	19.4	17	14.9	21	14.5
Inappropriate	0	0.0	0	0.0	1	0.7
Total	196	100.0	114	100.0	145	100.0

cantly decreasing to 46.9% after 1 week in the hospice, as against 58.4% of the same 243 patients on admission ($P<0.001$). The percentage of patients receiving ANH increased again, to 53.1%, in the 48 h before death, although it was still lower than the percentage of the same 273 patients receiving ANH (57.5%) on admission ($P=0.169$).

Concerning the types of ANH, we found the percentage of patients using parenteral hydration (including electrolytes) 1 week after admission declined to a statistically significant extent from the percentage of the same 243 patients at the time of admission (37.0% vs 44.5%, $P<0.05$). However, there was no further statistically significant decline in the percentage in the 48 h before death (43.2%, $P=0.597$). Compared with the situation at the time of admission, the percentage of patients being tube fed and receiving glucose or other nutrients parenterally was not significantly lower either 1 week after ad-

mission or 48 h before death. Furthermore, in the study the volume of parenteral fluids used in the patients was calculated, revealing that the mean amount of i.v. fluid used declined significantly from 862±618 ml at the time of admission to 714±528 ml 1 week after admission ($t=10.82$, $P<0.001$). This tendency to decline persisted into the 2 days before death, when the mean volume was 637±420 ml ($t=8.671$, $P<0.001$).

Table 4 shows the effects and the moral acceptability of using ANH. As far as the effects perceived by patients after ANH are concerned, only 4 (2.0%) out of 196 patients complained of discomfort on admission, which was assessed by the medical staff from the aspect of care. On admission, in the majority (80.6%) of patients receiving ANH this was recognized as an appropriate decision by the medical staff in the weekly ethical discussions, but in some cases (19.4%) the decision to implement ANH was thought to be acceptable only from the

Table 5 The influence of ANH use on the survival of patients by using multiple Cox regression analysis

	Hazard ratios (95% CI)	<i>p</i> -Value
Using ANH at the time of admission	0.88 (0.58–1.07)	0.34
Using ANH 2 days before death	1.03 (0.76–1.38)	0.86

moral aspect. It is worth mentioning that the percentage of those feeling there was an inappropriate use of ANH persisted until very near the death of the patients concerned, implying potential conflicts among patients, families, and medical staff. In this study the clinical circumstances of each patient were also analyzed and the decision-making conflicts experienced among patients, families and medical staff in relation to the use of ANH were investigated. Twenty-three (6.7%) out of 344 patients or their families insisted on the use of ANH immediately on admission although it was thought to be inappropriate on the basis of a careful assessment made by medical staff. These conflicts persisted into the 48 h before death in 17 (6.2%) of the 273 patients remaining.

Both the families and the medical staff always worry that if ANH is withheld from terminally ill patients this may shorten the patient's life. Therefore, this study also examined the influence of ANH on patients' survival. The results of multiple Cox regression analysis (Table 5) show that ANH, either on admission or 2 days before death, does not significantly influence survival (hazard ratios: 0.88, 95% CI: 0.58–1.07; hazard ratios: 1.03, 95% CI: 0.76–1.38).

Discussion

This prospective study not only recorded the frequency and causes of eating and drinking impairment, but also investigated the details and morality of ANH in terminal cancer patients. Past experience in Taiwanese hospices has shown that one of the most common controversies at the interface between general hospital wards and palliative care units is that over the use of ANH. When we have more evidence about the appropriate use of hydration and nutrition in terminal cancer patients, this may lead to better care both in palliative care units and on general hospital wards.

Although in this study the percentage of patients unable to take fluid or food by mouth as a result of the disease process increased after admission, the percentage of patients using ANH significantly declined after admission because of constant care and appropriate information from the several aspects. Clinically, more than one third (38.7%) of the patients studied were unable to eat or drink at the time of admission. The fact that the proportion is so large indicates the importance of managing this problem. First, we comprehensively assessed the reasons for these difficulties, noting: incorrect types of

food, inappropriate time to supply, stomatitis, physiological causes, and any emotional factors. Many patients in the study were able to take more food or water by mouth after improved oral hygiene, a change in food type, or assistance with family–patient interaction. Corticosteroids (time-limited trials) and prokinetic agents were often given to improve the appetite and facilitate the passage of food, lowering the need for ANH. It then became possible for the mutual interaction among patients, families and medical staff to be more intimate, thereby paving the way for a higher quality of care. In this study, the percentage of ANH use increased again before death, implying renewed difficulties with decisions about ANH use near death. Further exploration of the concerns of patients and families in this phase will be valuable. Moreover, although hydration by a subcutaneous route is a preferred approach in many hospices [4, 11], this procedure is still rarely used in Taiwan. Development of this simple technique may be very helpful in solving some of these difficulties arising in the time immediately before death.

Concerning socio-cultural issues, in most cultures the provision of food or drink is seen as a basic act of caring. Feeding has powerful symbolic and social significance [17], especially in Asia. Difficulty in eating or drinking often leads to anxiety in the patient's loved ones, who worry that the patient will starve to death and therefore become a "starving soul" after death. Such cultural concerns in Taiwan are behind family requests to provide food or fluids, particularly nutrients, which is reflected in the findings of this study, indicating that it would be possible to reduce the use of artificial hydration more than the use of nutrition. These concerns might cause greater discomfort for patients and make it necessary for them to be in hospital rather than at home.

With regard to withholding or providing ANH, we explain the causes of problems with eating or drinking and the potential benefits and drawbacks of ANH to the patients (if possible) and to their families, although the evidence for some of these benefits and drawbacks remains inconclusive. Communication seems to have improved in the study hospice, where 25% of patients reported conflicts about the use of ANH in 1998 [7], but only under 10% of patients admitted to this study encountered the same trouble in 2001. Furthermore, perhaps since the majority of Taiwanese are Buddhists, they usually believe that a "good death" can only be achieved in a Buddhist care model, especially in the very terminal stage. The staff in the study hospice always gently explained that in

Buddhism excessive nutrition or hydration is inappropriate to enlightenment and inspiration, both of which are helpful in achieving a better afterlife. Families usually understand and accept this explanation, and it relieves their anxiety to some extent. The staff also encourage family members to stay with the patients and provide delicate care in such forms as touching, kissing, or speaking Buddhist phrases; this replaces the use of ANH, which may be linked with the idea of the best care in the minds of the families. After such care, although the inability to take fluid or food by mouth becomes very prominent in the dying process, the number of patients using ANH did not increase (53.1%), and the proportion of cases in which there were conflicts between the medical staff and the families was not considered remarkable (6.7%).

With regard to ethical implications, the U.S. Supreme Court has made a clear distinction between withdrawal of life support and assisted suicide, namely, between allowing death and killing. When the intention behind discontinuation of ANH is to cause death it is not ethically permissible. If the intention is to cease futile treatment, discontinuation is ethically justified [14, 23]. The staff of Taiwanese hospices have also received intensive training in the ethical implications of ANH in recent years. The findings of this study also show that ANH has no significant influence on survival, which could be explained with reference to the "terminal common pathway" in cancer patients [6, 21], which may validate the ethical nature of withholding ANH, which always involves drawbacks or risks that are disproportionate to the benefits for these patients. Legally, ANH has been recognized as a medical treatment, which can be refused by a competent adult or a surrogate decision maker appointed

through an advance directive [16, 22]. This is embodied in the Natural Death Act enacted in Taiwan in June 2000 [13]. This law not only represents respect for the dignity of the terminally ill, but also facilitates ethical decision-making in end-of-life care including the use of ANH.

Certain caveats should be mentioned in relation to this study. First, the authors have attempted to research artificial nutrition and artificial hydration together in this exploratory study, owing to the generally held ideas about mixing the provision of nutrients and fluid in Taiwan. However, it may be better to clarify this issue in further empirical work. Second, the energy of the nutrients administered was not calculated in the study, though this may also be important in the decision-making behind the use of ANH.

In conclusion, the prevalence of inability to eat or drink in terminal cancer patients is rather high, which is due to the natural course of the disease. Delicate care and continuing communication can be helpful in avoiding unnecessary artificial nutrition or hydration. Artificial hydration is found to be easier to decrease than nutrition. Whether or not ANH was given did not influence survival in the study. Thus, the goals of care for these terminal cancer patients should be re-focused on the promotion of quality of life and preparation for a good death, rather than on simply making every effort to improve the hydration and nutrition status.

Acknowledgements This research was supported by the National Science Council in Taiwan (NSC 89-2314-B-002-560). The authors are indebted to the faculty staff of the Department of Family Medicine, National Taiwan University Hospital, for their full support in conducting this study and also to Ms. Y.Y. Pan for her assistance in preparing the manuscript.

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