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ORIGINAL ARTICLE

Decision making at the end of life—cancer patients' and their caregivers' views on artificial nutrition and hydration

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Abstract

Purpose Deciding on artificial nutrition and hydration (ANH) at the end of life (EoL) may cause concerns in patients and their family caregivers but there is scarce evidence regarding their preferences. Therefore, the aim of this study was to assess the impact of factors associated with ANH decision making.

Methods: Prospective, Cross-sectional survey. Adult patients admitted to hospital for symptoms of advanced cancer as well as their family caregivers completed a self-administered questionnaire. Items included personal views and concerns about ANH. Family caregivers additionally recorded their preference for their loved one and, if applicable, previous experience with ANH decisions.

Results Thirty-nine out of sixty-five patients and 30/72 relatives responded. Higher age of the patient was significantly correlated with both the patient's and the relative's decision to forgo ANH (Kruskal-Wallis test, $p<0.01$). Thirty-nine percent of patients, 37 % of relatives if deciding for themselves, and 24 % of relatives if deciding on behalf of their loved one opted against ANH; 36, 40 and 52 % preferred artificial hydration (AH) only (χ^2 test, $p<0.001$), while 23, 23 and 24 %, respectively, wished to receive ANH. Patients felt more confident about decisions on artificial nutrition (AN) than caregivers (*T* test, $p<0.05$) and less concerned about adverse effects of forgoing ANH on pain, agitation and sensation of hunger and thirst (χ^2 test, $p<0.05$). Satisfaction of patients with communication regarding forgoing ANH (5.0±2.8 on a Likert scale from 0 to 10) correlated with their confidence (Spearman's rho, $p<0.01$). A thorough consultation with the attending physician on ANH issues was the favoured source of support for 77 % of patients and 97 % of relatives. A majority of patients considered their relatives' opinion (67 %) and their own advance directives (62 %) as crucial for making ANH decisions, and 46 % of them had such a document completed.

Conclusion Cancer patients and their relatives have similar preferences regarding ANH at the EoL, but relatives are reluctant to withhold AH if deciding for their loved one. While patients seem to be confident with ANH decision making, their caregivers may particularly benefit from discussing ANH options to dissipate fears.

Keywords Decision making · Caregivers · Artificial nutrition and hydration · Advance care planning · Questionnaire

Introduction

In patients with far-advanced and life-limiting conditions such as cancer, artificial nutrition and hydration (ANH) may be offered to those who suffer from potentially reversible malnutrition or dehydration and whose estimated prognosis allows them to benefit from ANH. However, reduced oral intake is itself recognized as a phenomenon indicating impending death [1]. When discussing ANH with these patients and their

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families it is paramount to ensure an open communication and to consider individual values and preferences.

Generally, there are inconsistent data about the benefit/burden ratio of ANH at the end of life (EoL) [2, 3]. While a recent randomized, placebo-controlled trial in the USA did not find any effect of artificial hydration (AH) on symptom control [4], a qualitative sub-study of this trial showed that AH was nevertheless valued by family caregivers and patients as improving comfort and "nourishing the body, mind, and spirit" [5]. In a UK qualitative study, AH was considered to be a key issue by the patients, and they wanted to be involved in decision making [6], while the authors point at health care professionals' perceptions that may differ from the patients' views [7, 8]. According to a Taiwanese survey, "patients with terminal cancer have insufficient knowledge about ANH and still believe in the benefits of ANH" [9]. In a large Japanese population-based survey, 33–50 % of the respondents thought that "AH should be continued as the minimum standard until death" [10].

The perception may change, however, during the dying process: an Australian qualitative study found gradual rather than abrupt cessation of intake and no associated signs of suffering in patients while families remained worried [11]. Moreover, a majority of physicians and nurses in Japan observed no beneficial effect of AH [7], a finding which is supported by a systematic review documenting generally less optimism among health care professionals than in patient/relatives cohorts that show large variation in attitudes towards AH [8]. A European survey (OPCARE9 collaboration) revealed that, regardless of the country, 89 % of physicians and nurses agreed that more evidence on ANH decisions could improve EoL care [12].

However, despite this body of literature with extensive documentation of attitudes, beliefs and meaning, it is not known how patients themselves and their relatives decide in "real life" conditions and which factors affect the decision-making process; moreover, these factors may be related to cultural background while most findings are from Far East countries. Therefore, the aim of this study was to prospectively evaluate the needs, concerns, preferences and experiences of patient-caregiver dyads in Germany when faced with a decision regarding ANH at the EoL.

Methods

Study subjects

From June 2009 to March 2010, in the University hospital of Munich, the following departments were contacted by a senior researcher (SL): Gynaecology, General Internal Medicine, Neurology, Neurosurgery, Ear, Nose and Throat Surgery, General Surgery, Urology (all of them providing active anticancer treatment and supportive care interventions such as parenteral nutrition, antibiotic courses or growth factors to manage side effects), and the Department of Palliative Medicine. Consecutive cancer patients and their family caregivers were screened for enrollment according to the study protocol by those units. A researcher (TU) then asked eligible patients and their closest relative or friend for informed consent.

Eligibility criteria included the following: (a) diagnosis of advanced or metastatic cancer, (b) age ≥18 years, (c) inpatient admission (except to an ICU) for treatment of cancer-related symptoms, (d) being fully informed about the nature and prognosis of the condition, (e) literacy in German and (f) no apparent signs of impaired cognition or decision-making capacity.

Approval was granted by the institutional ethics review board (project no. 184/84).

Study questionnaire

An anonymized questionnaire in German, used previously to explore the practices of ICU personnel in limiting life-sustaining treatment [13], was modified for the present work to cover specific issues of forgoing ANH (which includes withholding and withdrawal of ANH) in a palliative care population. This adapted version was initially evaluated in staff members of Palliative Care teams at our institution and at two other hospitals; furthermore, two hospices and a community hospital without Palliative Care services took part in the piloting.

To obtain an English version for publication, two persons who were not involved in study design and conduction (one native English speaker, one person with a degree in English language) translated the questionnaire into English. From these two resulting versions, the authors by consensus drafted a final version for publication (see Appendix), which was then translated back into German and finally compared with the original questionnaire to detect inconsistencies in the translating process.

Gender, age and religious denomination of all participants were recorded. The questionnaire for patients contained 10 items (patient questionnaire [PQ] 1–10). The 12 items of the version for relatives/friends (relative questionnaire [RQ] 1–12) include additional questions about the preference of relatives speaking on behalf of the patient (RQ 2) and about the relatives' satisfaction with previous ANH decisions they had been involved in (RQ 10). Both versions cover core domains of ANH decision making (questionnaires see Appendix). To document religiosity, the four-item tool “Idler Index of Religiosity” (IIR) [14] was included. Questionnaires were handed out by one of the researchers (TU) to patients and those relatives who were named as caregivers by the patients after voluntary written informed consent had been obtained, and they were returned by internal mail before discharge.

Another version of the questionnaire was designed for health care professionals (HCPs); results will be published separately.

Statistical analysis

Descriptive statistics (arithmetic mean, median and standard deviation) was used to characterize the study population. To test for normal (Gaussian) distribution, the Kolmogorov-Smirnov test was performed. If normal distribution was absent, the subsequent analyses were done by non-parametric testing.

To show correlation between ordinal variables, the spearman coefficient was calculated. For detecting significant differences between the groups, the χ^2 test, the T test and the Kruskal-Wallis test were used. To adjust for multiple testing, the Bonferroni correction was applied whenever appropriate. Significance was assumed for $p<0.05$. Data analysis was performed by commercially available statistics software (IBM SPSS, Version 21).

Results

Subject demographics

Between June 2009 and March 2010, 65 cancer patients and 72 relatives met the eligibility criteria. Of these, 39 patients (60 %) and 30 relatives (42 %) consented to study participation and returned the completed questionnaires. All subjects were from a Southern German region with a predominantly Roman Catholic background. They were receiving supportive care for cancer-related symptoms; none of the patients was imminently dying, and none of them was managed on an EoL care pathway. Relatives were mostly female (73 %) being life partners in 20 (67 %) or patients’ children in 6 (20 %) of cases (Table 1).

Table 1 Characteristics of patients and relatives

		Patients (n=39)	Relatives (n=30)
Gender, no. (%)	Female	16 (41)	22 (73)
Age, years	Mean±SD	63.9±12.8	59.6±10.9
	Median	68.0	65.0
Relatives’ relationship to patient, no. (%)[a]	Spouse		15 (50)
	Unmarried partner		5 (17)
	Child		6 (20)
	Sibling		1 (3)
	Not specified		3 (10)
Religious denomination, no. (%)[a]	Roman Catholic	21 (54)	17 (56)
	Protestant	10 (26)	8 (27)
	No denomination	6 (15)	3 (10)
	Not specified	2 (5)	2 (7)

SD standard deviation

[a] Categories derived from free text answers in the RQ

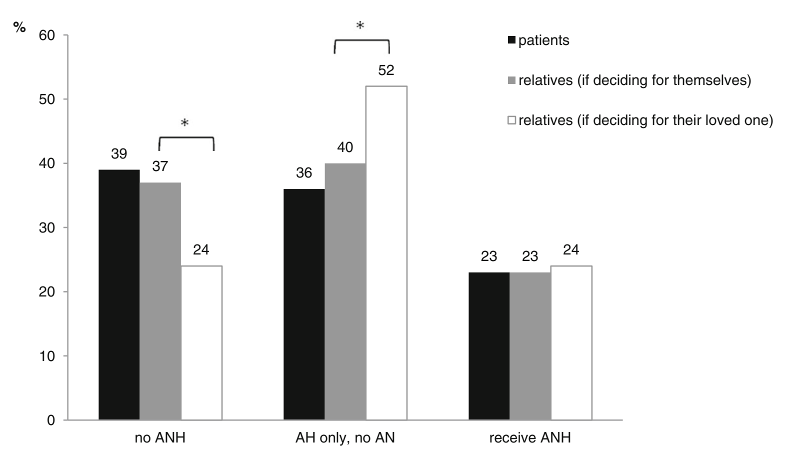
Preferences and confidence about ANH decisions

When asked about preferences regarding ANH for themselves at the EoL, both patients and their relatives responded in a similar pattern favouring no ANH or AH only over receiving ANH (χ^2 test, p=0.0045, Fig. 1, black and grey columns). However, if asked to decide on behalf of the patient (white columns), relatives were more likely to opt for AH and less likely to forgo ANH altogether than patients (χ^2 test, p=0.00048) or relatives deciding for themselves (χ^2 test, p=0.0051). The theoretical possibility to forgo AH but to opt for AN was not chosen by the participants.

Patients’ older age was associated with their own decision to forgo ANH (Kruskal-Wallis test, p=0.001). In addition, relatives of older patients were more likely to be opposed to ANH, both when deciding for themselves (Kruskal-Wallis test, p=0.008) and on behalf of the patient (Kruskal-Wallis test, p=0.007). The age of the relatives, however, was not related to their own ANH preferences (Kruskal-Wallis test, p= 0.254).

In the patients’ and caregivers’ perception, the amount of information received did not influence that attitude (Kruskal-Wallis test, patients: p=0.458; caregivers: p= 0.115). Moreover, in both patients (Kruskal-Wallis test, p=0.150) and relatives (Kruskal-Wallis test, p=0.250), there was no association with religiosity. However, within the group of relatives, having been informed about ANH positively correlated with their confidence to decide about this matter (Spearman’s rho, AN 0.477, p=0.016; AH 0.433, p=0.034). When asked about their confidence to decide about AN, patients were significantly more confident than relatives (Table 2).

Having been previously involved in decision making about ANH for a dying family member (n=14) did not influence their attitudes (χ^2 test, p=0.236) nor raise the level of confidence (Kruskal-Wallis test, AN p=0.916; AH p=0.515), while confidence during that prior event correlated positively



Responses to items PQ 1 (black), RQ 1 (grey), and RQ 2 (white columns). The response option “AN only, no AH” was not chosen by any participant.

*χ^2-Test, $p < 0.05$ after adjustment for multiple testing (Bonferroni)

Fig. 1 How would you decide about ANH at the EoI?

with being satisfied with that previous decision (Spearman’s rho 0.684, $p=0.028$).

Concerns and fears regarding ANH decisions

Fears regarding the consequences of forgoing or withholding ANH relate to physical symptoms, the need of communicating and ethical and existential doubts. Regarding physical symptoms, relatives more frequently express concerns about pain, hunger/thirst and agitation than patients, while patients are more often bothered by ANH discussions with HCPs than relatives (Fig. 2, χ^2 test, $p<0.05$). No significant differences were found for religious, ethical/moral and legal issues and family discussions on ANH.

Support needs regarding ANH decisions

Regarding support, both patients and relatives preferred to receive detailed information on ANH decisions by their treating physician rather than by official guidelines or ethico-legal counselling (Fig. 3).

Table 2 Confidence regarding decision on

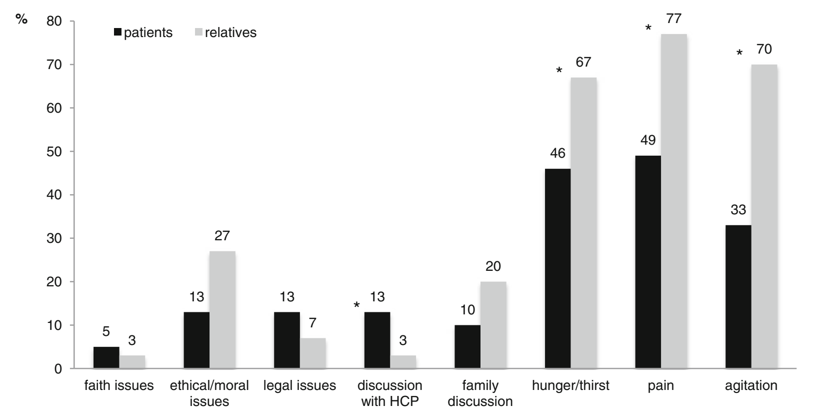
	Patients ($n=39$)	Relatives ($n=30$)	*T* test
Artificial nutrition (AN)	6.2±2.9	4.7±3.2	$p=0.0495$
Artificial hydration (AH)	6.5±3.0	5.0±3.2	$p=0.0769$

Values are means±SD on an 11-point Likert scale from 0 (extremely unconfident) to 10 (extremely confident). *p* values for comparison of patients’ with relatives’ group (normal distribution)

The mean overall satisfaction of patients with hitherto existing support and communication regarding forgoing ANH was 5.0±2.8 on a Likert scale from 0 to 10 and correlated positively with confidence regarding decisions on AN (Spearman’s rho 0.582, $p=0.008$) and AH (Spearman’s rho 0.603, $p=0.006$). Relatives who had been involved in a prior decision to discontinue ANH reported a satisfaction with communication in that situation of 5.5±3.4, which was not associated with past or present confidence (Spearman’s rho 0.595, $p=0.106$) or satisfaction with that decision 6.6±2.7 (Spearman’s rho 0.324, $p=0.662$).

Advance care planning in ANH decisions

Of all patients, 18 (46 %) had any form of advance care document (ACD) completed, of whom seven (18 %) had an advance directive (“Patientenverfügung”) only, one (3 %) a durable power of attorney (“Vorsorgevollmacht”) only and ten (25 %) had both documents. Among the 17 patients with documented living will, eight (47 %) opted for discontinuing ANH at the EoL, one (6 %) for continuing only AN and four (23.5 %) for providing only AH, while four (23.5 %) did not make explicit decisions on ANH issues. The patients’ score of confidence about their decision in the ACD was 6.4±2.8 which correlated with the overall confidence level regarding AN (Spearman’s rho 0.497, $p=0.02$) and AH (Spearman’s rho 0.579, $p=0.004$). In the relatives’ group, six (20 %) had an AD with one (3 %) having a



Responses to items PQ 6 (black) and RQ 6 (grey columns) with pre-specified answer options. All responses refer to possible adverse effects on the patient at the EoL.

* χ^2-Test, $p < 0.05$ after adjustment for multiple testing (Bonferroni)

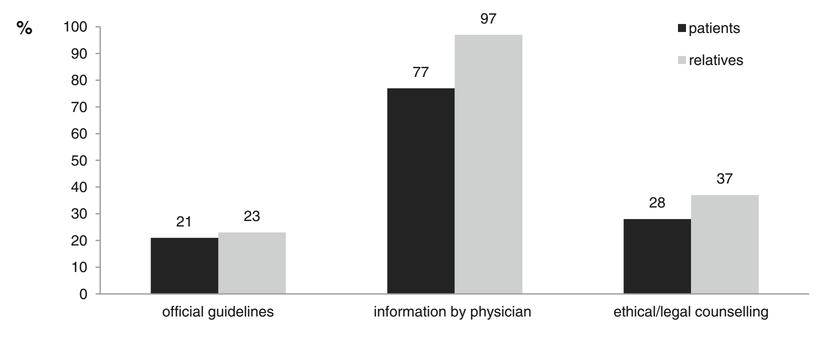
Fig. 2 What are you concerned about when deciding against ANH?

living will only, two (7 %) a durable power of attorney only and three (10 %) had both. Among the four relatives with a documented living will, two opted for discontinuing ANH and two for continuing only AH.

When asked about the preference of decision-making authority, 26 patients (67 %) wished their relatives to be involved, 24 (62 %) opted for a written ACD to be followed and 17 (44 %) wanted a team of physicians to make the decision (more than one option allowed). The subset of 14 relatives who had previously witnessed such a decision-making process reported involvement of ACDs, earlier patient statements, and relatives' opinions (Fig. 4).

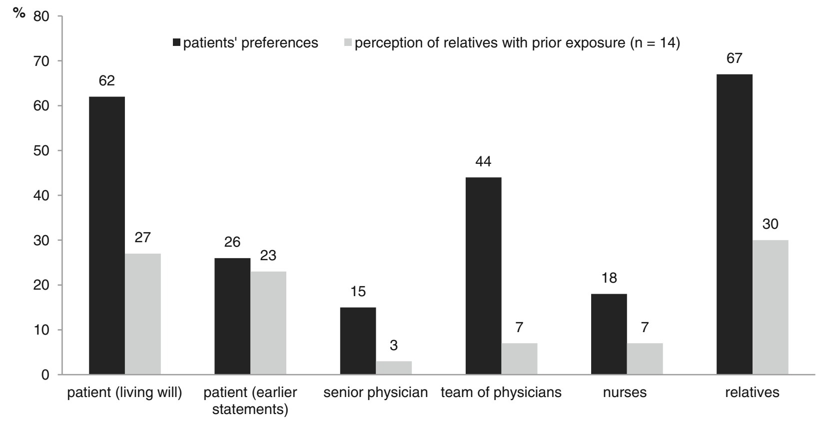
Discussion

The findings of this prospective, cross-sectional survey encompass: (1) advanced age of the patients was correlated with a decision to forgo ANH both by themselves and by their relatives; (2) 39 % of patients opted against ANH, 36 % allowed AH only and 23 % preferred receiving ANH at the



Responses to items PQ 4 (black) and RQ 5 (grey columns) with pre-specified answer options.

Fig. 3 Preferred sources of support



Responses to items PQ 9 (black) and RQ 9 (grey columns), pre-specified answer options. Patients were asked to give their current preference. Relatives with prior involvement in an ANH decision were asked to recall their perception. Multiple answers were allowed.

Fig. 4 Who makes the decision?

EoL; (3) relatives who had to decide on behalf of the patient were more likely to opt for providing AH (52 %) than relatives who spoke for themselves (40 %); (4) confidence regarding AN decisions was higher in patients than in relatives; (5) amount of information and grade of religiosity did not influence ANH decisions, but information was correlated with confidence in relatives; (6) previous exposure to a proxy ANH decision did not affect relatives' attitude or confidence; (7) relatives more frequently reported concerns about physical symptoms than patients when ANH is to be discontinued; (8) both patients and relatives preferred information provided by the clinicians as the main source of support and (9) the majority of the patients preferred their relatives and their own AD as the main basis for decision making.

Compared to published work [5, 9], this study focused on evaluation of practical preferences of patients actively treated for advanced cancer and their caregivers regarding ANH decisions rather than to address general attitudes or knowledge. The present findings—patients judging benefits more adequately, displaying less concerns and more confidence regarding ANH decisions than their relatives—concur with the empirical data [2, 4] and HCPs' opinions [7] that show, if any, very limited evidence of ANH benefits. Moreover, it has been shown in the general population [15] and in surrogates of patients in the vegetative state [16] that judgement may be more in favour of interventions if deciding for someone else. Regarding the role of ADs, the data corroborate an earlier German report that showed ADs to be highly important to terminally ill persons [17]. At the same time, the finding that more than a third of patients and relatives would rather not choose ANH at the EoL challenges the optimism about potential ANH benefits seen in qualitative studies [5, 6]. There are two complementary explanations for these findings: (A) Patients with advanced disease (even if not imminently dying) may yield other results than healthy subjects or caregivers. An Australian longitudinal, qualitative study exploring dying persons' and their caregivers' perspectives [11] has shown that patients experience a gradual decline in the need for oral intake rather than an abrupt cessation with little associated suffering while their caregivers report specific concerns about withdrawing ANH. (B) The large majority of data have been collected in Asian-Pacific patients [8]; the only European survey was done in Italy [18]. A strong belief in ANH benefits, both in terminal patients [9] and in the general population [10], seems to be predominant. It is not known whether (and if, to what extent) cultural background characteristics account for the rather moderate expectations regarding ANH in this German study. In another EoL setting (deciding on invasive ventilation for end-stage amyotrophic lateral sclerosis), Japanese physicians far more often recommended ventilator therapy than their US colleagues [19], a finding which supports this cultural hypothesis. The German Medical Association explicitly stated in 2004 that basic medical care does not necessarily include ANH "as this may pose a serious burden to dying persons" [20]. Thus, it encourages its members to choose a differentiated approach to care of the dying, but published data are lacking up to date.

There are limitations to this study. First of all, as the design was cross-sectional, there is no longitudinal description of ANH decision processes while preferences may change during the disease trajectory. Some more subtle and individual aspects may not be detected by the quantitative methodology of a structured questionnaire. Second, including both AH and AN in one survey might have blurred the respondents' distinction between otherwise separate decision-making pathways. Third, results from a single-centre study on cancer patients and their relatives may not be applied to other settings or subjects. And fourth, a comparison with international results was beyond the scope of this study.

Among the strengths are the use of a questionnaire that had been used to study a related question (limiting life-sustaining treatments) in another setting (ICU) [13] and included a structured and validated instrument to measure the grade of spirituality/religiosity in a person [14]. Several factors that affect decision making had been described as a result of a qualitative study [6] and were accounted for by the questionnaire used here (content, self-confidence, information/communication, support, concerns, advance directives, persons involved). Moreover, all data were self-reported. A key feature of this study was to collect data at the individual patient/caregiver rather than the HCP level. Furthermore, information on the impending decision process is linked with caregivers' experience of prior ANH decision making. This approach for the first time offers insights into the perspectives and preferences of German cancer patients regarding ANH at the EoL.

Open research questions are as follows: (1) Cross-cultural issues and differences in factors affecting EoL decisions between Asian and European countries have to be identified, but factors associated with lifestyle (e.g. "traditional" vs. liberal background) rather than ethnicity will also have to be accounted for. (2) Although the amount of information has been measured, the resulting level of knowledge regarding ANH—another contributing factor [6] possibly of greater importance—has not been assessed formally. (3) The individual relevance of EoL issues may be a function of disease status and thus subject to change over time. Also, the finding that old age of the patient was associated with a decision against ANH both by the patient and her/his relatives has to be addressed in order to exclude ageism. (4) Moreover, the entire population of interest includes also patients with diagnoses other than cancer whose specific needs will have to be addressed. Research projects therefore should address international variance, the impact of knowledge and disease trajectory and the needs of non-cancer patients.

Finally, these findings call in mind that seriously ill patients often have a clear opinion on what they prefer at the EoL. At the same time, misconceptions on ANH may cause emotional burden [21]. Therefore, discussions should start as long patients are capable of participating in decision making. While the mere amount of information, religious affiliation and relatives' prior experience seemed to be of lesser weight, HCPs have to pay attention to build both knowledge and confidence on ANH issues in patients and caregivers, to acknowledge the importance of family members' opinions and to actively address concerns and fears to dispel myths about ANH discontinuation.

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Conflict of interest The authors declare that there is no conflict of interest. In particular, there has not been any personal involvement of any of the authors with the funding agency. All authors have full control of the primary data and they agree to allow the journal to review their data if requested.

Appendix

Questionnaire for Patients (PQ1-10)

Demographic Data

Sex: female male
Occupation*:_________________________
Age:_________________________
Religion*:_________________________
* Fields marked with a star are optional.

If patients suffering from terminal illness are no longer able to eat or drink by themselves, the persons (relatives, doctors) responsible for their care are faced with the question of whether or not the patient should receive artificial nutrition and/or hydration therapy.

1. What would you decide to do for yourself in this situation?
   not to accept artificial nutrition or hydration
   accept only artificial nutrition
   accept only artificial hydration
   accept artificial nutrition and hydration

2. How many texts related to this topic (in books, newspapers, magazines, leaflets) have you already read?
   none <5 5-10 10-20 >20

3. (a) How confident do you feel in situations where decisions about artificial nutrition need to be made? (Please score your position by marking the appropriate number with an ‚X‘.)

0	1	2	3	4	5	6	7	8	9	10

extremely unconfident extremely confident

(b) How confident do you feel in situations where decisions about artificial hydration therapy near the end of life need to be made? (Please score your position by marking the appropriate number with an ‚X‘.)

0	1	2	3	4	5	6	7	8	9	10

extremely unconfident . extremely confident

4. What form of support would you wish for if you were in such a situation?
   more than one answer possible
   official guidelines that describe the procedure
   thorough consultation with the attending physician
   ethical/legal consultation
   other:_______________________

5. How satisfied were you with the communication you have so far experienced in these situations?

0	1	2	3	4	5	6	7	8	9	10

extremely dissatisfied extremely satisfied

6. What doubts or fears would you connect with the refusal of artificial nutrition and hydration therapy at the end of life?

more than one answer possible

religious doubts or beliefs
moral and ethical doubts, or a bad conscience
uncertainty relating to legal matters/fear of legal consequences for family members involved in the decision making process
uncertainty/fear of discussing the decision with doctors/nursing staff
uncertainty/fear of discussing the decision with family members
fear of experiencing hunger and thirst
fear of pain
fear of experiencing restlessness or agitation in one's last hours

7. Have you established a living will or a durable power of attorney for yourself?
I have …

a durable power of attorney a living will neither

8. What decision did you come to in filling out your living will?

not to carry out artificial nutrition or hydration
accept only artificial nutrition
accept only artificial hydration
no decision concerning artificial nutrition or hydration

9. Who would you rather have to decide in this situation?

more than one answer possible

My will as a patient must be carried out according to the existing written record (living will).
My assumed will as patient must be reconstructed from previous verbal statements if not available in written form.
A senior physician is to decide.
The decision is to be made collectively by the medical team.
The nursing staff is to be included in the decision making process.
The family members are to be consulted in this decision.
Other: ____

10. How confident did you feel about your decisions when you wrote your living will?

0	1	2	3	4	5	6	7	8	9	10

extremely unconfident . extremely confident

Further comments:

Questionnaire for Relatives (RQ 1-12)

Demographic Data

Sex: female male

Occupation∗: ___________________________
Age: ___________________________
Relationship to patient∗: ___________________________
Religion∗: ___________________________

∗ Fields marked with a star are optional.

If patients suffering from terminal illness are no longer able to eat or drink by themselves, the persons (relatives, doctors) responsible for their care are faced with the question of whether or not the patient should receive artificial nutrition and/or hydration therapy.

1. What would you decide to do for yourself in this situation?
   - not to accept artificial nutrition or hydration
   - accept only artificial nutrition
   - accept only artificial hydration
   - accept artificial nutrition and hydration

2. How would you decide for a relative in this situation?
   - not to accept artificial nutrition or hydration
   - accept only artificial nutrition
   - accept only artificial hydration
   - accept artificial nutrition and hydration

3. How many texts related to this topic (in books, newspapers, magazines, leaflets) have you already read?

   none <5 5-10 10-20 >20

4. (a) How confident do you feel in situations where decisions about artificial nutrition need to be made? (Please score your position by marking the appropriate number with an ‚X‘.)

0	1	2	3	4	5	6	7	8	9	10

extremely unconfident extremely confident

(b) How confident do you feel in situations where decisions about artificial hydration therapy near the end of life need to be made? (Please score your position by marking the appropriate number with an ‚X‘.)

0	1	2	3	4	5	6	7	8	9	10

extremely unconfident extremely confident

5. What form of support would you wish for if you were in such a situation?

   more than one answer possible

   - official guidelines that describe the procedure
   - thorough consultation with the attending physician
   - ethical/legal consultation
   - other:_______________________

6. What doubts or fears do you connect with the refusal of artificial nutrition and hydration therapy at the end of life?

more than one answer possible

religious doubts or beliefs
moral and ethical doubts, or a bad conscience
uncertainty relating to legal matters/fear of legal consequences for family members involved in the decision making process
uncertainty/fear of discussing the decision with the patient.
uncertainty/fear of discussing the decision with doctors/nursing staff
uncertainty/fear of discussing the decision with family members
fear that the dying person experiences hunger and thirst
fear that the dying person experiences pain
fear that the dying person experiences restlessness or agitation in her or his last hours

7. Have you established a living will or a durable power of attorney for yourself?
I have …
a durable power of attorney a living will neither

8. What decision did you come to in filling out your living will?
not to carry out artificial nutrition or hydration
accept only artificial nutrition
accept only artificial hydration
no decision concerning artificial nutrition or hydration

Please, answer the following questions only if you have already been engaged previously with making similar decisions:

9. In case you have had to make a similar decision in the past, in your own opinion, how did the decision process proceed?

more than one answer possible

The patient's requests were followed if there was a written document (living will).
If there was no written documentation, the alleged will of the patient is reconstructed from previous verbal statements.
A senior physician decided what is to be done.
The decision was made collectively by the medical team.
The nursing staff was included in the decision making process.
The family members were consulted in this decision.
Other:____

10. Looking back, how satisfied are you now with the decisions that were taken at that time?

0	1	2	3	4	5	6	7	8	9	10

extremely dissatisfied
extremely satisfied

11. How confident about the decision did you feel at that moment?

0	1	2	3	4	5	6	7	8	9	10

extremely unconfident
extremely confident

12. How satisfied were you with the communication in those situations?

0	1	2	3	4	5	6	7	8	9	10

extremely dissatisfied extremely satisfied

Further comments:

Idler Index of Religiosity

1. How often do you attend religious meetings, or religious services?

Never
1–2 times a year
Every couple of months
1-2 times a month
Once a week
Several times a week

2. How many people in your religious community (i.e. church, mosque, synagogue, bible group) do you know?

no one
a few
more than half
all, or almost all
not applicable, as I am not a member of a religious community

3. How would you describe yourself?

very religious
quite religious
slightly religious
not religious
I am opposed to religion.

4. How much strength and comfort do you draw from your religious beliefs?

no strength and comfort
some strength and comfort
a lot of strength and comfort

not applicable, as I am not religious

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