

Ethical issues in withholding or withdrawal of artificial nutrition and hydration

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A I M : The purpose of this study was to identify and explore the main ethical dilemmas arising for a health care team working in a clinical nutrition unit when decisions about withholding or withdrawal of artificial nutrition and hydration (ANH) of seriously ill patients have to be made. The potential factors influencing this decision-making process are also described.

M A T E R I A L - M E T H O D : Fifteen health carers working in a Clinical Nutrition Unit in the United Kingdom participated in the study and qualitative research methods were used to gather data.

R E S U L T S : The findings of the study illustrate that withdrawal of life-sustaining nourishment is one of the most difficult ethical dilemmas for the health care professionals. The reason for such difficulty is associated with the potential outcome of that intervention, as it brings about a patient's death. Furthermore, quality of life issues appear to influence the decision-making process. When the patient's voice is absent, the health care team takes into account the perspectives of the patient's family, in order to decide to abate life-sustaining nourishment.

C O N C L U S I O N S : By exploring the health carers' attitudes on ethical issues and identifying their involvement in the decision-making process, an in-depth understanding of the process is provided. The ethical decision-making process is not an easy task. The question of whether ANH should be ethically withdrawn seems to be very complex. Health carers should take into consideration all the factors influencing the decision-making in order to contribute more effectively to facilitate the whole process.

K E Y - W O R D S : Ethical dilemmas, nutritional support, withdrawal of artificial nutrition and hydration, ANH

INTRODUCTION

Malnutrition among hospitalised patients is one of the most serious complications of many illnesses. Inadequate food intake, in combination with metabolic abnormalities, results in starvation (Arrowsmith 1999-2000). The inability to orally ingest nourishment can be overcome with artificial nutrition and hydra-

tion (ANH) (Brodgen 2004). The administration of ANH can be offered by using enteral or parenteral methods, which have become part of a daily practice in intensive care units (Quirk 2000). For health care professionals caring for seriously or terminally ill patients, decisions about providing nutritional support are often difficult and influenced by the patient's medical condition, by the wishes of family and by the patient's quality of life (The AM et al 2002). Although nutritional support is widely used in current practice, a sense of ambiguity concerning the appropriateness of nutritional support in all cases is also widespread (Daly 2000, Andrews 2003).



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The objective of this study was to elucidate the ethical dilemmas regarding withholding or withdrawal of ANH of seriously ill patients that a nutrition health care team face in everyday practice and to describe the factors influencing, inhibiting, or facilitating this decision-making process.

BACKGROUND

The debate on the morality of provision of ANH has caused dispute among professionals. The most common question that comes to mind when a decision about nutritional support has to be made is "What is it the health carers seek to achieve by initiating or withdrawing ANH?". As with all medical care, the answer should be to benefit the patient. ANH might benefit patients by preventing malnutrition and dehydration (Van Bokhoret de van der Schueren 2005), by improving survival or tolerance to treatment, by improving functional status or quality of life (Dy 2006, Stratton & Ella 2007). It can also relieve patients from pain and suffering (Dy 2006) and can prolong life expectancy in some cases (Chiu et al 2004).

However, many patients receiving ANH experience discomfort because of tubes and neck lines, which can cause infectious complications (Dy 2006, Seicuk et al 2006). Many problems also arise when it is necessary to remove or replace them, because they often become blocked or dislodged (Ackermann 2000). All these burdens are regarded as acceptable when the patient has a prospect to recover, but this changes when the patient's condition is irreversible (Ackermann 2000). In terminally ill patients nutritional support may also cause fluid overload, worsening edema, or shortening of breath (Dy 2006). When the risks exceed the benefits, ANH should not be provided or should be withdrawn (Ackermann 2000). This decision is very complicated, because it brings about the patient's death (Fine 2006).

There is one more difficulty and ambivalence in withdrawing ANH, because of the multiple meanings which are assigned to this therapy. Food and water are considered as human care and are essential to life, even when provided through artificial means and this fact affects the decision-making process.

MATERIAL-METHOD

The present study seeks to identify the main ethical issues associated in withholding or withdrawing ANH from seriously ill patients. It also describes the diffi-

culties associated in the decision-making process that health professionals of a clinical nutrition unit face in everyday practice. It is anticipated that findings of the study can be used to improve quality of care provided to patients in practice through a more in-depth understanding of the ethical decision-making process in the area of nutritional support.

Study design

The purpose of this study is to move beyond description and to identify ideas and assumptions around the ethical dilemmas. As such, an exploratory case study research design was required.

It is known that the most significant methods used in qualitative case studies are observations, interviews, and documentation from records (Bowling 1997). In this study participant observations and semi-structured interviews were selected as the main methods of data collection. This combination can overcome two potential problems: (a) The use of interviews alone will only represent the participant's point of view and (b) the use of observation alone will not allow the participants to present their own perspectives on the examining issues.

Sample

The study was undertaken at a nine-bed Clinical Nutrition Unit in a large teaching hospital in the United Kingdom, dedicated to the treatment of patients with nutritional problems, specifically those requiring total parenteral nutrition. Most of them are highly depended in nature and can be both physically and emotionally traumatised.

The data were collected using purposive sampling. Fifteen of the seventeen members of the health care team took part in this research study. The sample aged from 25 to 57 years old and it consisted of 2 consultants, 1 dietician and 12 registered nurses.

A reference code was given to each participant (i.e. Health Carers=HC1, HC2...), in order for his/her anonymity to be protected.

Ethical considerations

In this study there was not any involvement of the patients and thus ethical approval from the Trust Ethics Committee was not required. However, permission to observe and interview the staff was sought from the Clinical Nurse Specialist who had the managerial responsibility for the unit. All members of the health care

team in the unit were provided with written information about the study and were asked to complete a consent form, which would be a proof of voluntary participation. The participants were informed that the interviews were tape-recorded, that they had the right to withdraw at any point and that their anonymity would be strictly protected.

Data collection

All interviews were implemented under the same conditions in a quiet, private room in the Clinical Nutrition Unit and were tape-recorded. The questions in the interviews were handled by the researcher with great caution, in order for interviewer bias to be minimised.

An interview guide with a focus on the issues that had to be covered was previously prepared. It consisted of three parts. The first part was focused on the personal characteristics and the work experience of the participant. The second part was focused on the ethical dilemmas that are raised for the health professionals working in a clinical nutrition unit (i.e. "The provision or not of artificial nutrition and hydration to seriously ill patients is a common dilemma. Have you ever dealt with this dilemma? Can you tell me what happened?). The third part referred to the difficulties that health carers face in everyday practice when they deal with ethical problems regarding patient's ANH (i.e. How difficult is to decide on the part of somebody else?").

Before conducting the interviews, a pilot study was undertaken. The data collection lasted nine months. The participant observations were carried out during the whole study. During all this period the researcher had been training as a nurse (five days per week) in the Clinical Nutrition Unit studied, whilst undertaking her MSc. As such, she had the opportunity to openly observe the situation. Every time that something relevant to this issue was happening on the unit, she recorded field notes which later were organised into a kind of narrative of what was observed.

The cases referred to this unit include many categories of patients who would not survive without nutritional support. This includes patients who require Total Parenteral Nutrition (TPN) as in-patients, patients with gastrostomies, or those who have difficulty in maintaining their weight due to an illness. The researcher had the opportunity to meet and observe many medical patients, as well as patients who were waiting for or who had undergone complex and major surgery. She had also met and had taken care of two patients who suffered from Anorexia Nervosa.

Data analysis

The qualitative data was presented in a categorised manner, as the researcher carried out a content analysis. By the means of this technique the field data (tape-recordings and written field notes) were classified into categories according to meanings. It has to be mentioned that the tape recordings were transcribed verbatim. Using the "cut and paste" process proposed by Bowling (1997), relevant themes were highlighted in transcripts and then cut out and pasted onto index cards. Then, the index cards were also organised into theme order. Since the study was a small one, manual categorisation was used. This kind of analysis has the advantage that the researcher remains close to the whole situation.

Consideration of rigour

The pilot study resulted in a better understanding of the limitations of the initial interviewing guide and led to the correction of some questions that were not clear enough. The interview guide was used to collect similar data from all the interviewees and the field notes that were kept during the period of data collection were used to achieve a more detailed image of the whole situation.

In analysing the data, content analysis gave to the researcher the opportunity to handle the extensive data. Direct quotations from the interviews are used to present the data, in order for credibility to be confirmed. A detailed presentation of findings together with the representative quotations have also resulted in enhancing transferability of data.

RESULTS

From the analysis of the interview data there appear to be two key themes, which pervade all interviews: (a) death and dying and (b) quality of life. Table 1 presents the categories of data arising from the interviews related to these two key themes.

A. Death and dying

The decisions about the nutritional support of seriously ill patients were considered to be very difficult, because of the importance of food and water for the existence of life. The denial of food and water results in the patient's death. One of the participants mentioned characteristically:

Table 1. Categories and sub-categories present in the data

Theme	Category	Sub-Category
A. Death and Dying	A1. Withdrawal of ANH	A1.a. Uncertainty A1.b. Easy to start/Difficult to stop A1.c. Hope
	A2. Dignified death	A2.a. Dehydration in terminally ill patients
B. Quality of life	B1. Influences on decision-making	B1.a. Patient's voice B1.b. Family's views B1.c. Nurses' and doctors' interference

"We become anxious because we know that patients are going to become worse if they don't eat and automatically if you don't eat you will die." (HC 4)

A1. Withdrawal of ANH

When participants were asked about the main ethical dilemmas they faced working in this setting, they all spoke about the decision to withdraw ANH, as it is clearly demonstrated below:

"When you have nursed a very ill patient for, you know, a long time, like patient A for example, the decision to withdraw nutritional support, to withdraw major treatments is very, very difficult." (HC 9)

"When you start to give nutritional support, it's hard to stop and on occasions patients condition changes and therefore should be able to change your own decision-making as to what the expected outcomes are, but that can be difficult." (HC 10)

The final line of this quote reflects the importance of decision-making in relation to the potential outcomes of a treatment.

A1.a. *Uncertainty*. These health carers felt doubtful about what they had to do in order to offer the best possible solution to their patients. There was an uncertainty on their part regarding the ethical implications of making a decision to abate life-sustaining nourishment. The following quotes sum up the reasons of existence of such an uncertainty:

"There is no regulation, there is no line, there is no point where we do not feed, there is nothing like that." (HC 3)

"It's hard to remain emotionally detached enough to make decisions like this rationally and professionally." (HC 9)

According to the participants' views, they could not decide because they did not know whether withdrawal of treatment would be in the patient's best interest.

A1.b. *Easy to start/difficult to stop*. Although there is no ethical distinction between the responsibility of deciding to start or to withdraw ANH, in practice it was more difficult for the staff to decide to withdraw ANH than to start it. This is clearly demonstrated through the following comments:

"It is very easy to start, the only thing you need to have is an objective and to see some satisfactory goal, but the decision to stop is really hard." (HC 4)

The participants felt that by starting ANH they were giving patients a chance for recovery, but by withdrawing it, they were stopping every hope as withdrawal of ANH results in death.

A1.c. *Hope*. The respondents saw the continuance of ANH as being a continuance of hope for the patients. This is well described below:

"It is always that last hope, that hope that he will be better, that maybe if you continue the ANH a miracle may happen and then the patient will be able to recover, but this is very rare." (HC 13)

The feelings of hope that something will alter the disease's condition made them have more doubts about the appropriateness of this intervention.

A2. Dignified death

There was a general consensus between the participants of this study that when a treatment is "futile" as it cannot improve the patient's general state of health, it is plausible to be withdrawn to enable a dignified death.

"I think that somebody always has the right to die a dignified death and that if feeding is part of maintaining that dignity for that person and as part of that care and as much as possible included in that care, then feeding maybe, should be maintained. But there is always a point when we have to decide the withdrawal of treatment, because it just prolongs life without any benefit for the patient." (HC 2)

The respondents believed that prolonging a meaningless life is not fair for the patient.

A2.a. *Dehydration in the terminally ill patients.* Nowadays, it is strongly suggested in the literature that giving fluids in amounts adequate to rehydrate may be detrimental to the comfort of dying patients and that dehydration in those patients may in fact be beneficial for them (Lennard-Jones 2000, McAulay 2001). When the participants of this study were asked about their views on this issue, there was a general doubt about it, as the following quote sums up:

"I do not think that we know, it is really hard to know what they feel, their experience, whether the experience is discomfort and whether we give them more discomfort by hydrating and putting needles in. I think some of these cases you have to take on individually and see what is happening." (HC 4)

It is obvious that these health carers need more evidence in order to be sure that when the patients are dehydrated they do not suffer from any distressing symptoms.

B. Quality of life

The ethical decision-making process regarding the patient's nutritional support appears to be very much influenced by the concept of quality of life, as it is illustrated below:

"I don't see the point, unless by being fed for a while, it would help that patient become a little better, so that they go home and spend some quality time with the family, then yes, that's different, but if it's just time without quality I don't agree with prolonging." (HC 7)

B1. Influences on decision-making

The appropriateness of an intervention is dependent, as the findings show, not only on its utility but also on its burden for the patient, the family, and the health carers.

B1.a. *Patient's voice.* The respondents felt that if a patient is competent and fully informed of his/her prognosis, they had an ethical responsibility to respect the patient's right to continue or discontinue a treatment.

"The withdrawal or not of ANH is a decision that competent patients make themselves. The only thing you can do is to provide information for that person, in order to make a reasonable decision." (HC 2)

B1.b. *Family's views.* According to the views of the staff in the unit, when the patients are non-autonomous or in-

competent, opinions of the patient's relatives should be taken fully into account.

"I don't know how it would stand legally, but certainly initially the family's views would have to be respected." (HC 9)

"Then, time has to be given to the family to discuss why it should stop and may be they need a period of time to come to terms with that, but it must be discussed with them regularly and fairly. I think communication is one of the big keys to improve the relationships with the family." (HC 10)

The respondents felt that good co-operation between members of the staff and members of the patients' families facilitate the decision-making process.

B1.c. *Nurses' and doctors' interference.* All the participants accepted the view that they should work together as a team, in order for the best possible decisions to be made.

"In this unit, everybody has got an input and what everyone says is listened to and is taken into account." (HC 13)

Although it is supported that all the members of the health care team can help and do help the decision-making process in this unit, on the other hand it is also accepted that the final decision lies with the consultants, as they are responsible to assess the patient's medical condition and to propose an intervention or a treatment. This is demonstrated below:

"At the end of the day, it has to be a medical judgement and I think that the decision is really up to them (the consultants)." (HC 13)

"The decision-making process is still a chain that leads to the consultant." (HC 2)

DISCUSSION

This study provides further evidence for the fact that the difficulties in decision-making are associated with the types of decisions being made. When it is clear that a specific intervention is in the best interest of the patient, then it is easy for the health care team to take the appropriate decision. On the contrary, health carers are deeply concerned about decisions for which the outcome is not clear. This explains why withdrawal of ANH appeared to be the most difficult decision that the participants have to make. It is supported that food, even if it is artificially provided, represents the main link of a human being to the world of the living and denial of food and water results in patient's death.

The direct connection of withdrawal of ANH with the end of life and the fact that the health carers cannot establish reliable criteria for predicting at which point stopping it would be beneficial, creates feelings of uncertainty. From the researcher's observations it was obvious that this uncertainty was more apparent between nurses, who preferred not to express freely their views in the team. It is very difficult for them to take part in the decision regarding withdrawal of ANH, because nutrition and fluid are very closely linked to nursing care (Konishi, Davis & Aiba 2002).

On the other hand, the decision to start ANH appeared to be easier for all the health carers, as this type of decision does not hasten the patient's death, but may delay it. It is emotionally easier for them to communicate the possibility of recovery, however remote, than to give an end to every hope. At the heart of every human being lies always a hope that things will get better. Many respondents believe that at the last moment the condition of the patient may change and the whole situation may be reversed due to a miracle. Occasional stories of significant recovery of seriously ill patients after one or more years that have been described rarely by the media had an impact on the decision-making.

The respondents of this study accepted the fact that although it is very important to provide care to patients, it is also a challenging task to help them manage the process of dying with comfort and dignity when their condition is irreversible. There is no reason to prolong survival when it results in more suffering for the patient (Shinmi & Yunjung 2003). The provision of care is acceptable only if it ameliorates the patient's physiological or psychological condition. These findings support the idea that the combination of respect for the person and acceptance of the mortality of humankind should be basic to health care professions (Jeffery & Millard 1997).

The assumption that intravenous infusion has to be continued until the last minute, because electrolyte imbalance and dehydration could cause distress to patients is based on older studies of healthy people deprived of fluids (Zerwekh 1997). Nowadays, it is believed that dehydration does not cause discomfort to people who are dying, but it may lead to increased production of natural opioids which can increase the analgesic effects (Smith & Andrews 2000, Schwarte 2002). The only symptom caused is that of dry mouth, which can be relieved by good oral care (Van der Riet, Brooks & Ashby 2006). Since there is little specific evidence to prove that patients in the last hours of their lives do not feel discomfort if they are kept dehydrated, inevitably health carers

in this study faced the issue of dehydration with scepticism.

Another significant factor that seems to have an impressive impact on decision-making is the quality of the patient's life. The health carers accepted previously stated views that the continuance of life is good only if the prolongation of life results in the well-being of the patient (De Ridder & Gastmans 1996). The goals of care for terminally ill patients should be focused on the promotion of quality of life and preparation for death, rather than simply trying to improve their nutritional status (Chiu et al 2002).

The patients' right to decide by themselves the implementation or not of a recommended treatment or intervention is well established in health law (Chernoff 2006, Korner et al 2006). It is clear in the literature that the principle of autonomy, as well as the principles of beneficence, non-maleficence, and justice, should guide the decision-making regarding seriously or terminally ill patients (Smith & Andrews 2000, Schwarte 2002, Hewitt-Taylor 2003). The participants of this study strongly supported previously stated views that when a decision about the continuance or discontinuance of a treatment is made competently, voluntarily, and knowingly by the patient, it should always be taken into consideration.

It is obvious that sometimes the patient's voice in the nutrition unit studied does not exist, because most of the patients are highly depended in nature and are not often in a position to express their own opinions. According to the British Medical Association's Annual Representative Meeting in July 2004 patients who lose their capacity, but who have indicated in advance that they wish to receive ANH should have their wishes respected (British Medical Association 2005). Patient's wishes may be ascertained through family's members (End of Life Issues Organisation 2006). The assumption that family members best represent the patient's previous views seems to be established among these professionals.

From the researcher's observations it was clear that close relationships between family members and staff exist on the unit due to good communication and understanding. If the patient's relatives are convinced that the health carers have tried everything and that there is no hope for the patient, then they can accept more easily the withdrawal of ANH. In cases where there is no agreement between the family and the health professionals, in England and Wales, courts have the power to decide about the provision or not of treatment on behalf of an incompetent patient. According to the British Medical Association a court declaration is required only for pa-

tients in a “Persistent Vegetative State” (PVS). For other conditions, such as stroke or motor neuron disease, such a declaration is not needed and the decision to withdraw or to continue ANH can be taken after formal clinical review by a senior clinician (Eby 2000).

It was supported in the interviews that ethical decision-making in order to be effective requires good communication and well-established relationships between members of the health care team and especially between doctors and nurses. Each discipline has different information to be considered about the patient and the co-operation between them results in the amelioration of the patient’s quality of care (Varizani et al 2005). Although there was a consensus among the members of the nutrition unit that everybody had an input in the decision-making process, on the other hand they all agreed that the final decision lies with the consultants.

The lack of training and guidance concerning decisions to withdraw ANH in the nursing profession is the reason for the nurses’ limited participation in the final decision-making. Although there are several guidelines regarding ANH for doctors, there are no guidelines from the UKCC for nurses. They find themselves in the position of caring for a patient for whom the medical team, under the British Medical Association’s guidelines, has decided to withdraw or withhold ANH (UKCC 2000).

The multi-dimensioned issue of decision making regarding ANH cannot be examined in one single study. Further research is needed to clarify what sort of preparation could enable all the health carers, and especially nurses, to be more effective in the process. Examining these aspects in comparison with previous studies in the area would result in a deeper understanding of the decision-making process and would contribute to amelioration of the existing situation for the patient’s benefit.

Study limitations

The small sample size is a major limitation of the present study. Health carers from a single unit of a single medical centre were involved. A comparison between two or more units would have broadened the range of results. However, as Polit & Hungler (1997) have mentioned, in qualitative research sample size should be determined on the basis of informational needs. In this inquiry purposive sampling was used in order to give a better answer to the research question. This approach to sampling allows the researcher to select key informants with access to essential sources of knowledge (Mays & Pope 1995). All participants were working in the Clinical

Nutrition Unit mentioned for an extended period of time and they all had experience in dealing with ethical problems regarding patients’ artificial nutritional support. As such, they answered the research question appropriately and the informational needs of this study were fully covered.

Another limitation is the close relationship between members of the nutrition team after working together for many years, which may influence their beliefs. Additionally, as the researcher was training in the unit for nine months, she could have been influenced by the personal relationship that has been developed with the staff and this could have had an impact on the results. On the other hand, in this way the researcher had the opportunity to obtain a deeper understanding of the decision-making process. The fact also that the medical director of the unit and the clinical nurse specialist were actively involved with research about ethical issues in nutritional support, may have affected how the health carers dealt with these ethical dilemmas.

CONCLUSIONS

The decision-making process is not an easy task. The question of whether ANH should be ethically withdrawn seems to be very complex. The quality of life was a concept that had an impact on decision-making. It is clear that even when the continuation of a treatment has no benefit for the patient, the decision to withdraw is difficult, as inside every human being there is always hope that something will alter the course of the disease. The principle of respect for the patient’s autonomy appeared to be of great importance, but in the absence of the patient’s voice, collaboration between the patient’s family and health carers needs to be achieved. If health carers take into consideration all the above factors that influence the decision-making, they could contribute more effectively to facilitate the whole process.

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