From cure to palliation: concept, decision and acceptance

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The aim of this paper is to present and discuss nurses' and physicians' comments in a questionnaire relating to patients' transition from curative treatment to palliative care. The four-page questionnaire relating to experiences of and attitudes towards communication, decision-making, documentation and responsibility of nurses and physicians and towards the competence of patients was developed and sent to a random sample of 1672 nurses and physicians of 10 specialties. The response rate was 52% (n=844), and over one-third made comments. The respondents differed in their comments about three areas: the concept of palliative care, experiences of unclear decision-making and difficulties in acceptance of the patient's situation. The responses are analysed in terms of four ethical theories: virtue ethics, deontology, consequentialism and casuistry. Many virtues considered to be appropriate for healthcare personnel to possess were invoked. Compassion, honesty, justice and prudence are especially important. However, principles of medical ethics, such as the deontological principle of respect for self-determination and the consequence of avoidance of harm, are also implied. Casuistry may be particularly helpful in analysing certain areas of difficulty—namely, what is meant by "palliative care", decision-making and accepting the patient's situation. Keeping a patient in a state of uncertainty often causes more suffering than necessary. Communication among the staff and with patients must be explicit. Many of the staff have not had adequate training in communicating with patients who are at the end of their life. Time for joint reflection has to be regained, and training in decision-making is essential. In our opinion, palliative care in Sweden is in need of improvement.

ling, if indicated.¹ However, there are no clear boundaries between curative treatment and palliative care, and the transition may be defined according to the situation. In Sweden, there are no national standards for admission to palliative care.

We have found two studies about the process of transition from specialised palliative care. One, from Sweden, reported how 30 doctors perceived their strategies when giving information to cancer patients about discontinuing active tumour treatment.² The other study, from Australia,³ reported on a qualitative research project undertaken at a large metropolitan palliative care service and its referring public hospital. Interviews with patients and nurses identified a lack of knowledge of what palliative care actually involves, fear and (mis)-understanding, and a need for acceptance of palliative care, for information and education on palliative care, and for peer support and supervision for palliative care nurses. The transition process was also studied by Löfmark and colleagues.⁴ They found that most of the 780 respondents—nurses and physicians—wanted more internal communication and a more individualised decision-making procedure. A uniform documentation of the decision to transfer care focus was the ideal. Over 75% valued agreement as something worth striving for. None answered that the decisions were made too early, but some thought that they often were made too late. Almost all of the respondents stated that such decisions should not be changed. However, the experiences reported were different.

The transition is evidently a difficult process that needs to be elucidated, and the aim of this paper is to present and discuss nurses' and physicians' comments relating to the transition from curative treatment to palliative care. One way to analyse these comments is to use different ethical positions as points of departure. Here we use four of the most common ethical theories applied to healthcare—virtue ethics, deontology, consequentialism, and casuistry—to illustrate the various analyses.

QUESTIONNAIRE

Since no instrument focusing on the transition from curative treatment to palliative care was found in the literature, a four-page questionnaire was developed. The questions were related to experiences of and attitudes towards communication, decision-making, documentation, and the responsibility of nurses and physicians, as well as the competence of patients and the number of terminal patients the respondent had cared for during the preceding 12 months. To improve face validity, the questionnaire was discussed in

The aim of palliative care is to improve the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor to postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; and uses a team approach to address the needs of patients and their families, including bereavement counsel-

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doctoral seminars and judged by experts in the field, and 10 healthcare personnel (not included in the sample) answered and commented on preliminary versions of the questionnaire. The final version was sent to a random sample of nurses and physicians stratified by specialty: anaesthesiology/intensive care, general medicine, geriatrics, infectious diseases, internal medicine, obstetrics/gynaecology/paediatrics, oncology, palliative medicine, pulmonary diseases and surgery. Unfortunately, mailing addresses for nurses within anaesthesiology/intensive care and infectious and pulmonary diseases were not available, so these groups were excluded from the study. Thus, the questionnaire was sent to 700 nurses and 972 physicians in Sweden. Since the questionnaire was anonymous, one reminder was sent to everyone in the sample.

On the last page of the questionnaire, the respondents were invited to write general comments and comments related to a particular question. The focus here is on these comments. We used content analysis to find relevant meaning units and to submerge them into categories.⁵

The research ethics committee of Lund University approved the study (Dnr. 02-509, LU 852-02).

RESULTS

The response rate was 52% (excluding 55 questionnaires returned with unknown addresses). Of the 844 respondents, whose characteristics are shown in Table 1, more than one-third made comments. Three main categories were identified. These had to do with (1) *conceptual confusion* (the meaning of the expression “palliative care”), (2) *explicit decision-making* (the staff need to make and communicate such decisions) and (3) *acceptance of the patient’s situation* (by the staff, the patient and the family). The comments by the respondents about these three issues are presented below.

Conceptual confusion

Many respondents emphasised that there is a problem with differing opinions regarding the concept of *palliative care*. Some distinguished between an early and a late palliative phase. Others asked if a fluid infusion, an antibiotic or “palliative chemotherapy or radiotherapy” to a patient without life-prolonging prospects can be called palliative care. There are also questions about the difference between “palliative care” and “common end-of-life care”?

Several explanations of these various conceptions are possible. Palliative efforts may have different meanings in different fields of activity. “For breast oncology the terms are

not relevant. Transition from tumour limiting measures to plain palliative care would be better.” This transition is very often unclear. “There is always an element of palliative care right from the start.” Furthermore, there may often be several points of decision in palliative care. Finally, someone asked if palliative care was just a means of economic savings.

Explicit decision-making

The respondents brought up many aspects of decision-making and it was emphasised that the most difficult decisions deal with whether complications in palliative care should be treated. A palliative treatment with anticancer drugs may be misinterpreted as curative, and repeated blood tests, infusions, and so on may be similarly misinterpreted. To make good palliative care decisions, you need time, reflection and personal maturity.

Some of the repondents commented that sometimes patients are treated in ways that are not reasonable. For instance, “if a patient is deteriorating drastically during a course of treatment, the physician usually tries to carry out the treatment without changing the plan.” For some patients, “curative treatment shouldn’t even be started.”

Nurses often wanted the transition to palliative care earlier than the responsible physicians. Too-short hospital stays and a lack of intermediate or palliative care beds may be deleterious to good decision-making. Decisions may be taken in panic—perhaps because of a “deadly fear or dreading that everything has not been tried”. Physicians may also have insufficient knowledge about palliative care. “A decision to stop curative treatment ought to be taken as soon as the physician understands which way things are going—not sooner, not later.”

It can happen that a decision must be made without agreement within the staff. One respondent stated, “physicians at my hospital are totally incapable of agreement. We do not have a durable system for decision-making and documentation, and my own decisions are not respected.”

One respondent held that the general rule should be to inform the patient and the relatives before a decision is taken. But some respondents disagreed. In their opinion, the decision should be taken before the patient is informed. Many physicians also found it difficult to talk with patients and relatives about the transition to palliative care. According to nurses, some physicians were afraid to discuss stopping curative treatment.

Thus, “we desperately need uniform routines for communication with the staff, the patients and the relatives.” Better continuity was asked for, and a responsible physician and nurse

Table 1 Characteristics of Swedish nurses and physicians responding to a questionnaire on patients’ transition from curative treatment to palliative care

Specialty of respondent	Profession (n = 780)		Sex (n = 777)		Age (years) (n = 737)		Training in palliative care (n = 768)		Want more training (n = 734)		Number of terminal patients* (n = 634)			
	Physician	Nurse	Men	Women	≤ 50	> 50	Yes	No	Yes	No	0	1–5	6–20	> 20
Anaesthetics/intensive care	72	1	53	20	31	42	21	51	53	19	13	14	26	17
General practice	36	29	21	44	35	25	33	31	21	11	10	12	20	8
Geriatrics	46	19	15	50	40	23	38	27	52	8	4	9	22	27
Infectious disease	50	5	28	27	25	30	13	42	43	7	5	19	21	5
Internal medicine	42	25	29	38	25	41	16	51	52	10	7	5	34	19
Obstetrics/gynaecology/paediatrics	37	28	21	44	38	25	25	39	51	10	16	10	9	5
Oncology	34	60	22	72	31	60	64	30	72	19	4	4	30	39
Pain and palliative care	19	23	14	28	26	16	30	11	31	9	9	0	1	26
Pulmonary medicine	35	4	22	17	26	13	10	29	32	6	3	3	10	21
Surgery	50	54	42	61	39	54	40	61	73	26	6	10	38	30
Other	16	86	13	88	46	39	41	57	73	19	25	9	12	14

Values are numbers of respondents.
*Number of terminal patients cared for during the preceding 12 months.

should always be appointed. "You should always show your cards." A joint "care conference" with both physicians and nurses should make this kind of decision, sometimes also including patients and their relatives.

A uniform procedure would make decision-making easier, but "every single case must be assessed individually, and this is better done in small hospitals."

Acceptance of the patient's situation

Patients and relatives often come to an understanding that cure is not possible, but there is a problem when a decision is badly documented or blurred and when patients and relatives have not taken in the information. In a hospice you expect patients to accept the situation, but often they do not. One ground for inadequate understanding may be that physicians are afraid to make these decisions and to communicate them clearly. There are also situations in which patients and relatives cannot cope with bad news and the staff may postpone the information. Some patients are competent but have not accepted their situation, which may pose a problem. The relatives know, as a rule. It is hard to make the decision at the right time. "Such decisions ought to develop in an ongoing dialogue between the patient, the relatives, physician, and nurse." Emotional objectives were also noted: "It is hard to switch from curative care to palliative care as Hope is removed."

Most patients seem well informed when they come to a hospice, and they participate in all decisions until death. "However, some patients do not want to discuss their disease, and then you have to be very sensitive with the communication." Some patients want to shield the relatives from information, which can cause special difficulties. When patients want to stop treatment and the relatives do not, the relatives may need more information and time for acceptance.

A competent patient may have difficulty in making a decision to stop treatment, and healthcare professionals should not require this of the patient. Patients often understand that nothing more can be done "but do not give the show away, because they don't wish to make relatives and the staff sad." However, the process of understanding takes time. The relatives are usually satisfied with the palliative care but may have experienced indifference at the hospital. Sometimes patients recover enough to reconsider their situation and then do not want palliative care any more. When the patient is not competent, the relatives should participate in the decision-making, but sometimes they have not come to an acceptance.

Sometimes, even a short time more can give increased quality of life, for instance if there are children involved, or if the patient is trying to survive for a special occasion before dying.

ETHICAL ANALYSIS

Statements of facts, however, are not enough to draw any ethical conclusions. Values are also needed.⁶ Four ethical theories are used in the ethical analysis: virtue ethics (considering motive or character), deontology (considering acts regardless of their effect), consequentialism (considering foreseeable or factual results) and casuistry (comparison with uncontroversial cases).

Virtue ethics

According to the *Encyclopedia of ethics*,⁷ virtue ethics is the name of a family of ethical theories and there is no precisely agreed upon definition. Many, however, believe that benevolence and a disposition to treat people equally should be included,⁸ together with compassion, honesty, fidelity, courage, justice, temperance, magnanimity, prudence and wisdom. These virtues are required of the physician.⁹ MacIntyre asks how one can account for the trust that seems a necessary component of the doctor-patient relationship without relying on an ethic of

virtue. "Medicine is a practice in which the goods internal to the practice extend our powers in a manner that we are habituated in excellence."¹⁰

Compassion and fidelity with the patients would lead to a deeper patient-physician relationship, which could open up for an ongoing dialogue. Modern healthcare, with its shorter and shorter hospital stays, has to find other forms for patient-physician-family relationships.

Courage, honesty and justice are required to develop uniform procedures of communication and decision-making in order not to cause wrong expectations and to organise satisfactory care for all patients.

Prudence and wisdom are needed to develop adequate knowledge for optimal patient care and to make timely and mature decisions after due reflection. The comments of the respondents imply that the staff ought to have many virtues, and they describe the need for a specific type of character: a wise person, who wants and takes responsibility for communication and organisation of the care. According to Kupperman, "character is not simply the sum of the individual virtues; rather it names the pattern of thought and action that provides a continuity sufficient for humans to claim their lives as their own."¹¹

Thus, in our opinion, virtue ethics is needed but is not sufficient to justify a particular choice of action or the achievement of a certain state of affairs. Carrying out of professional duties, consideration of actual or anticipated consequences, and respect for other ethical principles are also needed.

Deontology

A deontological theory of ethics "is one which holds that at least some acts are morally obligatory regardless of their consequences for human weal or woe".¹² A deontological principle implies the duty to perform certain acts just because they are good and to avoid certain other acts because they are evil, regardless of the consequences.

Deontologists often stress honest communication. Acts should be intended to make patients and relatives understand the situation. This means that language understood by all involved must be used, both to avoid misunderstandings and to be explicit in the decision-making. The use of timely and explicit communication right from the start of the disease would probably be considered justified in the long run by most patients and relatives. In open communication, all participants must be free to show their apprehensions and get honest answers to their questions. This would certainly also increase the understanding and acceptance of the patient's situation.

A basic point of departure is that the staff is properly trained in communication and in palliative care. The staff should also have enough time and other resources to be able to respond to different demands. Failure to communicate at all, or to communicate in a rigid, clumsy, or tactless way, must be considered poor practice and should be avoided.

According to deontology, the patients' right to autonomy, if they are reasonably competent, is also important. This means that even if patients do not have the same preferences as the staff as to the desirable consequences, their opinion should be sought, if feasible, and considered before a decision is made. It seems important to delineate all consequences, factual or anticipated, so that patients can make their choice.

Consequentialism

According to this theory, human conduct should promote the interests or welfare of those affected. A utilitarian theory may be seen as combining (1) a conception of "intrinsic" value, or fundamental good, which says how consequences are basically to be appraised, with (2) a view about the relation between

"rightness" and "goodness", that is, between morally required or defensible conduct and the intrinsic value that can be realised.¹³

Autonomy and deliberation can, however, also be seen as good consequences in all healthcare and no doubt also in the transition from curative to palliative care. To be able to use these possibilities, patients have to be informed about their prospects so they can understand and make their individual choices. However, bad or evil consequences have also to be considered in the specific situation. Such consequences may be physical or psychological harm from treatment or reception. A dialogue with the patient and relatives may be the only way to chart their opinions, before any decisions can be made. Such a dialogue may also disclose apprehensions and misunderstandings not previously known to the staff. The same consequence of a treatment may be viewed differently by members of the staff and by different patients (and their relatives). Well-informed, the patient may be better equipped to understand and accept the situation.

Casuistry

This ethical theory refers to the use of analogy with case-comparison to reach moral conclusions. Casuists are sceptical of rules, rights and generated theories divorced from cases, history, precedents and circumstances.¹⁴

The more complex a case is, the more experiences may be gained. In the transition from curative to palliative care, complexity seems to be frequent. From the comments in the survey, we have identified three different difficulties, each complex.

The first has to do with the meaning of the expression "palliative care". This difficulty is not hard to understand, considering the various interpretations of the concept. The expression will be more frequently used as soon as the profession has learnt about it and realised its usefulness when communicating with their patients.

The second difficulty has to do with explicit decision-making. To make such decisions is a procedure that seems to be common in hospice care but that, according to our respondents, would be better if done earlier in the treatment of all end-of-life patients.

The third difficulty is with regard to the patient's situation, which should be accepted by the staff, the patient and the family. This seems to us to be the most difficult problem to handle, at least for the staff, because every patient and every context is unique. However, the more the staff shows an interest in a patient's thoughts, the more understanding will appear.

These three types of difficulty need their own individual solutions. But common to all is that the use of similar but uncontroversial cases can be helpful in trying to solve the ethical problems confronting the persons involved.

DISCUSSION

Principal findings

Comments from nurses and physicians from 10 specialties clearly show that the transition from curative treatment to palliative care is less than optimal in the Swedish healthcare system. The comments show that there are uncertainties about the concept of palliative care, about the decision-making process and about communication both among the staff and with patients and relatives. Acceptance of the patient's situation by the people involved is another difficulty, which ought to be addressed both in the clinical setting and in research. The respondents invoked many virtues considered to be appropriate for healthcare personnel to possess, with compassion, honesty, justice and prudence being considered especially important. However, principles of medical ethics,

such as the deontological principle of respect for self-determination and the consequence of avoidance of harm, were also implied. We have also identified three areas of difficulty: the meaning of "palliative care", decision-making and acceptance of the patient's situation. In cases involving such difficulties, we believe that casuistry can be particularly helpful.

Strengths and weaknesses of the study

Randomly selected nurses and physicians with widely varying experience of end-of-life care readily and anonymously expressed their attitudes towards the process of transition from curative to palliative care. This kind of data collection and ethical analysis has, to our knowledge, not been performed before. Most of the respondents' normative statements were oriented towards virtue ethics and are probably best understood using this approach in the ethical analysis. However, because the attrition rate was quite high, the results should be interpreted as hypotheses that have to be further tested before any generalisations can be made.

Clinical implications

Based on the results, some tentative recommendations may be formulated. Keeping a patient in a state of uncertainty often causes more suffering than necessary. Communication among the staff must be explicit and uniform, and since acceptance of the approach of death is a process, it may be wise that a smaller group of physicians and nurses, familiar with the particular patient, takes on continuous responsibility for the patient. Many of the staff have not been adequately trained in communicating with patients who are at the end of their life. Time for joint reflection has to be regained, and training in decision-making is essential. Thus, in our opinion, palliative care in Sweden is in need of improvement.

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