Ethical issues in palliative care

Views of patients, families, and nonphysician staff

Anna Towers, MD, CCFP   Neil MacDonald, MD, FRCP   Ellen Wallace

ABSTRACT

OBJECTIVE Much of what we know about ethical issues in palliative care comes from the perceptions of physicians and ethicists. In this study our goal was to hear other voices and to gain first-hand knowledge of the possibly contrasting views of patients, their families, nurses, volunteers, and other team members on end-of-life issues.

DESIGN Qualitative study using semistructured interviews.

SETTING Inpatient and consultation palliative care service of the Royal Victoria Hospital in Montreal, Que.

PARTICIPANTS Of 113 people interviewed, 13 were patients, 43 were family members, 32 were volunteers, 14 were nurses, and 11 were other staff.

METHOD Interviewers elicited subjects' perspectives on ethical issues. Content analysis was used to identify, code, and categorize themes in the data.

MAIN FINDINGS Communication difficulties and insufficient resources and staff were the most frequently mentioned problems in this palliative care setting.

CONCLUSION The findings of this study will help guide policy decisions and setting of educational priorities in end-of-life care, particularly regarding the importance of adequate communication.

RÉSUMÉ

OBJECTIF Nos notions d'éthique en rapport avec les soins palliatifs reposent en grande partie sur les perceptions de médecins et de déontologues. Le but de cette étude était d'obtenir auprès de patients, de parents, d'infirmières, de bénévoles et d'autres membres du personnel des points de vue éventuellement différents sur les problèmes suscités par l'approche de la mort.

TYPE D'ÉTUDE Étude qualitative à l'aide d'entrevues semi-structurées.

CONTEXTE Unité de soins palliatifs pour patients hospitalisés ou externes, à l'hôpital Royal Victoria de Montréal, Québec.

PARTICIPANTS Un total de 113 personnes ont été interviewées, dont 13 patients, 43 parents, 32 bénévoles, 14 infirmières et 11 autres membres du personnel.

MÉTHODE Dans les entrevues, on cherchait à connaître le point de vue des sujets sur des questions d'éthique. Une analyse de contenu a été utilisée pour identifier les thèmes, les coder et les classer par catégories.

PRINCIPALES OBSERVATIONS Les problèmes les plus fréquemment rapportés dans cette unité de soins palliatifs étaient les difficultés de communication et l'insuffisance des ressources matérielles et humaines.

CONCLUSION Les résultats obtenus serviront à mieux orienter les décisions de principe et les priorités de formation concernant les soins aux mourants, en insistant sur l'importance d'une communication adéquate.

P hysicians, other members of health care teams, patients, and their families are all linked in end-of-life decision making. Few studies have addressed the diversity in outlook on ethical issues in end-of-life care. Most reports describe the perceptions of physicians and ethicists on these issues.[1-3] Other parties might have different ethical views, modified by culture, economics, family integrity, and stressful events related to end-of-life care.

Solomon et al[4] surveyed 687 physicians and 759 nurses regarding their knowledge of and attitudes to ethics and law, guidelines for use of life supports, and perceived impediments to good decision making and quality of care. Important items that emerged included dissatisfaction caused by insufficient patient involvement in treatment decisions, concerns regarding overly burdensome treatment, and disagreement with dictums published by clinical ethicists on withdrawing and withholding therapy.

Rothstein[5] conducted seminars in which he explored ethical issues encountered by volunteers at the Victoria Hospice Society in Victoria, BC. Based on field notes from these seminars and from other discussions with volunteers, Rothstein found that they were principally concerned with issues of communication, conflict of interest, confidentiality, and compromised care. This was not a formal qualitative study, and sample size is not mentioned in the study report.

Singer and MacDonald[3] present a framework for improving end-of-life care with three main elements: control of pain and other symptoms, decisions on use of life-sustaining treatments, and support of dying patients and their families. Based on a review of the limited literature available, the authors state, "Although euthanasia consumes the attention of the media, the critical ethical issues vexing physicians, patients, and families lie elsewhere." The authors admit, however, that there are few empiric studies

of the types of ethical issues that actually come up day-to-day in end-of-life care.

Our goal in conducting this study was to hear the voices of patients and families supplemented by palliative care nurses and volunteers. Our study will add new perspectives and views to the few existing qualitative studies of end-of-life issues.

METHODS

This exploratory qualitative study involved patients, family members, staff, and volunteers in the 16-bed palliative care unit and the consultation service of the Royal Victoria Hospital in Montreal, Que. Data were collected during two spring-summer periods (May to August 1999 and April to August 2000). We obtained approval from the ethics board at the Royal Victoria Hospital.

All admitted patients were screened by the attending physician. We used purposeful sampling to find information-rich subjects whom the attending physician thought were complex cases that might present ethical concerns. No cases were purposely excluded, but limited interviewer time meant not all admitted patients and families could be interviewed. The attending physician approached patients or their families for permission for our research assistant to initiate contact. Incompetent patients were represented in the sample by family members with ethics board approval. Wanting to include as many views as possible, we invited all available staff and volunteers to participate (**Table 1**).

One challenge of the study was to develop and test language we could use to elicit and explore ethical issues with laypeople. The questions on the interview guide for patients and families were, therefore, broad to elicit information from which we could sift out

Dr Towers *is Director of the Palliative Care Division at the McGill University Health Centre and an Associate Professor in the Departments of Family Medicine, Medicine, and Oncology at McGill University in Montreal, Que.* **Dr MacDonald** *is a physician and researcher in the Palliative Care Division of the McGill University Health Centre and a Professor in the Departments of Oncology and Medicine at McGill University. He was until recently a consultant at the Clinical Research Institute of Montreal's Centre for Bioethics.* **Ms Wallace** *is a volunteer in the Palliative Care Unit at the Royal Victoria Hospital site of the McGill University Health Centre.*

Table 1. Subjects interviewed

SUBJECTS	N = 113
Family members	43
• of incompetent patients	23
• of competent patients	20
Patients	13
Volunteers	32
Staff other than volunteers	25
• Nurses	14
• Psychologists	3
• Staff physicians	3
• Occupational therapist	1
• Music therapist	1
• Pastor	1
• Resident physician	1
• Unit clerk	1

ethical issues (**Table 2**). The initial guiding interview questions were pilot-tested with family members. We reviewed patients' charts, but found little information on ethical issues in their medical records. All of our coding was done on interview data and field notes.

Table 2. Guiding interview questions

FOR FAMILY MEMBERS

How do you feel about the care your [family member] is receiving here on the palliative care unit?

Do you have any concerns or problems or difficulties with moral issues about the care here?

Do you have any concerns about decisions that might be taken for [him/her] in the near future?

Do any problems come to mind that might be called moral or ethical?

FOR STAFF AND VOLUNTEERS

What are the ethical or moral problems you see facing patients, families, and staff on the palliative care unit?

Patients and families were followed prospectively and were interviewed one to three times, when possible, given the short length of stay of terminally ill patients. Team members were interviewed once or twice. Interviews lasted 15 to 60 minutes, depending on subject availability, degree of physical or psychological discomfort, and ward routines. Specially trained research assistants conducted the interviews and took detailed notes that included verbatim comments.

Data analysis proceeded concurrently with data collection. We sought confirmatory and contradictory comments from staff, asking subsequent subjects questions based on our preliminary observations and results. The researchers ensured that all staff were represented. When we saw patients were underrepresented, we determined that this was because most were cognitively impaired; we therefore sought special ethics approval to interview family members of incompetent patients. Recruitment and interviews continued until saturation of data was obtained.

Inductive content analysis was used to identify, code, and categorize primary patterns in the data.[6-8] With this method, patterns, themes, and categories came from the data rather than being imposed on them before collection and analysis. Data from each subject were collated. Interviews were analyzed on a case basis first, then by subject type and family grouping, and then across cases. Data were analyzed in chronologic order.

The research assistants conducted preliminary content analysis and began to generate hypotheses shortly after recording the data. Content analysis was then done on all the data by one of the researchers. A representative sample of the data was analyzed independently by the second researcher. The research team met weekly to compare themes and develop theories. Validity was strengthened by using field notes, by checking with other subjects, and by including a volunteer on our research team. The team sought to achieve consensus on codes and themes. Alternative interpretations were encouraged and discussed. When more than one code was indicated and we did not reach consensus, we considered both interpretations. Finally, we developed hypotheses that could be tested in future research.

FINDINGS

"The average family is not average any more when facing palliative care," remarked a volunteer. Ethical issues are common on a palliative care service; most interviews brought up at least two or three. While our study enquired about problems and, therefore, elicited mostly critical comments, patients and families highly valued their palliative care experience overall. Our interviewers found that patients did not find it easy to complain. Family members were less inhibited. Volunteers were most open in voicing concerns, and they often spoke as patient and family advocates.

Communication

Communication problems and inadequate resource allocation emerged as the main areas of concern. These issues are intertwined and linked to the issue of staff "competence," interpreted as staff being unavailable and lacking communication skills (**Table 3**). The following quotations suggest the levels of complexity we encountered.

Therapy. The daughter of an incompetent patient said, "She has a strong fear of taking too much medication that I think comes from having seen some television show about people becoming dependent on drugs. She does not want to become an addict."

A music therapist commented:
We want to relieve suffering, but the family disagrees because they think that the medication will bring on death more quickly…. Even if we explain it to them, there is this myth. It could be related to denial—the family thinks that it is the medication that is making the person ill.

A bereavement worker added:
Families need to know as much as possible. Patients and families ought to have more involvement in decisions…. During bereavement follow up, families say that they

Table 3. Issues emerging from interview data

Insufficient communication
- Inadequate communication between staff and patients and their families
- "Conspiracy of silence" among family members (conflicts over telling the truth, denial of prognosis)
- Inadequate communication between team members and with consultants
- Language barriers
- Inadequate communication regarding therapy, degree of suffering, expectations, and need for solace

Resource allocation
- Insufficient staff (nurses)
- Lack of bedside time
- Lack of time to communicate
- Insufficient resources for home care

Staff "competence"
- Insufficient availability
- Inadequate communication skills

Conflicts regarding level of care, including withholding or withdrawing treatment

Uncertainty about euthanasia

Cultural, religious, and cultural-institutional issues* around the process of dying and care of dying people

Power issues regarding patient autonomy and loss of dignity

Inadequate symptom control

Wishes and needs of patients versus wishes and needs of their families

Patients feeling a burden to their families

Confidentiality

Issues around terminal sedation

Lack of privacy

Staff role conflicts

Culture includes reference to medical culture and the medicalization and institutionalization of death and dying.

don't know why a certain medication was given. If they had known the effects, they might not have agreed to it. Some have guilt issues and might blame the system.

Degree of suffering. Nurses had difficulty with patients who did not express their suffering to them.

> Patients do not always speak to us of their pain…. Pain is subjective. I can't do other than believe what a patient tells me when he speaks of his pain…. We give patients a pain scale to complete, scored from 0 to 10. That helps a lot. Sometimes the patient writes down that his pain is 7 on 10 when he hasn't even mentioned it to us!

A nurse mentioned the difficulty of respecting patient autonomy in family situations: Patients are sometimes very passive, so the family decides for the patient. Or the patient agrees with the family just to please them. Our priority is the patient, but

we have to deal with the family also. If we get to the point they don't agree, it's the patient first.

Expectations. Several nurses mentioned that they felt the public had unrealistic expectations regarding death and dying.

> Another problem I see quite a bit is that people's expectations are too high. You see this primarily with family members. The public is quite naïve about the capacity of the health care system. They think that doctors can fix everything, that they just give a needle and the pain disappears.

Patients and family members frequently expressed conflicting views and ambivalence. For example, one man wanted his chest tube removed and antibiotics stopped. At the same time, he wanted to be able to go home and to live longer. Conflicting objectives create three-dimensional ethical issues. "I'm anxious, depressed and not sure what I want" or "This makes me angry, causes me to have trouble making any decisions, which makes me angrier still."

Need for solace. Some patients find it difficult to express their need for comfort and solace. One of our volunteers said, "This morning we had a patient capable of feeding himself, but he wants help. He's into himself; he's not sociable. The patient says he can't do anything [and] sometimes he cries. Maybe this is his way of relating."

Resource allocation
Patients, families, and staff saw lack of resources for home care as a problem. A psychology intern said:

> There are many patients here who just want to go home to die, but they cannot get the resources they need, so they are stuck here for their last days. They are frustrated about being here and they have trouble feeling dignified with all that is going on around them, but their families either can't provide the care they need or simply don't want to.

Nurses made the link between resource allocation issues and difficulties with communication. We should have one or two nurses more, because I think that our workload is too great…. The quality of care is still good, but if we had more staff, we would have more time to speak with patients and to get to the root of their problems.

Many patients and families expressed the opinion that nurses were overworked. Nurses, in their comments, put patients' needs first. Their complaints about work conditions related to frustration in offering good patient care rather than personal concerns: "There isn't enough money, there aren't enough nurses, the equipment is old. We need more nurses."

Most agreed that although they felt overloaded, the quality of the care they gave was maintained.

> There is a lot of frustration. Patients are asking for us from all sides. We are exhausted. We don't have enough physicians. But … the only consequence is exhaustion. You have to understand that we continue to provide the same care— the difference is that we do it faster. That's why we're tired.

Some nurses mentioned that volunteers were doing what used to be paid nursing work.

> The volunteers are being asked to do a lot…. Because they are here, the quality of life on the ward is better for patients and for staff also. Sometimes they help us shift patients in their beds, which is the job of a nursing assistant. We ask them if they mind, and they say no. I think that we demand a lot of them.

Staff competence was mentioned as a concern by several family members. In the analysis, the researchers thought that references to staff competence did not reflect competence in symptom control, but rather a lack of time to do the work as they think it should be done. Poor communication probably meant a lack of bedside time.

DISCUSSION

This is the first reported study of patients' and families' ethical concerns at the end of life, and it adds to the limited existing literature on the views of health care workers other than physicians.[4,5] The three main intertwined areas of concern for our subjects were difficulties with communication, inappropriate or insufficient resource allocation, and staff "competence." The ethical issues raised in our interviews were not those commonly discussed in the popular press, such as euthanasia.

The public, through the media, is aware of resource allocation woes, but primarily in terms of access to operating rooms and technical resources. They might not realize how cutbacks affect time and ability to communicate with patients and families and to address emotional issues. Our subjects referred repeatedly to staff with insufficient time to communicate. While courses in communication are now commonly offered during medical training, they might not help health professionals deal with "real-time" situations where they can interact only briefly with patients and families.

Levels of communication

Problems in communication as ethical concerns emerged constantly throughout the interviews. On rereading the interviews, several categories of communication became apparent. At one level, they simply reflect resource allocation: "I don't have time to talk to you." At another level, they might reflect competence: "I don't know how to talk to you." At a third more complex level, they could reflect cultural issues related to ethnicity: "I'm not sure how I want you to be talking to my father, mother, etc." Staff label this a "conspiracy of silence". At a more complicated level, it reflects what we might call the "Get Smart" phenomenon: "I want more information from you, but I want the information to be positive!"

At their most profound level, the ethical connotations of communication sound like a cry of distress: "Spend more time with me, as I need solace. Talk about anything, just so that I have your presence, which gives me comfort."

Resource allocation and staff challenges

Resource allocation in its many forms certainly arose as a major ethical dilemma. Governments and institutions, through staff cutbacks, have prioritized crisis management and have jeopardized other aspects of care, thus eroding palliative care principles. We might prefer to give whole-person care and to do more than just manage symptoms, but what can we do? We have committed staff working extremely hard within a system that offers insufficient recognition and respect for their efforts and makes their work extremely difficult. Many thought staff's shortcomings were related to stress, overcommitment, and inadequate resources. Issues of staff competence seem to be largely issues of resource allocation.

Patients and families can disagree with professional caregivers as to the appropriateness of particular strategies of care. Invested as they are in their desire to give good care, palliative care workers do not always recognize situations where patients experience not empathy but patronization, not solicitude but invasion of privacy. Patients and families have a great desire to please and are truly grateful for expert care.

This makes occasional lapses or misunderstandings even harder for caregivers to discover.

A previous qualitative study showed that "patient- or family-centred care" can appear more successful to a palliative care team than to patients or families.[9] Future research should include qualitative studies to elicit the views of patients, families, and staff in end-of-life settings other than palliative care units (ie, intensive care units and medical and surgical wards).

Limitations

We did not give participants our definitions of "ethical or moral" problems; we were interested in what our patients and colleagues regarded as moral issues. It was a challenge to develop interview questions to collect information about the ethical concerns of lay-people. The wording of the interview guide for patients and families was broad and, therefore, some of the information we elicited referred to general institutional care or other problems not strictly ethical in nature.

Saturation was reached earlier with patients than with other groups because patients were close to dying and most were cognitively impaired. We conducted this study in a particular palliative care setting. Patients, families, and health care professionals in other settings might face different ethical issues.

Conclusion

Qualitative techniques that elicit many views can offer first-hand knowledge and new perspectives on ethical issues at the end of life, an area that has been dominated by physicians' and ethicists' preoccupations and by media concerns. Our findings point to an interplay between resource allocation issues and barriers to communication that patients and families find important. This information should guide policy makers in decisions about funding: it points to a need for staffing levels that allow time for adequate communication rather than just crisis care. The information should also help educators define curriculum priorities by underscoring the importance of good communication skills. ✤

Contributors

Drs Towers and **MacDonald** and **Ms Wallace** *conceived and designed the study, analyzed and interpreted the data, and wrote and revised the article for publication.*

Competing interests

None declared

Editor's key points

- This qualitative study carried out among patients hospitalized for palliative care, their families, non-physician staff, and volunteers found there were many ethical problems in this setting.
- Communication problems regarding treatment, patients' level of suffering, and unrealistic expectations of patients and families came to light.
- The lack of resources for caring for patients in hospital and at home were mentioned by patients, their families, and staff.
- The lack of "competence" among the staff mentioned by several families seemed more connected to the lack of resources (lack of time to accomplish tasks and to talk with patients) than to an inability to control symptoms.

Points de repère du rédacteur

- Cette étude qualitative réalisée auprès de patients hospitalisés en soins palliatifs, de leurs familles, de membres du personnel paramédical et de bénévoles indique que les problèmes éthiques sont fréquents dans ce contexte.
- Les problèmes de communication en regard du traitement, du niveau de souffrance des patients, des attentes irréalistes des patients et de leurs familles ont été soulevés.
- Le manque de ressources pour les soins aux patients admis à l'hôpital et à domicile ont été mentionnés par les patients, les familles et le personnel.
- Le manque de «compétence» du personnel, souligné par plusieurs familles, semble davantage relié au manque de ressources (manque de temps pour accomplir les tâches et pour parler avec les patients) qu'à une incapacité de contrôler les symptômes.

Correspondence to: Dr Anna Towers, MUHC, Royal Victoria Hospital, 687 Pine W, Room R6-07, Montreal, QC H3A 1A1; telephone (514) 934-1934, extension 35155; fax (514) 843-1471; e-mail **anna.towers@muhc.mcgill.ca**

References

1. MacDonald N. From the front lines. *J Palliat Care* 1994;10(3):44-7.
2. Pellegrino ED. Emerging ethical issues in palliative care. *JAMA* 1998;279(19):1521-2.
3. Singer PA, MacDonald N. Bioethics for clinicians: quality end-of-life care. *Can Med Assoc J* 1998;159(2):159-62.
4. Solomon MZ, O'Donnell L, Jennings B, Guilfoy V, Wolf SM, Nolan K, et al. Decisions near the end of life: professional views on life-sustaining treatments. *Am J Public Health* 1993;83(1):14-23.
5. Rothstein JM. Ethical challenges to the palliative care volunteer. *J Palliat Care* 1994;10(3):79-82.
6. Patton MQ. *Qualitative evaluation and research methods.* Newbury Park, Calif: Sage Publications; 1990.
7. Guba EG, Lincoln YS. *Fourth generation evaluation.* Newbury Park, Calif: Sage Publications; 1989.
8. Moustakis C. *Heuristic research design, methodology and applications.* Newbury Park, Calif: Sage Publications; 1990.
9. Barnard D, Towers A, Boston P, Lambrinidou Y. *Crossing over: case narratives in palliative care.* New York, NY: Oxford University Press; 2000.