Ethical dilemmas in palliative care: a study in Taiwan

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Abstract
Objectives—To investigate the incidence and solution of ethical dilemmas in a palliative care unit.
Setting—Palliative care unit of National Taiwan University Hospital in Taiwan.
Patients—Two hundred and forty-six consecutive patients with terminal cancer during 1997–8.
Main measurement—Ethical dilemmas in the questionnaire were categorised as follows: telling the truth; place of care; therapeutic strategy; hydration and nutrition; blood transfusion; alternative treatment; terminal sedation; use of medication, and others.
Results—The type and frequency of ethical dilemmas encountered were: place of care (33.3%); truth-telling (32.1%); hydration and nutrition (25.2%); therapeutic strategy (24.8%), and use of medication (19.1%). Ethical problems relating to the place of care and to therapeutic strategy were unlikely to be solved with increased hospital stay and some ethical dilemmas remained unsolved even in the final week in hospital, including place of care (23.2%), truth-telling (17.1%) and therapeutic strategy (11.4%). Problems of truth-telling occurred in nearly half (42.6%) of patients over sixty-five-years-old. Conflicts about blood transfusion were experienced in all patients below eighteen-years-old, and the dilemmas concerning the place of care occurred most frequently with head and neck cancer patients (43.8%).
Conclusions—The solution of ethical dilemmas required refocusing by medical professionals on the importance of continuing communication. Improved ethical training for professionals would contribute to solving the moral dilemmas of palliative care.

Keywords: Palliative care; terminal care; ethical dilemma

Introduction
Hospice and palliative care is well recognised as the ideal model of care for the terminally ill. As the numbers of terminal cancer patients in Taiwan have continued to increase in recent years, palliative care has been advocated as a moral responsibility. However, ethical issues are frequently encountered during the provision of hospice and palliative care. Bradshaw described how the spirit of hospice has been routinised, institutionalised and medicalised as the result of overemphasis on techniques and efficiency, thus deviating from its original goal. Kinzbrunner reported that the most frequently encountered ethical dilemmas in the US concerned predicting the survival of the terminally ill (as documented by the Medicare Hospice Benefit limitation of six months); truth-telling; hesitancy to use morphine for fear of causing respiratory failure; issues related to parenteral nutrition, and difficulty in meeting the needs of delirious patients. Finlay described difficult clinical decisions in hospice treatment in the UK such as the treatment of hypercalcaemia, uremia, abnormal serum sugar level, abnormal liver function; the principle of hydration and nutritional support; the use of antibiotics, steroids and analgesics; the place of care; strategies employed in medical emergencies, and the withholding or withdrawal of life-sustaining procedures. Despite cultural differences, it seems widely agreed that appropriate hospice and palliative care be given within the framework of the principles of medical ethics.

Major ethical principles in palliative care relate to:
1 Autonomy [respecting the values of the patient].
2Beneficence and non-maleficence [applied to therapeutic strategy and decision making, such as truth-telling and choice of medication].
3 Justice, the balance between personal need and social resources, as in the selection of place of care.

In Taiwan lack of professional training and manpower may explain the lack of solution of some ethical dilemmas, inevitably affecting the quality of care of the terminally ill. This study investigated the most frequently encountered ethical dilemmas in the palliative care unit of the National Taiwan University Hospital, following the outcome of each dilemma and exploring factors related to it. The results suggest improvements which may promote the local quality of care.

Patients and methods
PATIENTS
Two hundred and forty-six consecutive patients, whose duration of stay in the hospice and palliative care unit of the National Taiwan University Hospital was longer than two days between July 1997 and the end of June 1998, were enrolled in the study. Health care workers recorded daily all ethical dilemmas in caring for each patient. Each dilemma
was then examined in the weekly multidisciplinary

MEASUREMENTS

The study was conducted in two parts.

1. Field recording:

For six months prior to the investigation all ethical
dilemmas encountered during the care of patients
were summarised in discussions at weekly multi-
disciplinary team meetings.

2. Design and pretesting of a structured

questionnaire:

From the results of field recording, a questionnaire
covering the most frequently encountered ethical
dilemmas was designed. A group of experts
[comprising physicians, a nursing supervisor, sen-
ior nurses, a psychologist and a social worker] were
invited to review the questionnaire’s comprehen-
siveness and applicability. The questionnaire
was then piloted, and modified after weekly team
discussion, for a month.

3. Structured questionnaire

A structured questionnaire was designed after
analysis of the pilot and ethical dilemmas were cat-
egorised as follows: patient, family and medical
team had different opinions on:

1) Telling the truth.
2) Place of care.
3) Therapeutic strategy [patient or the family
could not accept the goal of treatment being
directed towards “care” rather than “cure”].
4) Hydration and nutrition.
5) Blood transfusion.
7) Terminal sedation.
8) Use of medication.
9) Other.

These dilemmas were graded by health care work-
ers on a three-point scale as follows: 0, never
happened; 1, happened, but was no longer a
dilemma; 2, happened and was still a dilemma.

Statistical analysis

Data management and statistical analysis were per-
formed using SPSS 6.0 statistical software. A
frequency distribution was used to describe the
demographic data and the distribution of each
variable. Mean values and standard deviations were
used to analyze the severity of each ethical
dilemma. Data on ethical dilemmas were followed
up on a weekly basis to assess dynamic change.
Finally, χ-square test and one way ANOVA were
used to compare the differences between demo-
graphic variable and ethical dilemmas. A p value
less than 0.05 was considered statistically signifi-
cant.

Results

Table 1 shows that the number of males and
females was similar (52% and 48%, respectively).
Nearly half of the 246 patients were older than 65
years, and only three patients were younger than
18. The mean age was 60.6±14.7 years. The
primary sites of cancer were lung (20.7 %), colon
(13.0%) and liver (11.0%). The mean length of
hospital stay was 19.3±16 days. A third of the
patients (34.6%) were discharged after symptom
control and 36 (14.6%) were admitted twice or
more during the period.

Table 2 gives the type and frequency of ethical
dilemmas encountered. Problems for the place of
care occurred in 33% of patients, with truth-telling
about the patients’ terminal status in 32% of
patients. Dilemmas concerning nutrition and ther-
apeutic strategy occurred in about a quarter of
patients; and with the use of medication in 19.1%.
Blood transfusion, terminal sedation and alterna-
tive treatment gave rise to fewer ethical dilemmas
perhaps because of established therapeutic guide-
lines for these issues on the ward.

Although there was a dilemma to do with truth-
telling for a quarter of patients during early hospi-
talisation, this gradually resolved with duration of
stay (table 3). However, the longer the hospital stay,
the greater the problem of place of care became. In

Table 1 Demographic characteristics of patients

<table>
<thead>
<tr>
<th>Variables</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>128</td>
<td>52.0</td>
</tr>
<tr>
<td>Female</td>
<td>118</td>
<td>48.0</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 18</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>19–35</td>
<td>7</td>
<td>2.9</td>
</tr>
<tr>
<td>&gt; 65</td>
<td>114</td>
<td>46.3</td>
</tr>
<tr>
<td>Mean±S.D.</td>
<td>60.6±14.7</td>
<td></td>
</tr>
<tr>
<td>Primary tumour site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>51</td>
<td>20.7</td>
</tr>
<tr>
<td>Colon and rectum</td>
<td>32</td>
<td>13.0</td>
</tr>
<tr>
<td>Liver</td>
<td>27</td>
<td>11.0</td>
</tr>
<tr>
<td>Stomach</td>
<td>22</td>
<td>8.9</td>
</tr>
<tr>
<td>Biliary - pancreas</td>
<td>20</td>
<td>8.1</td>
</tr>
<tr>
<td>Head and neck</td>
<td>16</td>
<td>6.5</td>
</tr>
<tr>
<td>Cervix</td>
<td>12</td>
<td>4.9</td>
</tr>
<tr>
<td>Breast</td>
<td>8</td>
<td>3.3</td>
</tr>
<tr>
<td>Prostate</td>
<td>4</td>
<td>1.6</td>
</tr>
<tr>
<td>Brain</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>Ovary</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Haematology</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Others</td>
<td>48</td>
<td>19.5</td>
</tr>
<tr>
<td>Length of hospitalisation (days)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 7</td>
<td>54</td>
<td>21.9</td>
</tr>
<tr>
<td>8–30</td>
<td>153</td>
<td>62.2</td>
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<tr>
<td>31–60</td>
<td>34</td>
<td>13.8</td>
</tr>
<tr>
<td>&gt; 61</td>
<td>5</td>
<td>2.1</td>
</tr>
<tr>
<td>Mean±S.D.</td>
<td>19.3±16.0</td>
<td></td>
</tr>
<tr>
<td>Outcome</td>
<td></td>
<td></td>
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<tr>
<td>Death</td>
<td>161</td>
<td>65.4</td>
</tr>
<tr>
<td>Discharge</td>
<td>85</td>
<td>34.6</td>
</tr>
<tr>
<td>No of admissions</td>
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<td></td>
</tr>
<tr>
<td>1</td>
<td>210</td>
<td>85.4</td>
</tr>
<tr>
<td>2</td>
<td>30</td>
<td>12.2</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>2.4</td>
</tr>
<tr>
<td>246</td>
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</table>
principle, in order to care for more patients, no patient may stay more than a month, unless there is a medical indication. Problems in discharge from hospital occurred in over forty per cent of patients (42.8%) in the fourth week of admission and another peak (50%) occurred on the seventh week of admission.

Thirty-seven (15.1%) patients insisted on cure as the goal of treatment on admission. However, by the fifth week in hospital all had changed their perspective regarding this goal. However, frustration with this issue appeared again in the following weeks, demonstrating that a fluctuation in acceptance of the goal of treatment creates increased need for clear communication between staff, patients and relatives.

It is more important to provide appropriate rather than excessive nutritional support in terminally ill patients. However, this general rule often conflicted with the traditional Chinese cultural traditions of medical care, which place heavy emphasis on the need for nutritional supplementation. In this study, 15% of patients had trouble with this issue during their early stay in hospital but these problems decreased with duration of stay, though among the eight patients who had been hospitalised for eight weeks, two still had problems with this issue.

Blood transfusion was given only if anaemia was present in 42.6% of patients older than 65 years (p<0.05). However, the problems with truth-telling occurred in only 3.2% of the patients.

It was more important to provide appropriate hydration and nutrition among patients, family and medical team, than its overall acceptability.

We also compared the demographic characteristics of patients with the incidence of ethical dilemmas. There was no apparent association of gender with change in any of the ethical dilemmas. However, the problems with truth-telling occurred in 42.6% of patients older than 65 years (p<0.05). The conflict of transfusion occurred in all patients but only if it was inexpensive and non-invasive.

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Table 2 Types and frequency of ethical dilemmas during hospitalisation assessed by health care workers

<table>
<thead>
<tr>
<th>Ethical dilemma</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of care</td>
<td>82 (33.3)</td>
</tr>
<tr>
<td>Truth-telling</td>
<td>79 (32.1)</td>
</tr>
<tr>
<td>Hydration and nutrition</td>
<td>62 (25.2)</td>
</tr>
<tr>
<td>Therapeutic strategy</td>
<td>61 (24.8)</td>
</tr>
<tr>
<td>Use of medications</td>
<td>47 (19.1)</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>18 (7.3)</td>
</tr>
<tr>
<td>Terminal sedation</td>
<td>18 (7.3)</td>
</tr>
<tr>
<td>Alternative treatment</td>
<td>11 (4.5)</td>
</tr>
</tbody>
</table>

Total patients: 246

The transition in the frequency of ethical dilemmas during the course of hospitalisation (%)

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>Truth-telling</td>
<td>25.6</td>
<td>17.9</td>
<td>20.5</td>
<td>15.8</td>
<td>6.4</td>
<td>5.6</td>
<td>7.1</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Place of care</td>
<td>9.0</td>
<td>21.8</td>
<td>30.4</td>
<td>42.8</td>
<td>22.6</td>
<td>30.0</td>
<td>50.0</td>
<td>37.5</td>
<td>16.7</td>
<td>20.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Therapeutic strategy</td>
<td>15.1</td>
<td>14.7</td>
<td>13.8</td>
<td>11.1</td>
<td>0.0</td>
<td>11.2</td>
<td>7.1</td>
<td>12.5</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Hydration and nutrition</td>
<td>15.0</td>
<td>13.4</td>
<td>6.8</td>
<td>11.1</td>
<td>9.7</td>
<td>5.6</td>
<td>7.1</td>
<td>25.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>2.8</td>
<td>3.2</td>
<td>4.9</td>
<td>3.2</td>
<td>0.0</td>
<td>0.0</td>
<td>7.1</td>
<td>12.5</td>
<td>0.0</td>
<td>20.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Terminal sedation</td>
<td>2.4</td>
<td>5.1</td>
<td>3.9</td>
<td>3.2</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>12.5</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Use of medications</td>
<td>12.2</td>
<td>9.6</td>
<td>10.8</td>
<td>6.4</td>
<td>16.1</td>
<td>0.0</td>
<td>7.1</td>
<td>12.5</td>
<td>0.0</td>
<td>0.0</td>
<td>25.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Total patients: 246
sixty per cent (59.1%) of patients with gastric cancer had ethical problems associated with hydration and nutrition, as did about a third of patients with either head and neck (37.5%) or colon cancer (34.4%). This finding may be related to common problems of dysphagia or bowel obstruction.

Regarding the length of stay, nearly two-thirds (64.1%) of patients in hospital from 31 to 60 days had trouble in accepting or complying with recommended discharge plans, and sixty per cent of those who stayed more than 61 days also had trouble with this issue. As for blood transfusion and terminal sedation, patients staying in for more than two months had a higher (40%) incidence of conflict in relation to these issues. Of patients who stayed on our ward for less than three days in 31.6 per cent there was a dilemma concerning therapeutic strategy.

The mean number of ethical dilemmas encountered for each patient was 1.5. More were reported among female patients than males (1.70 v 1.41). Patients younger than 18 years had more ethical dilemmas than the other age groups (2.33 v 1.53). Patients who received inpatient care for longer than two months had more ethical dilemmas (3.00±1.73, p<0.001) than others. Patients with gastric cancer or head/neck cancer had more ethical dilemmas (1.96±1.62, 1.75±1.73) than patients with other primary sites of cancer.

Problems with discharge during the last week of hospitalisation occurred in one fourth of patients (25.2%) (table 4). In addition, trouble with truth-telling occurred with 17.1% of patients, and in 10.6% of cases a solution to this problem was never reached. It was somewhat surprising that 11.4% of the patients or their families still requested curative treatment rather than palliative care in the last week of hospitalisation.

### Discussion

In this study, one-third (34.6%) of the terminally ill patients were discharged after control of symptoms. This contradicts the common perception that a Taiwanese hospice serves as a place only to wait for death. Our medical staff not only relieved the physical and psychological distress of the patients (beneficence), but also helped the patients to return home once their conditions became stable, according to their expectations (autonomy). However, ethical dilemmas surrounding the discharge plan occurred in one third of the patients in our study. In oriental culture, it is common practice not to disclose the truth of the illness especially to a terminal cancer patient, on the basis of non-maleficence. This mutual pretense prevails because both sides are unwilling to hurt each other and lack knowledge of how to communicate with each other. Nevertheless, evidence suggests that a good death is easier to obtain if patients have enough time to arrange their affairs. Our previous study found that a "good death score" was higher if the patient was aware of his or her own imminent death. However, we found that the intention and process of telling the truth were often interrupted by relatives, although this could be gradually resolved through continuing communication. In this study, rather than ten per cent of patients in their seventh week in hospital had this dilemma compared to one quarter of patients in the first week, and it was never an issue after the eighth week. Another commonly encountered ethical dilemma was the demand for hydration and nutrition. Because patients with terminal cancer often develop anorexia or dysphagia, parenteral fluids and nutrition are usually requested by the families of these patients. However, inappropriate hydration and nutrition may further increase patients’ distress by aggravating conditions such as ascites, limb oedema and gastrointestinal secretions. Moreover, parenteral nutrition can also be absorbed by cancer cells, violating the principle of non-maleficence. Meanwhile, use of parenteral hydration and nutrition too early may replace the family's delicate care and make the relationship between the patient and the family, and caregivers, more aloof. Improving the quality of life by encouraging more interaction between patient and family is an essential part of palliative care. One fourth of patients experienced difficulty in deciding on the appropriate goal of treatment between "cure" and "pursuing better quality of life" and this was not resolved by a longer period of hospitalisation. Emphasis on the need for communication appeared to be the only useful strategy in resolving this issue. Perhaps because of the widespread misunderstanding of the medical role of opioid-derived compounds since the opium wars in China in 1840, some patients and families still preferred to tolerate pain rather than use morphine. Poor pain control resulted in an unnecessary deterioration of physical function and life quality, which unfortunately was common in this patient group. Another important factor affecting pain control was the use of herbal drugs, in accordance with Taiwanese beliefs, which may have adverse interactions with Western medication.

The study found that a mean of 1.5 important ethical dilemmas were encountered by each patient during his or her stay. These dilemmas not only puzzled the medical team, but also impeded the pursuit of better quality of life and a meaningful and peaceful death. Further investigations are needed to fill the gaps in our understanding of the ethical dilemmas surrounding the discharge plan.
needed to establish guidelines suitable for dealing with these dilemmas.

In conclusion, many ethical dilemmas were encountered in caring for the terminally ill which troubled the patient, the family and the medical staff. Good communication between the medical staff and patients and family is essential if attitudes towards these ethical dilemmas are to be improved. Professional development based on good research evidence may help to solve these dilemmas. Education which focuses on medical ethics is crucial for appropriate decision making in palliative care. It is also important to emphasise that relieving the suffering of the terminally ill and providing them with adequate support, is an essential part of the health care system.

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References