ATTITUDES TO END-OF-LIFE DECISIONS IN PAEDIATRIC INTENSIVE CARE*

Aslihan Akpinar, Muesser Ozcan Senses and Rahime Aydin Er

Key words: attitudes of health personnel; clinical ethics; end-of-life care; paediatric intensive care; treatment futility

The aim of this study was to assess attitudes of intensive care nurses to selected ethical issues related to end-of-life decisions in paediatric intensive care units. A self-administered questionnaire was distributed in 2005 to intensive care nurses at two different scientific occasions in Turkey. Of the 155 intensive care nurse participants, 98% were women. Fifty-three percent of these had intensive care experience of more than four years. Most of the nurses failed to agree about withholding (65%) or withdrawing (60%) futile treatment. In addition, 68% agreed that intravenous nutrition must continue at all costs. In futile treatment cases, the nurses tended to leave the decision to parents or act maternally. The results showed that intensive care nurses could ignore essential ethical duties in end-of-life care. We suggest that it is necessary to educate Turkish intensive care nurses about ethical issues at the end of life.

Introduction

Prolonging life by artificial means has brought about various ethical problems in addition to the severe sequelae suffered by infants and children undergoing paediatric intensive care, apart from the high costs incurred. Recognition of the limits of good medicine requires effective monitoring of when continuing treatment is no longer in the patient's best interest. At this point, it would not be possible to determine futile treatment without consideration of both medical and ethical issues.¹,²

When children become seriously ill and experience life-threatening problems in paediatric intensive care units, they are dependent on nurses for their essential needs. The nurses are expected to provide care to a high degree of professional competence,

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Address for correspondence: Aslihan Akpinar, Kocaeli University Medical Faculty, Department of History of Medicine and Medical Ethics, Umuttepe 41380, Kocaeli, Turkey. Tel: +90 262 303 7450; Fax: +90 262 303 7003; E-mail: aslyakcay@yahoo.com
which should include ethical sensitivity about futile treatment. They are also expected to have some level of responsibility about providing comprehensive and compassionate end-of-life care, including promoting comfort and pain relief, giving an early explanation and counselling about a critical prognosis, informing about a diagnosis of brain death, and giving family counselling about death.3–5

In contrast to newborn intensive care units, paediatric units are recently established in Turkey. Paediatric patients are generally cared for in mixed intensive care units together with adult patients.6 The education of nurses who care for these children is not standardized. Nursing education is available by means of three different routes in Turkey: high schools, two-year associate degree courses and a bachelor’s degree, with limited ethics education.7 All students graduating from these courses can become intensive care nurses. For this reason, an intensive care staff certification programme was introduced by the Turkish Ministry of Health in 2003.8 The Ministry also published standards for intensive care units in 2007.9 However; there are still untrained nurses working in intensive care today. It was re-emphasized in 2007 that all intensive care nurses should have a certificate or they must obtain one within a year.9 In May 2008, the regulation concerning intensive care nursing certification was updated.10

In the suggested certification programme, the topic ‘ethics and patient rights’ is listed as a mandatory subject, without mentioning how much time should be devoted to it, or that is should include end-of-life issues.8,10 However, the intensive care nurses’ certification programmes that were started based on this regulation have no ethics content, even in an average curriculum of 300 hours.11–13

There is no established policy or code for end-of-life decisions in Turkey. Clinical ethics committees and ethics counselling services are limited in number. We can therefore say that Turkish nurses make decisions based on traditional nursing attitudes.14,15

For this reason it is important to collect and analyse information about intensive care nurses’ attitudes to end-of-life decisions. This could determine the need for ethics education and lead to proposals for an effective management role in intensive care units to ensure not only the best interests of the children but also provide knowledge and understanding for parents and medical teams participating in the treatment process.

Methods

Study design

We used an 18-item self-administered questionnaire developed by the researchers after carrying out a literature review.16–19 This consisted of 10 questions on the personal and professional characteristics of the participant nurses and five questions about their attitudes to end-of-life decisions. The remaining three items were cases concerning futile treatment. A pilot study was conducted with six nurses to ensure clarity of the questionnaire.

Setting

The study was carried out at one local and one national scientific meeting held in 2005 (the Paediatric Intensive Care Nursing Symposium at the Golcuk Navy
Selection of participants

The questionnaires were distributed to all nurses present at these meetings who volunteered to participate. Seventy per cent (54/77) of the symposium members and 28% (101/360) of the congress members participated in the study.

Primary data analysis

The personal and professional characteristics (age, children, duration of professional and intensive care experience) of the intensive care nurses were used as independent variables. Attitudes to end-of-life decisions were used as dependent variables. The relationship among these variables was determined using the Pearson chi-squared test; a value of $P < 0.05$ was considered to be significant.

Limitations

The study has some limitations. First, we conducted the study at two conferences and thus the limited number of intensive care nurses who attended them were the total target group. The participants were those nurses who were willing to give their time to fill in the questionnaire. In addition, the study was a tabletop exercise; real world preferences may be different from those noted by the participant nurses.

Results

Three of the 155 participants were men. The participants’ mean age was $29.2 \pm 4.8$ years and mean years of professional experience was $9.1 \pm 5.1$. Most of the nurses were adult intensive care unit staff and their mean years of intensive care experience was $6.1 \pm 4.6$. Eighty percent of the nurses reported that religious values were important in their life and nearly half did not answer the question about their political opinions (Table 1).

Attitudes to the end-of-life decision-making process

The first two questions were related to the role of nurses in end-of-life decisions. First, the participants were asked if they felt confident to help families who were making end-of-life decisions, such as continuing artificial nutrition, or withholding or withdrawing treatments. More than half of the nurses (53%) reported that they were unable to help families in making critical decisions.

In the second question the nurses were asked if they agreed that end-of-life care planning was appropriate for only patients who are expected to die in the near future. A majority of the nurses (58%) disagreed. There was no statistically significant relationship between these answers and the nurses’ personal characteristics. In addition, we did not observe any statistically significant relationship between other preferences or decisions and the nurses’ characteristics.
Attitudes to ethical issues at the end of life

The next three questions were related to attitudes to withholding and withdrawing treatments at the end-of-life. Thirty-five percent of the intensive care nurses declared that ‘when there is no medical benefit, withholding treatment could be morally justified’. The same statement for ‘withdrawing treatment’ was true for 40% of the participants.

Sixty-eight percent of the participants agreed that ‘for a dying patient, even when all treatments have been withdrawn, artificial nutrition must always be continued’.

Decisions about cases

The nurses were also asked to make decisions about three treatment futility cases relating to paediatric and neonatal intensive care units. Short descriptions were given and the nurses were asked to make decisions on these cases. For ‘A newborn may survive with treatment but will have an enormous degree of physical or mental impairment’, 41% of the nurses said that the decision should be left to the family, 37% decided for scheduled treatment, and 22% proposed that a decision should be made based on prediction of the future quality of life of the baby.

The second case was ‘A child who has a progressive and irreversible illness, the recommended treatment for which may cause additional pain and suffering, and create an unbearable situation, but probably with some benefit.’ For this case, 65% of the nurses said the decision should be left to the child or the family. Nineteen percent of the nurses preferred that the treatment should be started or continued, and 16% gave an opinion that the treatment should not have been started and should not be continued.
The last case was of a child in a persistent vegetative state whose diagnosis was definite. Half of the participants preferred continuing aggressive treatment until brain death occurred. Thirty-one percent preferred continuing aggressive treatment, but with no mention of brain death. The remaining nurses chose withdrawing all aggressive treatments and continuing with only palliative care.

**Discussion**

Futile care prolongs suffering, does not improve quality of life and fails to achieve a good outcome for the child. Nurses are expected to understand the implications of their patients’ medical condition and to become familiar with the customs, feelings and attitudes of the family. In addition to communication skills, nurses must therefore equip themselves with ethical sensitivity about futile treatment. They should also be involved in the decision-making process and facilitate this process for the family.20,21

These roles and nurses’ patient advocate role have been considered by other researchers.5,21,22 It is worrisome that more than half of the intensive care nurses felt unprepared to facilitate end-of-life decisions. More than half also thought that it was not necessary to wait for the end of life before starting to plan care, even if the patient was expected to die in the near future. This is not unusual because the time of death is often difficult to predict. The American Academy of Pediatrics suggested that ‘if the nearness of death is used to determine which children receive palliative care, some children may die without the benefits of individualized family-centred palliative care.’23 Although in Europe and the USA standards for palliative care in children are laid down,23,24 in Turkey there are no such services, although palliative care units have recently begun to cater especially for cancer patients.

Our results suggest that these intensive care nurses believed end-of-life care planning should begin at an earlier stage, although they did not feel prepared well enough to discuss and facilitate this process with families.

Intensive care nurses must recognize their important role in the decision-making process and also their patient advocate role. In our previous study, however, we observed that nearly half of the nurses were not involved in decision-making processes in intensive care units.25 Researchers from the USA, Europe and Australia have reported that nurses are not always involved in discussions or in clinical-ethical decision making.1,26,27 They were also unaware of their patients’ preferences, thus they were usually unable to advocate for them.28

It has been accepted that there is no ethical distinction between withholding or withdrawing treatments. It is, however, considered that withdrawing treatment may cause more emotional distress for health care providers and may even be harmful to patients.19,29 In contrast to health care providers, parents may find it easier to withdraw treatment after its institution, because they believe that everything possible has been done.16,30 To our surprise, some nurses in our study expressed the same opinion. When there is no medical benefit, withdrawing and withholding treatment is ethical; in fact, continuing or initiating treatments that are no use to the patient are unethical.31–33 The nurses in our study did not agree with withdrawing and withholding treatments, even if there was no medical benefit. This preference, however, could result in postponing death, increased suffering and wasting of limited
resources. Any treatment decision should therefore be based on ‘the best interest standard’ and futility criteria.\textsuperscript{19,34}

The withdrawal of artificial nutrition and hydration is one of the most controversial issues in medical ethics. Feeding is a particularly emotive area for parents and staff. Food and water given orally (e.g. breastfeeding for infants) is the usual means of providing nutrition to patients. The administration of nourishment and hydration by artificial means is qualitatively different from merely assisting with feeding.\textsuperscript{16,19,35} Medically supplied nutrition and hydration may prolong the dying process and are not ethically required in all circumstances. They can be stopped or forgone as can all other medical interventions when their burden outweighs their benefit.\textsuperscript{35–37}

In another study, nurses supported the withdrawal of artificial food and fluid if it would relieve the patient’s suffering, as the American Nurses Association and the American Academy of Pediatrics have recommended.\textsuperscript{38} In the current study, the intensive care nurses had negative attitudes towards limiting all modes of treatment, including artificial nutrition and hydration. This result suggests that the nurses might violate their duties imposed by the principles of ‘do not harm’ and ‘justice’. Theoretical and applied ethics training programmes should therefore be established for intensive care nurses who are expected to care for and comfort children and improve their quality of life when end-of-life decisions are being made. When curative goals can no longer be achieved, the aim for intensive care nurses may be to assist patients to achieve a peaceful death.\textsuperscript{39}

The ethical focus of surrogate decision making for children is in their best interests.\textsuperscript{40} It is accepted that parents have the authority to make treatment decisions on behalf of their babies and children. It is assumed that parents will have profound love for their children and commitment to their welfare.\textsuperscript{1} However, there are limitations to parents’ decisions. Some family preferences or treatment requests are outside the goals of medicine and may be incompatible with the principle of proportionality (which requires that each treatment must be weighed against the expected benefits and burdens)\textsuperscript{19} or are not successful in increasing quality of life.\textsuperscript{19,40,41}

For the first two cases, the nurses preferred to leave the decision to the family. This result suggested that the nurses could not recognize their supportive role in the intensive care unit and the limits of family preferences.\textsuperscript{20,21} Their second preference for the first two cases was to schedule treatment without the family’s decision. This expressed a maternalistic attitude that could ignore patient preferences and interests. If implemented, the decisions made by the nurses could not only prolong the suffering of the child but also violate the principle of justice.\textsuperscript{19,42} Only a few of the nurses’ preferred decisions were ethically acceptable in that they chose the actual and probable quality of life of the newborn in the first case and the principle of proportionality for the second; however, assessment of quality of life and using the principle of proportionality is an important part of planning end-of-life care.\textsuperscript{23,41,43}

We observed that the nurses had a supportive attitude to including children in decision making. This was important in terms of the patient advocate role. Children should take part in decision making as their capacity permits. In this way they may have a chance to say goodbye to their loved ones by taking a role in their end-of-life decisions.\textsuperscript{23,43,44} Similar to international codes, the involvement of children in decision making is required by the Turkish Patients’ Bill of Rights.\textsuperscript{45}

The third case was about a child in persistent vegetative state. Feeding and other medical treatment may be withdrawn from such patients\textsuperscript{16,46,47} because aggressive
treatment does not ensure medical benefit, achieve the goals of medicine, or improve
quality of life; rather, it may only use scarce medical resources. For an infant or
child, death can be a more humane choice than continuing a life full of pain and suffer-
ing.48

Half of the intensive care nurses preferred continuing treatment until brain death
occurs. Although it is recommended that all medical treatments can be withdrawn
in patients in persistent vegetative state, the nurses’ preferences could be explained
by their legal concerns.

One-third of the nurses preferred that all aggressive and palliative treatments
should be continued, whether brain death occurs or not. Brain death is accepted in
Turkey as a legal criterion of death and thus intensive care nurses should have ade-
quate knowledge about this. In addition, nurses should co-operate with families
who may have difficulty in accepting a diagnosis of brain death. For this reason,
the nurses’ preference that treatment must be continued at all costs raises serious
concerns about the principle of justice. In postponing the peaceful death of a child,
the principle of doing no harm could also be violated. Only one-fifth of the inten-
sive care nurses preferred withdrawing all aggressive treatments and continuing
with only palliative care, which is ethically acceptable.

Conclusions and suggestions

We observed that Turkish intensive care nurses definitely need education on the
ethics of end-of-life issues, such as the principle of doing no harm, the principle
of justice, and treatment futility. The ethical issues and our recommended solutions are
presented in Table 2.

It has been suggested that ‘cultural values directly affect healthcare professional
attitudes, and these attitudes are deeply ingrained and are not likely to be changed
by educational programs. However, if attitudes are based on misguided assump-
tions, education may well change one’s attitudes. We conclude that if intensive care
nurses are educated in ethical issues in end-of-life care, particularly treatment futil-
ity, their attitudes may change.

Theoretical education on ‘ethics and patient rights’ in the certification programme
of the Turkish Ministry of Health provides a limited theoretical basis. However,
intensive care nurses should be trained in applied ethics and clinical ethical decision
making with real-life cases.

In addition to ethics training programmes, intensive care nurses should also be
supported by ethics consultation services. It would be even better to train experi-
enced intensive care nurses to carry out in-service education and consultation.

Finally, to fulfil the patient advocate role in paediatric end-of-life decisions, nurses
must be supported by institutional and national policies. These policies should be
developed in collaboration with the national nursing associations.

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Table 2  Examples of ethical issues that intensive care nurses could encounter and suggestions for solutions

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<tr>
<th>Question</th>
<th>Ethical issue</th>
<th>Solution</th>
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<td>Withholding and withdrawing life-prolonging treatments</td>
<td>Principle of do no harm</td>
<td>Planning both theoretical and clinical ethics training sessions</td>
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<td></td>
<td>Principle of justice</td>
<td>Establishment of institutional and national policies, and legal regulations</td>
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<td></td>
<td>Distributive justice</td>
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<td></td>
<td>Treatment futility</td>
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<tr>
<td>Withholding and withdrawing intravenous nutrition and hydration</td>
<td>Principle of do no harm</td>
<td>Planning clinical ethics training and clinical-ethical decision-making training with true-life case studies</td>
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<td></td>
<td>Principle of justice</td>
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<td>Case 1: quality of life</td>
<td>Limits of parental consent</td>
<td>Establishment of ethics consultation services in which experienced intensive care nurses who were educated about clinical ethics could play a significant role</td>
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<td>Maternalistic attitudes</td>
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<td>Quality of life</td>
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<td>Principle of proportionality</td>
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<td>Case 2: unbearable situation</td>
<td>Principle of do no harm</td>
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<td></td>
<td>Principle of justice</td>
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<td>Limitations of parent consent</td>
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<td>Maternalistic attitudes</td>
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<td>Principle of proportionality</td>
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<td>Case 3: persistent vegetative state</td>
<td>Principle of do no harm</td>
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<td>Treatment futility</td>
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Aslihan Akpinar, Muesser Ozcan Senses and Rahime Aydin Er, Kocaeli University, Kocaeli, Turkey.

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