UNDERTAKING THE ROLE OF PATIENT ADVOCATE: A LONGITUDINAL STUDY OF NURSING STUDENTS

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Key words: nursing ethics training; nursing students; patient advocate role; patients’ bill of rights

Patient advocacy has been claimed as a new role for professional nurses and many codes of ethics for nurses state that they act as patient advocates. Nursing education is faced with the challenge of preparing nurses for this role. In this article we describe the results of a study that considered the tendencies of a cohort of nursing students at the Kocaeli University School of Nursing to act as advocates and to respect patients’ rights, and how their capacities to do so changed (or not) as a result of their nursing education.

This longitudinal study used a questionnaire consisting of 10 statements relating to patient care. It was performed both at the start (1998) and at the end (2002) of the nursing training. At the beginning of their course 77 students participated; in the study. After four years, only 55 students participated, the reason for this drop in number being unknown.

The questions asked nurses if patients should have: the right to receive health care; the right to participate in the decision-making process about their treatment; the right always to be told the truth; and the right to have access to their own medical records. They were also asked: if quality of life should be a criterion for discontinuing treatment; if patients have the right to die and the right to refuse treatment; if patients should be assisted to die or helped to undergo active euthanasia; and if severely disabled newborn babies should be allowed to die. The student nurses demonstrated considerable insight into contemporary nursing issues and were ready to act as patient advocates. Professional responsibility demands that good nurses advocate strongly for patients’ choices.

Introduction

In recent years patient advocacy has been claimed as an integral part of the nurse’s role in health care delivery. Advocacy has become an important concept in nursing practice; however, the interpretation of advocacy varies. One model includes the protection of rights, values-based decision making, and respect for the person.1 In the role of patient advocate, nurses protect patients’ human and legal

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rights and provide assistance in asserting those rights if the need arises.\textsuperscript{2–5} McGraw suggested that patient advocacy is to teach patients.\textsuperscript{6} Other models suggest that patient advocacy is to respect patients’ decisions and enhance their autonomy.\textsuperscript{7–9} If a patient lacks the ability to decide, nurses should assist the person to decide, based on his or her values, beliefs and expectations.\textsuperscript{10} However, patient advocacy is not only involved in helping patients to decide for themselves, it is also to utilize their rights. Some nurse leaders recognize patient advocacy as a role integral to the moral values system in nursing, enhanced by the nurse–patient relationship.\textsuperscript{11–13} According to Leddy and Pepper, the belief in advocacy as an appropriate role for nurses has evolved in harmony with earlier social movement characterized by consumerism, self-care, justice and human rights, equal opportunities for all, and individual accountability for control.\textsuperscript{14} Given these values, nurses today readily accept the obligation to act as an advocate in their relationship with patients.\textsuperscript{4,14} Advocacy involves active support of autonomy, beneficence and human dignity,\textsuperscript{14} and many nursing codes of ethics\textsuperscript{3,5} bind nurses to the role of patient advocate and urge them to take action when the rights or safety of patients are jeopardized.\textsuperscript{10,13,15}

Nurses need to be prepared to advocate for patients who may be at risk of violation of their basic rights.\textsuperscript{16} Nursing students should therefore develop their sensitivity to advocate for patients’ rights. Because clinical and ethical knowledge are significantly related to the development of ethical conduct in nursing students,\textsuperscript{7,17,18} schools of nursing, health institutions and the professional organizations have obligations to prepare nurses and nursing students for the role of advocate for patients’ health and safety.\textsuperscript{2,14,19–22}

Because of these issues, we wanted to establish if training in nursing ethics during nursing education is effective in developing the advocacy role. First we tried to determine the students’ opinions about patients’ rights at both the beginning and the end of their nursing course. Then we planned to discover if their opinions relating to patients’ rights had or had not changed during their professional training. A course in nursing ethics or nursing deontology is taught in the curriculum of all nursing schools in Turkey.\textsuperscript{21} Physicians and nurses have to respect patients’ rights in Turkey, according to the Turkish Patients’ Bill of Rights and the Turkish Standards of Patient Rights.\textsuperscript{23,24}

**Method**

We planned this longitudinal study with nursing students at Kocaeli University School of Nursing to explore the tendencies that nursing students exhibit with respect to patients’ rights, and to determine the changes in these tendencies or attitudes during their education.

**Design**

A questionnaire consisting of two parts was developed, based on the rights of patients and the laws and literature in Turkey.\textsuperscript{4,25,24} The first part included descriptive data about students, such as gender, age and number of siblings. The second part consisted of 10 questions that were prepared in the light of the
Patients’ Bill of Rights of the Council of Europe Draft Convention for the Protection of Human Rights, the Turkish Patients’ Bill of Rights, Turkish Standards of Patients’ Rights, and codes of professional ethics.\textsuperscript{19,22–26} The questionnaire was approved by the Ethics Committee of Kocaeli University in September 1998.

The questionnaire part of the study consisted of the following questions. Do you believe that:

1. Health care is a right?
2. People have the right to participate in all decisions related to their health?
3. Patients should always be told the truth?
4. Patients have a right to examine their health record?
5. Children should be allowed to make their own treatment decisions after the age of seven years?
6. Patients have the right to die?
7. A person has the right to refuse treatment, even if it will hasten his or her death?
8. Quality of life should be the criterion for making a decision concerning discontinuing treatment?
9. Proposals to allow members of the health professions actively to end a dying person’s life at his or her request should be opposed by nurses and physicians?
10. Severely disabled newborn babies should be allowed to die?

Setting and participants

The study was carried out with the students at the School of Nursing of Kocaeli University between November 1998 and May 2002. The length of undergraduate education at schools of nursing in Turkey is four years.\textsuperscript{27,28} The questionnaire was presented to all students ($n = 77$) who commenced training in November 1998. After four years, at the end of their studies, the same questionnaire was presented to the same students, then numbering 55.

Analysis

The findings were statistically evaluated by Pearson’s test ($\chi^2$) and probability ratios. Sex, number of siblings and attitudes relating to some patients’ rights were used as independent variables.

Findings

We aimed to explore the tendencies demonstrated by nursing students towards patients’ rights and to determine how effective was the nursing education and training in ethics in encouraging students to become patient advocates. As a result of this and other similar studies, we believe we can say that nursing education that includes teaching on nursing ethics is effective in developing the role of patient advocacy.

Of the 77 students who participated in this study in the first year of their course,
30% \((n = 23)\) were men and 70% \((n = 54)\) women. The average age of the students was 18.3 years. Almost half of the students had four or more siblings. Of the 55 students who graduated, 38 were women and 17 were men.

Table 1 shows the opinions of student nurses concerning patients’ rights: 92.7% of the students at the beginning and 96.4% of the students in last year of their course stated that health care should be a right for all individuals. After four years, 87.3% of these students strongly agreed with this statement. In the first year, 45.4%, and four years later, 72.7%, of the student nurses believed that patients should have the right to know the truth about their condition. At the end of their course, the students’ tendency to always tell the truth to patients increased by almost 50% (Table 1). A substantial, but smaller, increase is evident with regard to the right of patients to obtain a copy of their medical records.

At the beginning of the course, 20.0% of the students stated that children aged over seven years should participate in their own decision-making process, but, after four years, almost half of the students (47.2%) agreed with this statement.

The students’ tendencies with regard to the right to die increased in favour of this question after four years, there being a twofold increase in agreement. The difference between the answers about the right to refuse treatment, even if it will hasten the patient’s death, increased by about two-thirds. First-year students seemed to be hesitant about assisting patients to claim their rights, but fourth-year students were more convinced and willing to assist patients in this way. First-year students believed that taking quality of life as a basis for maintaining treatment was a fair statement but, after four years, they were not so sure.

A striking finding is that about one-third of the students (38.2% at the beginning, 36.4% at the end of their education) stated that physicians and nurses should be allowed to perform euthanasia in accordance with patients’ wishes. More female than male students disagreed with the statement that members of the health professions should actively end a dying person’s life at his or her request \(\chi^2 = 9.57; \text{df} = 4; \ p = 0.004\). At the beginning and the end of their studies, the numbers of students who agreed that newborn babies with severe disabilities should not be allowed to survive were roughly equal (Table 1).

## Discussion

In Turkey, each person has, ethically and legally, the right to health care, to be informed, to give consent, and to refuse any treatment.\(^{23,24,29,30}\) Health care providers have a moral obligation to ensure that patients give informed consent and also permission for specific procedures based on their own knowledge.\(^ {2,5,23,24,29,30}\) The majority of respondents (first year 81.8%; fourth year 94.5%) believe that patients should have the right to participate in the decision-making process about their treatment (self-determination). This finding indicates that student nurses are inclined to implement their ethical duty of respecting and protecting patients’ autonomy. Another finding supporting this is that 32.8% of the respondents in the first year and 54.5% in the fourth year believe that patients have the right to refuse treatment. Evaluation of the professional values of respondents who believe that patients have a right to refuse treatment shows that these nurses respect other persons’ autonomy and human dignity. Nurses’ right of
<table>
<thead>
<tr>
<th>Do you believe that ...</th>
<th>First year</th>
<th>Fourth year</th>
<th>( \chi^2 )</th>
<th>df</th>
<th>p-value</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>SA: no. (%)</td>
<td>A: no. (%)</td>
<td>U: no. (%)</td>
<td>D: no. (%)</td>
<td>SD: no. (%)</td>
</tr>
<tr>
<td>Health care is a right?</td>
<td>35 (63.6)</td>
<td>16 (29.1)</td>
<td>1 (1.8)</td>
<td>2 (3.6)</td>
<td>48 (87.3)</td>
</tr>
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<td>Patients have the right to self-determination?</td>
<td>30 (45.5)</td>
<td>15 (27.3)</td>
<td>3 (5.5)</td>
<td>2 (3.6)</td>
<td>5 (9.1)</td>
</tr>
<tr>
<td>You should always tell the truth to patients?</td>
<td>13 (23.6)</td>
<td>12 (21.8)</td>
<td>13 (23.6)</td>
<td>10 (18.2)</td>
<td>7 (12.7)</td>
</tr>
<tr>
<td>Patients have a right to examine their health record?</td>
<td>17 (30.9)</td>
<td>20 (36.4)</td>
<td>11 (20.0)</td>
<td>4 (7.3)</td>
<td>3 (5.5)</td>
</tr>
<tr>
<td>Children over 7 years should be allowed to make decisions?</td>
<td>6 (10.9)</td>
<td>5 (9.1)</td>
<td>9 (16.4)</td>
<td>17 (30.9)</td>
<td>18 (32.7)</td>
</tr>
<tr>
<td>Patients have the right to die?</td>
<td>4 (7.3)</td>
<td>11 (20.0)</td>
<td>12 (21.8)</td>
<td>14 (25.5)</td>
<td>14 (25.5)</td>
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<tr>
<td>Patients have the right to refuse treatment?</td>
<td>4 (7.3)</td>
<td>14 (25.5)</td>
<td>11 (20.0)</td>
<td>13 (23.6)</td>
<td>13 (23.6)</td>
</tr>
<tr>
<td>Quality of life should be the criterion for making a decision?</td>
<td>21 (38.2)</td>
<td>16 (29.1)</td>
<td>3 (5.5)</td>
<td>6 (10.9)</td>
<td>9 (16.4)</td>
</tr>
<tr>
<td>Health care professionals should be allowed actively to end a dying person's life?</td>
<td>7 (12.7)</td>
<td>14 (25.5)</td>
<td>11 (20.0)</td>
<td>7 (12.7)</td>
<td>16 (29.1)</td>
</tr>
<tr>
<td>Severely impaired newborns should be allowed to die?</td>
<td>9 (16.4)</td>
<td>7 (12.7)</td>
<td>20 (36.4)</td>
<td>8 (14.5)</td>
<td>11 (20.9)</td>
</tr>
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SA, strongly agree; A, agree; U, undecided; D, disagree; SD, strongly disagree
refusal of treatment to patients is opposed in both Turkish Law\textsuperscript{30} and by the International Council of Nurses (ICN) \textit{Code of ethics for nurses}.\textsuperscript{3}

Some of the nursing students (first year 20.0%; fourth year 47.2%) believe that children should have the right to participate in the decision-making process after the age of seven years. This increased percentage shows that nurses care more about children’s consent or assent as they proceed with their training. This difference can be related to recently improved nurse training in Turkey. In a prior study,\textsuperscript{4} the majority of registered nurses (41.5% disagreed; 46.2% undecided) stated that children should not participate in their own treatment decisions, even after reaching the age of seven years. The findings show that the nurse candidates, like registered nurses, have a tendency towards paternalistic and maternalistic attitudes.\textsuperscript{4,26,31}

More than half of the students stated that patients should have the right to obtain and examine their medical records. This outcome is in accordance with the previously mentioned study on patients’ rights in Turkey.\textsuperscript{4} The right to be informed is a basic right that helps to define a person’s freedom and dignity. Telling the truth is essential to the integrity of the patient–health-care-provider relationship. Health care professionals are obliged to be honest with clients and, at the end of their nursing education, more students concurred with the code of ethics of health care professionals and Turkish law than at the beginning (45.4% first year; 72.7% fourth year).

In spite of this, telling patients about their serious health problems can be distressing for both patients and health care professionals, but coping with this dilemma can be helped by adequate training in ethics.\textsuperscript{2,32} This has implications for Turkey. Studies performed in early 1996, after the implementation of improved nursing ethics training in Turkish nursing schools, indicated that 63.9% of nurses supported patients’ right to be informed about their illness.\textsuperscript{4} A study performed in the early 1990s indicated that only 24.45% of nurses and 31.85% of physicians supported patients’ right to be informed.\textsuperscript{33} In a second part of this study, more than half of the medical students surveyed in the first year preferred to tell the truth to patients. Davis and Jameton stated that nursing students clearly showed more support than medical students for active disclosure, informed consent, expressing professional opinions, and patients’ decision making.\textsuperscript{18} Another study revealed that only 14.8% of surgeons regarded the same issues to be patients’ rights. In contrast, 93.2% of patients in the same study stated that they wanted to be informed about everything concerning themselves.\textsuperscript{34} In a study published in 2000, 74.5% of patients on haemodialysis stated that they wanted to be informed about their prognosis, even if it was a bad prognosis.\textsuperscript{32}

Nurses assess patients’ quality of life when they observe how patients are managing or adapting to constraints resulting from illness or injury.\textsuperscript{2,19–22} Most of the respondents in the present study were in favour of taking quality of life as the basis for maintaining treatment; this reflects the influence of aesthetic judgements as well as the nurses’ opinion that patients should have the right to die with dignity. We believe that this attitude reflects that nurses are focusing on showing respect to patients and that it is influenced by nursing values of protecting patients’ dignity. In addition, nurses in our country seem to give special thought to the principle of respect for life and human dignity. Thus, these results suggest
that nurses may play a considerable role in helping patients to exercise their rights.

Another striking finding is that over a third of the participants (first year 38.2%; fourth year 37.0%) stated that physicians and nurses should be allowed to perform euthanasia in accordance with patients’ wishes. Although this is in sharp contrast with Turkish legal, moral and religious rules, in our other study, almost half (49%) of the nurses surveyed stated that physicians and nurses should be allowed to perform euthanasia when this is requested by patients.4 In other studies, the idea of supplying ways or means of facilitating death was found to be morally acceptable.26,35 In Kowalski’s study36 it is reported that 44% of the nurses, and in Tanida et al.’s37 study that 20% of the nurses, thought that active euthanasia was permissible under certain circumstances. For this reason, in nursing ethics education, ethical issues related to euthanasia and assisted suicide should be considered from all points of view. However, we can say that these findings do imply that nurses give particular importance to the principle of respecting patients, and to the value of protecting their dignity.

Another controversial issue in our country is whether newborn babies with severe disabilities should live or die. One-third of the respondents said that severely disabled newborn babies should be allowed to die. A significant number of first-year and fourth-year students declined to answer the questions on this topic. This attitude is similar to that found in our previous study,4 in which half of the registered nurse respondents indicated that medical resources, especially when limited, need to be distributed according to medical necessity and medical indications.38 The outcomes of that study, which was performed in eight European countries, were similar to those in the present study.39 Like the nurses who stated that quality of life should be taken as the basis for the maintenance of treatment, these nurses supported allowing severely disabled newborn babies to die on the basis of aesthetics and dignity of life as a fundamental value.

Conclusion

The social contract between nursing and society is to protect or preserve life, to avoid doing harm, and to create a relationship of trust and loyalty with the recipients of nursing actions. Hence, an expected outcome of nursing education is how to protect patients and be their advocate. The ideal patient advocate is a nurse who is nonjudgemental and able to empower patients to exercise their individual rights to self-determination. Even if nurses do not agree with patients’ decisions, they must respect their wishes.

We believe that the outcomes of this study demonstrate the need to include instruction in ethics in nursing education. Because, more recently, nurse education has included ethical issues, the students’ opinions about patients’ rights were seen to have changed slightly. Opinions on these issues are very important for nurses in their advocacy role concerning patients participating in their treatment decisions, children consenting or assenting to treatment, respecting patients’ right to refuse treatment, and patients obtaining and examining their own medical records. Nurses’ agreement about telling the truth and that patients have the right to die increased over the course of the study. However, the uncertainties caused
by taking quality of life as a treatment criterion for patients, giving permission to perform active euthanasia, and allowing severely disabled newborn babies to die was either preserved or increased.

For these reasons, nurse teachers have an important responsibility for integrating new ideas and concepts about patient advocacy and nursing ethics into their educational programmes. They must develop an awareness of and sensitivity to these significant behaviours and make sure that student nurses gain the necessary knowledge, value and skills by making these behaviours expected learning outcomes. Thus we can say that nurses have tended to recognize and carry out the duty of patient advocacy as one of the requisites of contemporary nursing if nursing ethics training is included in the nursing curriculum. Professionalization of the role may be the only way forward if codes of ethics continue to make patient advocacy a mandatory activity for professional nurses.

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Nursing Ethics 2003  10 (5)

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