



KNOWLEDGE OF COMMUNITY PEOPLE ABOUT THE RIGHTS OF TERMINAL PATIENTS

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ABSTRACT

Scientific and technological developments in health have improved treatment options and assistance, conveying increases in life expectancy. Despite this, literature is still scarce in research about the rights of terminal patients. This information allows the vindication of a dignified and respectful health care, besides contributing to the exercise of autonomy. Thus, the aim of this study was to identify the knowledge and respect for the rights of terminal patients by community people. This was an exploratory, descriptive study with a quantitative approach. The sample consisted of 136 community people. The instrument was a questionnaire to identify the knowledge and respect for the rights of terminal patients. Rights were unknown by 78.7% of respondents. Participants who reported acknowledging the rights (21.3%) were asked to mention the rights they knew. Among the most cited were the right of free access to medicines (30%), access to health goods and services (23.3%), right to continuity of basic care (20%), and good quality, dignified and human treatment (16.7%). In conclusion, most individuals were unaware of the rights of terminal patients and had a low perception of respect toward them.

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INTRODUCTION

Scientific and technological developments in health have improved treatment options and assistance for patients with chronic diseases, conveying increases in life expectancy. At the same time, the provision of quality of life to these patients is not much considered during the terminal phase. It is often observed that a slow, threatening and painful death only leads to an extension of the death process. A sophisticated technological arsenal is employed in the attempt to prolong life indefinitely, at the cost of intense suffering (Marquis, 2007; Pessini, 1996). In this situation, the rights of terminal patients are not always taken into account, such as the right to the truth, the clarification for decision making, the refusal to receive painful treatments, choosing the place of death, among others (Sao Paulo, 1999; FCM, 2006).

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Acknowledging these rights allows the vindication of a dignified and respectful health care, besides contributing to the exercise of autonomy, enabling the deconstruction of beliefs and inappropriate attitudes. When the individuals are unaware of their rights, they might not demand them and be violated. Thus, assessing the population's knowledge about their rights related to health care may positively interfere in specific interventions. To the best of our knowledge, there is no research in indexed publications up to now that have focused on people's knowledge about the rights of terminal patients. Some authors had patients or health professionals as study participants and aimed at identifying the knowledge of these specific groups about the rights of hospitalized individuals (Veloso and Spindola, 2005; Gomes et al., 2010). Others have studied the same issue in patients with cancer (Sonobe et al., 2011), diabetes mellitus (Santos et al., 2011), in elderly individuals (Martins and Massarollo, 2010) and in participants of clinical investigations (Sakaguti and Ramos, 2006). The small number of national studies on the subject and the current

scenario of terminal patient care, commonly based on the practice of dysthanasia, with disrespect for the rights of these patients, justify the importance of this investigation. Thus, the aim of this study was to identify the knowledge and respect for the rights of terminal patients by community people.

MATERIALS AND METHODS

This was an exploratory, descriptive study with a quantitative approach. The non-probabilistic sample consisted of 136 individuals. To determine the sample size, a level of significance of 5% and a margin of error of 2% was considered (Bolfarine and Bussab, 2005). The study was conducted with people addressed at different places and situations (relatives, acquaintances, members of religious institutions, among others), who were invited to answer a questionnaire. Persons under 18 years of age and health professionals were excluded from the sample.

Data collection instrument was composed by:

- Socio demographic data;
- Questions about the experience with terminally ill patients, knowledge of the rights of the terminally ill patients, perception regarding the respect for those rights;
- Seven statements in a Likert scale form based on the Sao Paulo State law number 10.241 (Sao Paulo, 1999) and the FCM Resolution number 1.805 (FCM, 2006). This part of the instrument aimed at identifying favorable and unfavorable positions related to the knowledge about the rights of terminally ill patients
- Two numerical visual scales, to assess the general knowledge and perception of the participant regarding the respect for the rights of terminal patients.

The Likert scale is used to measure opinions and attitudes. It varies between agreement and disagreement. The statements were graduated from the most unfavorable to the most favorable position. The scale had five degrees: the two extremes representing disagreement or agreement, and the intermediate point (grade 3) representing indecision. The existence of positive and negative affirmations avoided the conditioning of the answers of the participants. Blank alternatives were considered as "I do not know how to respond".

The instrument contained an explanation about the term "terminal patient" and researchers were present during data collection to clarify any doubts. The instrument was sent to 10 judges to assess whether the questions and statements were formulated in a clear and easy to understand way, considering that the subjects of the research were not health professionals. A pilot test was applied in 30 individuals, to verify the clarity of the questions and allow later modifications to the instrument. This pilot test also assisted the calculation of the study sample, which was based on the proportion of the responses. Data were collected after the approval of the Research Ethics Committee of the University of Sao Paulo School of Nursing. The principles of voluntariness and anonymity were respected, and all participants have signed a written informed consent form. Participants were given the option to answer the questionnaire through an interview (assisted by the researchers), or to receive the instrument to complete it on their own. The ones who chose the second option programmed with the researchers the day and time for delivering the questionnaire. The majority of participants

chose this option. After completing the instrument, the participant received a booklet with the current legislation about the rights of users of health services and health actions in the State of Sao Paulo (Sao Paulo, 1999). The study variables were analyzed descriptively, calculating absolute and relative frequencies, means, standard deviations, minimum and maximum values.

RESULTS

One hundred and thirty-six (136) individuals participated in the study. Most of them ($n=83$, 61%) were female, and 53 (39%) were male. The average age was 37.3 (± 12.6) years. Most were married (47.8%), 30.9% were single, 13.2% lived with a partner and 2.2% were widowers. Regarding the level of education, 31 (22.8%) attended school for up to 8 years, 64 (47.1%) between 9 and 12 years, and 27 (30.1%) attended school for more than 12 years. When asked about ever living with terminally ill patient, 92 (67.7%) have denied, but 43 (31.6%) participants answered affirmatively to this question, and one person (0.7%) did not respond. Regarding the knowledge about the rights of terminal patients, 6 (4.4%) persons claimed to acknowledge them, 23 (16.9%) mentioned knowing some of the rights, but 107 (78.7%) were not aware of the rights of terminal patients. Among people who reported living with terminally ill patients, only 4 (9.3%) answered affirmatively to this question, 9 (20.9%) had some knowledge, and the other 30 (69.8%) did not know the rights.

The sum of the interviewees who claimed to know the rights or to know some of them added up to 29 (21.3%). Participants were asked to cite what rights they knew. Twenty-two rights were cited:

- 9 (30%) free access to medications;
- 7 (23,3%) access to health goods and services;
- 6 (20%) continuity of basic care;
- 5 (16,7%) good quality, dignified and humane care;
- 4 (13,3%) dignified and natural death;
- 3 (10%) retirement due to disability.

The rights to illness relief, transportation gratuity, choosing the place of death, redeeming social benefits, companion and visits, alleviating suffering, and invasive support were cited 2 times each. The rights of free assistance, making decisions regarding own care, priority attention, assistance in the right environment, information about the own health status, tax exemption, visits at home, being cared by the family, and the continuity of care by the health insurance were cited once each. The item continuity of basic care refers to care with body hygiene, food and pain relief. The item "access to health goods and services" includes vacancies for hospitalization in hospitals, medical and psychological care and assistance in emergency units, early relief and pre-hospital care. The maximum number of rights mentioned by participant was five, the minimum was one. This knowledge was self-related on a scale of 0 to 10. For 107 (78.7%) participants, the knowledge they had on the subject was between 0 and 4, and 40 (29.4%) persons evaluated their knowledge as zero. Fifteen (11.0%) declared grade 5 and another 14 (10.3%) participants said they had knowledge between 6 and 9. The mean of the answers corresponded to 2.5 (± 2.4). The knowledge was positive for the right to reject invasive and painful treatments, decision making and guarantee of basic life care.

Regarding the knowledge and / or beliefs related to the right to choose the place of death, it was observed that participants were divergent from the provisions of the legislation, since most of them (59.2%) affirmed that the terminal patient should be hospitalized in the ICU (intensive care unit), regardless of his/her will. Regarding respect for the rights of terminally ill patients, 14 (10.3%) persons believed that these rights were respected; 35 (25.7%) of the individuals stated that they were sometimes respected; 31 (22.8%) did not believe in respecting these rights; and 56 (41.2%) did not know how to respond. The analysis of the responses of the participants who had lived with a terminal patient, 6 (14.0%) believed that these rights were respected, 16 (37.2%) thought they were sometimes respected, 10 (23.3%) individuals did not believe in respecting those rights, and 11 (25.6%) did not know how to respond.

The reasons why the rights of patients with terminal illnesses were sometimes respected, according to 23 participants were: the lack of dignified attention and abandonment, negative influence of the family, lack of responsibility and commitment of professionals, withdrawal of invasive supports, sensitization for compassion, lack of knowledge about their rights, individuals of low economic status are more disrespectful, the relationship of respect among human beings is tenuous, long delays in queues, the lack of health resources, lack of disclosure of their rights, hospital management. The reasons why the rights of terminal patients were not respected were the lack of dignified attention and abandonment, lack of good quality in public services, influence of economic status on respect for the rights, withdrawal of invasive supports, imposition of health professionals in decision making, high cost to have a dignified assistance, the fragility of the relationship of respect among human beings. Considering a scale of 0 to 10, for 81 (59.5%) participants, the intensity of respect for the rights of terminal patients was between 0 and 4, 22 (16.2%) of them attributed score 5 and 31 (22.8%) persons considered the respect to be between 6 and 10, and only 2 (1.5%) did not think about the issue. The average score was 3.7 ± 2.6 .

DISCUSSION

The present study assessed the knowledge of community people about the rights of terminally ill patients. Most of them were unaware about this topic. Even many of those who already lived with patients in this condition ignored these rights. Among the ones who believed that the rights of terminally ill patients were respected, most did not know how to justify the answer. Men showed greater constraint when approached and invited to participate in the research, and claimed not to have knowledge on the subject. After clarifications, 53 (39%) men participated in the study. A study involving cancer patients showed that male individuals presented greater constraint in answering questions about their rights, while female patients demonstrated better understanding regarding the topic and considered the interview as an informal conversation (Sonobe et al., 2011). The number of individuals who said they did not know the rights of terminal patients corresponds to 107 (78.7%), of which 30 (28%) reported having lived with these patients. Several investigations, conducted with specific groups, demonstrated the ignorance of the individuals about their rights as patients (Veloso and Spindola, 2005; Gomes et al., 2010; Sonobe et al., 2011; Santos et al., 2011; Sakaguti and Ramos, 2006; Kreisler et al., 1996).

In a qualitative study aimed at analyzing the attitude of seven nurses in relation to the manifestation of the autonomy of terminal patients, as results, among other aspects, the authors observed that they recognized autonomy as a right of the terminal patient and tried to respect it (Oliveira and Silva, 2007). A survey that enrolled 50 health professionals (nurses and doctors), 17 had a regular level of knowledge about the rights of their patients and 7 had very low level of knowledge (Kreisler et al., 1996). Regarding the study with cancer patients, 19 (45%) did not know their rights (Sonobe et al., 2011). Contrary to the results presented here, the study conducted with 63 elderly persons identified that 49.2% of them declared to know their rights (Martins and Massarollo, 2010). The rights of terminally ill patients are contemplated in legislations concerning the rights of users of health services in general (Sao Paulo, 1999). By knowing these laws, people would also have access to the rights of terminally ill patients. However, the difficulty of understanding this type of information prevents people from exercising his / her citizenship. Justice and equity are essential for the deconstruction of health inequalities (Pellegrini, 2004). Nurses play an important role as disseminators and providers of health information to patients, families and the community, promoting health education. By assuming this social function, nurses provide assistance based on bioethical principles, and also exert the profession with quality and responsibility (Santos et al., 2011). Participants of this study perceived that it was important to know their rights as patients. They showed great interest in obtaining more information about this, including committing to read the booklet containing the law number 10.241 (Sao Paulo, 1999). In addition, the verbalization of the participants in the interest of receiving information about their rights was evidenced in a research that investigated the perception of hospitalized clients about their rights and duties (Veloso and Spindola, 2005).

The majority (59.2%) of the participants agreed that the terminal patient should remain in the ICU, regardless of his / her will. In first world countries, more than 80% of citizens die in hospitals. This percentage has been increasing in the last decades: it was 50% in 1949, 61% in 1958, 70% in 1977 and 75% in 1987 (Council on Ethical and Judicial Affairs of the American Medical Association, 1992). Considering the new improvements in national health systems and plans, many countries will reach those percentages. At the same time, most individuals who die in hospitals are unable to exercise their autonomy in the phase that precedes their death (Buchanan and Brock, 1989). The non-acceptance of the family regarding the patient's death process or the lack of clarification about the family's health condition can generate a wrong decision regarding assistance behaviors to the terminally ill patient, culminating with the use of invasive support. The wishes and autonomy of the terminal patient may be limited or even suppressed due to the influence of the family and medical team (Chaves and Massarollo, 2009). For the 35 (25.7%) participants of the present research, the rights of terminally ill patients are sometimes respected, and another 31 (22.8%) individuals believed that these rights were not respected. Hospitalized patients feel oppressed and neglected by health professionals regarding their rights, especially by the nursing team. The fear of reprisal and the impotence felt by the patient can lead to limitations in the continuity of the treatment (Veloso and Spindola, 2005). For doctors and nurses, some patient rights may be more difficult to respect, including clarifying the diagnosis, carrying out individualized and

attentive treatment, and the right to have a companion (Kreischer et al., 1996). It is noteworthy that 56 (41.2%) individuals did not know how to answer the question about respecting the rights of terminally ill patients. The ignorance of about these rights and / or not living with a terminal patient can be barriers against the recognition of respect to the rights.

The lack of knowledge of the general population on the issue of terminality makes it necessary to think over how to improve this situation. Ventres (2014) suggests that physicians should educate their adult patients about how they can approach death with dignity, consistently with their needs, and aware of the reality that will be faced in the end. According to this author, this process must occur in ambulatory contexts, as part of ongoing care, and in the context of serious illness or hospitalization. However, the study by Cartwright et al. (2015), shows that even physicians have a significant gap in knowledge about the rights of terminally ill patients. Addressing this topic in the under graduation and medical residence in a more incisive way could attenuate this failure and consequently improve the knowledge of the general population as well.

Conclusion

Most individuals are unaware of the rights of terminally ill patients and have a low perception of respect towards such rights. In addition, participants had beliefs that oppose to the right of manifestation of the autonomy of terminal patients regarding the choice of the place of death.

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