

Editorial

What are the factors influencing nurses to neglect patients' autonomy and decision-making?

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The concept of autonomy has been derived from two Greek words “autos” means self and “nomos” means law and discretion. The official history of emphasizing the right of patients to have autonomy goes back to the Nuremberg Declaration in 1947. This concept has attracted much attention over the last few decades. For instance, according to a statement by the World Medical Association (1981), the patient is not only entitled to receive medical information but also has the right to choose the most appropriate option among existing treatments and care (1). In the area of health service delivery, medical ethics experts believe that the patient has autonomy and should choose the best way of treatment among different ways, based on the received information (2). What is obvious is that children also have the right to have proper and fair treatment and to reduce the pain and suffering of unnecessary treatments. When it comes to children's decision making, according to existing laws, this right is always defined for their parents.

On the other hand, one of the dimensions of family-oriented care is enhancing the adequacy and empowerment of the family, and respecting their autonomy and decision-making in child care and treatment. The studies indicate that

providing support and information for the parents in the hospital environment during child care, notifying parents about the treatment plan, educating them and using their participation are the most important needs of the parents. This requires the supportive educational relationship of personnel, especially nurses with parents (3). However, there are many situations in nursing care that, if nurses are unaware or negligent, this patient's fundamental right will be violated. In this article, we will examine these factors and the findings of the studies conducted in this area.

The study of Beykmirza et al (2017) revealed that among the nursing ethical codes, the domain of respect for autonomy and decision making from the perspective of mothers with a child with cancer was at the most unfavorable level of performance. In this study, nurses also acknowledged that they presented poor performance in this domain (4). These findings support the results of other studies on the contentment of parents of children with cancer with giving them the right to make decisions (5, 6). The findings from these studies may indicate the nurses' lack of knowledge about patient rights and the need for values-based practice. The health system in Iran is mainly far from the concept of patient and family orientation and giving

decision-making rights on the basis of sufficient information. This is due to several reasons, such as lack of sufficient information from health care professionals, including doctors and nurses, about patient rights, having a stereotypical view about the lack of preparedness and competency of families to obtain information, the lack of a caring communication between the patient's family and caregivers along with empathy and attempt for empowerment, the high workload of professionals and in turn, assigning less time to the functions that include the non-physical aspects of patient and his or her family, as well as the lack of familiarity with professional ethics.

It seems that most nurses' beliefs is that if they give the families of children with cancer the right to autonomy in treatment, health and nursing interventions, they may face the families' irrational decisions. So, respecting this right is overlooked (7, 8). From their point of views, for example, if the families are familiar with the side effects of drugs, even if that drug is helpful to the physician, they may refrain from continuing treatment with that medication. Perhaps this is also the reason for the weakness in nurses' performance in the area of patient education. A study by Bartholdson et al. (2015) in Sweden showed the most ethical issues in pediatric cancer care were due to the violation of the patient's right to autonomy, limitation in reflecting facts, how to decide on the process of treatment and palliative care. Given the different perspectives and cultures, the degree of collaboration between the treatment team, the child with cancer and her/his family is challenged (9). The results of the study of Rahmani et al. indicated that most patients believed that nurses were at a poor level in respecting their autonomy in terms of providing

information to them and their participation in the therapeutic decision-making process. In addition, Sadeghi's study (2009), entitled "respecting autonomy during nursing care from the perspectives of adolescents admitted to children's hospitals affiliated to Tehran University of Medical Sciences in 2008 showed that 66.7 percent of adolescents believed that their autonomy was slightly respected, and only 4 percent of them stated that their autonomy was fully respected. In the similar studies, the lack of sufficient time, insufficient personnel, and lack of readiness and experience of nurses to provide illness-related information and to give the right to autonomy and decision making to the family, were suggested as three important factors in nurses' neglect in this regard (10, 11).

Indeed, there is a gap between theory and practice in the nursing profession, and nurses often emphasize their profession's technical aspects in order to achieve the main nature of nursing that is the consideration of professional ethics standards and respect for the patients' rights, including cultural rights, the right to life and choose, respect for dignity and treating respectfully. Several studies have shown that patients also had the highest satisfaction with the technical aspect of nursing profession. High satisfaction in this aspect can be due to the supervision and control by the managers, the importance of professional care and the nurses' high level of skill in this regard (12). Hajinejad et al. (2012) pointed out in their research that nurses mostly considered physical aspect of care, while most patients prioritized education and listening to the patient. From the perspective of Taleghani et al. (2012), the mothers in the oncology ward, more than

anything, needed an empathic relationship and comprehensive support. They emphasized their educational needs for receiving information on the stages of illness and treatment, comprehensive understanding, actions to reduce the child's suffering and the availability of nurses. However, they believed that nurses spend little time on these services among the technical activities of their profession. This reduces the human and ethical aspects of nursing care in pediatric oncology (13). Furthermore, according to the results of studies, fatigue and lack of enough time lead to negative attitudes and emotional stress in nursing staff, resulting in emotional and physical withdrawal from the patient and neglecting their rights and emotional needs (14-16).

In fact, it can be said that nurses, in the situations where there is not enough time and a lot of work, only perform the tasks that in case of not doing, they will be scolded. In a study by the American Nurses Association, the nurses believed there were barriers to ethical performance in the work place, which impaired their abilities to compassionately care for the patients. From their viewpoints, insufficient number of nursing staff, high workload, lack of enough time, and financial and organizational restrictions were important obstacles to professional ethics (16-18).

The results of the above studies showed that patients' autonomy and decision-making as their main rights are neglected by nurses. Therefore, this issue should be taken into account by clinical nurses, managers, educators and nursing researchers to improve patient's autonomy by adopting applied strategies and programs at different operational levels.

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