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Giving information to family members of patients in the intensive care unit: Iranian nurses' ethical approaches

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Abstract

Receiving information related to patients hospitalized in the intensive care unit is among the most important needs of the family members of such patients. When health care professionals should decide whether to be honest or to give hope, giving information becomes an ethical challenge.

We conducted a research to study the ethical approaches of Iranian nurses to giving information to the family members of patients in the intensive care units. This research was conducted in the intensive care units of three teaching hospitals in Iran. It employed a qualitative approach involving semi-structured and in-depth interviews with a purposive sample of 12 nurses to identify the ethical approaches to giving information to family members of the intensive care unit patients. A conventional content analysis of the data produced two categories and five subcategories. The two categories were as follows: a) informational support, and b) emotional support. Informational support had 2 subcategories consisting of being honest in giving information, and providing complete and understandable information. Emotional support in giving information had 3 sub-categories consisting of gradual revelation, empathy and assurance. Findings of the study indicated that ethical approaches to giving information can be in the form of either informational support or emotional support, based on patients' conditions and prognoses, their families' emotional state, the necessity of providing a calm atmosphere in the ICU and the hospital, and other patients and their families' peace. Findings of the present study can be used as a basis for further studies and for offering ethical guidelines in giving information to the families of patients hospitalized in the ICU.

Keywords: ***intensive care unit (ICU), family members, nursing ethics, giving information***

Introduction

As the first social institution, each family bears culture, roles and special structures signifying the physical, mental, social, spiritual and cultural health of its members. Any disorder in these areas will lead to a holistic disorder (1 - 4). One of the changes affecting the family is when one of its members is hospitalized. When a patient is hospitalized in the intensive care unit due to a serious illness or a life threatening condition, the effect of this phenomenon becomes more severe (5). A patient's critical situation and unclear prognosis can cause reactions such as fear, anxiety, physical and mental fatigue, hopelessness, disappointment and frustration in family members (5 - 9). When one of the family members is hospitalized in the intensive care unit, the family will have some needs (10); information, assurance, empathy and mental support are among these needs (11-13).

The results of a review prioritizing the needs of the family members of patients in the intensive care unit show that receiving information about the patient is among the most important needs of such families (14). The results of another study also show that most of the stress and anxiety in patients' family members is due to inadequate information about prognosis and treatment, and lack of familiarity with the environment and the complicated equipment in the intensive care unit (15). Researchers also asserted that the uncertainty and lack of information experienced by patients' family members is an important factor in increasing their depression and anxiety (16). Giving information to the family members of patients in the intensive care unit equips them with a better understanding of the stressful situation and decreases their level of anxiety (17). Using confrontation sources and strategies and giving information to the family members of the patients hospitalized in the ICU also helps them to better adapt when confronted with such stressful conditions and can bring their expectations about their patients' prognosis closer to reality (18-20).

Health care professionals working in the intensive care unit are confronted with lots of ethical challenges because of the complications in giving care (21). Families of patients hospitalized in the intensive care unit often want their questions to be answered honestly and comprehensibly. They also want to be informed about changes in the clinical conditions of the patients as soon as possible (22). In contrast, because of the instability of patients' clinical condition and their family members' emotional state, health care professionals tend to give general and ambiguous information about the patients' condition to protect their families against anxiety and stress (23). Sometimes health care professionals should decide whether to be honest or to give hope (24), and that is when giving information becomes an ethical challenge (25).

Literature review on the information needs of the families of patients in the ICU) (10, 13, 26-30). revealed a lack of studies on ethical approaches to giving information to family members of such patients. Therefore, further studies for identification of nurses' approaches can provide the basic knowledge for ethical family-centered care in nursing.

Method

This qualitative study adopted a conventional qualitative content analysis approach. This method is one of the approaches of qualitative research and also of qualitative data analysis (31); it examines written, spoken or visual messages consisting of raw data that are summarized and then categorized. In conventional content analysis data provides the basis for developing categories and their names (32).

The study was conducted in the intensive care units of three teaching hospitals in Iran (a total of 26 beds), where patients were admitted due to various medical conditions such as medical-surgical problems, neurosurgical problems and trauma.

Participants

Participants were selected by purposive sampling method. In this research, sampling was done from nurses with maximum variation (sex, level of education, and job experience) to the point of data saturation. Selection criteria for nurses were having Iranian nationality, a minimum of one-year work experience in the critical care unit, and being interested in participating in the study.

Ethical Considerations

After approaching the participants and explaining the objectives of the study and also obtaining their consent, the researcher began to collect the data. Ethical principles such as autonomy of the participants, confidentiality and anonymity were considered throughout the study. Letters of recommendation were obtained from the Research Deputy of the university affiliated with each hospital. Ethical approval was obtained from the Ethics Committee of Iran University of Medical Sciences.

Data Collection

In this study, semi-structured and face-to-face interviews were conducted with 12 nurses. The duration of the interviews varied between 35 and 85 minutes with a mean of 60 minutes. Interviews continued until data saturation was attained. At the beginning of the interview, the nurses were asked a general question: "What is your experience in giving information to patients' families?" In order

to obtain more information, the interviews continued with probing questions. All interviews were audio recorded and then transcribed verbatim in order to analyze data.

Data analysis

For data analysis, the researcher used conventional content analysis according to the Graneheim and Lundman method (33). This approach is usually appropriate when existing theory or research literature on a phenomenon is limited. Researchers used inductive category development, i.e., avoided using preconceived categories and instead allowed the categories to flow from the data. Researchers also immersed themselves in the data to allow new insights to emerge (32).

According to the content analysis process, at first each interview was read again and again carefully in order to gain a universal and primary understanding of the important underlined statements. Meaning units were then determined through investigating participants' experiences in the interview texts. In the next phase, the meaning units were extracted through condensation and were labeled as codes. Participants' statements and implicit concepts were used for coding. Codes were compared for similarities and differences within the same interview and in different interviews, and then categorization of codes was done accordingly. In the following stage, categories and subcategories were examined under supervision of experts who were experienced in qualitative analysis.

Rigor of the Study

Concepts of credibility, confirmability, auditability and transferability were used to measure the trustworthiness of the data (34). Credibility of the data in this study was evaluated through member check, peer check and prolonged engagement. After the analysis, the participants were contacted and given a full transcript of their respective coded interviews with a summary of the emergent categories to approve interpretations of the researchers. An expert supervisor and two doctoral students of nursing checked the study process.

Prolonged engagement with the participants within the research field for a period of 9 months helped us in gaining the participants' trust and a better understanding of their world. We saved all evidence and documents securely to maintain auditability. Moreover, we carried out a thick description of the context adequately so that a judgment of transferability could be made by readers.

Results

Of the twelve nurses who participated in this study, 8 were female and 4 were male. The mean age of the study participants was 40.42 ± 2.16 years, and their work experience in critical care ranged from 4 to 12 years. The results of the data analysis identified two main categories: informational support and emotional support (table 1).

Informational Support

One of the categories clarified in this study was informational support. This category had two subcategories: being honest in giving information, and giving complete and understandable information.

Based on the data from the interviews, it became clear that using informational support in giving information can act as an effective moderating factor in decreasing anxiety and concern. Honesty is a characteristic that families expect from physicians when receiving information. Family members demand to be informed of the patients' condition and of whatever the health care professionals know. In brief, they seek out honesty and trustworthiness in the process of their interaction with health care professionals. In this respect, one of the nurses said:

"*Families insist on receiving correct information and expect the nurses to tell them the truth. If they feel any falsehood in the information they are offered, they will lose their faith in the personnel including the doctor and the nurse*" [Participant No. 2].

Giving complete and understandable information was the second subcategory of informational support. In this regard, many of the nurses said that information must be offered completely and understandably. They also asserted that if the provided information meets the knowledge level of patients' families, they can better understand it, and their interpretations will be accurate. This can decrease the level of their anxiety and concern. In this regard, one of the nurses said:

"*The families of patients in the ICU suffer from severe stress and anxiety, and if they cannot attain thorough and precise information about their patients' situation, their stress gets intensified, which can negatively affect their relation with the health care providers*" [Participant No. 5].

Many nurses commented on misinterpretation or misunderstanding of the information and incomprehensible information. In this respect, a nurse said:

"*Sometimes the interpretations are different. Unfortunately, because of misinterpretation, sometimes families become more disappointed or more hopeful*" [participant No. 3]. In this regard, health care professionals' statements showed that incomplete information given by physicians and nurses to patients' family members could cause confusion and ambiguity. One nurse said:

"*The information that the nurse offers may not be complete, and this may lead to contradictory information*" [Participant No. 12].

Nurses also announced that there was a disagreement between nurses and physicians in terms of giving information to patients and their families. They believed that the main reasons for this disagreement were lack of communication and coordination between physicians and nurses,

physicians' reluctance to provide information to patients' families, and nurses' de-motivation. One of the nurses said:

"One reason why health care professionals aren't functioning properly is because of the personnel's fatigue. Another reason is that the personnel see nobody appreciates what they've done and families are grateful to physicians, and the nurses' role as the most important factor in patient care in the ICU is not highlighted. The life of a patient in the ICU is at the hands of the nurses. Lack of motivation in nurses can affect their relationship with the patients' families" [Participant No. 9].

Emotional Support

The second category identified in this study was emotional support. This category had three subcategories: gradual revelation, empathy, and assurance. Most of the interviews highlighted the fact that emotional support in giving information can be one of the moderating factors of stress and anxiety in patients' families.

One of the subcategories of emotional support in giving information was gradual revelation. Information control by health care providers was one of the strategies hidden in gradual revelation. There were many reasons to choose this strategy (that is, information control). Families' mental and emotional condition, patients' instability, physicians' reluctance to give thorough information and constrictions related to the organization (such as the special conditions of the intensive care unit) are to name a few. In this regard, one of the nurses said:

"Under certain circumstances, we can't tell the truth to the patients' families about their illness or the possible consequences due to the situation in the ward. For example, if a patient suffers from brain death and the news is given to his family abruptly, they may react in a negative way and make the ward and the hospital agitated, which can badly affect other patients and their families. As nurses, we can inform the families within the nursing scope of practice and based on the hospital regulations, and we aren't allowed to give them detailed information about the medical scope. In such cases, they are referred to the doctors" [Participant No. 8].

The second subcategory of emotional support in giving information was empathy. In nursing, especially in emotional family-centered care, empathizing with families is a crucial factor in giving care. Most of the nurses participating in this study believed that patients' families needed health care professionals to sympathize with them and to give them the necessary information in an empathic and effective relationship. They declared that an empathic and sympathetic relationship kept families hopeful and to a great extent decreased their mental suffering and protected them against emotional vulnerability. The following statements show such effects:

"When families talk to physicians and nurses, especially the ICU personnel, and ask about patients' conditions, if the doctors or nurses explain the patients' conditions clearly, if they have empathy with the families and ask them to be patient, they can bring the families some hope" [Participant No. 1].

From the viewpoint of the nurses, assurance was another factor related to emotional support in giving information. Compassion, empathy and giving honest answers to the questions of patients' families are among the factors which can create security and assurance in families. Concerning assurance, one of the nurses said:

"If we have an empathic and honest relation with the families of these patients, and if we show them that we understand them, we will be able to create a connection and will have their cooperation accompanied by a feeling of security and trust. When such an atmosphere is created, whatever the health care providers pick is accepted by the families, and they trust us" [Participant No. 11].

Table1- Categories, subcategories and codes demonstrating the ethical approaches to giving information to family members of the intensive care unit patients

Categories	Subcategories	Codes
Informational support	Being honest in giving information Giving complete and understandable information	Honesty, informing patients' family members honestly, telling the truth, offering real information Complete information, giving clear and plain information
Emotional support	Gradual revelation Empathy Assurance	Informing patients' families based on the existing conditions Empathy in informing patients' families, empathy through health care providers' empathic relationship Showing empathy through health care providers' availability, creating emotional security by providing appropriate answers to the questions.

Discussion

This qualitative study showed different categories of Iranian nurses ethical approaches to giving information to ICU patients' families. The results of the data analysis identified two categories and five subcategories.

Informational support was the approach employed by most of the nurses in this study, and the strategies used in this approach were generally satisfactory and acceptable to families. The findings of a study by Azoulay et al., which showed families' dissatisfaction with the quantity and quality of the received information, also confirmed the importance of informational support (35). One of the strategies mentioned in informational support was health care professionals' honesty in giving information to patients' family members. Bond et al. reported that families wanted their questions about the patients' conditions to be answered honestly and realistically (36).

The challenge offered here is that patients' family members expect health care providers to treat them honestly, and health care providers eschew giving thorough and honest information due to reasons such as the mental and emotional state of the family members and patients' unstable conditions. In fact, they are dubious to choose to be honest. If they tell the truth, there is a possibility that the family will not be able to tolerate the pressure. Similarly, in cases where an accurate prognosis is not possible, giving true and thorough information could create false hopes and lead to mental suffering in patients' family members. A study showed that withholding the truth can be effective in protecting individuals against mental after-effects such as losing hope and its consequent suffering (37). The most important need of families is to receive real and appropriate information about patients' prognosis based on the current situation. On the other hand, health care professionals believe that general and ambiguous information should be given to families based on the patients' prognosis and instability. In this regard, the findings of two studies showed that one of the major concerns of all family members is receiving truthful and complete information that allows building realistic hope (38, 39).

It is inferred from the statements of health care providers that withholding the truth does not mean to lie, but to use gradual revelation as a form of emotional support. In such situations, it is difficult to determine which approach should be used in giving information to the patients' families and whether to tell the truth or not. Based on the reasons extracted from participants' attitudes, telling the truth can be ethical in some circumstances and unethical in others. Issues such as patients' stability, families' emotional situation and the existing conditions in the ICU and the hospital can determine the health care professionals' ethical decisions in this regard.

Moreover, studies have shown that although families expect correct and complete information, physicians and nurses are not always able to accommodate them. This is due to the patients' unstable situation at the time of hospitalization in the ICU and lack of comprehensive information about their prognosis (2, 40).

Another strategy in informational support was to give complete and understandable information, which was mostly demanded by patients' families. Health care providers used the information control strategy. They determined the family member to whom information should be given and the method of providing information. This manner of giving information was sometimes in sharp contrast with the needs of the families. In a study health care providers confessed that families need information about changes in their patients' condition and they have the right to receive understandable information, but they cannot bear to receive all the information at once. Therefore, information must be constantly and gradually offered (37).

Most participants viewed empathy as one of the subcategories of emotional support. An empathic and honest interaction with the families can make them hopeful about their patients' situation. It is never meant to give them false hope, but through appropriate interaction, health care providers can equip family members with internal powers to confront critical moments and prepare them to accept the patients' situation. Based on the results of a study, an empathic and trusted relationship is one of the necessities of nursing care in the ICU (41). Giving contradictory information to families results in distrust, frequent questioning and requests to stay by the patient in the ICU. As Bond et al. mentioned, when families receive contradictory information, they try to use strategies such as visiting the patient and participating in the process of care in order to test the accuracy of the received information (36). Another study revealed the interplay between perceived hope and health care providers' approaches to giving information, and confirmed that contradictory information created false hopes in families and caused them to lose their trust in health care providers (38).

In general, based on the findings of the present study, the patients' conditions and prognoses, families' emotional state, the necessity of providing a calm atmosphere in the ICU and the hospital, and other patients and their families' peace determine the appropriate and ethical approaches to give information to the families of patients in ICU.

Conclusion

This study revealed a small portion of ethical approaches to giving information to the families of patients in the ICU. The results of this study

showed two ethical approaches to giving information: informational support and emotional support. Generally, health care professionals should give complete and understandable information to the families of ICU patients as far as conditions of the patients, families and the hospital permit.

Since the present study focused on the ethical approaches to giving information to the families of patients in the ICU, different dimensions of each of the strategies in these approaches were not studied here. Therefore, it is recommended that more studies be conducted on the abovementioned dimensions of ethical approaches to giving information, especially on how to tell the truth to the families of patients in the ICU. It is also necessary to conduct studies on providing and employing guidelines for confronting ethical challenges in giving information to the families of patients in the ICU.

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