

Sources of hope: Perception of Iranian family members of patients in the Intensive Care Unit

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ABSTRACT

Background: Admission to an Intensive Care Unit (ICU) is recognized as a situation with emotional strain, uncertainty, and fear of losing the patient. In such stressful situations, it is hope that can promote psychological stability in the patient's family members. Related literature revealed that sources of hope in this situation have still not been discussed well in studies. The purpose of this qualitative study was to explore the sources of hope from the perspective of families of ICU patients in Iran.

Materials and Methods: In this qualitative study that was carried out adopting the conventional qualitative content analysis approach, 19 family members of 13 patients hospitalized in the ICU from three teaching hospitals were selected, through purposive sampling. Semi-structured interviews were used for data collection. The interviews were transcribed verbatim and analyzed using conventional content analysis, through the process of data reduction and condensation, coding, and also generating categories and subcategories.

Results: Analysis of the data revealed sources of hope in families of ICU patients. These sources appeared as two main categories- internal sources and external sources. The internal sources had two subcategories consisting of 'religious-spirituality beliefs' and 'positive attitude'. The external sources had four subcategories consisting of healthcare professionals' interactions, empathy of families and friends, patient's condition, and participation in care.

Conclusions: The results of this study showed the sources of hope in the families of the patients in the ICU. These sources, as moderating factors, could reduce physical and psychological damages caused to the families. In the present study, the categorizations of the participants' in-depth experience could develop a new horizon for healthcare professionals, especially nurses, on the sources of hope, based on culture.

Key words: Family, Intensive Care Unit, Iran, nurses, qualitative study, sources of hope

INTRODUCTION

The term 'intensive care' refers to the supportive care of a patient with advanced medical equipment, in order to save the patient's life.^[1] Admission to the Intensive Care Units (ICU) is recognized as a stressful situation for both the patient and family members, which usually occurs unexpectedly and suddenly.^[2] The experience of such a situation, for family members, is normally full of stress, anxiety, uncertainty, and fear.^[3]

Hospitalization of a patient in the ICU may bring about complications for the patient's family, such as, psychological

disruption, despair, fear, and anxiety. Some critical consequences that result could be interruption in the family's routine life and despair, which can cause adverse effects such as losing job, impaired decision making, or mental and physical disease.^[4-8] The family might experience a psychological crisis in this stressful situation. The emotional responses of family members of ICU patients include despair, helplessness, and frustration. If unresolved, these responses adversely affect the family's well-being, and subsequently, the patient's health.^[9]

Families find a variety of coping ways to cope when a member is admitted to a hospital on account of a critical illness.^[4] Family members use different coping strategies to maintain emotional health.^[10] Coping is a process of adaptation to a stressful situation and it includes all the cognitive and behavioral measures adopted by an individual in response to specific internal and/or external demands that are deemed to exceed his or her normal resources.^[11] Hope is one of the most effective coping strategies and it is a resource that influences an individual's ability to cope with stressful, life-threatening situations.^[10,12,13] Hope is a process of anticipation that involves the interaction of thinking, acting,

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feeling, and relating.^[14] Hope is a vital force in adaptation and has been associated with a higher quality of life.^[15] Hope illustrates the basic human needs.^[16] Another definition states that it is a belief that the present situation can be modified to a better situation.^[17] The result of a study shows that hope is an essential psychological process in adapting to stressful situations.^[13] Johnson and Roberts (1996), emphasize the importance of hope as a coping strategy for the family members of critically ill patients.^[18]

According to Yates (1993), even though it always exists, there are many sources that can improve or maintain hope. For Yates, future orientation to a current situation, passing of time, cognitive restructuring, support, current stress, level of energy, beliefs, decision-making, and an individual's mood are the main sources of hope, which helps individuals to cope with life-threatening situations.^[19] Hope can be important in a situation of a major event, such as a disease or an injury, which an individual needs to adapt to.^[10] Hope is one of the crucial needs for the family members of ICU patients.^[12,20] Hope helps the family members to cope with the stressful situation.

In Iran, family is the most influential institution in the life of an individual. Families have complex networks of relationships with relatives and they are the center of emotional support for the members of families. Based on Islamic values, which have shaped the way of life in the Iranian society, families support and protect their individuals in crisis situations.^[21] The family network has a great influence on holding hope when one of the family members is in a critical situation. Family members of critical patients seek hope when one of their members is admitted to the ICU.^[22] Maintaining hope, therefore, is a significant strategy for patients and their families.^[23] Nurses are vital to sustaining a family's sense of hope. Professional nurses would benefit from knowing the families' experiences of hope to better understand their sources of hope during illness and other critical life situations.^[24] Nurses need to know the families' perceptions from sources of hope that are associated with hospitalization of critically ill members. This knowledge is essential to optimize the families' well-being and coping, so that they can provide appropriate and effective support to their critically ill members. The practice of holistic care implies that healthcare professionals consider the needs of patients and their family members.^[25] Therefore, healthcare professionals have to consider their role in providing hope for families.^[13]

Although hope is viewed as an essential and vital component in family members to adapt to the stressful situation of admitting one of their members to ICU,^[10] the sources of hope have still not been discussed well

in the studies. From the earlier studies and review of literature, it has become clear that most of the studies were conducted quantitatively and were related to the needs, the participation level, and involvement of the family members of the patients in the ICU. The qualitative studies were also related to the experience of hospitalization in the ICU from the point of view of the patients, nurses, and families. The hope concept, especially the hope resource, is taken less into consideration from the point of view of the patients' family members. To achieve a deeper understanding of the promising resources in family members of the patients admitted to the ICU, this qualitative study was designed to explore hope resources from the point of view of the families of patients admitted to the ICU.

MATERIALS AND METHODS

This article presents part of a larger study that served as the first author's doctoral dissertation. The large study focused on the process of the family members coping with the patient's hospitalization in the ICU. To achieve the aim of the study, the conventional content analysis approach was used.

Setting

The study was carried out in the ICUs of three teaching hospitals in Iran, where patients were admitted due to various medical conditions, such as, medical-surgical disorders, neurosurgical problems, and trauma. Each ICU had eight beds and there was restriction for visitors to visit their patients.

Participants

The participants were selected by purposeful sampling, as it was suitable for conducting a qualitative study. The participants were 19 family members of 13 patients hospitalized in the ICU; (thirteen females and six males). The family members were selected in the following criteria: Close family members (spouse, children, father, mother, sister or brother) and family members involved in the patient's follow-up, having a good bond with the study subject, age older than 18 years, of Iranian nationality, and with a desire to participate in the study. The mean age of the family members was 34 years (range 19 – 49 years). The length of hospitalization for patients in ICU ranged from 20–160 days (mean of 90 days).

Ethical consideration

After approaching the research units and explaining the objectives of the study and also after obtaining the consent of the participants, the researcher began to collect data. Ethical principles such as autonomy of the participants, confidentiality, and anonymity were maintained throughout the study. Letters of recommendation were obtained from

the Research Deputy of the University, for the places under study. Ethical approval was obtained from the Ethics Committee of the Iran University of Medical Sciences. (Date and code number: Apr 8, 2012; 130/2576).

Data collection

In this study, semi-structured and face-to-face interviews were conducted with 19 family members. The data collection process was continued, to achieve data saturation, and it took nine months, from June 2012 to March 2013. The participants were interviewed in their house or hospital, wherever they were comfortable. The interview took between 35 and 85 minutes, with a mean of 60 minutes. All interviews were recorded by a voice recorder and then typed verbatim into transcripts, in order to analyze the data.

Some examples of the open questions to family members are: "Tell me what sources made you hopeful in this situation?" "What sources helped you maintain hope?" The interview process was continued with supplementary questions.

Data analysis

For data analysis, the researcher have used conventional content analysis, as per the Graneheim and Lundman method.^[26] This approach is usually appropriate when the existing theory or research literature on a phenomenon is limited. The researchers have used inductive category development, that is, avoided using preconceived categories; instead they have allowed the categories to flow from the data. The researchers also immersed themselves in the data, to allow new insights to emerge.^[27]

According to the content analysis process, each interview was read carefully, several times, in order to gain a universal and primary understanding of the important underlined statements. Then, meaningful units about the participants' experiences of the relationship existent in the interview text were determined. In the next phase, the meaningful units were abstracted through condensation and were labeled as codes. The participants' statements and implicit concepts were used for coding. The codes were compared for similarities and differences within the same interview and in different interviews, and then categorization of the codes was done accordingly. In the next stage, categories and subcategories were examined under the supervision of expert supervisors, who were experienced in qualitative analysis.

Rigor of the study

The Guba and Lincoln criteria were used to measure the trustworthiness of the data.^[28] 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, for them to approve the 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 nine months, helped gain the participants' trust and better understanding of their real world. For dependability, renewed coding of the interviews was carried out by colleagues who had experience in coding qualitative data. Moreover, the researchers documented the research details in order to provide the possibility of an external review.

RESULTS

The results of the data analysis have led to the identification of two major categories: (1) Internal sources and (2) External sources [Table 1]. Each category is explained in detail a little later in the text.

Internal sources

Internal sources is the first category obtained in this study, which includes two subcategories - religious-spirituality beliefs and positive attitude.

Religious-spirituality beliefs

On the basis of the participants' perception in this study, religious-spirituality beliefs were one of the most important sources of hope in the stressful situations of a patient's admission to the ICU. Religion or spirituality was reported by some family members as a significant source of hope.

Given the religious atmosphere in Iranian families, there are certain spiritual beliefs in these families such as prayers. They believe that prayers create a sense of confidence, safety, calmness, and hope in them. Participants use a variety of strategies in the form of recourse to spirituality, such as, recourse to God and the Shia Imams, prayer to God, Blessing the water and food and giving it to patient.

The mother of an eight-year-old patient said:
"The night my son was taken to CT-Scan, he was not feeling good, it was there that I felt God so closely; I went to the

Table 1: Categories and Subcategories demonstrating the sources of hope in participants

Categories	Subcategories
Internal sources	Religious-Spirituality beliefs
	Positive attitude
External sources	Healthcare professionals' interactions
	Family and friends' empathy
	Patient's condition
	Participation in care

hospital courtyard and asked for God's help. At that moment I felt His help and I was filled with hope and peace" (p3).

Superstitious beliefs are another spectrum of beliefs. As there are different subcultures in Iran, different superstitious beliefs are seen among Iranian families. As the participants were from different subcultures in the present study, there were superstitious practices such as tying a blessed piece of cloth to patient, breaking eggs at the patient's bedside, writing prayers, fortune telling, and the like.

In this regard a patient's mother said:

"I asked nurses' permission to attach evil eye to my son's clothes, and asked them not to take it off his clothes because it was for protecting against sore eyes and destroying bad luck" (p8).

Positive attitude

The subcategory of positive attitude was another source of hope for families of patients in the ICU.

Participants in this study considered inner hope (being hopeful) and being positive about life events like diseases, as hope from internal resources. They also mentioned that the power of hope was reinforced due to the positive attitude they had about this critical situation. This made families control their emotional reactions better and manage the conditions better. The impact of this positive attitude can be found in the statements of one of the patient's daughter:

"Gradually, I tried to be positive about this event, and this positive attitude helped me accept this situation and be hopeful about my dad's improvement. I gradually came to this conclusion that if I concentrate on negative outcomes, nothing will change. I should use things to help me accept that condition." (p17)

The mother of a child hospitalized in the ICU because of a car accident expressed the effects of a positive attitude, as follows:

"My husband supported me during this period. He always saw the bright side. As far as he could, he logically confronted this incident and tried to make me hopeful. He ensured me our son would be fine. These supports and consolation made me hopeful about Abolfazl's improvement, and I could bear this sorrow." (p3)

External sources

Besides internal factors affecting the level of hope in the families of the patients, there were factors and resources in their social environment that could give, reinforce, and maintain hope in these families. These external factors of hope were interactions with 'healthcare professionals',

empathy of their family and friends, patient's condition, and participation in care.

Healthcare professionals' interactions

Among the ways that families sought to be hopeful about the outcomes and better future for the patient, there were resources that redoubled their sense of hope. They functioned as if they were amplifiers, which made a dim light of hope blaze up again in the families, and gave them energy. Of these sources, it can be clearly pointed out from the families' statements that the promising care from the healthcare professionals was one such resource.

The son of one of the patients stated about the healthcare professionals' promising care:

"I think it's a good idea that a nurse be promising to both the patient and his family since if the families are in a good mood, they can be supportive in patient's care. It can help families to regain the natural family life and can help the patients." (p16)

Appropriate support from the healthcare professionals was a resource repeated in a majority of the participants' statements. They stated that the kind and empathetic behavior of healthcare providers made them keep their spirit and strengthened hope in them.

In this regard, most of the participants stated:

"The personnel's behavior is really effective in maintaining our hope; receiving right and proper answers, we leave the hospital with confidence and hope for our patient's improvement."

Also, honesty and empathy were other concepts that participants referred to as one of the important aspects of the healthcare professionals' interactions. Families expected that the healthcare professionals pay attention and listen to them and create a sense of security and a window of hope in them by giving correct information about the patient's condition and treatment outcomes.

In this regard, a participant said:

"When I talked to the doctors and nurses, especially the ICU personnel, and asked about Elham's condition, it could make me hopeful when they completely explained everything to me. They comforted me well and told me they had so many patients in the same condition who improved. They asked me to be patient. They made me strong and be hopeful." (p19)

On the other hand, the healthcare professionals were among the factors that could voluntarily or involuntarily undermine

the spirit and hope in these families through their behavior, by giving false promises or inducing despair.

One of the participants stated the following about false promises given by healthcare professionals:

"The first day my dad was hospitalized, they told me he's in a fair condition, and there's nothing to worry about. They next day when I insisted to know the truth and asked them to tell me everything, they told me he's not in a fair condition. I asked a nurse about my dad, and she told me he's in coma, but he'll be fine, God willing. She told there were patients who had worse condition than my dad, but they gained their consciousness." (p5)

A girl whose mother suffered from thyroid cancer complained about the healthcare professionals inducing despair:

"One of the nurses told me she had over 25 years of experience of nursing, and such patients hospitalized in the ICU would die. Maybe she didn't understand what she told me that time, but she adversely affected me. It was too heavy for me. When I came out of the ICU, I couldn't stand on my feet. I always wondered there was no hope, and my mom couldn't survive the ICU." (p13)

Family and friends' empathy

Empathy of family and friends, another subcategory of external sources can be considered as a source of hope for patients' families. Most participants emphasized on the support from family members and people around. They believed that the support from family members was the most important factor to help them deal with the crisis caused by their patient's admission. They believed that such sympathetic relations and support from resources, such as, the spouse, other members of the family, and families with common experiences could function as moderating factors for their worry and anxiety, and create some element of hope in them. A spouse's support had a distinct role that participants referred to.

In this regard, one of the female participants said:

"My husband often comforted me and said, "That's right, you were driving at the time, but don't blame yourself for our son's accident. If I had been driving, it could have happened, too". His positive words and empathy really made me tolerate the event and didn't lose my hope. If I didn't have my husband's support." (p3)

In conditions where families seek a source of hope and support to relieve their emotions after experiencing a stage of shock and mental distress, people around, including relatives, friends, and even families of patients with common experience can play an effective role. Their positive insights

could create sparkles of hope in the families of these patients.

A patient's daughter said:

"People around and our relatives empathized with us, helped us in providing care, and they gave us hope. If they weren't, we couldn't tolerate the event." (p14)

Regarding the support from families with a common experience, one of the participants said:

"I often asked families whose patients were transferred from ICU about the conditions when they were in ICU, I asked about what they had done for the improvement of their patients. I became hopeful that my son would get well and be transferred to the ward. I calmed myself in this way." (p3)

Patient's condition

The condition of the patient is one factor among the many that can be effective in making sense of hope and confidence in families of patients in the ICU. According to the participants, appearance of the patients and the equipments connected to them can create a certain frame of mind in families. How families perceive and interpret the situation can affect the revival of hope in them.

The families also said that with their patient's improvement, they did not come regularly to the ICU. They achieved self-control and reached a partial acceptance of the patients' condition, which created hope and assurance in them and motivated the families to participate more in their patients' care.

In this regard, one of the participants commented:

"Definitely, passing of time was effective in my mom's cure, and we were certain that her cancer didn't make any progress. They could separate her from the respiratory tract. It showed she responded well to the treatment, and she'll be finally fine. One the other hand, it helped us to have more control on ourselves." (p14)

The mother of an eight-year-old patient who had an accident said:

"When I came to the ICU and saw that they removed intubation and my son was breathing by himself, I wanted to cry out of joy. The ward supervisor told me to call him, he would open his eyes. I didn't believe it. The light of hope increased in my heart and I was thanking God repeatedly saying "I was sure of you. You returned my son". (p3)

Participation in care

Participation in care is identified as an important source in having and maintaining hope in families. Families tended

to participate with nurses to ensure that their patients received adequate care and this also increased hope for their patients' recovery.

The daughter of a patient said:

"I asked nurses permission to give my mother's food and give her body massage myself, for when I was right there next to her and saw her conditions, both her and my anxiety decreased and I became sure she received very good care and my hope for her improvement increased more." (p13)

Participation in care, even if it is allowed in primary care, can have a great emotional effect, such as, reduced anxiety and it helps families achieve a sense of hope and confidence. The families believe that when they are allowed to be beside their patient, to touch him/her for a few minutes or to care for him/her by cleaning the patient's face and hands, it can create some sort of emotional relationship with their patient, improve their mental and emotional condition, and it can be effective and supportive, with a better understanding of the current situation. It redoubled the hope of the patient's improvement. One of the participants said:

"Taking care of my dad comforted me. When I was away from him, I was stressed, but it lessened when they allowed me to be beside him and to care about him, and I could well admit his condition. I was sure and hopeful if he's progressing in this way, he would be discharged from the ICU while he was fine". (p12)

DISCUSSION

Many studies on hope in patients' families, especially patients in ICU, have been conducted quantitatively and qualitatively. A few studies have been performed based on the inner experience of patients' families and their sources of hope. The current study has aimed to provide knowledge about the sources of hope from the perspective of families of patients in the ICU.

In the current study, families drew their hopefulness from both internal and external sources. Internal sources were in the form of religious-spirituality beliefs and positive attitude. The external sources included healthcare professionals' interactions, empathy of family and friends, patient's condition, and families' participation in care.

Our study has shown that the participants used a variety of strategies, including recourse to spirituality, like recourse to God and the Shia Imams, prayers, and giving sacred water and food to the patient. Based on the religious, spiritual, and cultural beliefs, these families use such strategies to help the patient improve sooner. People are different and use different strategies to promote and continue their

spiritual beliefs. It is a completely a personal issue of how individuals express their spiritual beliefs.^[12] Prayer, reading prayer books, or attending religious rituals are among the sources that some religious people draw from, to reduce the damage caused by stressful life events.^[29] In a systematic review of studies, the reported strategies for strengthening the spiritual dimension were often, prayer, reading religious writing, listening to others pray, listening to religious music, participating in religious activities, talking about feelings about God, and visiting a spiritual community.^[30]

According to Koenig, spirituality creates a positive attitude in people toward the world, and protects them against adverse life events, such as bereavement or illness, and makes them hopeful of a better life, by creating motivation and energy in them. This helps in tolerating and accepting the unchangeable situations much better.^[31] Also, Carone and Barone (2001), stated that religious beliefs justifying control by others more powerful (a God and His/Her appointees) allow people to maintain hope for themselves and their loved ones, and regulate the negative emotions, when no active coping strategy seems possible.^[32]

It seems that in a society with rich intellectual, cultural, and religious beliefs, a positive relationship between spirituality and hope can be interpreted as a manner in which people believe that they can feel God's presence in their lives, that He guides them, makes them happy. and every time they are in need, He will support them. In a systematic review of studies, it is revealed that spiritual and religious beliefs are among the factors that will create hope.^[33]

Given the context of the present study, the participants in the study were of different ethnicities and with different subcultures and this made them use some non-religious rituals such as breaking eggs at patient's bedside, attaching an evil eye to patient's clothes, fortune telling, and writing magic spells, all based on superstitious beliefs. Yip's study (2004) reinforces this finding.^[34]

Another finding of this study was the positive attitude in the patient's family. A positive attitude resulted from maintaining a positive optimistic view to life events.^[35] Some participants in this research attributed their hopefulness to their positive approach to a difficult situation. Similar findings were found in a study by Bland and Darlington's study (2002), which showed that a positive attitude was a source of hope. In that study, some caregivers described their own strength and positive view as a source of hope.^[35]

The results of this study showed that interactions with healthcare professionals was a source of hope and was

an effective factor in establishing trust and hopefulness in the families of patients in the ICU. Most families identified healthcare workers as either a source of hope or destroyer of hope. However, based on the participants' statements, every relationship was not helpful in creating security, trust, and hope, but the relationship had to lead to understanding the patient and his family. For effective communication, respecting and valuing patients and their families should be considered. According to the reports of the families in the study, they identified healthcare professionals as a source of hope. In this study, some families also reported negative experiences with healthcare professionals, claiming they did nothing to encourage families or maintain their hope.^[35]

The empathy of the family and friends was another subcategory obtained in this study. Based on the findings of the current study, most families noted that in addition to receiving support from the healthcare providers, they were supported by their family members. They received this support in different forms - financial, emotional, mental, and spiritual. Jussila's (2008) study showed the power of the family to provide the required emotional support for the patient and other family members.^[36] In the current study, the findings showed that the support and the empathy of the family and people around were effective factors in providing hope for the families of patients in the ICU. In this regard, the result of a study reported that protective networks (nurses and family members) created support and security for patients' families, and thus sparked a hope in them. According to the findings of a qualitative study, families of patients also stated that because of their constant encouragement and support, family and friends were sources of hope. Furthermore, participants stated that they sought help from families with a common experience, to reduce stress and increase hope for their patients' improvement.^[37] The findings of Verhaeghe *et al.*, (2010), similarly demonstrated that sharing common experiences of other patients' families could serve as a source of hope and support.^[38]

In this study, another important source of hope was the patient's condition. Loss of hope was clearly linked to times when the patient was most ill, and hope returned as the patient became better. Families were most vulnerable to loss of hope when the patient suffered from an unstable condition. Most families participating in this study reported ups and downs, hope and despair, especially when the patient had an unstable condition. This finding was consistent with the findings of another qualitative study.^[35] In that study, maintaining hope for full recovery also served to protect the family members from painful experiences in a stressful situation of the patient's unstable condition.

According to findings of the present study, participation in care was another source for maintaining hope in the family of ICU patients. Results show the importance of families being allowed to participate in the care of critically ill patients, by being close to the patients in the ICU. Families pointed out that when they were allowed to be present and participate in the care of their loved ones in the ICU, their fear and anxiety reduced. Also, most of the participants reported that participation in care enhanced their sense of security and hopefulness. Similar findings have been reported in research studies regarding family participation in the care of critically ill patients in the ICU. Those studies reported that when families were excluded from participation, they experienced stress and insecurity, as well as despair, regarding the patients' recovery.^[39,40]

These findings confirm the statement that hope appears to be central to the family members who have loved ones in the ICU. Based on the findings of the present study, the sources of hope can give and maintain hope in the family members and help them endure stressful situations of a patient's hospitalization in the ICU. In addition, research to identify sources of hope from the healthcare professionals' point of view, especially nurses, is needed. Nursing interventions to support hope in these families are another area for further research.

LIMITATIONS

The study was conducted in three large referral hospitals in Tehran and Qom; thus, the findings should be interpreted in the light of this context. Also, cultural beliefs of participants may have influenced the interviews.

CONCLUSION

The findings of this study corroborate the previous findings of studies on hope and at the same time offer new information on the sources of hope in the context of Iranian families with patients in the ICU.

Analysis and discussion of the findings of this study showed that the sources of hope among families of patients in ICU were of two categories. These sources, as moderating factors, could reduce the physical and psychological damages caused to families.

Also, the current study provided a deeper knowledge about the need for holding hope in patients' families, particularly families of patients in the ICU. In this study, the categories shown in the participants' in-depth experience can open up a new horizon for healthcare professionals, especially nurses, about sources of hope based on culture. Furthermore, due to the finding that

having and maintaining hope is based on both the family's and healthcare professionals' perceptions of these sources of hope, healthcare providers can devise family-centered care by further developing this new insight, based on the knowledge and reliable evidence from these families.

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