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A B S T R A C T

Introduction: Structured Abstract. Headings in blue color. Font: Calibri light (heading), Bold. Style: Normal. Font size: 10. Alignment: Justified. Patient admission into the critical care unit is usually an unpleasant and unexpected life experience for the family members. It is unusual for family members to cope with stress and anxiety during their hospital stay.

Purpose: This study aimed to explore the expectations and needs of family members of the patients in critical care units at two tertiary care hospitals in Islamabad.

Methodology: An exploratory descriptive design was used to address the study questions. Using purposive sampling, 14 family members were individually interviewed through a semi- structured interview guide. A conventional content analysis method was used to analyze the data through which categories and sub-categories were identified.

Findings: The data analysis revealed three roles of the family members, which included assistance in physical care, facilitator in the provision of treatment and the decision maker. Although the physical facilities for meeting the comfort were available in private hospital, it did not match the family members' expectations.

Conclusion: The text of the structured abstract shall be in Font: Calibri (body). Style: Normal. Font size: 10. Alignment: Justified. This study revealed that despite some similarities in the role and needs, the expectations and satisfaction of the family members is linked to their awareness of the healthcare system as well as the cost of the obtained services.

Keywords: *Critically Care patients, expectations, experiences, family caregivers, needs.* The text of the Keywords shall be in Font: Calibri (body), Italics. Style: Normal. Font size: 10. Alignment: Justified, and Sentence case.

Introduction

Text shall have Font: Arial Narrow. Size: 11. Style: Normal. Alignment: Justified. Indentation Left-0cm, Right 0cm, Special-First line, By-0.48cm. Spacing: Before-0pt, After-3pt, Line Spacing-Multiple, At-1.15. Uncheck: Don't add space between paragraph of the same styles. References in superscript, after the period of the sentence. Hospitalization in Critical Care Units (CCUs) has never been a pleasant experience, but always stressful and devastating. Admission in the critical unit is usually unplanned and occurs without warning to patients and their family members.[1] The CCUs deal with patients of high acuity, and uncertain outcomes that require complex care and are perceived as highly mortal places of the hospital. Due to this perception, admission of a beloved one in a critical care unit could be a highly threatening situation for the patients and their family members. [2]

Patients admitted to the CCUs may experience physiological stress due to their illness. Moreover, they may have psychological stress due to fear of unknown, loneliness and unfamiliarity with the environment of CCUs and sometimes due to effects of medicines.[3,4] These 1 reasons make them incapable of making decisions. At this time, the family members are considered decision maker on the patient's behalf.[5]

Family members are the best source of providing support to the patients at the time of stress, but they generally experience psychological stress.[6-8] They are also frightened due to uncertain prognosis, fear of death or permanent disability of their patients.[9, 10] They may not be able to perform their role as supporter due to stress and anxiety related to their patient's prognosis and financial crisis during the stay at CCUs. If their concerns are not addressed, family members may face physical and psychological stress. They may experience feelings of helplessness and hopelessness.[11] Unaddressed stress of the family members leads to lack of trust towards the health care provider and this situation may result in noncompliance with the hospital rules, aggressiveness and lawsuits from family members.[12]

Literature reveals that during the time of serious illness, the family members of the critically ill patient have a unique set of needs.[13] These needs must be fulfilled to alleviate their anxiety and stress level; furthermore, fulfillment of such needs improve the satisfaction level of the family members with the care provision, promoting trust and assurance.[14] The emerging challenge for the critical care nurses is to take care of the patients along with meeting the needs of their family members. Assisting the family members to perform their role effectively in patient care the nurses must understand and address their needs.[15-17] However, as this research area has not received its due consideration in Pakistan so, there was a great need to explore this area.

Purpose of Study

The study was undertaken to answer the following questions:

1. What are the roles of family members of critically ill patients?
2. What are the needs of these family members?
3. What is their experience of meeting these needs?

Methodology

Study Setting and Sampling

This study was conducted from June to September 2018 in two tertiary care hospitals (one Public and one Private hospital) of Islamabad. Fourteen Family members were interviewed using purposive sampling.

Inclusion criteria

Family members of the patients who were admitted for more than 72 hours and were able to spend most of the time with their patients were considered eligible for interview.

Exclusion Criteria

The family members who were emotionally disturbed due to condition of their patients or unwilling to participate.

Ethical Consideration

The approval of Institutional Review Board of private hospital of the relevant University and permission for data collection were obtained from public hospital. The participants were assured that this participation is voluntary without any penalty or pressure. Furthermore, they were told that the dissemination of the findings will be done without revealing their identity.

Recruitment of participants

In both hospitals, the primary researcher obtained the list of admitted patient from the head nurse of the unit. The patients who were admitted since more than 72 hours were identified. Then the family members who were staying most of the time with the patients were recognized with the help of patients' bedside nurses. The family members were contacted with the help of head nurse either in the waiting areas or through a phone call. The head nurse informed the potential participants about the study and introduced the researcher. The participants were inquired individually about the extent of their interest and willingness to participate in the study.

Data Collection

Using an interview guide, face-to-face individual interviews were conducted to collect data. The demographic information of the family members including age, gender, and relationship with the patient, qualification, and occupation were obtained. The time spent with the patient was also noted. Each interview lasted for almost 30

minutes and was conducted in Urdu language except two or three participants who had used mixed language. During the interview, field notes were taken to note the gestures and expressions of the participants. Each interview was recorded and transcribed verbatim in Urdu and translated into English, and where appropriate the field notes were incorporated.

Rigor of the study

The Rigor was ensured by following the criteria of trustworthiness given by Lincoln and Guba (1986) which include credibility, dependability, conformability and transferability. [18-20] The Table 1 below elaborates the features of the research that were considered while ensuring the criteria of trustworthiness.

Data Analysis

Data were analyzed manually by using the steps suggested by Mores and Richard.[21] Responses of all participants to each question were collected in one document. After this, the text was read several times before coding.[21]

Table 1: Rigors of the study. Table Numbering and title at the top of the table. Figure numbering and title at the bottom of the figure.

Criterion	Definition	Actions to ensure the criterion
Credibility	The credibility means the confidence in the truth of the data and their interpretation from sources Lincoln and Guba, (1986) [20]	• During the interview, the participants were encouraged to express their ideas openly. Clarification was sought in case of ambiguity. • Planned and unplanned probes were used for elaboration. • Reaffirming, repetition and expansion of question were done during the interview. • Field notes were taken in the form of non-verbal gestures.
Dependability	Dependability refers to the stability of the data over a period of time and in different settings and conditions Lincoln and Guba, (1986) [20]	• Transcripts were validated with the audiotaped interviews. • Data collection was stopped at or as? data saturation was achieved.
Conformability	Conformability refers to the objectivity, that is observed as an agreement between two or more people going through the findings to check for accuracy and meaning Lincoln and Guba, (1986) [20]	• Reflection on the information provided by the participants and confirming whether the information was the experiences or the ideas of the informant. • Employing latent and manifest content analysis. • Member check during and after the interview as and when required. • Excerpts from the participant's interview are used to support the analysis commentary.
Transferability	Transferability deals with the ability of the findings to be transferred to other settings or context Lincoln and Guba, (1986) [20]	• It is facilitated through a detailed description of the process. And, this would permit reader to decide the level to which the findings could be relevant to other settings. • A similar group of participants, in an identical context would yield comparable results if the process is repeated.

meaning such as; "The family members of patients suffer a lot" and "In fact this hospital is not providing any facility to the family members respectively. Following this, all similar codes were grouped together to generate categories and sub-categories through a cyclic reflective process.

Findings

The analysis of participants' narratives was organized into two main categories which are; Roles of the family members and the needs and expectations of the family members. These categories are further divided 3 to 4 subcategories as depicted in the table below:

Table 2: Categories and sub-categories

Categories and Sub-categories

Categories	Sub-Categories	Examples
Roles of the family Members	Assistant in patient's *ADLs	Help the healthcare provider Provision of independent care
	Facilitator in patient's treatment	Run Errands Purchase Medicines / Supplies
	Decision maker for patient's treatment	
Needs and Expectations Along with Suggestions of the Family Members	Professional Behavior	Nurses/ doctors Allied staff
	Provision of information	
	Support & comfort	Physical Facilitation System Facilitation

*ADL- activities of daily living

The categories and subcategories are described in the proceeding sections and substantiated with excerpts from the participant's interviews. To improve their readability, the excerpts have been corrected to reduce grammatical errors, but without changing the intent of their responses.

1-Roles of the family members

Analysis of the participants' responses with regard to their roles revealed that they performed various roles; mainly as an assistant in patient's activities of daily livings (ADLs), facilitator in provision of treatment and being the decision maker for patient's treatment. Although the latter two roles were being performed by the family members in both hospitals, the role of assistant in (ADLs) was only expressed by the participants in the public hospital.

1.1 *Role of assistant in ADLs*

The participants explained that most of the times they assisted nurses in ADLs of their patients, but sometimes they were required to perform this role independently. As one of the participants expressed:

"I am helping him [patient] in moving, sitting and lying. I also move his bed accordingly [Just raise the head or making him comfortable]. I help the nursing staff to give the medications to my patient as they [nurses] guide. I am also helping him [my patient] to take his food" (AM- 02).

1.2 Facilitator in patient's treatment

Most of the participants shared that they facilitated their patient's treatment as per guidance of the healthcare providers (HCPs). They have to collaborate with the HCPs for the diagnostic tests of their patients not only inside the hospitals, but also outside the hospitals. A family member posited,

"Time to time we have to go for tests to different places such as, private labs for the tests which are not available in the hospital" (AM-01).

Some of the participants shared that they have to arrange blood and blood products for their patients. The family members revealed in their narrative that sometimes they have to purchase medicines for their patients. Although these responses were very few in number, but still it was considered bothersome for the family members. One of the study participants explained,

"They [doctors] have advised a medicine for my patient. This medicine is not available here in Pakistan. They [doctors] told me that drug is available in India, and I have to arrange it by my personal means" (BM-08).

1.3 Role of decision maker for patient's treatment

Participants' narratives revealed that most of the time doctors had informed them about the best solution to their patient's problem, but ultimate decision was left on the family members. One of the participants highlighted:

"The consultant of CCU called me in the unit and told me that my mother needs assistance in breathing, so he explained me all the possible outcomes and draw backs of the procedure [of artificial ventilator]. After explaining he asked me whether I will allow him [the doctor] to place my mother on ventilator or not" (BM-12).

2. Family member's needs and expectations along with their suggestions

While identifying their needs, the participants also articulated their expectations and to what extent these expectations were fulfilled. These expectations were varied from different health care providers; such as nurses, doctors and allied health staff.

The expressed expectations could be subcategorized into three areas; Professional Behavior; Provision of

information; Comfort and Support. Generally, the expectations were high in the private hospital and low in the public hospital.

2.1 Professional behavior of HCPs

Most of the family members reported that the professional behavior of nurses, doctors and other staff matters a lot. However, they have different expectations from the HCPs. Among all, most of their examples were related to nurses, and to some extent with the security guards. They also reflected on the responsibilities of nurses. They expect that the nurses must be competent, prompt, and cooperative. However, a few expressed that the behavior of nurses and doctors was not up to the mark. One of the participants shared,

"Nurses are responding to patient needs, but after 2-3 reminders" (AM-01).

The participants' expressed that sometime their expectations regarding the professional behavior of the HCPs were not being met. In contrast, some of the participants acknowledged the role and skills of the nurses.

As one participant eloquently summarized:

"The nurses are giving medicines, injections, and drips to the patients. They are performing cleaning of the respiratory tube [suction of the tracheotomy tube]. If they have time, they are helping us when we are involved in providing care to our patient" (AM-06).

While discussing the behavior of nurses, some participants also articulated the inappropriate behavior of doctors. As one of the participants expounded:

"One of my cousin sisters is doctor and she came to the CCU and asked about the results of laboratory tests from on duty doctor. He did not discuss anything with us and simply said that she [my cousin] can go to laboratory to receive those results. At least they can inform us that whether the results are normal or not" (BM-12).

Likewise, the participants' experience with doctors, nurses, and security guards was very similar at both hospitals. While sharing their experiences almost all of the participants complained against the unprofessional behavior of security guards.

"Security guard came and talked to me so rudely that even I could have slapped to him, but I controlled my anger. They even do not know how to talk to anyone. He did not allow me to sit on the sofa that was laying there in the lounge" (AM-01).

While discussing the behavior of security guards the participants proposed some suggestion to improve their professional behavior. As one of them proposed,

"The security guard should do his job according to his job description. The hospital must train these security guards for public dealing" (BM-09).

Except security guards their experience with other staff working at blood bank and laboratory was good. The participants of the study also highlighted some system errors which needs improvement. One of the participants expressed:

"The staff working in the blood bank is very nice, cooperative, and respectful especially Mr. ### [name] It was my first experience to donate blood for my patient, I never gave blood before this time, but he convinced me so nicely that I agreed to donate blood immediately" (AM-02).

2.2 Provision of information

Responses of the participant's revealed that although the information need was being met up to some extent, sometime the information was inadequate or was not being provided at all. Almost all the participants have expressed that most of the time the doctors are the ones who provide them information, but some of the participants also explained receiving information from nurses.

As one of the participants reflected:

"I know that my patient is not well enough. I know his progress and details of disease. The hospital staff-doctors and nurses told us all the details of my patient's disease from very first day and I know how much chances of recovery, my patient have?" (AM-01)

During the discussion, the participants of the study insisted on some points for the improvement of the information provision. A participant proposed,

"They must have an information policy. They can identify one or two persons from the family of patient and tell them about all situation in simple and easy to understandable terms" (BF-11).

2.3 Support and comfort

The participants of both hospitals revealed that their need for comfort and support was not being met. They shared several expectations indicating their requirement of

support and comfort. It was expected that waiting area must be cleaned, properly furnished with separate sitting arrangement for both males and females. The provision of toilets was considered most important as it is a basic human need. The participants of the study also expect that there must be an adequate place available for taking rest, especially at night. as one of the participants' reckoned,

"There is no place where patients' family members can sit. There is no proper space for them to take rest at night. We have to stay in the lawns of the hospital, which is challenging for us" (AM-01).

Another female participant articulated,

"The male and females have to stay together. There are too many males staying in this area. So, it is difficult for me and my relative [both females] here in between these male members" (AF-04).

The participants of the public hospital expressed that in fact they were not being facilitated at all. According to them the hospital was doing a lot for their patients, but they family members were suffering during their stay at hospital.

Although the family members of the private hospital acknowledged the facilitation of support and comfort; they wanted some improvement in those facilitation. The study participants in the private hospital shared that the facilities were available, but still some improvements were required to meet their needs. As one of them explained:

"There are some chairs in the waiting area. The sitting arrangement is good enough. The cooling system is fit. There is a canteen of tea and coffee. The waiting area is well furnished, but there is no place where someone can take rest especially in night" (BF-11).

Most of the participants were satisfied with their proximity level with their patients and they appreciated the hospital visiting policy.

Discussion

This study identified the needs and expectations of the family members of critically ill patients in tertiary care hospitals of Islamabad, Pakistan. The role of family members in decision making has been well reported in the international studies,[5,6] their contribution in the provision of care directly or indirectly was found unique to the current study. Moreover, the level of facilitation of the family members in the treatment of their patients was also more prominent in this study. The main factors that compel the family members assist patients' in ADLs in the public hospitals are lack of assistance in non-nursing tasks, and shortage of nurses. The shortage of nurses is well known in Pakistan; the nurse ratio patient is unfortunately very low.[16] The shortage of nurses was also acknowledged by the family members in this study.

It was gratifying that the family members were happy to be involved in the care. The findings of the current study can be utilized to enhance care provision in public sector. However, a systematic approach is required to organize the role of family care provider. In researchers' point of view, the capability of the family members for the identified tasks to be delegated must be assessed and ensured. Involving the family members in providing care could be beneficial, as they can help nurses by providing information regarding the wishes of their patients.[21]

Beside the shortage of nurses, in the public sector there is lack of assistance in non-nursing tasks. Unlike the private hospital, there is no concept of the respiratory therapists or technicians, unit receptionists, phlebotomists, nursing assistants and housekeeping staff in the public hospital. Therefore, in addition to the nurses' primary responsibility of patients care all the non-nursing tasks are being done by them. Thus, the nurses of the critical care units must perform the tasks that are not related to their cadre. Consequently, nurses are over worked in public sector due to shortage [22] and additional tasks. Employment of the nursing assistants and supporting staff may reduce nurses' workload and will be helpful to reduce the burden of the family members. [23-25]

Narratives of the participants have also indicated that sometimes due to lack of facilities or incase available facilities became out of order in the hospital, they were asked to seek services from outside the hospital. The family members not only found it difficult to coordinate with the outside facilities but perceived it as an extra financial burden on them. They expected that the hospital staff should perform these roles instead of the family members.

With regards to needs and expectations the finding of the study revealed that although most of the time the professional behavior of the nurses, doctors and allied health care staff was up to the mark, there were some instances of disappointment regarding non- professional

behavior of the nurses, doctors, and security guards. Most of the times the family members have trust in the care provided by the nurses as revealed in their narratives and they also acknowledged the contribution of nurses to their patients care. This finding was similar to the findings of a previous study in Pakistan which reported that nurses are considered hard working by the family members and that the hospital cannot work without them.[25]

Although the importance of nurses was well recognized by the family members, the need for improvement in the behavior was also expressed. In the current study the participants reported that sometime nurses were not able to respond to their patients' needs timely. In researchers' point of view this lack of promptness can be explained to some extent by the workload and associated stress[16] in the nurses. While nurses working in public hospitals in Pakistan are stressed due to being overworked and nurses working in the private sector are under stress due to excessive accountability,[16] so these reasons may affect their behavior.

The study participants highlighted the inappropriate behavior of the security guards explicitly. Security guards of the hospital are responsible to control the crowd in the hospital. Family members and friends come to visit their patients according to their ease. In addition, the number of the visitors is high which is aligned with the cultural and religious norms in Muslim society.[2] Given the low literacy rate in Pakistan, family members may not respond well when they are controlled because they do not want to follow the rules and keep insisting to visit their patients. These reasons make it difficult for security guard to control them. Moreover, the security guards may not be professionally trained for public dealing.

With regards to the needs and expectations this study identified that family members' need of information was being met up to some extent. International studies indicate that family members always appreciated when the need for information was being met.[3,19] A study in Pakistan also indicated that 85.0% of the participants rated provision of information as their most important need.[22] The information provision or communication with the family members of critically ill patients in Pakistan remains a grey area,[26] the participants in the current study also shared that they wanted improvement in information provision. The family members expected and required information related to treatment, prognosis, and important decisions. Similar to a study in Hong Kong,[27] in the current study, the need for provision of information was mostly addressed by the physician, but to a limited extent by nurses, which is contrary to the role of nurses, because their availability is more extensive at bedside.

Physical facility and comfort is also a significant need of family member, whether in Pakistan or elsewhere, contrary to the international literature,[26, 27] in the current study the family members mentioned several issues particularly related to the facilities available to them, these issues were more prevalent in the public hospital; as facilities like comfortable chairs, adequate but separate place for males and females, fans, toilets and space for taking rest at night were non existing there. It was reported that most of the times the males and females had to stay together. Considering the cultural aspects of Pakistan, it was evident that participants were highly uncomfortable in staying together in common waiting room. Although these facilities in the private hospital were good, but the expectations of the family members were high because they were paying for that. The findings of the current study warrant the need to develop strategies that may enhance the comfort of the family members, particularly in the public hospitals.

Although this study provided an in-depth understanding of patients' family members' needs in two tertiary care hospitals, the researchers believes that the knowledge gained from this study may be of some benefit to nursing practice, education, and future research. Meeting the needs of the family members will not only reduce their anxiety level, but also build confidence of family members in the healthcare system and ultimately improve health outcomes.[28, 29] Implementation of the current study findings on institutional level will enhance the understanding of the needs of family members that can provide a foundation for improving their services. Several suggestions given by family members can be easily incorporated in the hospitals to enhance their comfort and consequently their contribution in the care of their patients' recovery.

Conclusion

This study focused on the identification of the needs of family members. Although the needs related to information, support and proximity were being met up to some extent; the need for comfort was not being met especially at the

public hospitals which calls for attention by the leaders and administrators in the healthcare sectors.

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