

Family Caregivers of Critically Ill Patients: Psychosocial Needs and Quality of Life

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1.ABSTRACT

Background: When a loved one is hospitalized in a critical care unit (CCU), their families may experience stressful and challenging times. Therefore, family members might have specific needs during this time, and their quality of life (QoL) might be impacted. **Aim:** This study aimed to investigate the psychosocial needs and QoL of family caregivers of critically ill patients. **Method:** A cross-sectional descriptive research design was used in this study with a convenience sample of 110 adult primary caregivers in the CCUs of Doctor Soliman Fakeeh Hospital in Jeddah, Kingdom of Saudi Arabia. The Family Caregivers' Psychosocial Needs Assessment Tool and Short Form (SF)-36 Standard QoL Questionnaire were used to collecting the data. **Results:** Assurance needs were the most significant need reported by the family caregivers (22.62 ± 1.13), followed by information needs (25.25 ± 1.34). The least important need reported by family caregivers were comfort needs (16.25 ± 1.22). The majority of family caregivers had a fair QoL level. Furthermore, the bodily pain domain had the highest quality of life mean percentage score (7.90 ± 1.57), while the physical functioning domain had the lowest QoL mean percentage score (3.37 ± 2.52). **Conclusion:** This study gives the CCU team a complete view of the needs and QoL of critically ill patients' caregivers in Saudi Arabia. According to our research, critical care nurses should give careful consideration to meeting the needs of family caregivers and improving their QoL while planning patient care. Initiatives supporting family caregivers are required, with an emphasis on addressing their assurance and information needs

Keywords: Critically ill patients, Family caregivers, Psychosocial needs, Quality of life

2.Introduction:

Families of patients in the CCU go through a lot of physical and mental stress. The lack of timely understanding of the patient's condition and needs made them feel anxious (Yahui, et al. 2022). Providing care and support to family members during a critical illness can significantly improve the patient's recovery and outcome of care (Babaei, & Abolhasani, 2020). The ability of individuals to cope with the emotional and psychological aspects of admission to CCUs is challenging (El-Masri, & Fox-Wasylyshyn, 2007). Such experience has a negative impact on family members' QoL, especially those who have high psychosocial needs (Divdar, Foroughameri, & Farokhzadian, 2019).

It is well documented in the literature that family members can play a variety of important roles in a critically ill patient's care plan (Al-Motlaq, 2018). These responsibilities include making decisions on the patient's behalf, especially when the patient has a severe illness that has impaired his/her physical or mental well-being, as well as offering social support (Morton, Fontaine, Hudak, & Gallo, 2018). The family relationship is the most important support system that enhances a patient's outcomes (Kandasamy, Vijayakumar,

Natarajan, Sangaralingam, & Krishnamoorthi, 2017).

Families of patients in ICUs have needs, and the healthcare team must attend to and meet these needs to give them good care and social support and to guarantee the continuity of care (Caqueo-Urizar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009). The needs of critically ill patients' families have been investigated using both quantitative and qualitative research approaches (Omari, 2009). A scoping review of the needs and satisfaction of the families of patients in CCUs was carried out by Scott, Thomson, and Shepherd (2019). This review involved research conducted in a wide range of countries in various critical care settings. The authors of this review reported that information and reassurance were the most identified needs. They also concluded that families' perceived needs were not always met by healthcare members, and this negatively affected their satisfaction level and psychological health.

Al-Mutair, Plummer, Clerehan, and O'brien (2014) investigated the needs and experiences of intensive care patients' families in Saudi Arabia using a qualitative study. They reported that the family needed information about

the patient's condition readily, to be reassured that the best care was being delivered to their patient and to feel supported during this critical time. In addition, maintaining proximity to their critically ill patient was considered of the greatest importance to the families. **Alsharari (2019)** conducted a cross-sectional study to identify the most important needs of family members of patients admitted to the CCU in Saudi Arabia. The author concluded that family members have elevated needs in the assurance, proximity, and information dimensions that require to be met.

A critical illness is an unexpected, sudden, and often fatal event that puts the family's internal equilibrium in danger. The well-being of the family is put at risk when a loved one is in a life-threatening condition. This can also cause stress reactions in both the patient and the family. In the CCU, families of patients may experience stress, disarray, and helplessness (**Morton et al., 2018**).

According to **Health Management Organization (2009)**, significantly higher attributable mortality rates have been linked to patients who experience critical illnesses. However, it may also have a significant negative effect on QoL. A recent study conducted by **Avgeri, Zakynthinos, Tsolaki, and Makris (2021)** concluded that reduced QoL is caused by the patient's serious illness and the length of their hospital stay, which is an extremely stressful and demanding scenario for both patients and their families.

Quality of life is described by the World Health Organization (WHO, 1995) as how people view their place in life concerning their goals, aspirations, standards, and concerns as well as their culture and value systems. It covers many factors including people's physical and mental health, level of independence, social ties, and religious and philosophical beliefs, as well as their links to important aspects of the environment. **According to Sajadi, Farsi, Akbari, Sadeghi, and Akbarzadeh Pasha (2021)**, the implementation of hope-based training programs for caregivers and enhancing their QoL will improve patient care.

Significance of the Study

Few studies had been done in Saudi Arabia to look at the psychosocial needs and QoL of critically ill patients' family caregivers, and these studies highlighted the importance of addressing such needs (**Al-Mutair, et al, 2014; Alsharari, 2019**). Another study suggested that since families' needs are rarely satisfied by healthcare professionals, nurses should evaluate the needs of

family caregivers and assist them in coping with the psychological components of care (**Mahfoodh, Alamoudi, Aljedaani, Alghamdi, & Babkair, 2021**). In addition, families of patients in CCUs reported a decline in social activities and an inability to cope with stress (**Hekmatpou, & Ebrahimi-Fakhar, 2015**), lower energy levels, and poor emotional health (**Rückholdt, et al., 2021**). These findings emphasize the need for additional research in this area.

Aim of the Study

The aim of this study was to investigate the psychosocial needs and QoL of family caregivers of critically ill patients.

Research questions

To fulfill the aim of this study, the following research questions were formulated:

Q1: What are the psychosocial needs of family caregivers of critically ill patients?

Q2: What is the QoL level of family caregivers of critically ill patients?

Method

Design

This study has a cross-sectional descriptive research design. This type of design permits the researcher to observe the trends as they occur naturally without introducing any external variables. Thus, the researcher collects the data without making changes or introducing treatments. A descriptive design provides rich data about a situation, person or event, or a certain phenomenon (**Polit & Beck, 2018**).

Setting

This study was carried out in three CCUs at Dr. Soliman Fakeeh Hospital which is a private hospital located in Jeddah, Makkah Province, Kingdom of Saudi Arabia. The study was conducted in CCU1, CCU2, and the cardiac care unit. The CCU1 includes 10 beds, and it receives patients with critical conditions that need intermediate care and long stays. The CCU2 includes 15 beds, and it receives patients with neurological disorders. The cardiac care unit includes 10 beds and it provides health care services for patients with different cardiac conditions. These units have the most recent technology and the necessary staff to provide patient care.

Participants

A convenience sample of 110 participants was recruited in this study according to the following inclusion criteria:

- Gender: Males and females.
- Age: Adult patient ≥ 18 years.
- Having a relative (patient) who was admitted to one of the previously selected CCUs for at least 48 hours.
- A primary caregiver who has the most regular and continuous contact with the patient.
- Able to read and write Arabic or English.

Sample Size Calculation

Cohen's table was used to determine the required sample, considering the level of confidence at 95%, $p = 0.05$, study power at 80%, and the required sample size are 99 (Cohen, 1988). To overcome the problem of incomplete or missing data, an additional 11 participants were added to have 110 participants in the final sample size.

Data Collection Tools

Two tools were used to gather data. These include:

Tool I: Family Caregivers' Psychosocial Needs Assessment Tool

It contains two parts:

Part 1: Family Caregivers' Socio-demographic Data and their Patients' Health-Relevant Information

This part was developed by the primary investigator (PI) after reviewing related literature (Alsharari, 2019; Divdar et al., 2019; Mostafa, Abdelrahman, & Mansour, 2017). It included family caregivers' sociodemographic data such as age, gender, level of education, occupation, marital status, previous experience of CCU admission, and family relationship with the patient. It also covered patients' health-relevant information including the age, gender, clinical diagnosis, CCU, and the length of CCU stay.

Part 2: Critical Care Family Needs Inventory (CCFNI) Questionnaire

This part was adopted from Molter (1979) to assess the psychosocial needs of the family of critically ill patients. The 45 items of the CCFNI questionnaire were divided into five categories: information (8 items), proximity (9 items), assurance (7 items), comfort (6 items), and support (13 items). Each item was scored on a 4-point Likert scale (1 = not important, 2 = slightly important, 3 = important, and 4 = very important). Each subscale score was computed as the sum of points from each item divided by the number of items.

Tool II: Short Form (SF)-36 Standard Quality of life Questionnaire

This tool was adopted from Ware Jr and Gandek (1998) to assess the participant family caregivers' QoL level. This questionnaire consists of 36 questions categorized under eight sub-dimensions: general health (6 sub-dimensions), physical functioning (10 sub-dimensions), physical role (4 sub-dimensions), emotional role (3 sub-dimensions), social functioning (2 sub-dimensions), bodily pain (2 sub-dimensions), Vitality (4 sub-dimensions) and mental health (5 sub-dimensions). The items were reverse-scored and linearly transformed on a scale ranging from 0–100. The sum of the points from each item divided by the number of answered items was used to calculate each subscale score, with 0 representing the worst health and 100 representing the highest health (Winger et al., 2015).

Validity and Reliability of the Tool

The content validity of the tools was evaluated by a panel of five experts from the Critical Care and Emergency Nursing Department, Faculty of Nursing, Mansoura University. The tools were translated into Arabic version by an expert translator. To ensure the validity of the translation, a back-translation technique was used. The translated version of the tools was reviewed by the panel of experts. Their suggestions were considered.

The reliability of the data collection tools was tested by using Cronbach's alpha test. Tool I reliability was 0.92 for the original English version and 0.89 for the Arabic version. The reliability of tool II was 0.84 for the original English version and 0.82 for the Arabic version. These values indicate that the two tools are reliable.

Ethical Considerations

The study was approved by the local Research Ethics Committee and the Scientific Research Review Committee of Doctor Soliman Fakeeh Hospital. The study participants were given detailed information about the study including the aim, benefits, and risks. They were also informed that their participation in the study was voluntary and they had the right to withdraw at any time without any responsibility. In addition, they were assured that their data were coded and that their personal information was kept confidential. Those who consented to participate in this investigation provided their informed consent.

Data Collection

Data were gathered from June to August 2020. The PI communicated with the family caregivers briefed them on the study and invited them to take part in this investigation. The PI communicated with the nurse managers in the chosen setting who had Bachelor's degrees in nursing and had sufficient experience with nursing research principles to get access to eligible family caregivers.

In the chosen departments, a poster promoting the study and soliciting volunteers was posted on note cards. The poster was simple and presented basic information about the study including the purpose, potential benefits, duration, process, and participants' rights. The poster was large enough and placed in a prominent area to ensure that the target population was informed about the study. Potential participants were allowed to contact the PI directly for clarifications.

Written and verbal information about the study was provided to each prospective participant who fulfilled the inclusion requirements. The PI emphasized that involvement in the study was voluntary. Participants in the study signed an informed consent form.

Participants' health-relevant information was collected from their medical records. The PI distributed the questionnaires to the participants during the visiting hours in the waiting areas of the selected CCUs. As the participants filled out the questionnaire, the PI remained nearby to answer any questions and offer clarifications as necessary. The participants completed the questionnaire in 15-20 minutes and returned it to the PI.

Statistical Data Analysis

Statistical Package for the Social Sciences, version 26, was used to analyze the data (SPSS Inc. Chicago, IL, USA). Frequencies and percentages were used to display the category variables. Means and standard deviations were used to present continuous variables. The normality distribution of the data was tested by the Shapiro-Wilk test, and the Kolmogorov-Smirnov test. The Mann-Whitney U test was used to evaluate the difference between two means of non-parametric continuous variables. Kruskal-Wallis Test was used to assess the difference between more than two means of non-parametric continuous variables. The Spearman correlation coefficient test was used to test the association between two continuous variables. A p -value of ≤ 0.05 indicates statistically significant results.

Results

Table 1 describes the socio-demographic characteristics of the studied family caregivers. It showed that 39.1% of family caregivers were between the ages of 41 and 50 (38.13 ± 10.21). The results illustrated that 58.2% were males and 61.8% were married. Concerning their education level and occupation, 65.5% of the family caregivers had a Bachelor's degree and 66.4% were employed. In addition, 56.4% were residents in urban areas and 43.6% were residents in rural areas. A brotherhood relationship with the patient was reported in 27.3% of the family caregivers. Slightly more than half (50.9%) of the family caregivers had previous CCU admission experience, and 88.2% had visited the patient between 1 and 3 times since the CCU admission.

Table 1 Socio-Demographic Characteristics of the Studied Family Caregivers

Variables	n (110)	%
Age in years:		
▪ 18-29	17	15.5
▪ 30-40	29	26.4
▪ 41-50	43	39.1
▪ 51-60	19	17.2
▪ > 60	2	1.8
Mean \pm SD	38.13 \pm 10.21	
Gender		
▪ Male	64	58.2
▪ Female	46	41.8
Marital Status		
▪ Single	23	20.9
▪ Married	68	61.8
▪ Widow	8	7.3
▪ Divorced	11	10.0
Level of Education		
▪ Preparatory	18	16.3
▪ Secondary	10	9.1
▪ Bachelor	72	65.5

▪ Postgraduate	10	9.1
Occupation		
▪ Employee	73	66.4
▪ Not employee	18	16.3
▪ Housewife	6	5.5
▪ Retired	13	11.8
Residence		
▪ Rural	48	43.6
▪ Urban	62	56.4
Family relationship with the patient		
▪ Husband	22	20.0
▪ Father	18	16.3
▪ Mother	19	17.3
▪ Sister	21	19.1
▪ Brother	30	27.3
Previous experience with CCU admission		
▪ Yes	56	50.9
▪ No	54	49.1
Number of patients' visits		
▪ 1-3	97	88.2
▪ >3	13	11.8
Mean ± SD	2.42±0.99	

Data are expressed as frequency (n) and percentage (%), \bar{X} : Mean, SD: Standard Deviation

Table 2 presents different mean scores and ranking of the needs of family caregivers according to the CCFN. It revealed that assurance needs were the most important for family caregivers (22.62±1.13), followed by information needs (25.25±1.34). The comfort needs were the least important for family caregivers (16.25±1.22).

Family caregivers' needs	No of items	Min - Max	Mean ± SD	Mean percentages	Rank
A. Information needs	8	22.0-29.0	25.25±1.34	78.91	2
B. Proximity needs	9	23.0-31.0	27.06±1.51	75.17	3
C. Assurance needs	7	19.0-25.0	22.62±1.13	80.79	1
D. Comfort needs	6	11.0-20.0	16.25±1.22	67.71	5
E. Support needs	15	36.0-47.0	40.99±2.13	68.32	4
Overall needs	45	122.0-143.0	132.17±3.89	73.43	

Table 2 Mean Scores and Ranking of the Studied Family Caregivers' Psychosocial Needs

Data are expressed as mean and SD: Standard Deviation

Table 3 shows the mean scores and ranking domains of the QoL among the studied family caregivers. The results illustrated that the bodily pain domain had the highest QoL mean percentage score with a mean ± SD of 7.90±1.57. While the physical functioning domain had the lowest QoL mean percentage score with a mean ± SD of 3.37±2.52.

Table 3 Mean Scores and Rank of Quality of Life Among the Studied Family Caregivers

Quality of life domains	No of items	Min - Max	Mean ± SD	Mean percentages*	Rank
A. General health	6	5.0-17.0	11.43±2.42	47.63	6
B. Physical functioning	10	0.0-16.0	3.37±2.52	16.85	8
C. Physical role	4	0.0-4.0	1.78±1.32	44.50	7
D. Emotional role	3	0.0-3.0	1.62±1.15	54.00	5
E. Social functioning	2	3.0-8.0	6.20±1.21	77.50	2
F. Bodily pain	2	3.0-9.0	7.90±1.57	87.78	1
G. Vitality	4	8.0-19.0	14.04±1.94	70.2	4
H. Mental health	5	13.0-23.0	18.48±1.98	73.92	3
The overall quality of life	36	50.0-82.0	64.82±4.82	57.36	

*Mean percentages calculated according to the maximum score of each domain

Table 4 describes the levels of QoL among the studied family caregivers. It showed that the majority of the family caregivers (93.6%) had a fair level of QoL.

Table 4 Levels of QoL Among the Studied Family Caregivers

Levels of quality of life		Score	n	%
▪	Poor (<50%)	0-56	7	6.4
▪	Fair (50%-75%)	57-84	103	93.6
▪	Good (>75%)	85-100	0	

Table 5 illustrated that there was no significant correlation between family caregivers' psychosocial needs and their QoL scores.

Table 5 Correlation Between Psychosocial Needs of the Studied Family Caregivers and their Quality of Life

Family caregivers' needs	Total quality of life scores	
	r	p
A. Information	0.08	0.40
B. Proximity	0.08	0.40
C. Assurance	0.13	0.17
D. Comfort	0.12	0.19
E. Support	0.007	0.94
Overall needs	0.002	0.98

* Statistically significant ($p \leq 0.05$)

Discussion

The findings of the present study showed that the total number of participants in the study was 110. More than one-third of them were between the ages of 41 and 50 years old and more than half were married males. These findings may be highlighted by the fact that male relatives are typically in contact with the caregiver and are responsible for looking after their families, especially in critical situations.

These findings are consistent with the results of other investigations (Almagharbeh, Alhassan, Al-Motlaq, & Almagarbeh, 2019; Hasandoost et al., 2018). While these findings disagree with the findings of several studies which reported that more than half of the family caregivers were married females (Abdel-Aziz, Ahmed, & Younis, 2017; Divdar et al., 2019; Mostafa et al., 2017; Shorofi, Jannati, Moghaddam & Yazdani-Charati, 2016).

The current study findings illustrated that assurance needs were the most important needs for family caregivers, followed by information needs. While comfort needs were the least important needs for family caregivers. This could be explained by the fact that family caregivers pay more attention to the comfort and recovery of their loved ones when a family member is in a critical condition and less attention to their own comfort. These findings are harmonious with those of other studies that investigated the needs of families of critical care ill patients and found that assurance and information needs were the most important

needs for the family (Al-Mutair et al., 2014; Alsharari, 2019; Divdar et al., 2019; Liu, Zhu, Liu, & Guo, 2015; Omari, 2009).

The present findings revealed that the majority of the family caregivers had a fair level of QoL. This may be explained by the caregivers' previous experience and exposure to CCU admission or hospital staying of loved ones which enhances their tolerance for stress and their capacity to adapt their life to it. In Saudi Arabian culture, family, friends, and neighbors frequently offer assistance and support to caregivers, helping them to cope with stressful events and enhance their QoL (Al-Mutair et al., 2014). These findings are inconsistent with earlier research that investigated the QoL of family caregivers and reported that they had a reduced QoL (Alfheim et al., 2019). This may be attributed to that QoL was measured in the previous study by 12-month questionnaire that has a substantial response burden on the family caregivers.

The findings of the current study illustrated that the psychological needs of family caregivers and their QoL scores did not significantly correlate. In contrast, the results of some investigations revealed a negative, significant link between family caregivers' QoL and their psychosocial needs (Divdar et al., 2019; Kim and Yi, 2015). This difference could be due to the type of services hospitals offer to caregivers. Hence, healthcare providers should pay close attention to the needs and concerns of family caregivers.

Limitations

The generalizability of research findings may be limited by the use of a convenience sample and the collection of data from three CCUs of one private hospital in Saudi Arabia.

Conclusion and Recommendations

Based on the current study findings, it can be concluded that the most important needs reported by the family caregivers were assurance needs, followed by information needs. The majority of family caregivers had a fair QoL. This study provides the CCU team with a rounded picture of the needs and QoL of family caregivers of critically ill patients in Saudi Arabia. Our research suggests that when planning patient care, critical care nurses pay close attention to addressing the needs of family caregivers and enhancing their QoL. There is a need for establishing supportive initiatives for family caregivers with a specific focus on meeting their assurance and information needs.

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest regarding the research or publication of the article.

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