Cogitare Enfermagem

ORIGINAL ARTICLE

QUALITY OF LIFE AND SATISFACTION OF RELATIVES OF PATIENTS ADMITTED TO INTENSIVE CARE UNITS*

HIGHLIGHTS
1. Satisfaction with patient care in the ICU was satisfactory.
2. Family members who had lost loved ones were more depressed and stressed.
3. Female relatives predominated as caregivers.

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ABSTRACT
Objective: To evaluate the satisfaction of family members of patients admitted to the Intensive Care Unit and symptoms of anxiety, depression, post-traumatic stress, and quality of life. **Method:** a longitudinal study with relatives of patients in an Intensive Care Unit in southern Brazil, carried out at two points: after the patient was discharged, followed by three months, using the following instruments: FS-ICU 24, HADS, IES-6, EQ-5D-3L. The analysis was carried out using the Statistical Package for the Social Sciences (SPSS) program. **Results:** 73/100% of relatives, 58/79.5% of whom were female. Family member satisfaction was 77.42%. There was a significant difference in symptoms of depression (p=0.001), post-traumatic stress (p=0.000) and quality of life, (p=0.007) and "anxiety and depression" (p=0.009) when compared to family members. Anxiety was not significant (p=0.095). **Conclusion:** Satisfaction with care was satisfactory. Those who lost their loved ones were more depressed, stressed and had worse quality of life scores, thus contributing to clinical practice.

DESCRIPTORS: Patient Satisfaction; Professional-Family Relations; Intensive Care Units; Patient-Centered Care.

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INTRODUCTION

Family members of critically ill patients are a vulnerable group with a high risk of decline in their own health, probably due to the uncertainty and fear associated with critical illness and the frightening impressions associated with the Intensive Care Unit (ICU) environment[1].

The approach to the hospitalized patient's family has been the subject of research for over 30 years, and it has been shown that the policy of open visitation, although still rare in Brazil and worldwide, allows the patient to benefit from family support, favoring more effective communication and family member satisfaction. In Brazil, ICUs (2.6%) with a 24-hour open visitation policy remain rare[2] and studies associating satisfaction with post-ICU patient outcomes and the need for the family member to stay with the critically ill patient are still scarce[1].

When a patient enters the ICU, their family members are also at risk of losing their own health. Uncertainty about the patient's survival or rehabilitation, as well as the inhospitable environment of the ICU[1] and the lack of support for shared decisions overburden the family of the critically ill patient, with repercussions in the short and medium term. Studies show high rates of psychological symptoms in this population[1-2], anxiety (73%), depression (35%) and post-traumatic stress (56%), with a consequent loss of Quality of Life (QOL)[3-4].

The American Society of Critical Care Medicine (SCCM) has called it Post-ICU Family Syndrome (PICS-F) to address the physical, cognitive, and psychological burden of this population, which can extend over the long term after ICU discharge[5], with a variable incidence between studies - 6-66% in the first six months after ICU discharge[6].

Some studies have linked family dissatisfaction with critical care and a higher incidence of psychological illness after ICU discharge. Brazilian studies have shown greater family satisfaction and lower rates of anxiety and depression with the policy of making family visits in the ICU more flexible, probably associated with better communication and support from the care team and proximity to the patient[1,7-8]. Family involvement in decision-making about treatment seems to have an important effect on reducing PICS-F9, facilitated by the family's greater presence in the ICU.

The role of patient outcome on family satisfaction and the onset of psychological illness is still unknown. The literature is inconclusive in relation to the outcome of death on the development of PICS-F. It is known that post-ICU outcomes are not always dichotomous, such as discharge or death[10], and may be followed by a worsening of some underlying disease or sequelae of the critical illness. A study indicates that the discharge of ICU survivors with functional limitations causes an imbalance in the family system7 and, consequently, an increase in PICS-F and a decrease in quality of life[3-4]. On the other hand, studies indicate that relatives of patients who have died have a higher risk of psychological distress8; other studies show no difference between the different outcomes[6].

The objective of this study was to evaluate the satisfaction of family members of patients admitted to the Intensive Care Unit and symptoms of anxiety, depression, post-traumatic stress, and quality of life.

METHOD

This is a prospective longitudinal study carried out in a public university hospital in southern Brazil. The study included family members of patients with a minimum stay of 48 hours in the ICU, aged ≥18 years; close family members or family members with legal power of attorney, main caregiver, responsible family member (preferably in this

order: spouse, adult child, parent, sibling, grandparent, grandchild). Family members with communication difficulties (aphasia, severe hearing loss, not speaking Portuguese) were excluded. An average overall satisfaction score of 78.1 points was used: 78.1 points, to detect a difference of 8 points between the groups, thus n=65 family members of ICU patients. An α-bicaudal of 0.05 and a power of 80% were considered.

The study was carried out in two phases. In the first phase, critically ill ICU patients were assessed daily as to whether they could be discharged from the units. Family members who met the eligibility criteria were invited to take part in the study while still in the ICU. This phase took place from May to September 2019. After discharge, within a period of up to 96 hours, family members were approached in the hospitalization unit by the research team. After reading and signing the Free and Informed Consent Form (FICF), they were given the research forms with questions to collect sociodemographic variables from family members and the Family Satisfaction with Care in the Intensive Care Unit (FS-ICU 24) instrument[11].

The FS-ICU 24 questionnaires are structured in two sections: care provided by the team (14 questions), and satisfaction with decision-making (10 questions). The results are obtained on a Likert scale ranging from one to five points on a scale of 0% to 100%, as follows: 1- excellent (100%), 2- very good (75%), 3- good (50%), 4- average (25%), 5- poor (0%). The average time taken to return the questionnaires was twenty-four hours after they were handed in, which was extended whenever there was interest and a request from family members.

The second phase of the survey was carried out by telephone call three months after the patient's discharge from the ICU, and the following outcomes were analyzed: quality of life, symptoms of anxiety and depression and post-traumatic stress of family members.

Quality of life was assessed using the EQ-5D-3L[12], an instrument made up of five scales (mobility, personal care, usual activities, pain, anxiety, and depression) with scores ranging from one to three, the higher the score, the more health limitations. Symptoms of anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS)[13], made up of two subscales for anxiety and depression with seven items each, and each item can score from zero to three. The overall score ranges from 0 to 21 on each subscale, with 0 to 7 being unlikely, 8 to 11, possible case, and 12 to 21, probable cause. Post-traumatic stress was assessed using the Impact of Event Scale (IES-6)[14], which consists of six items. The score for each question ranges from zero to four, and the total score is the sum of the results of the sub-scales.

The analysis was carried out using the SPSS program version 22.0.16. Continuous variables were presented as means and standard deviations or medians and interquartile ranges, and categorical variables as simple and relative frequencies. The normality of the quantitative data was assessed using the Kolmogorov-Smirnov test. The t-test was used to compare the IES-6. The Mann-Whitney U-test was used for the quantitative variables (HADS and EQ-5D-3L).

This research is linked to the project "Evaluating the impact of implementing a care program centered on critically ill patients and their families on clinical outcomes: a before and after study", approved by the institution's Ethics Committee under registration number 2.984.429.

RESULTS

This study included 73 family members, 58 (79.5%) of whom were female, with a mean age of 48.65±13.80 years. There was a predominance of married couples, 45 (61.64%), 41 (57.75%) of the relatives lived with the patient and 59 (83.10%) were responsible for decisions relating to the patient's health care.

Table 1 - Profile of relatives of critically ill patients (n=73). Porto Alegre, RS, Brazil, 2021

Sample characterization	Family members Mean ± SD or n (%)
Age (Years)	48.65±13.80
Gender	
Female	58 (79.5)
Male	15 (20.5)
Complete years of study	9.70±3.79
Monthly family income (R$)	2,000 (1,500-3,500)‡
Degree of relationship	
Spouse	28 (38.4)
Child	28 (38.4)
Father/mother	7 (9.6)
Sibling	6 (8.2)
Other	4 (5.5)
Marital Status	
Married	45 (61.64)
Single	22 (30.14)
Other	6 (8.36)
Living with the patient	
Yes	41 (57.7)
No	32 (42.3)
Frequency of patient visits	
Daily	61 (58.6)
Weekly	9 (31)
Fortnightly, monthly, half-yearly or yearly	3 (10,2)
Responsible for patient care decisions†	
Yes	59 (83.1)
No	14 (17.9)

Mean ±SD: standard deviation. †† Variables with missing data. *
Source: The authors (2020/2021).

Table 2 shows family members' satisfaction with each aspect covered by the instrument. Satisfaction with the atmosphere of the ICU had the lowest average, 53.52±28.37.

Table 2- Satisfaction of patients' relatives after ICU admission (n=73). Porto Alegre, RS, Brazil, 2021

FS-ICU 24 items	N	Excellent (%)	Very Good (%)	Good (%)	Average (%)	Poor (%)	NA (%)	Mean ± SD
Care and concern for the patient								
*Courtesy, respect, and compassion towards the patient**	71	67.6	32.4	0	0	0	0	75.44±12.26
*Pain management**	69	53.6	29.0	2.9	0	0	14.5	
*Management of breathlessness**	66	37.9	28.8	9.1	0	0	24.2	
*Management of agitation**	67	43.3	22.4	10.4	0	0	23.9	

	N							Mean±SD
Family care								81.22±14.13
Assessment of their needs*	72	50.0	38.9	8.3	0	0	2.8	
Emotional support*	72	38.9	20.8	8.3	0	0	31.9	
Coordination of care*	71	64.8	29.6	5.6	0	0	0	
Care and concern*	72	66.7	30.6	2.8	0	0	0	
Health Care Team								90.42±3.36
Skill and competence of nurses*	72	69.4	30.6	0	0	0	0	
Frequency and communication with nurses*	72	62.5	27.8	4.2	4.2	0	1.4	
Doctors' skill and competence*	72	72.2	25.0	2.8	0	0	0	
ICU Atmosphere								53.52±28.37
ICU environment*	71	39.4	25.4	26.8	8.5	0	0	
ICU waiting room*	71	25.4	22.5	42,3	8.5	1.4	0	
Level of amount of patient care*	71	5.6	15.5	31.0	47.9	0	0	
Necessary information								85.42±2.13
Frequency of communication with doctors*	72	58.3	27.8	8.3	2.8	2.8	0	
Ease of obtaining information*	72	51.4	34.7	8.3	2.8	2.8	0	
Understanding of information*	71	56.3	32.4	9.9	1.4	0	0	
Honesty of information*	71	64.8	25.4	7.0	2.8	0	0	
Integrity of information*	71	64.8	23.9	8.5	1.4	1.4	0	
Consistency of information*	68	55.9	32.4	8.8	1.5	1.5	0	
Decision-making process								66.05±11.87
Included in decision-making*	71	36.6	26.8	33.8	2.8	0	0	
Supported in decision-making*	71	26.8	42.3	25.4	4.2	1.4	0	
Control over the family member's care*	69	29.0	27.5	37.7	2.9	2.9	0	
Time for decision-making*	68	0	0	97.1	0	2.9	0	

ICU: Intensive Care Unit. FS-ICU 24: Family Satisfaction Intensive Care Unit SD: standard deviation. *Variables with missing data.
Source: The authors (2021).

Total satisfaction, with the care provided and with family members' decision-making, were considered satisfactory, as shown in Table 3.

Table 3 - Final Family Satisfaction scores from the FS-ICU 24. Porto Alegre, RS, Brazil, 2021

Question	N	Mean	Standard Deviation
Total Satisfaction	73	76.47	16.55
Satisfaction with Care	73	75.60	19.47
Satisfaction with Decision Making	73	77.67	12.23

FS-ICU 24: *Family Satisfaction Intensive Care Unit.*
Source: The authors (2021).

In the evaluation carried out three months after the patients were discharged from the ICU, responses were obtained from 57 relatives of surviving patients and 16 relatives of non-surviving patients. When comparing the results, there was a significant difference in depression (p=0.001), post-traumatic stress (p<0.001) and personal care (p=0.007) and anxiety and depression (p=0.009) quality of life scores (on the EQ-5D-3L scale) between the relatives of surviving and non-surviving patients. Tables 4 and 5 shows the evaluation of the outcomes described.

Table 4 - Evaluation of the outcomes' anxiety, depression, and post-traumatic stress among relatives of critically ill patients three months after discharge from the ICU (n = 47). Porto Alegre, RS, Brazil, 2021

Variables for comparison	Relatives of non-surviving patients (n=16)	Family members of surviving patients (n=31)	p
HADS - Anxiety	7.5 (5.2-10.0) †	5.0 (2.7-10.0) †	0.095
HADS – Depression	10.5 (7.2-12.0) †	3.0 (2.0-8.0) †	0.001*
IES-6 Total	11.19±3.17	6.13±3.74	<0.001*

HADS: Hospital Anxiety and Depression Scale. IES-6: Impact of Event Scale. *p<0,05. †Median and interquartile ranges.
Source: The authors (2020/2021).

Table 5 - Assessment of the health-related quality of life of relatives of critically ill patients three months after discharge from the ICU (n = 47). Porto Alegre, RS, Brazil, 2021

Comparison variables	Relatives of patients non-survivors (n=16) n (%)	Relatives of patients survivors (n=31) n (%)	P
EQ-5D-3L - Patient mobility			0.167
No problems walking	12 (75.0)	28 (90.30)	
With walking problems	4 (25.0)	3 (9.70)	
EQ-5D-3L - Personal care			0.007*
No problems with personal care	11 (68.80)	30 (96.80)	
With personal care problems	5 (31.30)	1 (3.20)	
EQ-5D-3L - Normal activities			0.065
No problems performing usual activities	11 (68.80)	28 (90.30)	
Problems performing usual activities	5 (31.30)	3 (9.70)	
EQ-5D-3L - Pain or discomfort			0.937
No pain or discomfort	10 (62.50)	19 (61.30)	
Moderate pain or discomfort	05 (31.30)	12 (38.70)	
With extreme pain or discomfort	1 (6.30)	0 (0.0)	
EQ-5D-3L - Anxiety and depression			0.009*
Not anxious or depressed	2 (12.50)	13 (41.90)	
Moderately anxious or depressed	10 (62.50)	17 (54.80)	
Extremely anxious or depressed	4 (25.0)	1 (3.20)	

EQ-5D-3L: ICU: Intensive Care Unit. ES: Effect size. † Variables with missing data* p<0.05.
Source: The authors (2020/2021).

DISCUSSION

The study evaluated the perception of nursing professionals from two basic health units regarding clinical simulation in adult cardiac arrest care; using the simulation design scale and student satisfaction and self-confidence in learning, the results show that clinical simulation is a pedagogical practice capable of providing sufficient elements for the development of technical and attitudinal skills, bringing satisfaction and self-confidence and that the scenario close to reality favors understanding of the proposed activity.

Knowledge of CPR care was higher after the simulated activity for all categories. Comparing the groups, those with prior knowledge had a higher percentage of correct answers than the trainees. This result differs from the study carried out in 2021 with 150 nursing students from different semesters, in which there was no significant difference in the increase in knowledge measured after the CS[12].

In the study's SDS domain (objective and information), item three (the simulation provides enough information for me to solve the problem situation) was the one with the highest score, demonstrating that the objectives were clear so that the situation presented in the CS could be solved; a similar result was presented in another [study19], in which the clarity of the objectives was a determining factor for the CS to be understood by the participants.

The (support) domain reflects the facilitator's responsibility during the implementation of the CS, guiding the participants so that the objectives are achieved. The support provided by the facilitator and the conduct of the CS are fundamental to this process[20].

The (feedback/reflection) domain scored the highest on the scale, which is in line with another study that considers this domain to be the key moment in CS[21], being essential for learning, as it is an opportunity for the participant to reflect and provides a reflection on the scenario, which may reveal additional insights into the CS presented.

The reflection process should be carried out immediately after the CS[8], as it allows the participant to highlight feelings, discuss important points that were presented during the CS, as well as the possibility of taking knowledge to another level through discussion with the participants, and it is a dynamic process.

Studies have shown the importance of constructing and validating scenarios for CS, and their objective must be measurable[22-23].

The results of this study are similar to another[20] carried out with 35 participants. In terms of the construction and evaluation of the CS scenario, this favors the interaction between practice and reality.

The scenario used in this study was of low fidelity, and the realism domain obtained the lowest score in the agreement factor, so it is clear that low-fidelity scenarios can directly impact the CS carried out and the achievement of its established objectives. Other studies state that the greater the realism, the better the interaction between knowledge and practice[9,24].

Participants expressed satisfaction with using CS for teaching CPR to adults, showing that this methodology reinforces technical skills, leadership, and decision-making. In a similar study with 94 participants, they expressed satisfaction with using CS in the teaching and learning process compared to the control group in traditional teaching[25].
A study with 273 participants reported that simulated practice favored a relationship between satisfaction and self-confidence in the educational context and also stated that the environment and debriefing are important during simulation[26].

Satisfaction with the learning process used to teach CRP through CS favors learning, minimizes feelings of fear, and stimulates development. In a study with 35 nursing students,

they expressed satisfaction with CS teaching emergencies at various levels of complexity[20]. In this way, it is understood that CS provides learning results for participants who can articulate the theory and practice of the subject[20]. It promotes an increase in satisfaction with the activity, reducing the level of anxiety and nervousness.

Participants feel self-confident in their learning through the use of the CS methodology; the greater the satisfaction, the greater the self-confidence in developing professional activities; this result aligns with other studies[18,22]. This study showed that the participants consider CS a tool capable of helping them control their emotions improving their self-confidence in caring for real patients. Thus, CS enables training for emergencies such as CPR[27].

Even though CS is considered an active methodology, this study did not observe the protagonism of the participant; a similar result was found in another study when they stated that it is the teacher's responsibility to say what the student should learn[22]. So, satisfaction is a positive reaction to the student's expectations or experiences. This helps to improve their performance and professional development. In addition, self-confidence is achieved when there is a positive view of oneself, recognizing one's ability to achieve something. These elements also directly influence the quality of the experience[28].

The study was limited by the number of participants in the research, and the low fidelity in constructing the scenario for the CS may have interfered with the results obtained.

CONCLUSION

In this study, family members' satisfaction with critical care was considered satisfactory after discharge from the ICU. The items "Concern and care by the ICU team", "Care for the family" and "Care by the healthcare team" were identified as having the greatest impact on satisfaction, with scores above 80%, and the "ICU" having the worst score.

Three months after discharge from the ICU, family members of non-surviving patients showed a significant difference in symptoms of depression, post-traumatic stress and worse quality of life scores in the areas of personal care and anxiety and depression, when compared to family members of surviving patients.

These results make it possible to assess the need for family members to be accompanied after being admitted to the ICU, and to improve knowledge on the subject of assessing family members' satisfaction with the care received by the care team.

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