Quality of Life and Family Support in Critically Ill Patients Following ICU Discharge

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Abstract

Background: Patients following intensive care unit hospitalization may present disability and dysfunction in their physical and cognitive functions.

Objectives: We investigated the quality of life (QoL) of patients following discharge from the intensive care unit and we assessed the role of support by the family members.

Methodology: This retrospective study was conducted at the University Hospital of Thessaly and included patients who stayed for at least 48 hours in ICU and were alive at discharge between 2014 and 2019. The quality of life was assessed by the questionnaire SF-36. The scale of SF-36 score range from 0-100.

Results: A total of 671 participants were included in the study. The mean (SD) SF-36 score was 51.98 (28.18.) Overall, patients characterized their health fair [mean (SD) SF-item score 2.68 (1.47) out of 5]. Patients actual view on their health condition was similar to what believed for their condition one year before [mean (SD) SF-item score 3.36 (1.49)]. Mortality at ICU discharge was 32.7%. Mortality at 6 months following was 33.2%.

Conclusion: The present study shows that the QoL of patients following ICU discharge may be positively affected by the support from spouses or friends.

Keywords: ICU; Patients' support; Family support; PICS; Quality of life; Critical care

Introduction

Critical illness management often includes Intensive Care Unit (ICU) hospitalization is a considerably stressful situation both for patient and their family [1,2], and has various physical and mental implications. Patients following ICU management may present reduced neuromuscular dysfunction, weakness, dyspnea, anxiety and depression. These disorders in physical, intellectual and mental health have been described as post ICU traumatic syndrome [1] and may be present for years compromising the quality of life [3,4].

Family members may have an important role in the management of critical illness because they are often responsible for making decisions which the patients are unable to make on their own. Studies show that more than 50% of patients have to be taken care by their family members [5,6]. In this respect, family members support is pivotal in improving the patients' health by contributing to quality care and creating a pleasant [7]. In turn, this has an impact in the life of those family members. Indeed, when a patient is at ICU in critical condition, family members may suffer from symptoms such as anxiety, acute stress disorder, post-traumatic stress disorder, depression and complicated grief

[7].

In Greece, data suggest that the QoL of patients' remains at low levels leaving the ICU. For example, more than 80% of patients present neuromuscular dysfunction [3,4]. Nevertheless, data regarding family support post ICU in Greece are limited. In this study we therefore aimed to investigate the QoL of ICU patients after their discharge from the ICU and to evaluate the role of support from family members in a semi-urban area of central Greece.

Materials & Methods

This is a retrospective study conducted in the University Hospital of Larissa (UHL). Patients hospitalized in the ICU of the University Hospital of Larissa during a six years period between 2014 and 2019 by consecutive sampling. Approval was obtained from the responsible department of the UHL (No 43704).

Criteria of inclusion i) length of ICU stay> 24 hours.

Questionnaire – interview

The research implements of the study were a dedicated questionnaire and carrying out of interviews, by telephone

communication with each participant. SF-36 health survey a valid, authoritative and widely widespread questionnaire for the appraisal of QoL was used. It includes multi-item scales measuring each of eight generic health concepts: physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), general health perceptions (GH), vitality (VT) tapping energy levels and fatigue, social functioning (SF), role limitations due to emotional problems (RE), and mental health (MH). Each item is weighted with an additive scaling to calculate the final domain score. A high score indicates a low impairment and a low score designates an important impairment. The questionnaire is valid for the Greek population. In addition, questions about the support which the patients had from the members of their family and their relatives or their friends were also added. In cases where the participant was not in the position to be up to the necessities of the questionnaire, questions were answered with the assistance of the next of keen.

Patient medical records were evaluated to obtain demographic data, length of ICU stay, medical problems and drug consumption, diet habits and quality of life variables.

Statistical analysis

Data are expressed as mean (standard deviation [SD]). Normality was assessed by Shapiro-Wilcoxon test. Comparisons between patients were performed using a Mann–Whitney test for continuous variables by t-test and non-parametric test. Correlations between variables were assessed either by Pearson's r or Spearman's Rho as appropriate. All statistical tests were 2-sided. A result was considered statistically significant when $P < 0.05$. Analysis was performed using the GraphPad Prism 8 (USA).

Results

Overall, 671 patients were included in the study **(Figure 1)**. Their characteristics are shown in Figure 1. Mortality at ICU discharge was 32.7%. A 67.76% of patients were hospitalized for more than 15 days and a 44.33% of patients did not recover their daily routine, n (65.52%) patients were hospitalized at a rehabilitation center after their discharge from hospital. Mortality at 6 months following was 33.2%.

Quality of life

The mean (SD) SF-36 score was 51.98 (28.18.) Overall, patients characterized their health fair [mean (SD) SF-item score 2.68 (1.47) out of 5]. Patients actual view on their health condition was similar to what believed for their condition one year before [mean (SD) SF-item score 3.36 (1.49)]. From the analysis of survey's results were shown that the patients who died after their discharge had worse quality of life [mean (SD) 22.79 (6.321)] than the patients who are alive [mean (SD) 63.35 (25.03)].

Family support

The majority of participants [n=533 (79.6%)] had support from three or more family members, while they were taken care of by their caregiver all day. Three hundred-thirteen (46.72%) patients had support from their spouses all day and from other relatives for more than 8 hours every day. Patients also received more than three visits every week from their friendly environment had also better quality of life. Four hundred five (60.45%) participants responded that they were satisfied with the course of their health.

Patients who were supported for two or more members of their family or by their spouses all day or by their friends for more than three times/week presented increased SF score compared to the rest of the cohort [Mean (SD) 50.43 (28.00) vs. 50.06 (28.12), p=0.0013 and 54.25 (27.43) vs. 49.73 (28.80), p=<0.0395 and 59.67 (27.76) vs. 42.41 (25.69), p=<0.0001. Patients who were
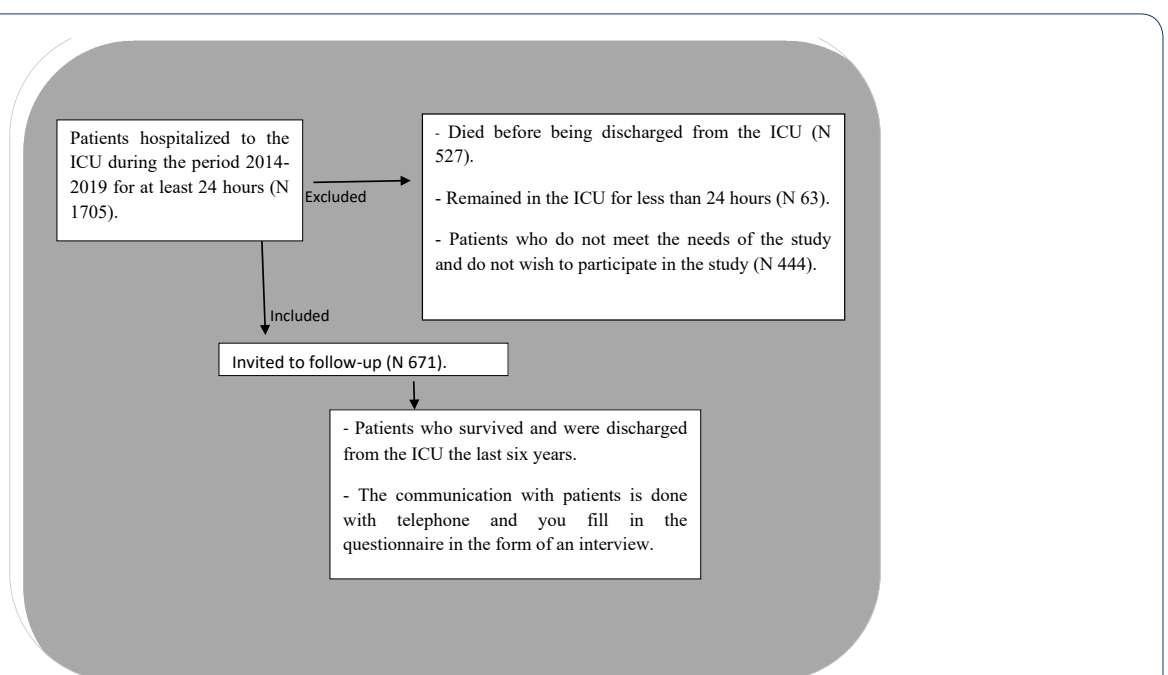

Figure 1 Flowchart.

hospitalized in the ICU for less than ten days presented increased SF score compared to the rest of the cohort [89.94 (30.24) vs. 48.87 (27.27), p=<0.0001]. The acute neurologic illness such as ischemic stroke episode or hemorrhagic stroke episode was associated with decreased SF score compared to the other illnesses [86.70 (38.34) vs. 53.73 (28.24), p=<0.0001 respectively].

Discussion

The present study suggests that (1) patients who received care by more than 2-3 members of their families presented better QoL compared to patients who received care by fewer than 2 members; (2) patients who were hospitalized for fewer than 10 days had also better QoL compared to those who were hospitalized for longer periods; (3) there was a significantly higher SF-36 score in patients who received care by their spouses for more than 8 hours and (4) patients who were hospitalized with acute neurologic illness presented significantly worse QoL compared to patients who suffered from other diseases.

The support of family members for critically ill patients is vital as it contributes to their recovery and reduces their length of stay in the ICU [8-10]. Previous reports underlined the importance of having people to help. However, no number of relatives/siblings was reported to be associated with outcome in terms of QoL. The present study shows that the care from more than 2-3 people has a better QoL compared to patients receiving less care. The most plausible explanation is that when many members in a family deal with a patient, they may receive more psychological support that helps them to recover faster. On the other hand, when there are many people in the care of a patient, there will always be someone close to them and help them in whatever they need. So, their QoL improves significantly. Thus this whole condition is particularly beneficial to the patient's health.

The length of stay in the ICU is related to the QoL of patients, because a long stay there reflects usually serious illness. Moreover, complications that are likely to affect the health of critically ill patients may occur [11]. The present study showed that the shorter the stay in the ICU for a patient, the better their QoL will be. This agrees with previously published studies which showed an adverse association between the length of stay in the ICU and the QoL of patients. Particularly, when mechanical ventilation was used for more than seven days, patients manifested worse QoL. In addition, staying in the ICU for more than ten days has a higher mortality rate [11,12]. The contribution of the family is very important in this case as well. The support from family members and the visits at ICU can improve patients' progress and reduce the length of stay there, because they were communicating with them showing deep love and affection [9,10].

Many studies have dealt with the care of spouses who have become ill and were admitted to the ICU. The relationship between spouses' care and the course of patients' health is very important. They are accountable for the course of their health as it is associated with post- traumatic stress and depression of caregiver spouses [13]. Similarly, the present study shows that caring for their spouses for more than 8 hours daily contributes to a better QoL. Spouses usually spend long hours every day to transfer and help their spouses who cannot care for themselves [14]. Previous studies show that the 2/3 of patients' spouses who were critically ill are the persons who cared for their patients after their discharge from ICU. Furthermore, the younger spouses played a more active and regular role in the care of patients compared to the elderly spouses. As for the sex, female spouses have a greater burden for the care of their spouses compared to male ones [12,14].

This study suggested that when the care of spouses to their partners was more than 8 hours daily, it had a positive impact to the improvement of their health. It is similar to the care provided by family members to their patients. In Greece in particular, there are certain deficiencies in the organized and widely distributed support [15] by the state to seriously ill patients when they return to their home environment. There should be specialized groups of professionals that can provide home care and can assist spouses and other siblings who live by the side of the critically ill patients.

In addition, we found that QoL was associated with the presence of acute neurologic illness. Studies show that stroke is the second leading cause of death and disability worldwide [16]. Depending on the severity of the stroke it can cause reduced physical fitness and quality of life. Patients cannot be independent because most of them have permanent disabilities and must change their daily life. The consequences for the reduced QoL of patients suffering from a stroke are related to the duration of stay at hospital and the program which they followed when discharged from it [14,17]. A stroke is a critically serious disease as it causes many mobility and function problems in patients. They need support from their family environment for their self-care [18-20]. Needless to say, the contribution of a specialized staff to help them deal with their problems and improve their health is of crucial important. However, a percentage of these patients fail to cope with these problems and eventually die.

Conclusion

Recapitulating, a critical illness and the duration of stay at hospital is a very stressful and strenuous situation both for the patient and their family members causing reduced QoL. However, this study shows that the patient can recover more quickly with the best of care and with fewer psychological problems as well.

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