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Mortality assessment and quality of life two years after discharge from the ICU: preliminary data from a prospective cohort

Avaliação da mortalidade e qualidade de vida dois anos após a alta do CTI: dados preliminares de uma coorte prospectiva

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ABSTRACT

Objectives: To evaluate mortality and long term quality of life of patients who were discharged from the intensive care unit.

Methods: A prospective cohort, in which all the admitted patients in a intensive care unit (ICU) during 6 months were evaluated and interviewed by telephone after two years of discharge, aiming the completion of two quality of live scales: Karnofsky scale and activities of daily living (ADL) scale.

Results: From a total of 380 patients, 100 (26.5%) individuals were alive at the time of interview, 94% living in their homes and 90% without the need for family or specialized care. There was a significant reduction in quality of life of the survivors (Karnofsky pre-ICU = 90±10 vs. Karnofsky after two years = 79±11; $p<0.05$), although maintaining their functional capacity (ADL pre-ICU = 28±4 vs. ADL after two years = 25±8; $p=0.09$). This drop in the quality of life occurred mainly to patients who suffered stroke (Karnofsky pre-ICU = 88±7 vs. Karnofsky after two years = 60±15; $p<0.01$).

Conclusion: These preliminary data suggest that the performance of patients after two years of the intensive care discharge is preserved, since they retain the ability to perform self care, except in those with brain damage which shows an inferior quality of life.

Keywords: Quality of life; Mortality; Karnofsky performance status evaluation; Intensive care units

INTRODUCTION

In Brazil, the life expectancy increased by 8.8 years from 1980 to 2000, achieving 71.3 years in 2003 and up to this moment we are at the 86th position in the United Nations longevity ranking, when 192 countries were studied throughout the world.[1] The life-extending of individuals occurs due to the medical development in all areas and, among them the available resources in intensive care units (ICU). Authors[2,3] have demonstrated that the reduction of ICU and hospital mortality, occurs due to a large staff and technological investment.

The return of patients who are discharged from the ICU to society, in a way which they can maintain appropriate social coexistence or perform their activities satisfactorily, is not well known.[4-6] Garcia Lizana et al.,[7] analyzing the degree of dependence of the survivors from a clinical ICU, have demonstrated that 38% of the patients presented a inferior quality

of life. From those, 8.3% were severely handicapped, 24% had mobility reduction, , 25% have changed their usual daily activities, 30.2% had a diagnosis of anxiety or depression and 44% complained about pain or an inespecific disconfort .

We do not know the parcel of patients who, after one year, are still ill or how many of them are able to maintain their daily activities (ex: regressing to work, physical activities, social activities, travelling, among others). We know too little in Brazil about hospital and ICU readmissions, degree of dependence or ability to perform self care. Therefore, this study aimed to evaluate the late mortality and the conditions of functional capacity and autonomy of patients after two years of discharged from ICU.

METHODS

This is a prospective cohort study, in which all admitted patients in a surgical ICU of 21 beds were followed, from July 2003 to January 2004. The study was approved by the Ethics Committee of the hospital Moinhos de Vento. The data from the ICU patients registration are collected routinely by the medical team and includes demographic data, Acute Physiology and Chronic Health Evaluation II (APACHE II) score, ICU and hospital length of stay, diagnoses on admission, co-morbidities, invasive procedures, need of mechanical ventilation, dialytic support, type of prescribed nutrition and ICU outcomes. These data, collected by interview with patients or with their family at the moment of the admission in ICU, enabled the completion of the Karnofsky scales and Activities of Daily Living (ADL) characterized as pre-ICU.

After a review of the admission data, the researchers made a telephone contact with the patient or their closest family to enlighten the purpose of research, request their address to send a informed consent form (IC) by mail and to schedule an interview. Along with the IC a sealed envelope was send to facilitate its return. Exclusion criteria for this study were patients who refused to sign the IC.

From the interview schedule and the return of IC it was held the data collection by applying the research instrument in the form of interview. The interviewers were trained prior to the completion of a structured questionnaire and its application via telephone. This questionnaire was developed based on previous studies,[8-11] and applied in order to define: (a) degree of dependency, (b) physical sequelae and (c) aspects related to readmissions, co-morbidities and death of patients. The completion of the ques-

tionnaire has enabled the fulfilling of two scales scored: (a) scale Karnofsky and (b) ADL scale.

Statistical analysis

The data were expressed as mean ± standard deviation (SD), median (25%-75%) or percentage of group. The categorical variables were analyzed with chi-squared and Fisher's Exact test; and numerical variables, with t-Student test for paired samples. A $p < 0.05$ was considered significant. The data were analyzed by package SPSS version 16.0. (*Statistical Package for Social Science*, Inc., Chicago IL, USA).

RESULTS

From a total of 380 patients admitted in the ICU in the study period, 100 (26.5%) individuals were evaluated after 24 months of ICU discharge (Figure 1). A total of 280 patients was excluded from the study due to: (a) death in the ICU - 70 (18.4%); (b) death after discharge from the ICU, still in the hospital - 88 (23.1%); (c) death in less than 6 months - 58 (15.2%); (d) death between 6 and 12 months - 25 (6.6%) and (e) death between 12 and 24 months - 12 (3.1%). Beyond it, 27 patients (7.1%) were excluded from the study: (a) those which did not consent to participate 15(3.9%) and (b) were not found for the interview – 12(3.1%).
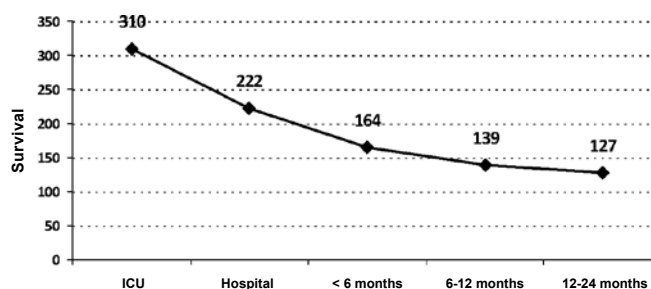

Figure 1 - Number of patients alive after discharge from the intensive care until the period of two years. During the study, 380 patients were admitted in ICU and 70 died during hospitalization in intensive care unit. From a total of 27 patients (excluded from the study), 15 did not consent to participate and 12 were not found to perform the interview.

From the 100 effective participants of the study, 64% were male, with mean age of 68± 14 years, remaining 8 ± 3 days hospitalized in the ICU and 20 ± 7 days in hospital (Table 1). The reasons for ICU admission were mainly due to ischemic cardiopathy (55%) and sepsis (31%).

Table 1 also shows that 94% of the interviewees live in their homes and 90% of them do not need family or

specialized assistance to perform their daily activities. However, there was a significant reduction in quality of life of the survivors (Karnofsky pre-ICU = 90 ±10 vs. Karnofsky after two years = 79 ±11; p <0.05), although maintaining their functional capacity (ADL pre-ICU = 28 ±4 vs. ADL after two years = 25 ±8; p =0.09). This drop in the quality of life occurred mainly due to the subgroup of patients who suffered stroke (Karnofsky pre-ICU = 88 ±7 vs. Karnofsky after two years = 60 ±15; p <0.01). The same subgroup of patients had also disenabled the patients for their

activities of daily living execution (ADL pre-ICU = 28 ±5 vs. ADL after two years = 23 ±6; p <0.05), as presented on table 2.

DISCUSSION

These preliminary data suggest that the performance of patients after two years of the ICU discharge is preserved, since they retain the ability to perform self care, except in those with brain damage which shows an inferior quality of life. Another fact that stands out is the high mortality rate of the patients found in the first two years after high from the ICU.

The mortality of patients in the ICU, as previously mentioned, has been reduced substantially, but we do not have actual estimates of rates of survival after the discharge from ICU. Hamel et al.[12] demonstrated that, six months after the ICU discharge, mortality rates ranged from 47% to 60% depending on the type of disease studied. In Rio Grande do Sul, Moraes et al.[3] showed a mortality of 50% after 30 months of ICU discharge. Other authors[5,13-15] have shown mortality rates of 30-40% in the first year after ICU discharge. When specific subpopulations were evaluated, Ulvik et al.[13] showed 25% of mortality seven years after ICU discharge. Bagshaw et al.[15] showed that mortality after discharge from ICU was related to the degree of renal injury presented by patients during acute critical illness. However, Kaarlola et al.[16] found 66% of mortality after one month of ICU discharge when they evaluated a subgroup of patients, and Laupland et al.,[14] 36% of mortality in one year of ICU discharge in survivors from septic shock. The mortality of our sample was 23.1% during hospitalization, 15.2% in less than 6 months after hospital discharge, 6.6% between 6 and 12 mon-

Table 1 - Clinical characteristics of population (n=100)

Characteristics	Result
Male	64 (64)
Age (years)*	68 ± 14
APACHE II*	18 (9-28)
Reason for ICU admission	
Ischemic heart disease	55 (55)
Sepse	31 (31)
Peripheral vascular disease	9 (9)
Chronic obstructive pulmonary disease	5 (5)
Admission length (days)	
In ICU	7 ± 5
In the hospital	20 ± 7
Where they live today	
At home	94 (94)
In clinics	6 (6)
Care needs	
Self-care	90 (90)
Family care	4 (4)
Specialized care	6 (6)

APACHE – *Acute Physiologic Chronic Health Evaluation*; ICU - intensive care unit.
Results expressed in mean± standard deviation, median (25% - 75%) or n (%).

Table 2 - Evolution of the Karnofsky and Activity of Daily Living scales

Scales	Pre-ICU admission	2 years after ICU discharge	P-value
Karnofsky			
Total population (n=100)	90 ± 10	79 ± 11	< 0.05
Ischemic heart disease (n=55)	92 ± 8	91 ± 11	0.12
Sepse (n=31)	89 ± 10	87 ± 8	0.08
Stroke (n=9)	88 ± 7	60 ± 15	< 0.01
COPD (n=5)	93 ± 9	89 ± 12	0.07
ADL			
Total population (n=100)	28 ± 4	25 ± 8	0.09
Ischemic heart disease (n=55)	29 ± 3	29 ± 5	0.15
Sepse (n=31)	26 ± 5	24 ± 10	0.07
Stroke (n=9)	28 ± 5	23 ± 6	< 0.05
COPD (n=5)	27 ± 4	25 ± 7	0.06

ADL - *Activity Daily Living*; COPD - chronic obstructive pulmonary disease; ICU - intensive care unit. Results expressed in mean ± standard deviation.

ths and 3.1% between 12 and 24 months, similar to data presented in other studies.[17,18]

The return of these patients to society, in way which makes them capable to maintain social interaction and appropriate exercise of its activities satisfactorily is still not well known.[4-6] From those ones, it is still unknown the part that after a year continues sick or how many of them returned to perform physical activities.[19] The return to work and diverse information about daily activities of these patients are still poorly known.

The main sequelae that affect the individual after discharge from ICU are: neuromuscular diseases,[20] terminal renal failure[15] and cognitive disability.[11] The critical illness polyneuropathy, which affects almost all the critical patients, reduces the success of ventilator weaning and delays the recovery and discharge of patients.[20,21] Patients on mechanical ventilation (MV) for more than seven days showed higher mortality (48%) among patients with polyneuropathy of critical illness, when compared to those without polyneuropathy (19%).[2] Therefore, the polyneuropathy is characterized as a predictor of poor prognosis in long term follow up of the critically ill patients. Renal failure is other common sequelae in patients who survive major diseases. It was shown that in 23 countries, 5.7% of acute renal failure (ARF) incidence during hospitalization in ICU.[22] Recent data[23] indicate that critical illness can lead to significant neurocognitive deterioration. This deterioration may persist for months or even years, and may have important consequences on the quality of life, in the ability to return to work, in the overall functional capacity and economic costs generated by the patient surviving to the ICU.

The terms "health conditions", "social functioning" and "quality of life" have been used in clinical studies, as synonymous and defined as "Health-related quality of life."[24] Aiming to measure the clinical, psychological conditions and the autonomy of patients who were seriously ill hospitalized in ICU, the authors[10,19,25-27] have graduated the patients conditions in ranges of (a) health conditions, (b) functional independence, and (c) ability to make small and simple activities of daily living. By viewing the scales, the patient degree of dependency, the ability to perform self care, mobility, swallowing, labor activity and emotional aspects related to the disease stress can be defined. Each scale directs itself to a specific type of patient.[19,28,29] The scale "Activities of Daily Living"[8,30] graduates the ability of elderly individuals in performing activities of daily life (taking their medication, using the telephone, preparing their food, etc.). The Karnofsky scale[9,13,31] is widely used in cancer patients and measures for

self care, employment and the ability to mobilize these patients, evaluating the need for assistance to implementing these tasks. Our data shows that patients who survived more than 2 years after discharge from ICU had reduced quality of life (decrease in the Karnofsky scale), but with maintenance of functional capacity (no change in ADL). However, this drop in quality of life in our casuistic is due to the subgroup of patients who suffered stroke, although there was a trend towards dropping for other subgroups of patients. The same subgroup of patients also disabled the patients for performing their daily activities. The comparison of our results with other authors was made by the scales diversity and the non-uniformity concepts. Finally studies that measured the quality of life of patients after ICU admission in reported a worst quality of life prior to admission to the ICU than the general population.[19] After their discharge from the unit, the survivors may have had an improvement in their quality of life, but still below the general population,[30] in our study 90% of patients were responsible for taking care of themselves, which was surprising, since a worsening in functional capacity after discharge from ICU was expected.

The study by Ulvik et al.,[13] which uses the same scales used in our study, analyzed 322 trauma patients after five years from ICU discharge. These authors showed that multiple organ dysfunction during ICU hospitalization had a higher mortality (28% vs. 52%) and a six times higher increase of disability when compared to those with a single organ failure.

The quality of life scores are subjective measures of physical and emotional health used as predictors of functional capacity. This evaluation is controversial, so the relationship between the measurement and functional difference with clinical relevance is not well established; the long-term survival depends on the synergistic effect of the whole health system and may have potential biases.[32,33] Most of the studies use standardized scales to evaluate quality of life through questionnaires sent by mail. Hurel et al.[34] followed cohort of 329 hospitalized patients in four ICU, using questionnaires addressing quality of life related to health (Nottingham Health Profile-NHP and Perceived Quality of Life Scale - PQOL) and professional activity, had complete data for 223 patients reporting small changes in professional capacity. The quality of life measured by both scales was poor mainly depending on the reason for the hospitalization. Dimopoulou et al.[35] reported that patients submitted to surgery and resuscitated from cardiac arrest had a survival rate of 55% after four years of follow up. Most of them with good functional capacity and quality of life both measured by the NHP.

Wehler et al.[36] had validated another instrument for measuring which included psychosocial aspects, physical health and associated factors such as residence and professional activity. After six months of follow-up the majority of survivors had returned to their condition of life pre-admission. Multivariate analysis showed that the age, the quality of life before admission and the disease severity were the factors most strongly associated with quality of life in the follow up.

As important as the application of resources in new treatments and technology in ICU, knowledge of epidemiological data of the population is a need that is required faced the increasing cost in health care. In this context, longitudinal studies are more appropriate as research design. This prospective cohort study aimed to evaluate the prognosis of hospitalized patients in the ICU and those who were discharged, to evaluate the survivor's quality of life after 2 years from CTI discharge. It should be notice that these preliminary data revealed a population with a mean age still in a very productive phase of life and, by the hospital characteristic, subjected to all the technological resources available for reducing their mortality and morbidity. Patients discharged from the ICU, after overcoming a very serious disease, may pay a heavy price for survival. This is charged as degrees of functional dependence and mental variables, and temporary or permanent inability to perform simple and daily activities.

CONCLUSION

These preliminary data suggest that the performance of patients after two years of the ICU discharge is preserved, since they retain the ability to perform self care, except in those with brain damage which shows an inferior quality of life. Another fact that stands out is the high mortality rate of the patients found in the first two years after high from the ICU.

CONTRIBUTIONS

Cláudia da Rocha Cabral and Cassiano Teixeira have reviewed the literature and wrote the article. Roselaine

Pinheiro de Oliveira, Jaqueline Sangiogo Haas and Cláudia da Rocha Cabral have collected the data. Roselaine Pinheiro de Oliveira and Karina Azzolin significantly contributed in the construction of the article. Cassiano Teixeira made the statistical analysis. Cláudia da Rocha Cabral assures the written data veracity.

RESUMO

Objetivos: Avaliar a mortalidade e qualidade de vida dos pacientes que receberam alta do centro de tratamento intensivo a longo prazo.

Métodos: Coorte prospectiva em que foram avaliados todos os pacientes que internaram em um centro de tratamento intensivo durante 6 meses e entrevistados, via telefone, após dois anos da alta do centro de tratamento intensivo, visando o preenchimento de duas escalas de qualidade de vida: escala de Karnofsky e escala de atividades de vida diária (ADL).

Resultados: De um total de 380 pacientes, 100 (26,5%) indivíduos estavam vivos na época da entrevista, 94% vivendo em suas casas e 90% sem necessidade de cuidado familiar ou especializado. Houve uma redução significativa na qualidade de vida dos sobreviventes (Karnofsky pré-CTI = 90 ±10 vs. Karnofsky após dois anos = 79 ±11; p <0,05), porém com manutenção da sua capacidade funcional (ADL pré-CTI = 28 ±4 vs. ADL após dois anos = 25 ±8; p =0,09). Esta queda na qualidade de vida deveu-se principalmente aos pacientes que sofreram acidente vascular encefálico (Karnofsky pré-CTI = 88 ±7 vs. Karnofsky após dois anos = 60 ±15; p <0,01).

Conclusão: Estes dados preliminares sugerem que o desempenho dos pacientes após dois anos da alta do centro de tratamento intensivo é preservado, pois os mesmos mantêm a capacidade de realizar auto cuidado, exceto naqueles com danos cerebrais, os quais pioram muito a sua qualidade de vida.

Descritores: Qualidade de vida; Mortalidade; Avaliação de estado de Karnofsky; Unidades de terapia intensiva

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