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Acute critically ill elderly patients: what about long term caregiver burden?

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On behalf of ICE-CUB2 network

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Abstract:

Purpose: Acute critical illness induce a high caregivers burden in the young population, however data in the older population are lacking. The objectives of this study were to evaluate caregiver burden in a critically ill old population and to assess factors associated with mild to severe burden level.

Materials and methods: All patients from two participating centers of the ICE-CUB 2 trial were included in the study. Inclusion criteria were an age ≥ 75 , at least one critical condition and preserved functional status. The primary endpoint was a Zarit Burden Interview (ZBI) ≥ 21 at 6 months.

Results: One hundred ninety-one patients (median age 86 [81-89] years) were included. Median caregiver ZBI at 6 months was 13 [5-27]. In the multivariate analysis, factors significantly associated with moderate to severe burden were the 6-month ADL decrease (OR: 1.3, $p = 0.049$) and the 6-month mental component of the quality of life score (OR: 0.94, $p = 0.0009$). In contrast, age, ICU admission and length of hospital stay were not associated with moderate to severe load.

Conclusion: In our study, functional status and mental health at 6 months were associated with mild to severe burden unlike age and admission in ICU.

Keys word: acute critical illness; older patients; caregiver burden; Zarit

Introduction

The proportion of patients older than 75 years is steadily growing worldwide. Logically, this affects Intensive Care Unit (ICU) admission rates [1], with a fast increase in admission of older adults to ICUs these last years [2]. The high mortality rate and potential risk of loss of autonomy in critically ill older patients raises the question of the benefits of intensive care in this population. For the intensivist, selecting “good” candidates both able to survive an ICU and hospital stay and to recover their previous functional autonomy is challenging [3]. Several studies have addressed ICU triage and identification of admission criteria [4–6]. In the ICE-CUB1 trial, age, active cancer, a lower functional autonomy, unknown hospitalization status and living arrangements were associated with a lower intensive care unit referral by emergency physicians [6]. Furthermore, there was a high variation of ICU eligibility rate according to centers, independently of patient and hospital characteristics [7].

One reason for ICU admission limitations could be fear of a high burden for the patients’ relatives after hospital discharge. Several studies in younger populations report anxiety, depressive symptoms, poor sleep quality and post-traumatic stress disorder in family caregivers of ICU survivors [8–10]. In the older population, no data are available in the ICU context, but some studies show that high caregiver burden is strongly associated with dementia, neuropsychiatric symptoms, delirium and decrease of patient’s functional autonomy [11–13].

The objectives of this study were to evaluate caregiver burden in a critically ill older population 6 months after an acute medical event and to assess factors associated with mild to severe burden level.

Methods

All patients from two of the centers participating in the ICE-CUB 2 trial (clinical trial gouv NCT 01508819) were included in this study. The ICE-CUB 2 trial was a large cluster-randomized clinical trial whose aim was to determine whether a recommendation for systematic ICU admission in critically ill older patients reduced six-month mortality, as compared to usual practices (ICE-CUB 2).

This sub-study was planned a priori, the study design is described in detail elsewhere [14,15] and the protocol is available online [15]. Briefly, in this cluster-randomized clinical trial, healthcare centers were randomly assigned either to the intervention group (the systematic-strategy group) or the control group. In healthcare centers assigned to the systematic-strategy group, a program promoting systematic ICU admission was implemented. In healthcare centers assigned to the control group, there was no specific recommendation regarding the ICU triage process (standard-strategy group). In both groups, the final decision for admission or not in ICU was made by the physicians at bedside.

Participant Selection

All patients were included in the ICE-CUB 2 clinical trial. Inclusion criteria were an age ≥ 75 years, at least one of the pre-established critical conditions [15], a preserved functional status as assessed by an Index of Independence in Activities of Daily Living (ADL) ≥ 4 (0=totally dependent, 6=independent) or an unknown ADL score, a preserved nutritional status (defined as the absence of cachexia, subjectively assessed by the physicians at bedside) and the absence of active cancer. Exclusion criteria were an emergency department stay over 24 hours, a secondary referral to the emergency department or refusal to participate. Patients in whom cancer was diagnosed after inclusion remained in the statistical analysis.

In two centers (one in each group) the Zarit Burden Interview was evaluated at 6 months. Only in caregivers with completed Zarit Burden interview (ZBI) related to patient data were used.

The ZBI is a 22-item questionnaire in which caregivers self-assess the level of burden [16]. Each item of the questionnaire is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). The score ranges from 0 to 88. The interpretation of the score is the following: from 0 to 20, there is no or a low burden; from 21 to 40 the burden is mild to moderate ; from 41 to 60 the burden is moderate to severe; and above 61 the burden is severe.

Data collection

The following data were collected: age, sex, ICU admission, SAPS III [17], diagnosis at admission, invasive procedure used in ICU, ADL at admission and 6 months, SF-12 [18] at 6 months, place of living at admission and 6 months, length of hospital stay, patient's and family's opinion about ICU admission.

Primary endpoint and objectives.

The primary endpoint was a ZBI ≥ 21 (mild to severe burden) at 6 months.

The primary objective was to identify factors associated with mild to severe burden (ZBI ≥ 21). Secondary objectives were ICU admission rate, in-hospital death, functional status at 6 months as assessed by the ADL scale, and quality of life at 6 months as assessed by the 12-item Short-Form (SF-12) Health Survey. For patients discharged alive, ZBI information was obtained via phone, from patient caregivers.

Statistical Analysis

Baseline characteristics of patients were analyzed as frequencies and percentages for categorical variables and as medians and interquartile ranges (IQR) for continuous variables. Bivariable associations were evaluated with t-test for continuous variables and Chi-square or Fisher exact test for categorical variables, as appropriate. Variables for all adjusted analyses were: age, illness severity, initial clinical diagnosis, seniority of the emergency physician, time of ICU admission, baseline functional status, place of residence and type of home support. Caregiver burden was categorized as light or moderate vs no or low and analyzed as a binary outcome by means of a logistic regression model. All analyses were performed at a two-sided alpha level of 5%. A p-value of less than 0.05 was considered to indicate statistical significance. All analyses were performed (AB) with R software, version 3.2.2 (R Foundation for Statistical Computing).

Results

Between January 2012 and April 2015, a total of 3,037 patients were enrolled in the ICE-CUB2 clinical trial; 1,519 patients in 11 healthcare centers allocated to the systematic-strategy group and 1,518 patients in 13 healthcare centers allocated to the standard-strategy group.

N= 191 caregivers (from 191 patients) were willing to complete the Zarit Burden Interview questionnaire (N=115 in the control group and N=76 in the systematic-strategy group). . ZBI were completed without missing answers for 148 caregivers (n=91 in the control group and n=57 in the systematic-strategy group). Missing answers were then imputed to 2 for each missing value and the score was computed for all 191 patients, the median being 13 [5-27].

Baseline characteristics of the patients for whom caregiver burden was assessed are presented in Table 1. Although the median age was 86 years, functional autonomy of included patients at Emergency Department (ED) visit was good (ADL 6 (5.5-6)). Main diagnosis were acute respiratory failure (n=69; 36.1%) and shock (n=37; 19.4%). Fifty three percent of patients were admitted to the ICU and 37.8% of them required organ support. A large majority of patients and family expressed no opinion regarding ICU admission (n=150; 78.5%). At 6 months, the median ADL scale decreased by 0.5 points and 13.8% of patients were admitted to a nursing home.

Compared to patients with no or low caregiver burden, patients with mild to severe caregiver burden at 6 months had stayed in the hospital longer, required more invasive procedures in the ICU, were less self-sufficient at 6 months, and had a lower quality of life.

Furthermore, caregiver burden was not significantly different between groups (systematic-strategy vs control) ($p=0.61$) and between admission location (ICU vs not) ($p=0.68$) (**Figure 1**)

Factors associated with mild to severe caregiver burden

In the univariate analysis, male sex, length of hospital stay, loss of functional autonomy, and lower quality of life at 6 months were associated with mild to severe

burden. Age, ICU admission and all factors associated with high level burden with a p-value <0.2 in univariate analysis were included in a regression logistic model (Table 2). In the multivariate analysis, decrease in ADL scale was significantly associated with mild to severe burden (OR: 1.3 [1-1.68], $p=0.049$) and a higher mental SF12 scale was negatively correlate with a mild to severe burden (OR: 0.94 [0.89-0.98], $p=0.009$). Interestingly enough, age, admission to the ICU and length of hospital stay were not associated with mild to severe burden (OR: 0.84 [0.41-1.73], $p=0.64$; OR: 0.99 [0.93-1.06], $p=0.85$; OR: 1.02 [0.99-1.06], $p=0.12$ respectively).

Discussion

Our study focuses on caregiver burden 6 months after critical illness in the older population. We found that more than one third of caregivers suffer from mild to severe burden (ZBI ≥ 21). Patient factors associated with this burden are the loss of functional autonomy and lower mental health status 6 months after initial admission. Surprisingly, age, admission to the ICU and hospital length of stay were not associated with the severity of burden in the multivariate analysis.

In a younger population, Cameron et al. found that a high burden level was common for caregivers of critically ill patients more frequently than in our study (53% to 69%

[10,19] vs 37%). More than half of caregivers presented depressive symptoms initially, these symptoms decreasing partially with time [8]. One explanation to the difference in burden perception could be age. Older patient caregivers (spouses) are often old themselves, and a younger age in caregivers is associated with more depressive symptoms [8]. One could also wonder whether the caregiver's relationship to the patient impacts the level of burden, since caring for a spouse could be viewed by some as more natural than caring for a parent. In Cameron et al's study, 60% of caregivers were spouses, 6.7% were siblings, 14.7% were children of patients and 13.9% were parents of patients. Caregivers caring for their spouses had fewer depressive symptoms than others (mean difference in outcome -2.46, $p < 0.05$) [8]. Unfortunately, in our study, we were lacking data regarding caregiver status and so could not investigate this hypothesis.

In the older population, caregiver burden has been described in several situations. In Alzheimer's disease and other dementia, burden is associated with the severity of dementia [20], behavioral disorders and loss of functional autonomy [20–22]. In other advanced illnesses such as cancer, congestive heart failure and chronic obstructive pulmonary disease, the main factor associated with burden is the need for help with activities of daily living [23]. In our study, patient's comorbidities are not reported notably dementia that could influence caregivers burden. Caregiver characteristics associated with a high burden level are being the only person in charge, living with the patient and being an adult child [22,24].

ZBI is lower in our study as compared to a population of caregivers of patients with Alzheimers' disease (15 to 41 in the AD study vs 13 in ours) [20,22]. Loss of functional autonomy plays a central role in the perception of burden. Although mortality is high after an intensive care unit stay, survivor's functional autonomy is relatively decent.

Only 28% to 37% did not restore their previous functional autonomy, based on the ADL score measured at 3, 6 and 12 months [25,26]. At 12 months, 50% of survival patients had recovered their previous ADL score, IALD and physical capacities [27]. Thus, higher functional autonomy in patients after critical illness than in AD could partially explain a lower ZBI.

Our study included only unplanned patient since the inclusion took place in the emergency department. This strengthens the message since planned surgery are totally different from emergency admission [28] with less frail patients who are also the less dependent.

Conclusion/Implications:

In our study, functional status and mental health at 6 months were associated with mild to severe burden unlike age and admission in ICU. These results suggest that fear of inducing high caregiver burden shouldn't be an obstacle to the ICU admission of elderly patients. However, improving their long-term autonomy should be a priority as it plays a central role in the perception of burden. Furthermore, caregiver burden should be systematically evaluated during the initial geriatric assessment as well as during follow-up consultations, so as to better evaluate and prevent caregiver burnout [29].

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Author Contributions: HV, LM, CT, BG and AB contributed to the conception of the study. HV and AB analyzed the data. HV, LM, CT, BG and AB drafted the manuscript and contributed to the writing of the article.

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LEGENDS:

Table 1: patient's characteristics

Table 2: Univariate and multivariate analysis of factors associated with mild to severe burden (ZARIT ≥ 21)

Figure 1: Comparison of ZBI between patients admitted in ICU or not (A) and between the Systematic ICU admission and the standard group (

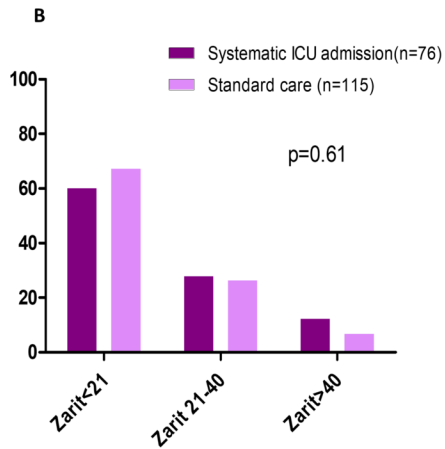
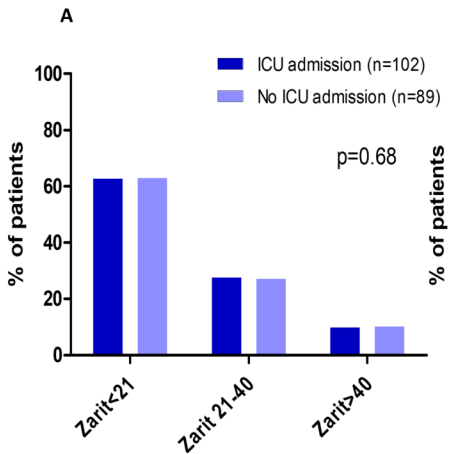


Table 1 : patients characteristics

	All patients (n=191)	mild to severe burden (n=71)	No or little burden (n=120)	P value
Age ; years	86 (81-89)	86 (82-88)	86 (80-89)	0.54
Male sex	74 (38.7)	35 (49.3)	39 (32.5)	0.03
ICU admission	102 (53.4)	38 (53.5)	64 (53.3)	1
SAPS3 ^a	62 (57-70)	63 (57-68)	61 (57-70)	0.72
Length of hospital stay; days	13 (8-21)	14 (9-27)	11 (8-20)	0.034
ADL at ED visit ^b	6 (5.5-6)	6 (5.5-6)	6 (5.5-6)	0.63
Diagnosis				0.56
Cardiology	25 (13.1)	11 (15.5)	14 (11.7)	
Surgery	2 (1)	1 (1.4)	1 (0.8)	
Coma	13 (6.8)	6 (8.5)	7 (5.8)	
Respiratory	69 (36.1)	29 (40.8)	40 (33.3)	
Gastrointestinal	19 (9.9)	6 (8.5)	13 (10.8)	
Shock	37 (19.4)	12 (16.9)	25 (20.8)	

Miscellaneous	26 (13.6)	6 (8.5)	20 (16.7)	
Invasive procedure in the ICU (invasive MV, renal replacement therapy, catecholamines) ^c	37 (37.8)	19 (51.4)	18 (29.5)	0.05
Patient and family opinions about ICU admission				0.26
Patient and relatives have no opinion	150 (78.5)	59 (83.1)	91 (75.8)	
Other	41 (21.5)	12 (16.9)	29 (24.2)	
ADL at 6 months ^d	5.5 (3.5-6)	4.5 (2.6-5.5)	5.5 (4.6-6)	<0.0001
SF 12 physical ^e	36 (30-46)	34 (29-42)	39 (31-48)	0.009
SF 12 mental ^e	45 (40-50)	43 (34-49)	46 (42-50)	0.01
Change in ADL at 6 months ^f	-0.5 (-2-0)	-1 (-3-0.5)	0 (-1-0)	<0.0001
Change in place of residence (home to institution) at 6 months ^g	26 (13.8)	16 (22.9)	10 (8.4)	0.008

Results are expressed in median (IQR) or number (percentage). ICU: intensive care unit; SAPS: simplified acute physiology scale; ADL: activity of daily living; ED: Emergency Department; SF: Short form. Missing value: ^a163 ^b17 ^c93 ^d7 ^e3 ^f24 ^g2

Table 2: Univariate and multivariate analysis of factors associated with mild to severe burden (ZARIT ≥ 21)

Variable	Univariate		Multivariate	
	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value
ICU admission	1.01 (0.56-1.81)	0.98	0.84 (0.41-1.73)	0.64
Age ; years	1 (0.95-1.06)	0.92	0.99 (0.93-1.06)	0.85
Length of hospital stay (one day increase)	1.03 (1.01-1.06)	0.01	1.02 (0.99-1.06)	0.12
Home at ED visit and follow-up	0.46 (0.15-1.39)	0.17	Not included in the model	
Home to institution	1.6 (0.43-5.94)	0.48	Not included in the model	
ADL at last follow-up (one point increase)	0.75 (0.64-0.89)	0.001	Not included in the model	
Change in ADL (one-point decrease)	1.46 (1.19-1.8)	0.0003	1.3 (1-1.68)	0.049
SAPS III (one point increase)	1.02 (0.94-1.1)	0.63	Not included in the model	
Male vs Female	2.02 (1.11-3.69)	0.02	2.03 (0.99-4.19)	0.054
Physical SF12 (one-point decrease)	0.96 (0.93-0.99)	0.01	0.97 (0.93-1.01)	0.14
Mental SF12 (one-point decrease)	0.94 (0.91-0.98)	0.005	0.94 (0.89-0.98)	0.009
Discharge form hospital: Other location vs home	0.87 (0.48-1.56)	0.64	Not included in the model	

ICU: intensive care unit; ED: emergency department; ADL: activity of daily living; SAPS: simplified acute physiology scale; SF: Short form