ORIGINAL ARTICLE

Defining needs and goals of post-ICU care for trauma patients: preliminary study

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ABSTRACT

BACKGROUND: The aim of this study was to assess the long-term physical and psychological disabilities and their economic impact in severe trauma survivors.

METHODS: Adult patients with Injury Severity Score >15 and Abbreviated Injury Scale ≤ 3 admitted to the ICU of a Level 1 trauma centre in the Lazio Region and discharged alive from hospital underwent a structured interview 12-24 months after the event. Self-reported somatic symptoms, autonomy, anxiety and depression were evaluated using a Likert-type Scale, Barthel Index and Hospital Anxiety and Depression Score (HADS), respectively. Patients' working and economic status were also investigated.

RESULTS: A total of 32/58 patients matching the inclusion criteria were included in the final analysis. Eighteen patients (56%) reported at least a partial restriction in daily activities. Most common symptoms included muscle or joint pain, fatigue, and headache. All patients were receiving rehabilitation 1-2 years after the event. Fifty-eight percent of the patients spent more than €3600/year from their family budget for rehabilitation and medical care, however only 25% were receiving financial support from regional social services and 44% were unemployed at the time of the interview. Thirty patients (94%) had HADS Depression Score≥11.

patients (94%) had HADS Depression Score≥11. CONCLUSION: Survivors of severe trauma in our cohort had limited autonomy and need long-term rehabilitation. Most of them rely on private healthcare services with a significant financial impact on their family budget. Almost all patients had moderate to severe depression. Future post-ICU counseling services should facilitate access to rehabilitation and psychological support for these patients.

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During the last 25 years a significant improvement has been observed in survival rates from severe trauma.^{1, 2} However, the number of patients admitted to intensive care unit (ICU) after severe trauma in Italy continues to increase, while their mean severity remains high.² As a consequence, an increas-

ing demand of health and social care from survivors of severe trauma is expected in Italy. In fact, patients discharged from acute care hospitals after critical illness suffer from significant physical and psychological disabilities and often need prolonged rehabilitation before they can be reintegrated into active society. This was well demonstrated in survivors of sepsis and septic shock ⁴⁻⁷ or of acute respiratory distress syndrome (ARDS).⁸⁻¹⁰ In comparison with these categories of patients, however, patients recovering from severe trauma are younger, with a longer life expectancy and almost always in their working age, ^{11, 12} so the psychological, social and economic impact of long-term disabilities in this population is expected to be even higher.

A series of studies aimed to provide aftercare in post-ICU patients were done recently.^{13, 14} However, none of these studies specifically focused on severe trauma survivors. In order to provide optimal aftercare, services need to know what the most important unmet needs in this specific target population are.^{15, 16}

The aim of the present pilot study was to identify the main self-reported disabilities and medical needs, and the relevant social and economic impact, in a convenience sample of severe trauma survivors who have been treated by our trauma center. Data collected into this pilot study will be used to plan a dedicated follow-up and counseling service aimed to facilitate the recovery of these patients.

Materials and methods

Background

The study was conducted at the Department of Anaesthesiology and Intensive Care of the "Agostino Gemelli" Teaching Hospital. This 1200-bed tertiary care hospital is one of the three adult Level I Trauma Centre in the Lazio Region. Its catchment area includes the northwestern quadrant of the Rome province and the territory of two other adjacent counties (total area 6364 km²), with a population of over 2 million inhabitants. An average of 150 adult major trauma patients are treated into our ICU each year.

Patient enrolment

The patients enrolled in this study were adult (18-70 years) victims of severe trauma (Injury Severity Score [ISS]>15), who were admitted

to our 18-bed ICU during the 10-month study period (May 2010 - February 2011) and were discharged alive from the hospital were considered for inclusion. Patients who stayed less than 48h, those with severe brain injury (Abbreviated Injury Scale [AIS] >4), and those with a history of pre-existing psychiatric illness were excluded. None of the patients suffered from a neurological deficit during the follow-up and all of them were able to answer autonomously the questionnaire they were given (Glasgow Coma Scale [GCS]>11 at ICU discharge and Glasgow Outcome Scale [GOS]=5 at the follow-up).

After approval from the institutional review board, patients who met the inclusion criteria were contacted 12-24 months after ICU discharge and were invited to attend a multidisciplinary interview. Patients' consent was obtained before starting the interview.

An intensivist-led team which included a nurse and a dedicated psychologist recorded data on family, working and economic status, disability and self-reported symptoms and medical needs. In addition, patients were asked to report the amount of the additional healthcare expenses related to trauma and their working status before and after the traumatic event.

The Barthel Index ^{17, 18} was used to report the patient's autonomy in his/her daily activity. Answers varied from autonomous, partial impairment and total impairment. We also investigated whether the patients were having any sexual activity and if so they were asked to indicate their satisfaction on a visual scale with scores ranging from 0 to 100%.¹⁹ Self-reported physical symptoms were assessed using the Therapy Impact Questionnaire.²⁰

To assess mood disturbances, patients were administered the Hospital Anxiety and Devpression Scale (HADS), a 14-item scale designed to measure anxiety and depressive symptoms in non-psychiatric hospital patients. Somatic symptoms are excluded from HADS, in order to avoid confusion with organic diseases. HADS includes separate subscales for anxiety and depression. For each subscale, a range of scores is assigned to the severity of symptoms: normal (0-7), mild (8-10), moderate (11-14), and severe (15-22).^{10, 22, 23}

Statistical analysis

Categorical variables were expressed as percentages while continuous variables were expressed as mean±standard deviation or median [IQR] as appropriate. For categorical variables, comparisons between groups were performed using the χ^2 Test or the Fisher's exact Test when required. Ordinal variables and non-normal quantitative variables were compared using the Mann-Whitney U Test. Associations between continuous variables were investigated with Pearson's correlation analysis or Spearman's correlation rank test as appropriate. A two-tailed P-value below 0.05 was considered as statistically significant. SPSS 20.0[®] was used to perform the statistical analyses.

Results

Fifty-eight of the 89 patients admitted to our ICU during the study period matched the inclusion criteria. Fourteen (24%) could not be reached, six declined the interview and six were unable to come to the follow-up clinic (Figure 1). Eventually, 32 patients (9% females, median age 38 [27-51] years) completed the interview. Patients' demographics and clinical characteristics are reported in Table I.

Socioeconomic and working status

Nineteen patients (59%) were married while ten (31%) were still living with their relatives when the trauma occurred. While the family status after the ICU stay did not change for this last group of patients, two out of three patients (67%) who were living on their own when the trauma occurred had moved to their relatives

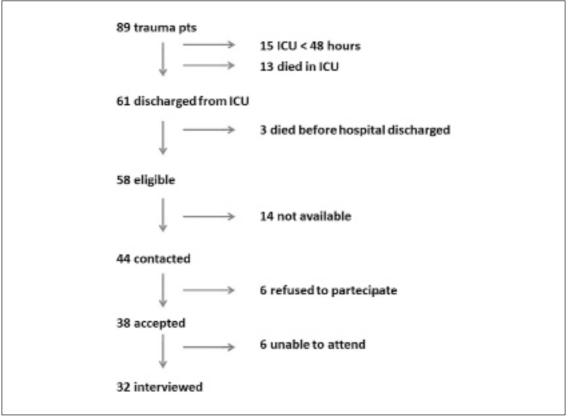


Figure 1.-CONSORT patient enrollment flow diagram.

TABLE I.—Characteristics of the study population.

Total number of patients	32
Female gender, N. (%)	3 (9)
Age, y	38 [27-51]
Family status on admission, N. (%)	
Married	19 (50)
Living with relatives	10 (39)
Living on their own	3 (11)
Working status on admission, n (%)	
employee	14 (44)
freelance professional	11 (34)
retired	4 (13)
unemployed	3 (9)
SAPSII	32 [25-43]
ISS	29 [22-38]
GCS	11 [8-15]
Days of ICU stay	23 [15-35]
Days of hospital stay	45 [34-78]
Days of mechanical ventilation	13 [4-20]
Tracheostomy, N. (%)	14 (44)
Respiratory comorbidities, N. (%)	1 (3)
Neurological comorbidities, N. (%)	3 (9)
Cardiac comorbidities, N. (%)	3 (9)
Other comorbidities, N. (%)	2 (6)

at the time of the follow up. Although eight patients (25%) reported they were receiving a financial support for their disability from the social security services, 19 patients (59%) reported spending more than \in 300/month for health care and rehabilitation related to the sequelae of their initial injury.

Twenty-five patients (78%) were employed when the trauma occurred, however eleven of them (44%) had not got back to work more than one year after the trauma, and one of them had retired. Freelance professionals compared to employees showed a significantly higher rate of return to work at follow-up (9/11 (81%) vs. 5/14 (31%); P=0.04).

Medical needs

Twelve patients (37%) required re-hospitalisation and 13 patients (40%) required surgery after ICU discharge. Twenty-eight patients (87%) accessed specialist assistance more than twice in a year. The most required specialists were orthopaedists, neurosurgeons, ophthalmologists, dentists and pulmonary medicine specialists. Twenty-three patients (72%) reported they had accessed primary care delivered by a family physician at least once a month after hospital discharge, mainly because of the need of medical prescriptions. All patients required rehabilitation; nine of them (28%) took advantage of the regional healthcare system, whereas the remaining patients (72%) relied on private rehabilitation services.

Six patients (19%) reported a daily use of drugs to dull somatic pain, and three patients (9%) stated they were taking drugs to alleviate neuropathic pain. Two patients were regularly taking antidepressant or sedative drugs. One patient reported alcohol abuse after the trauma and one patient admitted the use of illicit drugs (both before and after the trauma).

Disabilities

Eighteen patients (56%) reported at least a partial restriction in daily activities and six of them (19%) reported a loss of autonomy in these activities. The disability most frequently reported concerned movement (Table II). Four patients (12%) reported disability in micturition or defecation.

All patients complained of persistence of somatic symptoms 12-24 months after the

	Autonomous	Help needed	Dependent
Moving from chair to bed	28 (88)	1 (3)	3(9)
Climbing stairs	26 (81)	3 (9)	3 (9)
Walking	27 (85)	2 (6)	3 (9)
Personal hygiene	27 (85)	2 (6)	3 (9)
Feeding	28 (88)	2 (6)	2 (6)
Micturition	28 (88)	1 (3)	3(9)
Defecation	29(91)	1(3)	2 (6)

TABLE II.—Reported functional disabilities at follow-up.

TABLE III.—Reported symptoms at follow-up.

	Absent	Mild	Moderate	Severe
Headache	17	16	6	3
Fatigue	6	15	7	3
Gastralgia	19	9	3	
Nausea	25	6		
Diarrhea	25	4	2	
Constipation	20	5	2	4
Confusion	16	8	3	4
Sleep abnormalities	17	11		3
Coughing or wheezing	23	6	2	
Itching	20	7	3	1
Muscle pain	10	11	7	3
Joint pain	7	12	8	4

TABLE IV.—Correlation between clinical characteristics and HADS Score.

	HADS Anxiety	HADS Depression
Age	-0.07 (P=0.60)	0.16 (P=0.39)
ISS	0.16 (P=0.41)	-0.22 (P=0.24)
GCS	-0.06 (P=0.76)	0.03 (P=0.86)
SAPSII	0.14 (P=0.44)	-0.16 (P=0.38)
Days of ICU stay	0.02 (P=0.92)	-0.24 (P=0.18)
Days of hospital stay	-0.29 (P=0.11)	-0.19 (P=0.29)
Days of mechanical ventilation	-0.13 (P=0.48)	0.06 (P=0.73)

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event. These symptoms are reported in detail on Table III. Moderate to severe muscular or joint pain were the symptoms most commonly reported (32% and 38% respectively). Fatigue, confusion and headache were also common.

Anxiety and depression

The HADS questionnaire was administered to 31/32 patients. The median HADS anxiety and depression scores were 8 [5-13] and 15 [12-18], respectively. Fifteen patients (47%) suffered from moderate to severe anxiety, and 30/31 patients (94%) suffered from moderate or severe depression. Patients who had lost their jobs stated they feel anxious or depressed more often than those who had got back to work (12/18 [63%] vs. 4/14 [28%]; P=0.03).

No significant association was found between the anxiety and depression scores and the patients' age, clinical severity, and length of stay (Table IV).

Discussion

This is the first Italian follow-up study which investigates the long-term functional outcomes in patients who survived severe trauma. Previous studies included only patients with mild and moderate injury within six months after the event.²⁵ This is partly because the diffusion of outpatient ICU follow-up services in Italy is still limited.¹⁵

Consistently with previous reports,^{26, 27} results of our study showed that the vast majority of these patients had persistent functional disabilities 1-2 years after the event. Data from large cohort studies show that functional recovery in these patients is slow and that there is little improvement in functioning between the first and second year after the injury.²⁸ As expected, most of the functional disabilities we observed concerned the musculoskeletal system: one third of our patients had invalidating muscle or joint pain and one fifth of them were unable to walk or stand without assistance. Accordingly, orthopaedists were the specialists most frequently consulted after hospital discharge. All patients in our cohort were still receiving rehabilitation one year or more after the event, however only one quarter of them had their healthcare expenses entirely covered by the regional healthcare system; the rest of the patients had to pay extra fees for their therapies These fees (>3600 € per year) represented more than 16% of the average annual per capita income of the Lazio Region (€ 22,160 per year) for 59% of the patients in our cohort. The impact of additional healthcare expenses on the family budget for these patients was even higher if we consider that almost two thirds of these patients (12/19)had not got back to work at the time of the interview. This underlines the need for a more efficient regional healthcare system, able to provide free access to rehabilitation and specialised care for these patients when appropriate. Providing consultation and facilitating the access to these services is among the main duties of a follow-up service for post-ICU patients.16

All but one patient in our cohort were depressed and half of them suffered from moderate or severe anxiety. Depression in ICU survivors is commonly observed and, consistently with previous reports, ²⁹ its severity was not significantly correlated with clinical severity or length of stay. Rather, depression in these patients is likely to be reactive, due to physical disability and consequent social isolation, job loss and financial issues. On a long-term perspective, improving access to rehabilitation could enhance physical recovery and social reintegration in these patients and reduce their depression.^{30, 31} On a short-term perspective, however, the severity of mood disturbances we observed suggests that treatments to these patients should be provided by follow-up services, and referral to specialist care should be offered when necessary. It should be noted that only two patients in our cohort were taking pharmacological treatment for their depression and none of them received regular psychological or psychiatric support. Support and counseling for these issues should not be limited to patients but should be extended to their caregivers.32,33

We adopted the HADS Score to assess mood disorders in our patients; despite its simplicity and the fact of having been validated in hospital populations, this tool did not distinguish between patients in whom the depression was reactive, (*i.e.*, entirely due to the emotional distress) or those in whom it was favored by a depressive tract (i.e., a natural predisposition to depressive mood present in some individuals). For this reason, in our future studies mood disturbances will be investigated using more specific anxiety psychological tests to assess how disabilities affect the quality of life of severe trauma survivors and to measure the effects of future follow-up interventions.

Study limitations

Our study has many limitations. Firstly, it includes a limited number of patients. However, this was consistent with its scope and design, being a pilot study made on a convenience patient sample. A secondary cause of its reduced sample size was that only 55% of the eligible patients could be included. Similar rates are commonly observed in follow-up studies on ICU patients based on face-to-face interviews;¹⁶ in fact, those studies include only patients who survived to hospital discharge and are able to undergo a structured interview in an outpatient clinic. This may have caused a selection bias in our study, since patients who had the most severe physical or mood disabilities may have been less keen or able to participate in our study; as a consequence, we may have underestimated the severity of the disabilities in the total patient cohort. To limit this bias and reach a larger population, in our future investigations we will use telephone interviews to record self-reported patient disabilities.

Secondly, our study did not include a control group. As a consequence, we could not distinguish between the direct effect of trauma and those of the ICU stay in determining the changes we observed in our study population. However, this was beyond the scope of our investigation, which was designed to identify the long-term physical and psychological disabilities in these patients in order to facilitate their rehabilitation.

Finally, our study has been carried out in a single centre in a specific regional area. Therefore, its results cannot automatically be generalised to other regions or areas where the organisation of the regional health services and the social characteristics of the afferent populations are different. Multicentre studies will be necessary to confirm if our results can apply nationwide.

Conclusions

Our study showed that the majority of adult patients discharged alive from ICU after a severe trauma suffer from physical disabilities 12-24 months after the event. All of these patients need rehabilitation, however this is provided entirely from the regional healthcare service only for a minority of them. Severe depression or anxiety in these patients is very common, however virtually none of them could benefit from psychological support. Future follow-up services should facilitate access to rehabilitation and healthcare services and provide psychological consult for patients and their caregivers.

Key messages

— The majority of the patients admitted to ICU after a severe trauma in this followup study carried out in the Lazio Region reported significant physical disabilities and all of them received rehabilitation 1-2 years after the event; 40% of these patients needed surgery after ICU discharge and 37% needed further hospitalization due to sequelae of the initial trauma.

— Fifty-eight percent of these patients spent more than \notin 3600/year of their family budget for rehabilitation and medical care; however only 25% of them was receiving financial support from the regional social service.

— Forty-two percent of these patients were unemployed 1-2 years after the trauma; all but one of them had moderate to severe depression, as measured using the HADS Score.

— Patients discharged from hospital after severe trauma need long-term rehabilitation and have significant mood disturbances; a counseling service facilitating access to rehabilitation and medical care and providing psychological support could be beneficial for them.

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