Demand and consumption of care in long term ICU survivors in the Netherlands

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Abstract - Objective: To study the long-term impact of critical illness on demand and consumption of care after hospital discharge. Methods: In a prospective study all patients admitted to the ICU for > 48 hours who ultimately survived to follow up at six months were included. The Short Form 36 (SF-36) was used to evaluate the health-related quality of life (HRQOL) 6 months following ICU discharge. Additionally, consumption of medical care was analysed by querying survivors. Severity of illness was determined using the APACHE II score. Results: Of the 451 patients included, 252 were evaluated at 6 months. 64.6% of the patients were older than 65 years, 90.9% of the patients were living at home, although 66% of the patients who were employed before ICU admission did not resume their job. Eighty patients (31.7%) were still depending on professional help for medical care, more than half of them on a daily basis. Conclusions: Most long-term ICU survivors are discharged to their own home and are six months after ICU discharge frequently still dependent on complex care, as impairment occurs not only on a physical level, but also in psychological and social domains, probably related to a higher incidence of isolation from normal life. The burden of ICU stay seems substantial and long-lasting. This is not only important for patients and their relatives but also for care providers and society.

Keywords - Intensive Care, care consumption, Netherlands, health-related quality of life, critical illness, survival

Introduction
Patients who survive critical illness for which they were admitted to an intensive care unit (ICU) face long-lasting impairments in physical, psychological and social well-being [1,2]. The perceived long-term health-related quality of life (HRQOL) is, in many cases, reduced and survivors are frequently diagnosed with post-traumatic stress disorder, depression and anxiety [3]. Limited information is available on the impact of ICU stay on long-term consumption of medical care resources. However, continuing problems long after ICU discharge have implications not just for patients and relatives, but impose a continuing financial burden on health care services. To obtain insight into the long-lasting impairments in ICU survivors we previously studied HRQOL and daily functioning at 6 months after ICU discharge [4]. The aim of this study is to evaluate the impact of ICU stay on long-term consumption of medical care resources.

Material and methods
Data on HRQOL and long-term resource consumption were analyzed. The study was performed in a 654-bed university-affiliated hospital, with a 10-bed closed-format ICU. No cardiac or neuro-surgery is performed at this hospital. Daily medical care is delivered by intensivists and residents, while residents are only present during evening and night-time shifts when called upon. From September 2000 to April 2004 all patients admitted for more than 48 hours were eligible for the study. In total 2127 patients were screened for study participation. In patients readmitted to the ICU (n=36), only data on HRQOL after discharge from the final ICU admission period were included in the study. All patients surviving the six-month follow up period were included (i.e. long-term survivors). Non-survivors were defined as all patients who had died between ICU admission and the six-months following ICU discharge. The Acute Physiology, Age and Chronic Health Evaluation score (APACHE II score) was used for measuring the severity of illness. Patients or their close relatives were asked to complete the Short-Form 36 (SF-36) questionnaire (a generic widely used standardized health questionnaire [5] on admission to ICU (proxies and patients), and at six months after ICU discharge (patients). This approach has been previously validated [6].

Results
Of the 2127 patients screened, 1676 patients were excluded. Of the excluded patients, 179 died during ICU stay (10.7%) and 87 died while on the general ward (5.2%) (Figure 1). In total, 451 patients were included in the final analysis. HRQOL measurement was obtained on ICU admission in all cases. Six months after ICU discharge, 252 patients were re-evaluated, 40 patients (8.9%) were lost to follow up, while 159 had died within the duration of the study (35.3%). The ICU patients were mostly elderly; with a mean age in the survivors of 66.9 years (range 26-89 years), 64.6% of them exceeding 65 years of age (Table 1). Thirteen patients were still unable to resume their work, while 11 patients were only partially able to work six months after ICU discharge. At that time, 229 patients had returned home (90.9%); but specialist medical care frequently remained necessary. Eighty patients...
were still dependent on professional help for medical care and/or management of their household (31.7%). More than half of these patients (N=42) needed daily medical care, which involved wound care or help with a catheter, colon fistula or urinary fistula. The vast majority of patients (N=163, 64.7%) were not able to go shopping independently. Climbing only one staircase was still problematic for 116 patients (46%), while 50.4% of the patients noticed restrictions in the physical and emotional relationships with close relatives. In addition, 34.1% of the patients reported some physical pain after 6 months, of which 10.0% reported severe pain. Table 2 shows some additional dimensions of the need for care of the patients who were evaluated six months after ICU discharge. Given the increased age of the long-term survivors, we asked them how their limitations were related to the period spent on ICU. In 90% of cases, patients confirmed that their need for care was directly related to their ICU stay. After 6 months, weekly physiotherapy was needed by 41.2% of the patients, while 15.9% were seeing a social worker and 28.5% were still receiving medical care from a physician (e.g. surgeon, neurologist, internist, urologist or pulmonary physician). A smaller proportion (N=32, 12.7%) consulted a dietician at least weekly.

**Discussion**

This study demonstrates that patients had long-lasting restrictions in several dimensions of HRQOL after ICU discharge, especially in physical functioning (mobility) and social behaviour. Others have reported comparable data [4,7,8], which is important because of the potential impact of these restrictions on daily functioning, and for evaluating if interventions aimed at improved long-term functional outcome of ICU patients should be developed.

In our study, the vast majority of the patients were discharged home. This is comparable with previous data [8,9], although differences were found with a study where a smaller proportion (64%) of the patients were discharged home [2]. This may be explained by differences in case mix, social characteristics and geographic areas.

Of the patients who where employed before ICU admission, a substantial number did not resume their job after discharge (66%). This is in agreement with other studies [8,10,11] and implies that ICU admission has a severe impact and engenders very high costs. This effect is larger than reported in other studies [9,12]. However, these data are difficult to compare because they are also influenced by the job market and other external factors. Some patients may be still in the recovery phase, and these data should therefore be carefully interpreted as an end-point for work status.

Both in our study and in that of van der Schaaf et al., physiotherapy, assistance from social workers, as well as medical care from a physician or psychologist, were still needed at 6-12 months after ICU discharge [8]. Physical disabilities (e.g. neuropathy, reduced mobility) after ICU discharge requiring a physician and physiotherapist were also evident in many patients in other studies [13-15]. In addition, ICU patients continue to experience psychological problems, e.g. anxiety, depression and posttraumatic stress, and also need help from a psychologist or social worker for some time after ICU discharge [16,17]. Some studies even suggest that 14-27% of ICU patients may develop a posttraumatic stress reaction that may last for a number of years [16-18].

Approximately half of the patients in our study noticed restrictions in the physical and emotional relationships with close relatives. Since the impairment affects not only the physical level, but also the psychological and social domains with higher rates of depression, anxiety and other negative psychological feelings, this may be associated with a higher incidence of isolation from normal life. As the restrictions are found to be present 6-12 months after ICU discharge, they may be considered to be long-

**Table 2.** Additional results on dimensions of care needed; follow up six months

<table>
<thead>
<tr>
<th>DIMENSIONS OF CARE NEEDED</th>
<th>N</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home nursing/home care necessary</td>
<td>252</td>
<td>80 (31.7)</td>
</tr>
<tr>
<td>- Frequency of care: once a week</td>
<td>80</td>
<td>14 (17.5)</td>
</tr>
<tr>
<td>- Frequency of care: 1-2 times a week</td>
<td>80</td>
<td>17 (21.3)</td>
</tr>
<tr>
<td>- Frequency of care: 3-4 times a week</td>
<td>80</td>
<td>7 (8.8)</td>
</tr>
<tr>
<td>- Frequency of care: daily</td>
<td>80</td>
<td>42 (52.5)</td>
</tr>
<tr>
<td>Substantial effort (housework): severely limited</td>
<td>252</td>
<td>230 (91.3)</td>
</tr>
<tr>
<td>Moderate effort (housework): severely limited</td>
<td>252</td>
<td>211 (83.7)</td>
</tr>
<tr>
<td>Shopping (lifting shopping bag): severely limited</td>
<td>252</td>
<td>163 (64.7)</td>
</tr>
<tr>
<td>Getting up one staircase: severely limited</td>
<td>252</td>
<td>116 (46.0)</td>
</tr>
<tr>
<td>Bending, kneeling or squatting: severely limited</td>
<td>252</td>
<td>109 (43.3)</td>
</tr>
<tr>
<td>Walking few hundred yards: severely limited</td>
<td>252</td>
<td>112 (44.4)</td>
</tr>
<tr>
<td>Washing and dressing independently: severely limited</td>
<td>252</td>
<td>43 (17.1)</td>
</tr>
</tbody>
</table>
term negative consequences of critical illness and ICU treatment. Moreover, family members, especially the spouse, may show significant degrees of anxiety and depression during the patient’s ICU stay [19]. In addition, patients may experience guilt as they become aware of the strain placed on their family and loved ones, which may add to their psychological burden, thus predisposing them to affective disorders [13,20].

Several limitations to our study should be recognized. First, the patients were only followed for 6 months, which leaves room for potential improvement in the patient’s functional status in the second year after discharge, or even thereafter. However, other long-term studies on HRQOL after ICU stay have demonstrated that most changes occur in the first 6 months after ICU discharge [15,21]. Second, the influence of co-morbidity, age and socio-economic status was not taken in consideration. Finally, this is a single centre study in a rural area in the Netherlands, which makes the results difficult to translate to other areas or countries. However, the fact that our results are quite comparable to those found in another and more metropolitan part of the Netherlands [8] suggests that the findings probably reflect a common phenomenon, at least in the Netherlands.

Conclusion

The vast majority of ICU survivors return to their own homes. However, a considerable number of them are unable to resume their previous employment and many patients face dysfunction in social behaviour, mobility control and psychological functioning. Our findings suggest that it may be worthwhile to develop specific interventions such as an ICU outpatient clinic aiming at improved outcome of ICU patients, thus potentially reducing the financial burden for society by reducing consumption of medical resources.

References


