Hopelessness: Independent associations with health-related quality of life and short-term mortality after critical illness: A prospective, multicentre trial

Lotti Orwelius, PhD⁠, Margareta Kristenson, M.D., Professor, Mats Fredrikson, PhD, Sten Walther, PhD, Folke Sjöberg, M.D., Professor

A R T I C L E   I N F O

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A B S T R A C T

Purpose: To assess the independent associations between ability to cope and hopelessness with measures of health-related quality of life (HRQoL) and their effects on mortality up to 3 years after discharge in patients who have been treated in an intensive care unit (ICU).

Methods: A prospective, cross-sectional multicenter study of 980 patients. Ability to cope, hopelessness, and HRQoL were evaluated using validated scales. Questionnaires were sent to patients 6, 12, 24, and 36 months after discharge from ICU.

Results: After adjustment, low scores for ability to cope and high scores for hopelessness were both related to poorer HRQoL for all subscales (except for coping with bodily pain). Effects were in the same range as coexisting disease for physical subscales, and stronger for social and mental subscales. High scores for hopelessness also predicted mortality up to 3 years after discharge from ICU (p < 0.001).

Conclusions: The psychological factors ability to cope and hopelessness both strongly affected HRQoL after ICU care, and this effect was stronger than the effects of coexisting disease. Hopelessness also predicted mortality after critical illness. Awareness of the psychological state of patients after a stay in ICU is important to identify which of them are at risk.

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1. Introduction

During the past decade there has been an increased focus on the perceived health-related quality of life (HRQoL) for patients who survive critical illness. In addition to the effects of medical treatments, psychosocial factors may also influence HRQoL. These include factors related to the social environment [1,2] and individual psychological factors, which include psychological resources such as ability to cope, sense of coherence and perceived control, together with psychological risk factors such as depression, exhaustion, and hopelessness [3,4]. We have previously reported on the importance of availability of social integration for HRQoL in patients after critical illness [1,2], and in this paper we focus on individual psychological factors.

Having a serious illness is, for most people, a stressful experience. According to the cognitive activation theory of stress (CATS), coping is defined as “positive outcome expectancy based on earlier experiences on the interaction between the exposure and response to this exposure” [5]. This sense of ability to cope captures feelings of confidence and self-reliance together with a feeling that life is to some extent manageable. It describes the ability to respond to external stimuli to prevent, avoid, or control emotional distress, and the extent to which one regards one’s chances in life as being under one’s own control in contrast to being in the hands of others [6]. Little or no ability to cope was associated with poorer perceived health among patients with multiple sclerosis [7] and patients with asthma or chronic obstructive pulmonary disease [8]. In population-based studies little ability to cope was related to poor self-rated health [9], lower HRQoL scores [10] and, prospectively, to a higher risk of death from myocardial infarction as well as mortality from all other causes [11].
If a person cannot cope they lose a sense of expectancy and, if it is prolonged, it turns to a state of helplessness, exhaustion, and hopelessness [5,12]. Hopelessness has been associated with poorer HRQoL in patients with cancer [13] and HIV [14]. In cardiac patients, hopelessness was associated with a more than three-fold risk of clinical events 2 years after their first admission [15] and in normal populations it has been an independent predictor of myocardial infarction, and deaths both from cardiac disease and other conditions [16]. However, ability to cope and hopelessness have never been examined in relation to HRQoL or mortality in patients after critical care.

The aim of this study was to assess the independent associations between ability to cope and hopelessness with measures of HRQoL and their effects on mortality 3 years after discharge in patients who have been treated in ICU. We hypothesised that inability to cope and severe hopelessness, or both, would be associated with worse perceived HRQoL and with higher mortality after critical care.

2. Patients and methods

2.1. Design

This study is part of a larger, prospective, multicentre study in which we earlier explored social integration, HRQoL, and sleep disorders after critical illness [17,18]. The study took place in 3 mixed medical/surgical ICU in one university and 2 general hospitals in south-east Sweden, with a referral area that covers one million people. Patients with primary coronary disease, those recovering from cardiac or neurosurgery, neonates, or patients with burns (who were treated in other specialised units) were excluded. Each ICU admitted 500–750 patients annually and nearly all admissions were emergencies. The most common reasons for admission (primary diagnoses) were multiple trauma, sepsis, and respiratory or circulatory disturbances.

2.2. Participants

We included consecutive patients > 18 years old who were admitted to ICU during the period 1 August, 2000-July 2004, remained in the ICU for > 24 h, were alive 6 months after discharge from hospital, and consented to participate in the study. Only the first admission was considered. After we had checked the national Swedish Social Security register to avoid sending inquiries to patients who had died, information and a request to participate were sent by mail, together with a questionnaire and a preaddressed and prepaid envelope 6, 12, 24, and 36 months after discharge [17]. Patients who had not responded within 10 days were contacted by telephone and if there was no answer 2 more reminders were sent out (at 3 and 6 weeks). For the purpose of this study data at 6 months were used for analysing association between ability to cope, hopelessness, and HRQoL and for the prospective analysis of effects on mortality.

2.3. Ethics, consent and permissions

The patients gave their informed consent prior to participating in the study. The Ethics Committee at Linköping University approved the design of the original study (Dnr: 00-381).

2.4. Measurements

2.4.1. Ability to cope

We used the Mastery Scale questionnaire with 7 items developed by Pearlin [19] (see Appendix 1 for the questionnaire). Typical items were “What happens to me in the future mostly depends on me” and “I can do just about anything I really set my mind to”.

The strength of agreement or disagreement for each item was graded on a Likert scale and responses were graded from 1 to 4. The scores ranged from 7 to 28, and higher scores reflected better ability to cope.

2.4.2. Hopelessness

Hopelessness was measured using two items in a scale used by Everson et al. [16] “I feel that it is impossible to reach the goals I would like to strive for” and “The future to me seems hopeless, and I can’t believe that it will change to the better”. Responses were graded from 0 to 4 on a Likert scale and summed to create a hopelessness scale ranging from 0 to 8, with high scores indicating increasing hopelessness. The scores were also grouped, as originally proposed [16], into 3 categories: low (0–2), moderate [3–5], and high (6–8). Both scales have been used in many different settings internationally, by others and by members in our group, and their validity and reliability has been confirmed [20,21].

2.4.3. Health-related quality of life

The Swedish version of Medical Outcome Short Form (SF-36) [22,23] was chosen for the evaluation of HRQoL. The instrument is internationally well-known and has been recommended for assessment of HRQoL in critical care [24]. SF-36 has been validated in a representative Swedish sample [22], and in burned patients [25]. It has 36 questions and generates a health profile of 8 subscales of which 4 relate to physical dimensions (physical functioning; physical role; bodily pain, and general health), and 4 to mental dimensions (vitality; social functioning; emotional role, and mental health) [22]. The scores of all 8 scales were transformed to a scale ranging from 0 (worst) to 100 (best).

2.4.4. Confounding factors

The questionnaire contained standard questions on age, sex, education, marital status, country of origin, and the scale Availability of Social Integration.

The ICU clinical database was used to extract the reason for admission, Acute Physiology and Chronic health Evaluation II (APACHE II) score, time on the ventilator, and duration of stay on the ICU and hospital.

3. Statistical methods

Data are presented as mean (SD) and percentages. To assess the significance of differences between the groups, we used Student’s t-test for continuous data and the chi square test for categorical data. A linear mixed-model was used to get an overall test for significance between the groups with the follow-up time points taken into account. Multiple linear regression analyses were used to evaluate the independent effects of ability to cope and hopelessness on each of the 8 subscales of SF-36. In these models age and sex were entered first, followed by possible confounders (APACHE II scores on admission, duration of stay in ICU and hospital, reason for admission, time on ventilator, marital state, level of education, born in Sweden or not, availability of social integration, and coexisting diseases) in a stepwise manner and standardised beta. To investigate the predictive effects of coping and hopelessness on mortality we used a logistic regression model, and controlled for age and sex and other confounders as given above. In these models age, ability to cope, hopelessness, and availability of social integration were introduced as continuous variables, all others being categorical variables. Probabilities of < 0.05 were accepted as significant. We used IBM SPSS Statistics for Windows (version 20.0, IBM Corp, Armonk, NY, USA) in the statistical analyses.

4. Results

4.1. Study population

A total of 1663 patients met the inclusion criteria, and after two reminders, 980 patients (59%) answered the questionnaire at 6 months.
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