

Long-term follow-up after intensive care

Development of an ICU-specific questionnaire

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien,
Göteborgs universitet kommer att offentligens försvaras i Hjärtats Aula,
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Avhandlingen baseras på följande delarbeten

- I. **Long-term health-related quality of life and burden of disease after intensive care: Development of a patient-reported outcome measure**
Malmgren J, Waldenström AC, Rylander C, Johannesson E, Lundin S
Crit Care. 2021;25(1):82.
- II. **Effect modification of comorbidity and educational level on quality of life after intensive care: Analysis of a cross-sectional study**
Malmgren J, Waldenström AC, Rylander C, Lundin S, Johannesson E
Submitted
- III. **Quality of life-related and non-quality of life-related issues in ICU survivors and non-ICU-treated controls: A multi-group exploratory factor analysis of a cross-sectional study**
Malmgren J, Waldenström AC, Rylander C, Lundin S, Johannesson E
Manuscript
- IV. **Evaluating the structure of quality of life after intensive care: Confirmatory factor analysis and bifactor modelling of a cross-sectional study**
Malmgren J, Waldenström AC, Rylander C, Lundin S, Johannesson E
Manuscript

SAHLGRENKA AKADEMIN
INSTITUTIONEN FÖR KLINISKA VETENSKAPER



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Abstract

Background: With improved results in intensive care comes a shift in focus – from survival to survivorship. Studies show that ICU survivorship includes effects on, for example, mental and physical health, cognition, ADL, ability to return to work, and sensory organ functions. Measuring quality of life and burden of disease after intensive care is fundamental and needs to be facilitated by a relevant tool, explicitly developed for ICU survivorship.

Aim: This doctoral thesis reports on the first steps taken toward a specific questionnaire tailored for long-term follow-up on quality of life and burden of disease in ICU survivors.

Methodology: Interviews were conducted with long-term ICU survivors from the general ICU at Sahlgrenska University Hospital to extract as many post-intensive care issues as possible. All unique issues from the interviews were converted into questions and tested in a sample of ICU survivors and a non-ICU-treated control group. Alternative explanatory factors for differences between the two groups were evaluated, and the structure of quality of life was assessed.

Results: From interviews with 32 ICU survivors in **PAPER I**, questions in 13 areas were identified and included in a provisional questionnaire, subsequently distributed to 518 ICU survivors and 231 controls. The ICU survivor group had a significantly worse state in 77% of issues.

In **PAPER II**, we showed that neither significant differences in comorbidity between the two groups, nor educational level, had a major impact on explaining the differences in the responses to our questionnaire. Associations between ICU survivorship and issues were moderated by comorbidity, or educational level, in only six of 218 (2.8%) and 34 of 218 issues (15.6%), respectively.

In **PAPER III**, we found that only a minority of issues were related to quality of life in both groups, with different patterns in the ICU survivor and non-ICU-treated control groups. Finally, **PAPER IV** found that quality of life was best described in separate, domain-specific, quality of life-subcales rather than as an overarching construct.

Conclusions: This doctoral thesis reports on the initial work on creating a questionnaire specifically for evaluating long-term effects in quality of life and burden of disease after intensive care. After further validation and reduction of the number of questions, the questionnaire may be used in clinical evaluations of ICU survivors, as well as an outcome measure in trials.

Keywords: intensive care; critical illness; intensive care unit; quality of life; long-term follow-up; survivorship; health-related quality of life; burden of disease