Australian Critical Care 32 (2019) 479–485

Contents lists available at ScienceDirect

Australian Critical Care

journal homepage: www.elsevier.com/locate/aucc

Research paper

Quality of life in family caregivers of patients in the intensive care unit: A longitudinal study

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ARTICLE INFORMATION

Article history:
Received 14 June 2018
Received in revised form
27 August 2018
Accepted 29 September 2018

Keywords:
Caregivers
Critical care
Longitudinal studies
Quality of life

ABSTRACT

Background: Family caregivers of patients in the intensive care unit (ICU) experience impairments in the quality of life. Previous studies report that psychological quality of life improves over time, but there has been limited longitudinal research, and measurement points have differed. Factors such as age, gender, and posttraumatic stress symptoms have been found to be associated with the quality of life, but level of hope and its associations with the quality of life have not been investigated.
Objectives: The objective of this study was (1) to evaluate changes in the quality of life in family caregivers during the first year after a patient's admission to the ICU and (2) to identify associations between patients' and family caregivers' background characteristics, posttraumatic stress symptoms, hope, and quality of life.
Methods: A longitudinal study design with five measurement points was used. Family caregivers completed study questionnaires at enrolment into the study and at 1, 3, 6, and 12 months after the patient's admission to the ICU. The quality of life was measured with the 12-Item Short Form Health Survey.
Results: Family caregivers (N = 211) reported improved psychological quality of life during the first year after the patient's admission to the ICU, but it was still lower than the psychological quality of life reported in norm-based data. Being on sick leave, consulting healthcare professionals (e.g., general practitioner), and increased level of posttraumatic stress symptoms were significantly associated with psychological quality of life, whereas hope was not. Reported physical quality of life was comparable to norm-based data.
Conclusion: Family caregivers of patients in the ICU reported impairments in quality of life during the first year after the patient's admission to the ICU. Being on sick leave, consulting healthcare professionals, and reduced posttraumatic stress symptoms may improve mental quality of life.

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https://doi.org/10.1016/j.aucc.2018.09.005
1036-7314/

1. Introduction

Being a family caregiver of a patient in the intensive care unit (ICU) is associated with a broad range of psychological burdens, such as anxiety, depression, and posttraumatic stress symptoms, as well as impairments in quality of life (QOL).[1–4] We identified seven studies (supplementary table) that examined QOL measures for family caregivers of ICU patients,[1,2,5–9] and the majority of these studies reported decreased QOL. However, comparisons among the seven studies are challenging because they used different questionnaires and measurement points. Most studies used 36-Item Short Form Health Survey (SF-36),[1,2,5,6,9] whereas others used 12-Item Short Form Health Survey (SF-12)[7] or Euro-Quality of Life.[8] The timing of the measurements varied from 3–5 days to 55 months after the patient's injury or discharge from the ICU.[6,7] Most studies reported QOL measures less than 6 months after the patient's admission to the ICU, including cross-sectional and longitudinal studies,[5,6,8] and only two studies reported a 12-month follow-up.[1,9]

Research also shows that factors related to the QOL over time are limited. Cameron et al.[1] revealed that younger family caregivers, those with less social support, and those with a weaker sense of control over life had worse psychological QOL. In a cross-sectional study, women and those who had been prescribed psychotropic medication since the ICU admission had lower psychological QOL.[5] In a separate study,[8] the presence of posttraumatic stress symptoms in FCs is found to be associated with lower QOL.

As hope is future oriented,[10] and because the future may be threatened for family caregivers of patients in the ICU, hope is an interesting phenomenon to investigate. Hope has been described as important for coping with traumatic situations,[11] but it is underexplored among family caregivers of patients in the ICU, as are its associations with QOL. Research from related areas indicates that there is a significant correlation between hope and QOL, but this work has not shown that hope predicts changes in QOL.[12]

Family caregivers' QOL and factors related to alterations in QOL are not fully understood. Therefore, it is important to identify the QOL trajectory and factors that can impact one's QOL. Recently,[13] we described family caregivers QOL (reported at enrolment into the study) in the current sample, however, in a cross-sectional study.

2. Objectives

2.1. Primary objective

The primary objective was to evaluate changes in the QOL in family caregivers during the first year after a patient's admission to the ICU

2.2. Secondary objective

The secondary objective was to identify associations between patients' and family caregivers' background characteristics, posttraumatic stress symptoms, hope, and QOL.

3. Materials and methods

3.1. Ethical considerations

The study was approved by the Regional Ethical Review Committee of South-East Norway (reference number: 2012-1162) and supported by the institutional data security officer at the hospital involved in this study. Written informed consent was obtained from patients and family caregivers. If patients were unable to consent (e.g., comatose patients), the patients were contacted and asked for consent in retrospect. In these cases, a research nurse contacted the family caregivers 6 months after inclusion in the study and asked if the patient was able to provide consent. If yes, a consent form was sent to the patient. If the patients were not able to consent, family caregivers were asked to provide consent on behalf of the patient.

3.2. Design and setting

The present study is part of a larger longitudinal study investigating symptoms, stress, and QOL in family caregivers of patients in the ICU. Family caregivers of patients in the ICU were invited to complete study questionnaires at enrolment (patients' admission to the ICU) and thereafter at 1, 3, 6, and 12 months after the patient's admission. Recruitment into the study was from a university hospital in Norway which provides regional and nationwide services for patients. The recruitment period was from June 2013 to March 2015.

3.3. Inclusion criteria for patients and family caregivers

- Patients ≥18 years admitted to the ICU for ≥24 h and able to read, write, and understand Norwegian.
- The patient's closest family caregivers, as defined in the patients' medical record, were considered for recruitment into the study. Family caregivers were eligible for inclusion if they were adults (≥18 years) and able to read, write, and understand Norwegian and to give informed consent. We allowed two family caregivers to be included for each patient.

3.4. Exclusion criteria for patients and family caregivers

- Cognitive deficit before admission to the ICU, suspicions of suicide attempt, family violence or drug abuse.
- Not able to obtain informed consent from the family caregivers during the first 2 weeks of the patient's stay in the ICU.

3.5. Data collection

Each patient's medical record was assessed for demographic (i.e., gender and age) and clinical characteristics (i.e., diagnosis, Simplified Acute Physiology Score [SAPS II],[14] Nursing Activities Score [NAS],[15] mortality, time on ventilation, and length of stay in the ICU and in the hospital). Family caregivers provided information using self-report questionnaires at all five measurement points. The study procedures are described in more detail elsewhere.[13]

At enrolment into the study, family caregivers provided data on gender, age, daily care of children aged <18 years, previous experience with an ICU (e.g., visited an ICU before), other life events (i.e., death of a family member or close friend or separation), level of education, cohabitation status, employment status, and relationship to the patient. At 1 month, family caregivers provided information on perceived support (e.g., from family, friends, colleagues, and healthcare professionals) and whether they had sought help from the healthcare system.

3.5.1. Assessment tools

3.5.1.1. Self-Administered Comorbidity Questionnaire. Family caregivers' comorbidity status was measured with the Self-Administered Comorbidity Questionnaire (SCQ).[16] The SCQ evaluates 13 medical and three optional comorbidities. For the present study, four comorbidities (i.e., bowel disease, headache, connective tissue and muscle disease, and skin disorders) were added to the questionnaire, leaving a total of 17 comorbidities and three optional. Family caregivers were asked to indicate whether they had each comorbidity (yes/no), if they received treatment for it (yes/no), and if it limited their activities (yes/no). The SCQ score can range from 0 to 60 when the three optional items are used. A higher score indicates more severe comorbidity profile. Only the number of comorbidities was used in the present study. The questionnaire is valid and reliable[16,17] and has been used in Norwegian samples.[18,19]

3.5.2. The 12-Item Short Form Health Survey

The SF-12, version 1,[20] was used to measure the QOL. The SF-12 is a valid and reliable generic QOL measure that consists of 12 questions[20] and has been used in general populations.[21] The SF-12 measures physical (physical component summary, PCS), mental (mental component summary, MCS), and overall health.[22] In the present study, the SF-12 PCS and MCS are scored using 1998 norm-based data from the US general population, in which the mean score is 50 (standard deviation [SD] = 10). PCS and MCS scores can vary from zero (indicates lowest level of health) to 100 (indicates highest level of health). Higher PCS and MCS scores indicate better QOL.[22]

3.5.3. Impact of Event Scale—Revised

The Impact of Event Scale—Revised (IES-R) was used to measure posttraumatic stress symptoms.[23] This questionnaire is a 22-item scale measuring the presence and degree of posttraumatic stress symptoms in the last week, and each item is reported on a 5-point Likert scale that ranges from 0 (not at all) to 4 (extremely). Scale scores can be grouped into subscales that reflect intrusive, avoidant, and hyperarousal domains. Total IES-R scores can range from 0 to 88, with higher scores indicating more symptoms. No specific cut-off score was proposed by Weiss and colleague when developing the IES-R[23] The IES-R has adequate psychometric properties.[23–25] We used the total IES-R score in the present study. All questionnaires with more than two items missing were excluded from analysis.

3.5.4. Herth Hope Index

Hope was measured using the Herth Hope Index,[26] which consists of 12 items. The response scale ranges from 1 (strongly disagree) to 4 (strongly agree), and a total score can be in the range of 12–48. Higher levels of hope are indicated by a higher Herth Hope Index score. No cut-off score has been proposed for the Herth Hope Index.[26] In the present study, the Herth Hope Index total score was dichotomised into high and low levels of hope. The median Herth Hope Index total score (as determined by the family caregivers' responses at enrolment into the study) was used as a cut-off score for high and low levels of hope. The Herth Hope Index questionnaires with more than two missing items were excluded from the analysis. The Herth Hope Index has shown acceptable psychometric properties in clinical and general population samples of Norwegian respondents.[27,28] Furthermore, the Herth Hope Index has previously been used in family caregivers of patients with advanced cancer,[29] stroke survivors[12] and patients with Alzheimer's disease.[30]

3.5.5. Multiple symptoms

We assessed multiple symptoms with 32 physical and psychological symptoms from the Memorial Symptom Assessment Scale.[31] Family caregivers were asked to indicate whether they had experienced the symptoms in the previous week (yes/no). If yes, they were asked to rate each symptom severity and distress by using numeric rating scales from 0 to 10. Zero indicated “not at all”, and 10, “very much”. Only the number of symptoms was used in the present study. The symptom list has been used previously in a Norwegian family caregiver sample.[13]

3.6. Statistical analyses

Data on patients' demographic and clinical characteristics were measured at admission to the ICU. Family caregivers' background characteristics were measured at the time of enrolment into the study and 1 month after enrolment. Data are presented as medians and ranges or means and SDs for continuous variables. Categorical variables are presented as counts and percentages.

PCS and MCS scores were used as dependent variables. The independent variables were each patient's demographic and clinical characteristics. Family caregivers' background characteristics, level of hope, number of symptoms, and posttraumatic stress symptoms were also treated as independent variables.

To analyse the longitudinal data, a linear mixed model for repeated measures was fitted. We examined both unadjusted and adjusted models, running the unadjusted models first. Based on available empirical work, we used statistical assessment (p-value <0.2 in univariate analysis) and our clinical judgement to decide which variables would be included in the adjusted analysis. We used adjusted models to examine possible associations between the dependent and independent variables. Family caregivers' age and gender were always included in the models as these variables are considered to be clinically important.

To account for possible dependencies across several measurement points for the same individuals, the model was fitted with an unstructured covariance matrix, meaning that we did not impose any constraints on the data. The model was fitted with a random slope, and the selected covariates were entered as fixed effects. All five of the measurement time points for the dependent variables (PCS and MCS scores) were used. By using linear mixed model, we included family caregivers' reported background characteristics at enrolment and 1 month into the model. As these measurement points were relatively close in time, we allowed covariates from both measurement points to be included into the model. P-values of <0.05 were considered statistically significant. All analyses were performed using SPSS (version 23; IBM Corp., Armonk, NY).

4. Results

Of the 323 family caregivers who were asked to participate in the study, 281 (87%) consented, but of these, five did not meet the inclusion criteria (length of stay <24 h or <18 years), and 65 did not return the first study questionnaire, leaving 211 (65%) FCs in the study. One hundred twenty-seven (60%) family cargivers answered the 12-month questionnaire. A detailed description of recruitment and a consolidated standards of reporting trials (CONSORT) diagram were published previously.[13]

4.1. Family caregivers' and patients' characteristics

Family caregivers' background characteristics are listed in Table 1. The median age was 50 years (range, 19–80), and 144 (68%) were women. The median number of comorbidities (SCQ) was 1 (range, 0–8).

A selection of patients' demographic and clinical characteristics is listed in Table 1. In brief, the median age was 56 years (18–88), and 38 (38%) of the patients were women. A full overview is presented in detail elsewhere.[13]

4.2. Evaluation of family caregivers' changes in QOL during the first year after the patient's admission to the ICU

Unadjusted QOL measures during the first year after the patient's admission to the ICU are depicted in Fig. 1. In brief, the mean PCS scores at enrolment and 12 months were 51.0 (SD = 9) and 50.7

Table 1
Characteristics of family caregivers (N = 211) and patients (N = 99).

Family caregiver characteristics reported at enrolment	Median (range)
Age (years)	50 (19–80)
Number of comorbidities	1 (0–8)
Posttraumatic stress symptoms[a]	34 (3–71)
Multiple symptoms[b]	9 (0–24)
	n (%)
Female	144 (68.2)
Daily care for children <18 years	72 (34.1)
Experience with ICU	111 (53.1)
Other life events (i.e., death of a family member/close friend or separation)	70 (33.2)
Cohabitation	
Living with someone	180 (86.1)
Living alone	29 (13.9)
Education	
Primary/secondary school	113 (56.3)
College/university	98 (46.4)
Sick leave	60 (28.4)
Relationship to the patient	
Parent	66 (32.8)
Spouse/partner/child/other	136 (67.2)
High levels of hope[c]	101 (48.6)
Family caregiver characteristics reported at one month	**n (%)**
Consulting health care professionals (e.g. general practitioner)	66 (42.9)
Perceived support from other than the closest family	
Not at all or slight/moderate degree	67 (47.5)
Rather high or very high degree	74 (52.5)
Colleagues	
Not at all/ to a slight degree/ to a moderate degree	84 (59.2)
To a rather high degree/ to a very high degree	58 (40.8)
Characteristics of patients	**Median (range)**
Age (years)	56 (18–88)
Length of stay in the hospital (days)	22 (4–126)
	n (%)
Female	38 (38)

[a] Post-traumatic stress symptoms, as measured by the Impact of Event Scale–Revised (IES-R).
[b] Multiple symptoms, as measured by 32 symptoms listed in Memorial Symptom Assessment Scale (MSAS).
[c] Level of hope, as measured by Herth Hope Index (HHI) >37.

(SD = 10.1), respectively. The mean MCS scores at enrolment and 12 months were 39.8 (SD = 12.4) and 45.2 (SD = 11.8), respectively. The unadjusted PCS score during the first year after the patient's admission to the ICU indicated no statistically significant change. The unadjusted MCS score showed a significant change over time, except between enrolment and 3 months ($p = 0.06$). Scoring of SF-12 in the present study was performed by using the US general population scores. These scores are comparable to the Norwegian norm-based scores, which have a mean MCS of 50.6 (SD = 9.9) and a mean PCS of 50.3 (SD = 8.8).[21]

4.3. *Associations between patient's and family caregiver characteristics and QOL*

In the adjusted analysis, the patients' demographic characteristics were not significantly associated with PCS or MCS scores. Regarding clinical characteristics, an increase of a comorbidity was associated with a 3.2-point decrease in the PCS score ($p < 0.001$) (Table 2). Furthermore, family caregivers who were on sick leave had a mean MCS score that was 3.7 points higher than those who were not on sick leave ($p = 0.048$). Family caregivers who consulted healthcare professionals (such as general practitioner, psychiatrist, or psychologist) had a mean MCS score that was 5.2 points lower than those who did not. An increase of one point in the total IES-R score was associated with a 0.4-point decrease in the MCS score ($p < 0.001$). Time was significantly associated with the MCS score at all measurement points, except at 3 months ($p = 0.44$) (Table 3).

Finally, the univariate analysis of hope was significantly associated with the MCS score ($p < 0.001$), and there was a significant correlation between the number of symptoms and MCS score (*r*, −0.43, $p < 0.001$). However; neither of these relationships was significant in the adjusted analysis.

5. Discussion

The main finding of this study was that the MCS scores for family caregivers of patients in the ICU increased throughout the first year after the patient's admission to the ICU, indicating an improvement in mental QOL. However, at 12 months after the patient's admission to the ICU, the family caregivers' MCS scores were still lower than those found in norm-based population data. Being on sick leave was significantly associated with better MCS score; furthermore, consulting healthcare professionals and an increased level of posttraumatic stress symptoms were significantly associated with lower MCS score.

The reduction in MCS scores found in the present study highlights the mental burden family caregivers experience and is consistent with previous research.[7,9] In general, descriptions of MCS scores over 12 months are rare. The findings from the present study are consistent with the results of Cameron et al.[1] who found that MCS scores improve during the first year after the patient's ICU discharge. However, the inclusion criteria for the study by Cameron et al. focused on patients in the ICU who were mechanically ventilated for ≥7 days, which was not a criterion in the present study. Despite these different inclusion criteria, the results were comparable, which may indicate that independent of mechanical ventilation, family caregivers of patients in the ICU may experience a reduction in mental QOL. However, this area needs further research.

In contrast, Petrinec and Martin found a decrease in MCS scores during the first 2 months after the patient's discharge from the ICU or death.[6] In the present study, we observed a decrease between enrolment and 1 month after enrolment, but thereafter, MCS scores increased. The family caregivers' psycholgical health improved over time, although it did not reach the level found in norm-based population data. This may mean that in addition to seeking healthcare help on their own initiative such as from their general practitioner, FCs need follow-up care organised by healthcare professionals.

We examined several factors for association with the QOL and found that family caregivers on sick leave had higher MCS scores than those who were not on sick leave. The fact that family caregivers need sick leave because of their duties is consistent with previous research.[32,33] The results from the present study suggest that family caregivers may need some time off from work to support the patient in the ICU in both the acute and recovery phases of the patient's illness. Having a period of sick leave may help prevent further deterioration of a low psychological QOL. Having reduced psychological QOL for a long period of time could affect the family caregivers' ability to take care of the patient. Sick leave may have a protective effect on family caregivers' psychological QOL. However, national differences regarding guidelines for sick leave need to be taken into consideration as the Norwegian healthcare system may differ from that in other countries.

We also found that consulting healthcare professionals was associated with lower MCS scores, indicating that family caregivers who sought professional help had lower psycholgoical

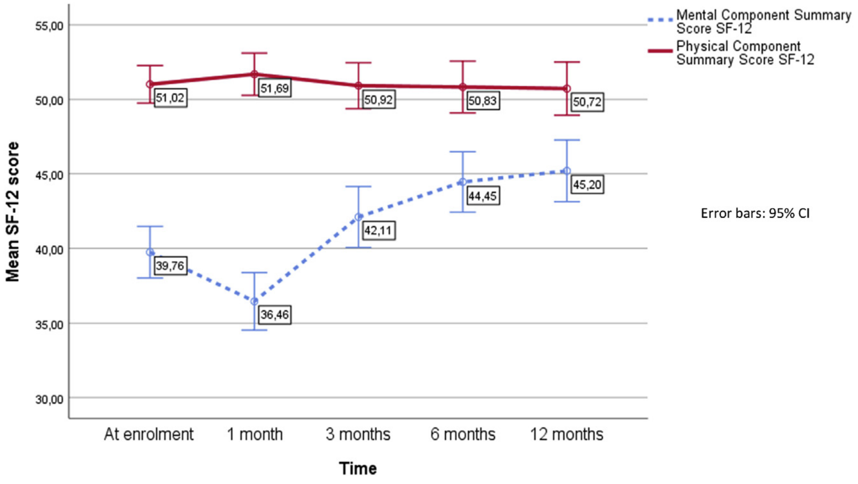

Fig. 1. Family caregivers' unadjusted physical component summary (PCS) score and mental component summary (MCS) score trajectories during the first year after the patient's admission to the ICU. Boxes show mean values for PCS and MCS at each measurement point. Norm-based data from the US general population with a mean score of 50 (SD = 10) are used when scoring PCS and MCS. CI, confidence interval; ICU, intensive care unit; SD, standard deviation; SF-12, 12-Item Short Form Health Survey.

QOL. Sixty-six (43%) of the family caregivers reported having consulted a general practitioner, psychiatrist, or psychologist (Table 1). This is higher than the results reported by Lemiale et al., who found that 8% of family members received support from psychologists 90 days after the patient's discharge or death.[5] The study by Lemiale et al. was based on data from 2003, whereas the data from the present study were from 2013. Since 2003, there has been an increased focus on the family caregivers of patients in the ICU and the psychological burden they may experience. This increased focus may have made it more likely that family caregivers in the present study would get help from the healthcare system and that healthcare professionals would more frequently urge family caregivers to seek help if needed. The fact that nearly half of the family caregivers in the present study needed help from the healthcare system may indicate that they need a follow-up throughout the first year after the patient's admission to the ICU.

Posttraumatic stress symptoms were significantly associated with lower MCS scores in the present study, indicating that higher levels of stress were associated with lower psychological QOL. An association between posttraumatic stress symptoms and QOL has been found in previous studies, indicating that family caregivers with more posttraumatic stress symptoms reported lower QOL.[8,34] Even though the result from the present study was statistically significant, the effect size was relatively small, suggesting that the clinical impact may be limited (Table 3).

Table 2
Family caregiver covariates associated with the Short Form-12 physical component summary scores from enrolment to 12 months after enrolment.

Covariate	Fixed effects		
	Estimate of beta (B)	95% CI[a]	P-value
Time			
1 month	0.78	−0.41 to −1.98	0.197
3 months	0.56	−0.82 to −1.93	0.422
6 months	0.66	−0.81 to −2.13	0.377
12 months	−0.7	−1.65 to 1.51	0.931
At enrolment	Reference value		
Covariates reported at enrolment			
Age	−0.05	−0.15 to −0.06	0.359
Gender			
Female	0.98	−1.39 to 3.35	0.417
Male	Reference value		
Experienced other life events[b]			
Yes	0.67	−3.02 to 1.68	0.575
No	Reference value		
Comorbidities[c]	−3.20	−4.06 to −2.36	<0.001
Relationship to the patient			
Spouse, child, or other	0.09	−2.93 to 2.74	0.948
Parent	Reference value		
Posttraumatic stress symptoms[d]	−0.32	− 0.12 to 0.06	0.490
Covariates reported at 1 month			
Consulting healthcare professionals[e]			
Yes	−0.87	−3.10 to 1.37	0.445
No	Reference value		

[a] Confidence interval.
[b] Experienced other life events, i.e., death, separation, or divorce.
[c] Comorbidities, as measured by the Self-Administered Comorbidity Questionnaire (SCQ).
[d] Posttraumatic stress symptoms, as measured by the Impact of Event Scale—Revised (IES-R).
[e] Consulting healthcare professionals, i.e., general practitioner, psychiatrist, or psychologist.

Table 3
Family caregiver and patient covariates associated with the Short Form-12 mental component summary scores from enrolment to 12 months after enrolment.

Covariate	Fixed effects		
	Estimate of beta (B)	95% CI[a]	P-value
Time			
1 month	−4.82	−7.98 to −1.67	0.003
3 months	1.17	−1.84 to 4.18	0.441
6 months	3.78	0.66–6.90	0.018
12 months	4.45	1.24–7.70	0.007
At enrolment	Reference value		
Family caregiver covariates reported at enrolment			
Age	−0.01	−0.14 to 0.11	0.840
Gender			
Female	−2.50	−5.91 to 0.92	0.150
Male	Reference value		
Experienced other life events[b]			
Yes	2.56	−0.66 to 5.78	0.118
No	Reference value		
Employment status			
Sick leave	3.67	0.03–7.31	0.048
Not on sick leave	Reference value		
Cohabitation			
Living with someone	4.24	−0.80 to 9.27	0.098
Living alone	Reference value		
Posttraumatic stress symptoms[c]	−0.38	−0.51 to −0.26	<0.001
Family caregiver covariates reported at 1 month			
Consulting healthcare professionals[d]			
Yes	−5.18	−8.52 to −1.84	0.003
No	Reference value		
Perceived support from other relatives			
Not at all or slight/moderate degree	−2.73	−5.76 to 0.29	0.076
Rather high or very high degree	Reference value		
Patient covariates reported at enrolment			
Gender			
Female	2.99	−0.19 to 6.17	0.065
Male	Reference value		
Length of stay in the hospital	0.06	−0.01 to 0.13	0.135

[a] Confidence interval.
[b] Experienced other life events, i.e., death, separation, or divorce.
[c] Posttraumatic stress symptoms, as measured by the Impact of Event Scale—Revised (IES-R).
[d] Consulting healthcare professionals, i.e., general practitioner, psychiatrist, or psychologist.

We also controlled for the family caregivers' level of hope and the number of symptoms in this study. Univariate analysis revealed a significant difference in MCS scores between family caregivers with high versus those with low levels of hope, and there was a significant correlation between the number of symptoms and MCS scores. However, neither the level of hope nor the number of symptoms had significant associations with the QOL in the multivariate model. One reason for this could be that the level of hope and/or number of symptoms acted as confounders for the relationship between posttraumatic stress symptoms and QOL. More research is needed to further explore these associations in family caregivers of patients in the ICU.

The effect of time on the MCS score was statistically significant with changes in MCS scores between enrolment and 1, 6, and 12 months after enrolment (Table 3). The family caregivers' MCS scores decreased in the first month after the patient's admission to the ICU, but thereafter their MCS scores increased. The observed trajectories in the present study differ from those described by Cameron et al.,[1] who found a significant difference in MCS scores between ICU discharge and 3 months later. No other statistically significant effect of time up to 12 months was reported. The effect of time on the QOL is not yet fully understood, and more research is needed to define the best time to implement relevant interventions intended to improve the QOL in family caregivers of patients in the ICU.

The family caregivers' PCS scores indicate a stable trajectory throughout the first year after the patient's admission to the ICU, which is consistent with previous research.[1,6] Not surprisingly, there was a significant association between the number of comorbidities and PCS scores, indicating that family caregivers with more comorbidities reported lower physical QOL. Many family caregivers reported having comorbidities as measured by the SCQ, which primarily assesses physical comorbidities. Despite this, the PCS scores in this study were in line with those for the general population. The MCS scores were below average, and therefore, it may be that healthcare professionals in ICUs should focus on the prevention and treatment of mental burdens rather than physical burdens.

The present study is not without limitations. First, the association between background characteristics and QOL may be associated with other variables that we did not account for in this study, such as previous mental health status. Second, the family caregivers who consented to participate may be less stressed and overwhelmed by the ICU experience than those who declined participation, which raises the possibility of bias in our results. Third, only 45% of the original sample (n = 281) returned the 12-month questionnaire. This may be related to the overwhelming situation family caregivers experience in the ICU. Finally, the present study is part of a larger study that contained several questionnaires, which may have created a heavy response burden. Fewer questionnaires may have increased the response rate.

6. Conclusion

The MCS scores of family caregivers of patients in the ICU improved during the first year after the patient's admission to the

ICU. However, their MCS scores were still lower than those found in the general population. Being on sick leave was associated with higher MCS scores, whereas consulting healthcare professionals and higher levels of posttraumatic stress symptoms were associated with lower MCS scores. Family caregivers' PCS scores were stable throughout the first year after the patient's admission to the ICU, and they were comparable with those found in the general population. To improve family caregivers' QOL, it is important to consider appropriate and timely interventions as we know that family caregivers report reduced QOL for as long as 1 year after a patient's ICU admission.

CRediT authorship contribution statement

Hanne Birgit Alfheim: Conceptualization, Investigation, Methodology, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Milada Cvancarova Småstuen:** Formal analysis, Data curation, Writing – original draft, Writing – review & editing. **Kristin Hofsø:** Supervision, Writing – review & editing. **Kirsti Tøien:** Writing - original draft. **Leiv Arne Rosseland:** Supervision, Writing – review & editing. **Tone Rustøen:** Conceptualization, Supervision, Project administration, Data curation, Formal analysis, Writing – review & editing.

Acknowledgement

The authors would like to thank the family caregivers and patients who participated in this study and the nurses who facilitated the recruitment of participants. We extend special thanks to Astrid Arnesen Hug (a nurse anaesthetist) for her enthusiasm and engagement in the study.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.aucc.2018.09.005.

Funding

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