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Research Article

Post-traumatic stress symptoms in family caregivers of intensive care unit patients: A longitudinal study

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ABSTRACT

Objectives: To describe the prevalence and trajectory of family caregivers' post-traumatic stress symptoms during the first year after a patient's admission to the intensive care unit and identify associations between family caregivers' background characteristics, hope and post-traumatic stress symptoms.

Research methodology/designs: Family caregivers of intensive care unit patients ($n = 211$) completed questionnaires at patient admission to the intensive care unit and thereafter at 1, 3, 6, and 12 months. Mixed-model analyses were performed.

Setting: Four intensive care units in a university hospital in Norway.

Main outcome measures: Impact of Event Scale—Revised and Herth Hope Index.

Results: On admission, 54% of family caregivers reported high post-traumatic stress symptom levels, which decreased during the first six months after patient discharge. Lower levels of hope, being younger, having more comorbidities and being on sick leave were associated with higher post-traumatic stress symptom levels. Being the parent of the patient was associated with decreased post-traumatic stress symptom levels.

Conclusions: Family caregivers of intensive care unit patients report high levels of post-traumatic stress symptoms. Higher levels of hope were associated with fewer post-traumatic stress symptoms.

Implications for clinical practice

- More than half of family caregivers report high levels of post-traumatic stress symptoms, indicating significant risk for developing post-traumatic stress disorder. Clinicians should inform family caregivers about potential post-traumatic stress symptoms.
- Early identification of post-traumatic stress symptoms is important and screening of family caregivers may identify vulnerable groups.
- Family caregiver's post-traumatic stress symptom trajectory varied throughout the first year after the patient's admission to the intensive care unit. More longitudinal studies are needed to investigate post-traumatic stress symptom trajectory with special attention to family caregivers with high levels of post-traumatic stress symptoms.
- Hope is an important factor associated with post-traumatic stress symptoms. Clinicians should support family caregivers' hope by establishing a relationship based on trust and encouragement. This may reduce the level of post-traumatic stress symptoms.

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Introduction

Family caregivers (FCs) of intensive care unit (ICU) patients may experience mental health challenges (van Beusekom et al., 2016) related to their role as FCs. Post-traumatic stress (PTS) symptoms are amongst the most thoroughly investigated outcomes amongst FCs (Davidson et al., 2012; Kentish-Barnes et al., 2009; Petrinec et al., 2015; van Beusekom et al., 2016). Longitudinal studies have also investigated the PTS symptom trajectory and how the symptoms fluctuate over time (Fumis et al., 2015; Kentish-Barnes et al., 2015; Komachi and Kamibeppu, 2016; McAdam et al., 2012; Paparrigopoulos et al., 2006; Pillai et al., 2010, 2006; Trevick and Lord, 2017; Warren et al., 2016) with varying results.

The majority of previous studies reported that PTS symptoms in FCs decrease over time (Kentish-Barnes et al., 2015; Komachi and Kamibeppu, 2016; McAdam et al., 2012; Pillai et al., 2006), while one study identified an increase in PTS symptoms from one to six months (Trevick and Lord, 2017). Due to the methodological differences between the previous studies it is difficult to make comparisons between them (Petrinec and Daly, 2016). First, sample size has varied considerably across studies (Kentish-Barnes et al., 2015; Komachi and Kamibeppu, 2016), and one study had very small sample size (n = 23). Second, different study questionnaires (e.g. Impact of Event Scale [IES], Impact of Event Scale–Revised [IES–R] and Primary Care post-traumatic stress disorder [PTSD] screen) have been used to measure PTS symptoms (Kentish-Barnes et al., 2015; Paparrigopoulos et al., 2006; Warren et al., 2016). Third, differing cutoff scores (Kentish-Barnes et al., 2015; McAdam et al., 2010; Pillai et al., 2010; Trevick and Lord, 2017) have been used to measure PTS symptom levels. Finally, the majority of studies report a follow-up time of ≤3 months (Fumis et al., 2015; Komachi and Kamibeppu, 2016; McAdam et al., 2012; Pillai et al., 2010; Warren et al., 2016). Due to the relatively small number of longitudinal research studies performed after an ICU stay, and the methodological challenges evident in the literature, further research is needed to more precisely investigate how PTS symptoms in FCs fluctuate during the first year after patient admission to the ICU.

Several FC characteristics have been investigated for associations with increased PTS symptom levels, including female gender (Azoulay et al., 2005; Gries et al., 2010; Kentish-Barnes et al., 2015), living alone (Kentish-Barnes et al., 2015), whether they visit the patients daily (Trevick and Lord, 2017), anxiety symptoms (Fumis et al., 2015; Paparrigopoulos et al., 2006; Sundararajan et al., 2014), depression (Fumis et al., 2015) and medical care in the year prior to the patients admission to the ICU (e.g., mental-illness related) (Gries et al., 2010). However, the results of these investigations tend to vary between different covariates. One unexplored phenomenon amongst the FC of ICU patient is hope and its association with PTS symptoms. Hope is described as important in coping with traumatic situations (Folkman, 2010) and FC must cope with serious illness, as well as an often-long rehabilitation phase. Research from the oncology setting has indicated that FCs with lower levels of hope also have significantly higher levels of psychiatric morbidity (e.g., PTSD, anxiety, and/or depression) (Rumpold et al., 2016).

The aims of this study were: 1) to describe the prevalence and trajectory of PTS symptoms in FCs during the first year after a patient's admission to the ICU and 2) to identify the associations between FCs' background characteristics, hope, and PTS symptoms.

Methods

Design and setting

This longitudinal study is part of a larger study of symptoms and quality of life in FCs of ICU patients. For this longitudinal study, FCs completed study questionnaires at enrolment (at the time of the patients admission to the ICU) and thereafter at 1, 3, 6, and 12 months after the patient's admission to the ICU. Adult patients and FCs were recruited from general and neuro ICUs in one university hospital in Norway. The recruitment period was from June 2013 to March 2015.

Ethical approval

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. All study participants gave informed consent.

Participants

The study procedures have been described in detail elsewhere (Alfheim et al., 2018). In brief, adult patient's (ICU length of stay ≥24 hours) closest FCs, as defined in their medical record, were considered for inclusion in the study during the first two weeks of the patient's stay in the ICU. FCs were eligible for inclusion if they were adults (≥18 years), able to read, write and understand Norwegian, and able to give informed consent. For each patient, we included up to two FCs. If the FCs agreed to participate in the study during the first two weeks of the patient's stay, they gave informed consent and answered the first study questionnaires.

Data collection

FCs provided information using self-reporting questionnaires at each of five measurement points. The questionnaires were pilot tested before initiating the study for linguistic purposes, and was evaluated as understandable and appropriate for use by the FCs.

Background characteristics of family caregivers

FCs 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 (e.g., death of a family member or close friend, separation, marriage, had children, new job), level of education, cohabitation status, employment status, and their relationship with the patient.

Self-administered comorbidity questionnaire

FCs' comorbidity status was measured with the Self-Administered Comorbidity Questionnaire (SCQ), which evaluates 13 medical comorbidities (Sangha et al., 2003). In the present study, four additional comorbidities (i.e., bowel disease, headache, connective tissue and muscle disease and skin disorders) were added to the list of comorbidities. FCs were asked to indicate whether they had each comorbidity (yes/no). A higher summed score indicates a more severe comorbidity profile. The SCQ is valid and reliable (Baron et al., 2009; Sangha et al., 2003) and has been used with Norwegian samples (Astrup et al., 2017; Hofso et al., 2012). Only data about number of comorbidities were used in the current study.

Impact of Event Scale-Revised

PTS symptoms were measured using the Impact of Event Scale-Revised (IES-R) (Weiss and Marmar, 1997). IES-R is a 22-item scale measuring the presence and severity of PTS symptoms during the last week, where each item is rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). Scaled scores can be grouped into subscales reflecting domains for intrusion, avoidance and hyperarousal. The total IES-R score range is 0–88; a higher score indicates higher symptom level. IES-R has adequate psychometric properties (Weiss, 2004) including for the Norwegian version (Eid et al., 2009). Only total IES-R score data were used for the current study. When calculating total IES-R scores, we allowed a maximum of two missing items. Surveys with more missing items were excluded from analysis.

No specific cutoff score was proposed by Weiss and colleagues when developing the instrument (Weiss, 2004). A cutoff score of ≥ 33 has been proposed to provide the best diagnostic accuracy of PTSD (Creamer et al., 2003) and has been used in Norwegian samples (Hussain et al., 2013). In the present study, we used a cutoff score ≥ 33 as an indication of high levels of PTS symptoms. Moreover, we also investigated our data using a cutoff score ≥ 26 to facilitate comparison with other studies.

Herth Hope Index

Hope was measured using the Herth Hope Index (HHI) (Herth, 1992). The HHI consists of 12 items measuring levels of hope related to cognitive and affective factors, and interconnectedness with self and others. Item scores range from 1 (strongly disagree) to 4 (strongly agree) and the total score ranges from 12 to 48. A high score indicates higher level of hope and no cutoff score have been proposed for the HHI (Herth, 1992). The HHI has shown satisfactory validity and reliability in different Norwegian samples (Rustoen et al., 2005; Wahl et al., 2004), and in the general Norwegian population (Rustoen et al., 2003). In the present study, the HHI total score was dichotomized into high and low levels of hope; i.e., the sample's median HHI total score was used as the cutoff score. When calculating the HHI total score, we allowed for a maximum of two missing single items. Questionnaires with more missing items were excluded from the analyses.

Statistical analysis

The FCs background characteristics, number of comorbidities and level of hope (continuous variables) which were measured at the time of enrolment into the study, are presented as median and ranges. Categorical variables are described as counts and percentages. A *t*-test was performed on enrolment data to check if there was any difference between IES-R scores amongst FCs who responded and those who did not respond at 12 months.

To analyse the longitudinal data, a linear mixed model for repeated measures was fitted. Variables to be included into the model were selected based on available empirical work, statistical assessment (p-value <0.2 in univariate analysis) and clinical judgment. The FCs' age, gender and relationship with the patient were always included into the model because they are considered clinically important variables.

To account for possible dependencies amongst several measurement points on the same individuals, the model was fitted with an unstructured covariance matrix, which means that we did not impose any constraints on the data. The model was fitted with a random slope and selected covariates were entered as fixed effects. All five measurement time points of the dependent variable (PTS symptoms as measured by IES-R) were used. Background characteristics, number of comorbidities and level of hope provided by the FCs at enrolment into the study were adjusted for in the model.

The linear mixed model uses all data in the dataset to estimate the covariance structure and model the dependencies; therefore, no imputation of missing data was necessary or performed. P-values of <0.05 were considered statistically significant. All analyses were performed using SPSS software (version 23; IBM Corp., Armonk, NY).

Results

A total of 323 FCs were asked to participate in the study, of these 281 (87%) consented and 211 (65%) returned the study questionnaires. Of the 281 FCs, 65 did not return the first study questionnaire and five did not fulfil the inclusion criteria (<18 years or patients length of stay in the ICU <24 h), leaving 211 FCs in the study. The 12-month study questionnaire was answered by 127 (60%) FCs. A consort diagram and a detailed description of recruitment of FCs are published previously (Alfheim et al., 2018).

Study participants

Table 1 lists the FCs' background characteristics. The median age was 50 years (range 19–80) and 144 (68%) were women. The median number of comorbidities was 1 (range 0–8) with e.g. back/neck pain and depression being reported by 57 (27%) and 22 (10%), respectively. High level of hope (HHI score >37) was reported by 101 (49%) of the FCs, while 107 (51%) reported a low level of hope (HHI score ≤ 37). Three questionnaires were excluded from the analysis due to missing items.

Post-traumatic stress symptoms (IES-R)

Table 2 shows the FCs' reported IES-R score, including results based on both cutoff scores ≥ 33 and of ≥ 26. Median IES-R score at enrolment and 12 months was 34 (range 3–71) and 19 (range 0–55), respectively. IES-R score decreased during the first six months. Thereafter a slight, though not statistically significant, (p = 0.506) increase was observed from six to 12 months (Table 2). One hundred eleven (54%) and 30 (24%) of the FCs reported an IES-R score of ≥ 33 at enrolment and 12 months, respectively. There were no statistically significant differences in IES-R scores at the initial measurement between FCs who responded and those who did not respond (n = 127) at 12 month (p = 0.689).

Associations between FCs' background characteristics, hope and PTS symptoms

In the multivariate model analysis, age, employment status, relationship with the patient, level of hope, comorbidity and time

Table 1
Background characteristics of family caregivers at enrolment (N = 211).

Characteristics	Median (range)
Age	50 (19–80)
Number of comorbidities	1 (0–8)
	n (%)
Gender	
Male	67 (32)
Female	144 (68)
Daily care for children <18 years	72 (34)
Experience with intensive care unit	111 (53)
Other life events (e.g. marriage, separation)	126 (60)
Cohabitation	
Living with someone	180 (86)
Living alone	29 (14)
Education	
Primary/secondary school	113 (56)
College/university	98 (46)
Sick leave	60 (28)
Relationship to the patient	
Parent	66 (33)
Spouse/partner/child/other	136 (67)

Table 2
Prevalence of post-traumatic stress symptoms in family caregivers during the first year after a patient's admission to the intensive care unit.

Measurement point	Total IES-R score Median (range)	Prevalence of PTS symptoms[1] n (%)	Prevalence of PTS symptoms[2] n (%)
At enrolment	34 (range 3–71)	111 (54.1%)	146 (71.2%)
1 month	27 (range 1–68)	57 (36.3%)	85 (54.1%)
3 months	22 (range 0–60)	35 (24.5%)	57 (39.9%)
6 months	18 (range 1–62)	29 (21.5%)	45 (33.3%)
12 months	19 (range 0–55)	30 (23.6%)	47 (37%)

[1] As measured by a total IES-R score ≥33.
[2] As measured by a total IES-R score ≥26.

Table 3
Linear mixed model of fixed effects for post-traumatic stress symptoms.

Variable	Fixed effects		
	Estimate	P-value	95% confidence interval
Age	−0.17	0.019	−0. 31 to −0.03
Gender			
Female	2.27	0.155	−0.87 to 5.41
Male	Reference value		
Education			
Primary/secondary	1.40	0.334	−1.45 to 4.25
College/university	Reference value		
Employment status			
Sick leave	4.25	0.010	1.03 to 7.47
Not on sick leave	Reference value		
Relationship to the patient			
Spouse, child, other	4.51	0.024	0.59 to 8.44
Parent	Reference value		
Hope (HHI)			
Low level of hope (score 0–37)	5.68	<0.001	2.77 to 8.59
High level of hope (score 38–48)	Reference value		
Comorbidities (SCQ)	2.27	<0.001	1.61 to 3.71
Time			
1 month	−6.18	<0.001	−8.02 to −4.33
3 months	−10.65	<0.001	−12.62 to −8.67
6 months	−13.50	<0.001	−15.44 to −11.54
12 months	−13.72	<0.001	−16.09 to −11.35
At enrolment	Reference value		

were significantly associated with the total IES-R score. An increase of 10 years in the FCs' age was associated with a decrease of 1.7-points in the total IES-R score. Moreover, if the FC was on sick leave, this was associated with a 4.25-points increase in total IES-R score. Being the parent of the patient was associated with a 4.5-point lower total IES-R score compared with all other relationships with the patients (e.g. spouse or friend). An increase of one comorbidity was associated with a 2.3-point increase in the total IES-R total score. FCs with high levels of hope (above the median HHI score) had an average of 5.7-points lower on their IES-R score compared to FCs who reported lower levels of hope. Finally, time was significantly associated with IES-R score, indicating that IES-R score decreased over time (Table 3).

There was not a significant interaction between HHI score and time, so this was not included in the final model.

Discussion

The main study finding was that more than half of the FCs reported high levels of PTS symptoms at enrolment (i.e. when the patient was admitted to the ICU), and that PTS symptom levels decreased the first six months after the patient's admission to the ICU. FCs' age, employment status, relationship with the patient and level of hope were significantly associated with number of PTS symptoms.

This is the first study to show a relationship between PTS symptoms and hope. Increased levels of hope were associated with 5.7-point reduction IES-R score, which shows that higher hope was associated with fewer PTS symptoms. Research focusing on the association between hope and PTS symptoms in FCs of ICU patients is limited; however, hope has been described as a coping strategy in this population (Verhaeghe et al., 2005, 2007a). Hope is not only related to patient survival, but also their coping with the situation. Hope has been reported to be the most prominent theme in helping FCs to believe in a positive outcome despite uncertainties with the situation (Verhaeghe et al., 2007b). The importance of hope needs to be further explored in future research. Health-care professionals need to support hope when meeting with FCs in the ICU (Verhaeghe et al., 2007a) and consider the complex situations FCs may experience during the patient's recovery from critical illness. Methods to strengthen hope have been described in cancer patients (Rustoen and Hanestad, 1998; Rustoen et al., 1998), but need to be further developed also for FCs of ICU patients. In the newly developed guidelines for family-centred care in the ICU, family support and communication are essential elements (Davidson et al., 2017). By focusing on building a program in the ICU where FCs are included as an active part of treatment, ICU clinicians can enhance potentials for allowing FCs to have hope.

It is unsurprising that FCs of ICU patients are overwhelmed and stressed in the ICU situation. Many FCs are exposed to unfamiliar and frightening environments and observe the patient when they are critically ill. That 54% of the FCs in the present study reported a total IES-R score of ≥33 at the time of the patient's admission to the ICU is higher than reported in previous studies (Komachi and

Kamibeppu, 2016; Kulkarni et al., 2011; Shaffer et al., 2016); however, two of these previous studies used IES-R cutoff scores of >25 (Komachi and Kamibeppu, 2016) and >30 (Kulkarni et al., 2011). The third study used the Posttraumatic Checklist-Specific Stressor to investigate PTS symptoms (Shaffer et al., 2016).

Furthermore, two previous studies (Paparrigopoulos et al., 2006; Pillai et al., 2010) reported a prevalence of PTS symptoms amongst FCs of ICU patients above 70% around the time of the patient's admission to the ICU. One had a low sample size (n = 32) (Paparrigopoulos et al., 2006), while the other (Pillai et al., 2010) used a lower cutoff score of >26 (compared to >33 in the present study). However, when using an IES-R cutoff score of >26 in the present study, our findings were comparable to those of Pillai and colleagues (2010) indicating that 68% of FCs report a high IES-R score (Table 2).

In the present study, 24% of FCs reported high levels of PTS symptoms 12 months after enrolment. A reduction was found in reported PTS symptoms during the first six months, with a slight but not statistically significant increase from six to 12 months (Table 2). Of six longitudinal studies that have investigated PTS symptoms using the IES-R, five studies (Kentish-Barnes et al., 2015; Komachi and Kamibeppu, 2016; McAdam et al., 2012; Pillai et al., 2010, 2006) reported a reduction in PTS symptoms over time. In another study it was revealed that 11% of the relatives who did not report PTS symptoms at 6 months did present these symptoms at 12 months (Kentish-Barnes et al., 2015).

Delayed PTSD is found in nearly half of injury survivors who reported PTSD at 12 months (Carty et al., 2006). The latter indicates a need for further longitudinal studies to investigate the trajectory of PTS symptoms. PTS symptoms may impact FCs' abilities to function in society, as well as their abilities to care for and support the ICU patient.

In addition to hope, FCs' age, number of comorbidities, being on sick leave and relationship with the patient were all significantly associated with PTS symptoms. The finding that older FCs reported fewer PTS symptoms (Table 3) is inconsistent with previous research (Anderson et al., 2008). Older FCs might have other coping strategies compared to younger, and may have had life experiences that makes them able to cope differently from younger FCs. Furthermore, in the present study number of comorbidities (e.g., pain or depression) was significantly associated with higher levels of PTS symptoms. Being affected by comorbidities might reduce FCs' capacity to tolerate stressful events. Pretrauma risk factors, such as prior psychiatric history have been found in previous research to be associated with higher levels of PTSD symptoms (Gries et al., 2010).

In the present study, FCs on sick leave reported higher levels of PTS symptoms compared with those not on sick leave. This might mean that those experiencing the highest levels of PTS symptoms are unable to also manage work. These findings are consistent with previous research revealing that many FCs go on sick-leave during the first year after the patient's admission to the ICU (Agard et al., 2014; Griffiths et al., 2013). Findings from the present study may also indicate that working is a protective factor. For health care professionals this may be important information in how to guide and support FCs in the ICU by encouraging them to try to stay employed. These findings emphasise the need to support FCs during this phase, so that they can return to work as soon as the situation allows.

In the present study, the FCs' relationship with the patient was significantly associated with PTS symptoms, with the patients' parent reporting fewer PTS symptoms than FCs who had other relationships with the patients (e.g., spouse or friend). It is hard to explain this finding, which contrast with Pillai and colleagues' (2010) study in which the patients' parent reported the highest prevalence of PTS symptoms (Pillai et al., 2010). Further research is needed to investigate the significance of how the relationship between ICU patients and their FCs impacts PTS symptoms.

Limitations

The present study is not without limitations. First, the association between background characteristics and PTS symptoms may be confounded by other factors than those investigated herein, such as previous mental health status. Second, FCs who consented to the study may be less affected by the ICU situation; i.e., FCs who are overwhelmed and experience high levels of stress may not be able to participate. Third, we dichotomized the HHI and proposed a cutoff score based on our sample's data rather than previous empirical studies. This may have led to loss of power in our HHI; therefore, caution must be made when interpreting our results. Fourth, to our knowledge HHI has not been used in FCs of ICU patients before and therefore adequate psychometric properties have not been established. The HHI has been used in the Norwegian general population showing satisfactory psychometric properties (Rustoen et al., 2003) however, further reliability and validity tests in FCs should be performed. Fifth, that only 45% of the original sample (n = 281) returned the 12 month questionnaire needs attention. This low response rate may be related to high respondent burden, as the present study was part of a larger study that included several questionnaires. Another explanation can be the stressful situation the FCs experienced related to the newly admittance to the ICU for the patients. Fewer items in the questionnaire provided and closer follow up of FCs could have increased the response rate.

Conclusions

More than half of FCs experience high levels of PTS symptoms around the time of a patient's admission to the ICU. These PTS symptom levels decrease during the first 6 months. Level of hope, relationship with the patient, the FCs' age and employment status are associated with PTS symptoms. It is important to direct information about potential PTS symptoms to FCs of ICU patients because high levels of PTS symptoms may be experienced both during and after ICU admission. A family-centred care approach in the ICU may help clinicians to identify vulnerable groups of FCs.

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Conflict of interest

There are no conflicts of interest to declare.

Ethical approval

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.

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