

Title:

Outcomes and Experiences of Relatives of Patients Discharged Home after Critical Illness: A Systematic Integrative Review

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Abstract:

Background: Patients discharged from Intensive Care may experience psychological and physical deficits resulting in a long and complex rehabilitation upon discharge. Relatives are also vulnerable to psychological pathologies and diminished health-related quality of life following the patients' critical illness. Relatives often provide care during the patients' rehabilitation which may influence their health.

Aim: To report the outcomes and experiences of relatives of patients discharged home after critical illness.

Design: Systematic integrative review

Methods: Electronic databases Cumulative Index of Nursing and Allied Health Literature, PubMed, Embase®, and PsychINFO® were searched using keywords, synonyms, and Medical Subject Headings. Reference lists of articles and critical care journals were manually searched. Studies eligible for inclusion reported primary research and were published in English between 2007-2017. Studies were appraised using the Critical Appraisal Skills Program checklists. Data were extracted and then analysed according to Whitemore and Knaf's (2005) framework.

Findings: Twenty-five studies were included: 19 quantitative, 4 qualitative and 1 mixed method study. Three themes were identified: Health and Well-being, Employment and Lifestyle, and Care-giving Role. Health and Well-being reports the incidence and significance of psychological morbidity such as post-traumatic stress disorder, anxiety and depression. Employment and Lifestyle describes the impact of care-giving on the relative's ability to work and engage in usual social activities. The final theme describes and discusses the care-giving role in terms of activities of daily living, knowledge and skills, and adaption to the role.

Conclusions: There is a significant and meaningful impact on outcomes and experiences of relatives of patients discharged home after critical illness. Relatives' care-giving is embedded within the context of their psychological morbidity and social adjustment.

Relevance to practice: If informal care giving is to be sustainable there is a need to design effective strategies of supporting families through all stages of the critical illness trajectory.

Introduction

Patients discharged from Intensive Care (ICU) may experience psychological, cognitive, and physical dysfunction (Wolters et al. 2014, Jones 2014) resulting in a complex rehabilitation that extends well beyond hospital discharge (Elliott et al. 2014, Kowalczyk et al. 2013). Patients' relatives are also vulnerable to psychological pathologies and diminished health-related quality of life (HRQoL) following the patients' critical illness (Wintermann et al. 2016). Relatives often adopt the role of caregiver, providing practical, physical, and emotional support during the patients' protracted rehabilitation (McPeake et al. 2016). The combination of enduring their own psychological morbidity and the challenges associated with adopting a caregiving role may have implications for the relatives' health and the sustainability of caregiving. The purpose of this review is to report the outcomes and experiences of relatives of patients discharged home after critical illness. The study adopts the five-stage integrative review strategy suggested by Whittemore and Knafl (2005): Problem Identification, Literature Search, Data Evaluation, Data Analysis, and Data Presentation.

Background: Problem Identification

Survivors of critical illness may endure psychological and physical pathologies such as anxiety, depression, post-traumatic stress disorder (PTSD), fatigue, polyneuromyopathy, reduced mobility, and shortness of breath and low HRQoL after hospital discharge (Fumis et al. 2015, Kowalczyk et al. 2013, Stricker et al. 2011). As a consequence, patients often require both physical and psychological support during their rehabilitation (Jones 2014, Needham et al. 2012). Patients' relatives are often in a key position to support the patient at home and frequently adopt the role of caregiver (Haines et al. 2015).

Patients' relatives may endure high levels of psychological stress and develop psychological pathology during the acute and rehabilitative phases of critical illness (Fumis et al. 2015). Clinically significant anxiety, depression, PTSD and poor HRQoL, collectively described by Davidson et al. (2012) as Post-Intensive Care Syndrome- Family (PICS-F), has been widely reported in relatives and may last for years (Jones 2014). PICS-F may be compounded by the patients' rehabilitation needs, and the resultant caregiving responsibilities. The physical and psychological burden of caregiving has been well documented in caregivers of patients with acute illness such as traumatic brain injury (Baker et al. 2017) and cancer (Tan et al. 2018) and in caregivers of patients with chronic conditions such as dementia (Brodsky et al. 2014). Preliminary data suggests that experiences may be similar in those caring for patients after critical illness. Several authors identify that relatives caring for the patient after critical illness may experience high levels of emotional, physical, and financial stress (Douglas et al. 2010, Griffiths et al. 2013). Such stressors may compromise caregiver wellbeing and their ability to sustain support to the patient rehabilitating from critical illness.

The experiences and outcomes of the relatives of patients rehabilitating from critical illness has not been extensively studied. Existing studies frequently focus on a single outcome measure or have relatives' outcomes as a secondary objective. There are few mixed methods or qualitative investigations into relatives' experiences of the recovery period after discharge from ICU. As a result, the demands placed on patients' relatives and the subsequent ramifications are not well defined. The purpose of this systematic integrative review is to synthesise the findings of quantitative and qualitative reports of relatives' experiences and outcomes after the patients' discharge from ICU. A comprehensive understanding of relatives' experiences and outcomes may assist in developing strategies that maximise support provision to the family throughout the critical illness trajectory.

Within this review, a relative is considered to be anybody with a close kinship or social tie with the patient including connections through blood, law, friendship, or sexual relationships (Alspach 2009).

Research Question

What are the experiences and outcomes of relatives of patients discharged home after critical illness?

Design and Method

A systematic integrative review aims to evaluate and synthesise studies adopting a range of research methodologies (Torraco 2016) which reflects the diverse paradigmatic demands of evidence-based nursing practice. Whilst an integrative review may offer a comprehensive analysis of all relevant data, it is imperative to acknowledge the inherent complexity in managing and analysing copious and diverse data. Adopting a systematic strategy to all phases of the integrative review, such as Whittemore and Knafel's (2005) framework, may prevent potential pitfalls.

Literature Search

Accurate and non-biased results of an integrative review rely upon a defined and transparent search strategy that adopts a minimum of two approaches (Whittemore and Knafel 2005). Three approaches were adopted in this review. Electronic databases Cumulative Index of Nursing and Allied Health Literature (CINAHL®), PubMed, Embase®, and PsychINFO® were searched utilising keywords such as families, carers, relatives, critical care, intensive care, discharge, rehabilitation, their synonyms, and Medical Subject Headings (MeSH) in consultation with the healthcare librarian. The second approach involved hand-searching the reference lists of relevant articles retrieved from the data base search. Thirdly, specific critical care journals (Nursing in Critical Care, Intensive and Critical Care Nursing, Critical Care Medicine, Journal of Critical Care) that regularly publish articles on this topic were searched.

The following eligibility criteria were adopted; articles were primary research reports concerning the adult population published in English, between 2007-2017. Twenty-five studies met the eligibility criteria. The stages of screening are depicted in the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses" (PRISMA) flow diagram (Moher D et al. 2009) in Figure 1.

Data Evaluation

There is no consensus on the optimal approach to appraise studies within an integrative review (Whittemore et al. 2014). Standard hierarchies of study designs, (Murad et al. 2016), do not reflect the multi-paradigmatic ideology of an integrative review, whilst there is no universal appraisal checklist that satisfies the conventional demands of rigour for all research approaches. Whittemore et al. (2014) recognise the complexities of evaluating the quality of diverse data and suggest that informational value and representativeness should be considered. Similarly, Dixon-Wood et al. (2006) suggest prioritising papers based on relevance to the research question over papers that meet particular methodological standards. As such, all researchers considered the significance of the study to the research question and evaluated the study design using the relevant Critical Appraisal Skills Programme Checklist (CASP 2018). No studies were excluded from the review based on their methodological quality and all studies relevant to the research question which met the eligibility criteria were included.

Data Analysis

The goal of data analysis is to provide an unbiased, interpretation and synthesis of the evidence adopting a systematic and transparent method (Whittemore and Knafelz 2005). The first stage of data analysis was data reduction, where studies were subdivided into methodological type. Studies were then further subdivided into categories of outcome measures. Each article was then read, and relevant data extracted and displayed in a spread sheet. Individual items were compared, and similar data grouped together. Groups of data were then compared to identify patterns and relationships. With constant reference to the original data, themes were developed and independently verified against the primary studies by both authors.

Findings: Data Presentation

Five of the included studies adopted a qualitative approach; one grounded theory, three phenomenology and one general qualitative approach. Data were collected using interviews and focus groups.

Nineteen studies adopted a quantitative approach using a cross-sectional, cohort, survey design; eleven were single centre and prospective, three were single centre and retrospective, four were multi-centre and prospective and one was multi-centre and retrospective. One study adopted a mixed method approach using a single site, cross-sectional cohort, prospective survey with qualitative interviews. Symptoms of anxiety, depression and PTSD were commonly measured. Other measured outcomes were HRQoL, sleep quality and caregiver burden. A variety of validated screening and diagnostic tools were used. An overview of each of the studies is presented in Table 1.

Three key themes were identified: *Health and Wellbeing* reports the incidence and significance of psychological morbidity, *Employment and Lifestyle* discusses the impact of caregiving on relatives' ability to work and engage in personal and social activities, *The Caregiving Role* discusses the support of activities of daily living (ADLs) and adaptation to the caregiving role.

HEALTH AND WELLBEING

The reviewed literature reveals that supporting a family member through critical illness may have a significant and meaningful impact on the relative's psychological, emotional and physical health and wellbeing.

Psychological Morbidity

Eight studies identified that 15- 57% of relatives reported the presence of PTSD symptoms at up to six months after the patients' discharge from ICU (Andresen et al. 2015, Dithole and Thupayagale-Tshweneagae 2013, McAdam et al. 2012, van den Born–van Zanten et al. 2016, Wintermann et al. 2016, Wolters et al. 2014, Warren et al. 2016, Sundararajan et al. 2014). Significantly, Andresen et al. (2015) reported that 22.89% of relatives met the criteria for PTSD according to the PTSD Checklist Version S (PCL-S) score at 60 days after discharge from ICU.

Thirteen studies reported moderate to severe depressive symptoms in 20-43% of relatives two- three months after ICU discharge (Andresen et al. 2015, Cameron et al. 2016, Choi et al. 2012, Douglas et al. 2010, Gallop et al. 2015, Hwang et al. 2014, Lemiale et al. 2010, McAdam et al. 2012, McPeake et al.

2016, Sundararajan et al. 2014, Van Pelt et al. 2007, Warren et al. 2016). Cameron et al. (2016) reported depressive symptoms persisting in 43% of relatives at 12 months. Lemiale et al. (2010) and de Miranda et al. (2011) stated 32% and 35.9%, respectively, of relatives reported taking anxiolytics or antidepressants at 90 days that they did not require prior to the patient's admission to ICU. Only 17% of the participants in de Miranda et al.'s study were receiving care from a psychiatrist or psychologist.

Relatives' qualitative accounts discuss the impact and causes of psychological stress. Relatives described feeling overwhelmed by anxiety and stress related to their role as a caregiver (Gallop et al. 2015, Ågård et al. 2015, Söderström et al. 2009). Many cited intense feelings of fear of the future and uncertainty about becoming a care-giver (Ågård et al. 2015, Frivold et al. 2016, Söderström et al. 2009). Other emotional responses were feelings of isolation, loneliness and guilt. Söderström et al. (2009) described how relatives were often living at the limits of their physical and emotional capacity. Worryingly, Frivold et al. (2016, p.398) reported how relatives felt their emotions and needs came secondary to the patients; one participant stated, "*what is bothering you is neglected. I have put it away...*" Participants also described how suppressing their emotion was stressful and exhausting. Conversely, there were examples of positive emotional consequences. Ågård et al. (2015) described how some participants expressed feelings of reward and experienced a renewed connectedness with their partner. Frivold et al. (2016) reported how relatives had found their inner strength and appreciated anew their own capabilities and resilience.

Fatigue and Sleep Disturbances

Four studies highlighted that relatives frequently experience poor sleep and fatigue (Choi et al. 2014, Choi et al. 2016, McPeake et al. 2016, Dithole and Thupayagale-Tshweneagae 2013). Choi et al. (2014; 2016) reported that 53.6% of relatives suffer from poor sleep two months after ICU discharge and may have clinically significant fatigue for up to four months after ICU discharge. Insomnia and fatigue have been correlated with worse care giver strain (MacPeake et al 2016; Choi et al 2014).

The qualitative data gives an insight into the cause of sleep disturbances and fatigue. Study participants report relentless caring demands during the night (Cox et al. 2009, Dithole and Thupayagale-Tshweneagae 2013, Söderström et al. 2009). Overwhelming worry for the patients' wellbeing, intrusive thoughts and nightmares were commonly cited factors that disturbed sleep. A participant in Frivold et al.'s (2016, p.397) study described how they were perpetually worried about their relative "stopping breathing during the night". Similarly, a participant in Dithole and Thupayagale-Tshweneaga's (2013, p.34) study described how they watched over their wife "even in her sleep".

Several variables that may increase risk of psychological morbidity in patients' relatives are suggested in the reviewed studies. Relatives baseline level of anxiety and depression upon and during the patients' admission to ICU appears to be positively correlated with the persistence of anxiety and depression and the development of PTSD symptoms (Andreson et al 2015; Sundarajan et al. 2014; Douglas et al. 2010; Van Pelt et al. 2007). Cameron et al. 2016 reported that a younger age and poor social support are associated with worse psychological outcomes in relatives. Choi et al. (2012) and McPeake et al (2016) both report an association with the prevalence of anxiety and depression and both increased fatigue and increased caregiver strain. Choi et al. (2012) also highlighted that increased

depression is associated with more health risk behaviours. Interestingly, Hwang et al (2014) found no correlation between length of stay in ICU (<48 hours vs >48 hours) and the prevalence of anxiety and depression.

EMPLOYMENT AND LIFESTYLE

Employment

After adopting a care giving role, 25-48% of relatives reported a reduction in employment; they reduced their working hours, quit, or were fired (Douglas et al. 2010, McPeake et al. 2016, van den Born–van Zanten et al. 2016). Conversely, Ågård et al. (2014) reported minimal effects on employment although did describe an increase in sick leave.

Personal and social activity

Choi et al. (2011) identified that relatives often have a restricted personal and social life. Van Pelt et al. (2007) reported that relatives endured a significant lifestyle disruption, as measured by the Activity Restriction Scale, which did not abate between two months to one-year after the patient's discharge. Qualitative studies (Frivold et al. 2016, Dithole and Thupayagale-Tshweneaga 2013) report changes in every aspect of life where relatives describe less time to engage in usual personal and social activities. A lack of time was commonly attributed to the practical demands of caregiving (Frivold et al. 2016; Gallop et al. 2015; Dithole and Thupayagale-Tshweneaga 2013; Cox et al. 2009). A relative in Gallop et al.'s (2015, p.304) study described how their day revolved around the patient's needs which restricted their freedom and independence. Attempts to quantify time spent delivering care, have been made within the empirical research. van den Born- van Zanten et al. (2016) using a self-report questionnaire, reported that relatives, at three months after the patients discharge home, spent a mean of 10 hours per week (ranging from 1-120 hours) providing care. Van Pelt et al.'s (2007) study suggests that relatives spend 6 hours a day at 3 months with no significant reduction at 12 months, however, it is not made clear how this information was gained.

A lack of engagement with personal and social activities was also attributed to emotional reasons. Personal accounts described how relatives did not want to leave the house, see friends or participate in social activities due to anxiety and fear (Gallop et al. 2015; Dithole and Thupayagale-Tshweneaga 2013; Söderström et al. 2009). Dithole and Thupayagale-Tshweneaga's (2013, p.34) participant poignantly described this as being "afraid of life". Frivold et al. (2016) concurred and described reports of fear restricting relative's social lives leaving them feeling isolated and unsupported.

THE CARE GIVING ROLE

Aspects of providing care and support to the patient rehabilitating from critical illness were predominantly described by relatives' qualitative accounts. The reviewed evidence suggests that relatives undergo a period of adaptation, making personal sacrifices and learning new skills to provide support to the patient upon discharge home.

Assisting with Fundamental and Instrumental Activities of Daily Living (ADL)

Findings describe how relatives adopt new roles that require the development of new knowledge and skills (Frivold et al. 2016; Ågård et al. 2015; Gallop et al. 2015; Söderström et al. 2007). Relatives describe the need to watch and monitor the physical and psychological needs of the patient, continually surveying for both improvement and deterioration (Ågård et al. 2015; Dithole and

Thupayagale-Tshweneaga 2013; Söderström et al. 2009). Relatives reported taking responsibility for fundamental ADLs such as medicine administration (Gallop et al. 2015), and meeting physical needs such as toileting, and personal hygiene (Söderström et al. 2009; Frivold et al. 2016). In addition, relatives frequently reported assisting with instrumental ADLs, such as problem solving, shopping, laundry, managing finances and housekeeping (Van Pelt et al. 2007 Ågård et al. 2015). The responsibility of coaching the patient through their recovery and negotiating the level of care throughout their illness trajectory was also highlighted (Ågård et al. 2015; Söderström et al. 2009). Mediating information and advocating for the patient were other new roles described in the data (Söderström et al. 2009; Frivold et al. 2016; van den Born-van Zanten et al. 2016).

Adaption to the caring role

It is evident that the practical demands and personal challenges associated with caregiving are great. Relatives struggled to reconcile their practical caring responsibilities with their role as a family member (Ågård et al. 2015, Söderström et al. 2009). Ågård et al. (2015) described this as a dynamic role shift requiring commitment, skill acquisition and negotiation. Throughout the qualitative accounts the need for relatives to garner their personal resources to adapt to their new role is apparent. Relatives frequently report relying on their inner strength and resilience (Ågård et al. 2015; Söderström et al. 2009). Relatives also expressed the need for both informational and emotional support (Frivold et al. 2016; Gallop et al. 2015; Söderström et al. 2009). Söderström et al. (2009, p. 254) described how *“sharing the suffering”* facilitated coping. A participant in Ågård et al’s (2015, p.1897) study, lamented, *“If I had only had some instructions or a contact person or someone who said: ‘Listen, I will take care of this.’”* Other qualitative accounts echoed this plea, reporting how overwhelmed relatives felt, often with limited sources of support (Frivold et al. 2016; van den Born- van Zanten et al. 2016; Mcpeake et al. 2016; Cox et al. 2009).

The reviewed evidence did not explore to what extent the relatives stated needs for information and emotional support were met, however, Wolters et al. (2014) reported that 23% of relatives of patients rehabilitating from critical illness were positive for carers overburden. Mcpeake et al. (2016) reported that 53% of relatives had significant strain as indicated on the carer strain index which was significantly associated with the patient’s quality of life.

Discussions

This systematic integrative review describes the psychological outcomes and experiences of relatives of patients discharged home after critical illness. Twenty-five studies were identified; the majority of which were single-centre, prospective, cohort studies utilising validated measurement scales in a variety of populations in a variety of countries at a range of time points after the patients discharge home. Qualitative studies were few and often relative’s experiences were only secondary research objectives. Overall the quality of the studies was low due to small sample sizes, single locations and short follow-up, however, inclusion in this review is justified due to the limited research available on this topic. Despite the variance in quality and methodologies of the reviewed studies, findings seemed to resonate with each other, providing a unique synthesis of relatives’ outcomes and experiences.

This review revealed a significant incidence of psychological morbidity in relatives of patients discharged home after critical illness. There is variation in the reported incidence attributable to the range of screening and diagnostic tools used, and time-range of data collection. Furthermore,

rehabilitation initiatives such as critical care follow-up clinics and rehabilitation programmes (NICE 2009) which may confer an indirect benefit on the patient's relatives may not be reflected in the older studies reviewed. Regardless, psychological morbidity in relatives is of concern as their experiences and outcomes are embedded within their role of supporting and caring for the patients' during their rehabilitation.

The unique synthesis of outcomes with experiences has revealed some of the sources of stress and the specific demands placed on relatives. Supporting and caring for the patient was a significant source of stress; fear and uncertainty of the patient's well-being, isolation and loneliness were highlighted as particularly overwhelming. These experiences resonate with caregivers of patients with other conditions such as dementia (Chiao et al. 2015), terminal cancer (Götze et al. 2018) and chronic illness (Årestedt et al. 2014), and traumatic brain injury (Baker et al. 2017), which serves to add to the review's trustworthiness and convergence with other studies. Of significant concern, is the apparent lack of practical, informational and emotional support reported within the reviewed literature (Cox et al. 2009; Frivold et al. 2016). Bench et al. (2011) identified in a focus group study that information and support and for both patients and their relatives is often inadequate. This coupled with reports of high levels of caregiver burden (Mcpeake et al. 2016) indicates an area in need of urgent practical and scholarly attention. The exact nature of the relationship between the relatives' health and wellbeing and caregiving role is not clear within the reviewed literature, however, it would be sensible to assume that one might influence the other. Since relatives are often the main source of care for the rehabilitating patient, it is essential that they are adequately supported in their role and stressors that may precipitate or exacerbate their own psychological morbidity, must be addressed. It would be worthwhile considering if established support strategies for caregivers of patients with conditions such as strokes, traumatic brain injury, dementia, such as carer support groups (Worrall et al. 2018), and psychoeducational interventions to improve caregiving skills and competence (Tang et al. 2018) would be effective in this population.

This review identified some positive aspects to providing care to the patient which is also reflected in other literature (Anderson and White 2018). Understanding the positive aspects of caring and the associated resilience and positive coping strategies may inform nurses how to effectively support families in their caring role.

Although precise data concerning relatives altered employment status, sick leave, and the associated financial implications is not comprehensively reported within the reviewed studies, and indeed minimally explored in the wider literature (Griffiths et al. 2013), this review offers tangible evidence of far-reaching secondary social disruptions associated with critical illness. The review indicated that both practical demands and emotional reasons influenced relatives' employment and engagement with personal social activities; both are potentially modifiable and amenable to support and intervention and indicates the need for a holistic, family orientated support strategy that traverses primary, secondary and tertiary care.

Limitations

The reviewed literature originates from a variety of countries with different cultural nuances and social support services; findings may not therefore be wholly transferable to other settings. Due to the paucity of focussed research regarding experiences and outcomes of relatives, many studies,

where relatives' outcomes and experiences were secondary research objectives were included. Only findings specifically relevant to the research question were reported within this review, therefore potentially leading to context stripping of the data. Whilst the literature search strategy was meticulous and robust, some work may have been missed; particularly where relatives' outcomes and experiences were secondary research objectives. As such the review may not fully represent the work in this area.

Implications and Recommendations for Practice

- Patient rehabilitation strategies should consider the wellbeing, the role and the needs of the family who provide support and care
- Proactive approaches to engaging and including family members in critical care follow up should be adopted. Family members should be invited to attend follow-up clinic rather than passively accompanying their relative.
- Further research is required to clearly define and explore specific stressors and areas of unmet need of families of patients discharged home after critical illness.
- A deeper understanding of which specific stressors are correlated with psychological morbidity and which of those are modifiable would enable nurses to develop targeted, preventative and supportive strategies for families.

Conclusions

Relatives are at significant risk of psychological morbidity, which has wider social implications. Relatives also undertake caregiving role which is a source of great stress, for which they receive little formal support. The sustainability of patients rehabilitating at home is under threat unless relatives' needs are addressed. A family-centred programme of rehabilitation is therefore required for the long-term rehabilitation of the critically ill.

What is known about this topic:

- Relatives of patients who are critically ill are vulnerable to psychological morbidities and a reduced health related quality of life through all phases of the critical illness trajectory.
- Relatives frequently provide care and support to patients discharged home after critical illness

What this paper adds:

- The impact of critical illness on relatives' psychological health, employment and lifestyle after the patients discharge home is significant and meaningful.
- Providing care and support to the patient rehabilitating from critical illness upon discharge home is a source of great disruption and stress to the relative

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Figure 1. PRISMA Flow Diagram (Moher D et al. 2009)

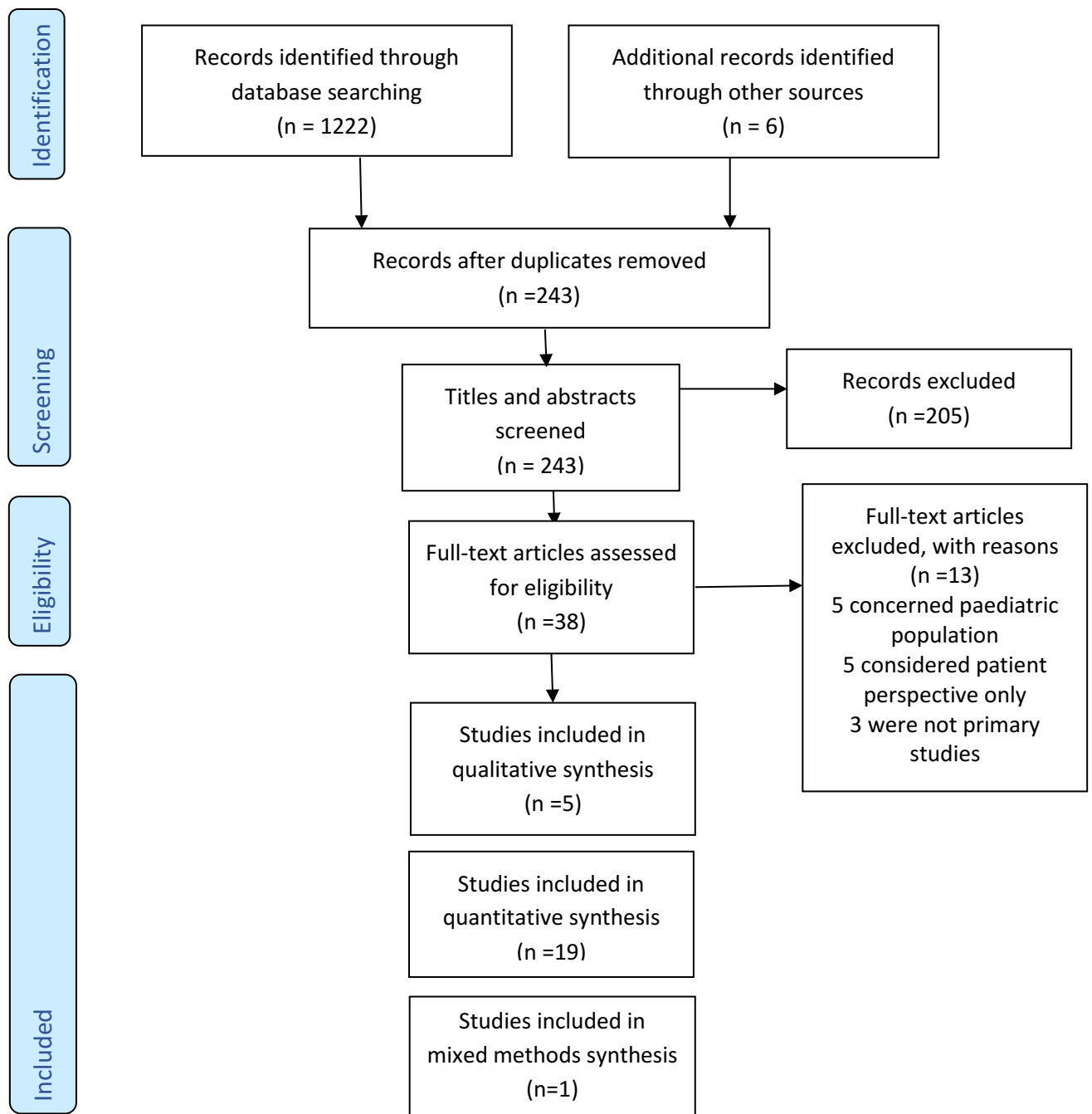


Table 1: Summary of included literature (n=25)

Author	Research Aim	Sample	Design	Outcome measures / Data generation	Data analysis	Results/ Findings	Study Evaluation
Ågård et al. 2015	To explore the challenges and caring activities of spouses of intensive care unit survivors during the first year of patient recovery.	18 patient-spouse dyads	Qualitative: Multi-centre, grounded theory study across 5 ICUs in Denmark	35 semi-structured dyad and group interviews at 3 and 12 months post-intensive care unit discharge	Open Glaserian coding	Spouses shifted their role from spouse to care-giver and back which was a dynamic process including four elements: committing to caregiving, acquiring caregiving skills, negotiating level of caregiving, and gradually leaving the caregiver role. Care giving comprised of 5 dimensions: observing, assisting, coaching, advocating and managing activities	The location of interviews varied. Spouses interviewed in the presence of the patient may not have offered truly authentic experiences. The characteristics of patients and therefore rehabilitation needs varied greatly in study group.
Cox et al. 2009	To explore the effects of critical illness on the daily lives and functioning of ARDS survivors.	23 patients, 24 caregivers	Qualitative: Multi-centre study adopting Colaizzi's qualitative methodology	Semi-structured telephone interviews	Colaizzi's analysis	Caregivers described distress during fluctuations in patients' mental status and cognition and described a perceived lack of support, difficulties in balancing child care and work. Caregivers also described the strain on their relationship with the patient	Most of the sample were carers of young, white males with minimal pre-existing co-morbidity, therefore limited transferability to other settings
Frivold et al. 2016	To explore relatives' experiences of everyday life after a loved one's stay in ICU.	13 relatives	Qualitative: Multi-centre, hermeneutic phenomenology in Norway	Interviewed 3 months to 1-year post discharge/ death	3-step coding: naïve reading, structural analysis, comprehensive understanding	Participants described changes in everyday life: taking on new roles and responsibilities, memories of ICU and new knowledge. They also described Managing changes and the need of support	Study included both relatives of survivors and the dead where experiences may be different in terms of caregiving responsibilities. There was a wide variation in time data collected
Gallop et al. 2015	To explore and describe the subjective experiences and long-term impact of severe sepsis on survivors and their informal caregivers	22 patients, 17 caregivers	Qualitative: Multi-centre, interview study in US, and UK	Semi-structured interviews face to face or via phone, Euro-Quality of life-5 Dimensions (EQ-5D), HADS	Descriptive statistics. Thematic analysis using inductive and deductive coding	Participants described coping with complex medical regimes, days revolving around patients' needs, and under-taking new roles. They also highlighted the emotional impact on carers, and the lack of information and support after discharge	No philosophical framework for methods identified. Time of data collection in relation to ICU discharge not disclosed. Not disclosed how integrated patient and caregiver data into themes. Specific to survivors of severe sepsis
Söderström et al. 2009	To describe and interpret the family adaptation during the ICU hospitalisation	27 relatives	Qualitative: Hermeneutic interview study in Sweden	Semi-structured interviews at ICU discharge and 12- 18 months later	Hermeneutic analysis	Three key themes were reported: Striving for endurance, Striving for consolation, Striving to rebuild life under new conditions	The characteristics of the participants are not explicitly reported. The interviewers influence on the data and how

	and up to 18 months after discharge.						perceptions were integrated not made clear. There was variation in who was present at each interview which may influence authenticity of participant accounts
Cameron et al. 2016	To describe health outcomes in caregivers, identify sub-groups with distinct health trajectories and identify variables associated with poor caregiver outcomes during the first year after patient discharge from an ICU.	280 Caregivers	Quantitative: Multicentre, prospective, cohort, cross-sectional study across 10 ICU's in Canada	Centre for Epidemiologic Studies Depression scale (CES-D), Positive Affect Scale of the Positive and Negative Affect Schedule (PANAS), Physical Component Summary (PCS) and Mental Component Summary (MCS) of the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) at 7 days and 3, 6, and 12 months after ICU discharge	Descriptive and inferential statistical analysis	Caregivers displayed high level of depressive symptoms (67% at 7 days reducing to 43% at 12 months). Physical health scores were above average and stable over time. Younger age, effect of caregiving role on other activities, less social support and less sense of control and less personal growth associated with worse caregiver outcomes. No patient variables consistently associated with caregiver outcomes over time.	The baseline mental health status of caregivers unknown therefore not known if depressive symptoms solely due to caregiving role. Utilised an unmatched population and self-report questionnaires therefore there is a potential for bias. Some study data missing but was accounted for.
Douglas et al. 2010	To describe characteristics of caregivers of chronically critically ill (CCI), patients	278 caregivers	Quantitative: Multi-centre, Prospective, cohort, cross-sectional study in US	CES-D, Single-item measures of HRQOL, Charlson Weighted Index of Co-morbidity on ICU admission and 2 months' post hospital discharge	Descriptive and inferential statistical analysis	39% of caregivers reported severe depressive symptoms on enrolment reducing to 20% severe at two months post discharge. There was no difference between white and non-white participants however, non-white caregivers of patients discharged to institutions had least improvement in depressive symptoms over time. 12.8% of all caregivers were taking antidepressants on enrolment. Statistically significant reduction in physical health over time. Significant predictors of depression 2 months' post-discharge were depression during hospitalization, health status, and residence of the	Study was conducted across two centres in one city with a large loss to follow-up (24.9%) and limited follow up time. There was a variability of where patients discharged too- some discharged to long term care facilities, others home.

						patient, with no change based on race. Two months post-hospital discharge, 48.2% of caregivers who had been employed at the time of study enrolment reduced their work hours, quit, or were fired due to assuming the caregiving role.	
de Miranda et al. 2011	To determine the prevalence and risk factors of anxiety, depression and PTSD symptoms in patients with chronic obstructive pulmonary disease (COPD) and their relatives	102 relatives	Quantitative: Multi-centre, prospective, cohort, cross-sectional study in 19 ICU's in France	Hospital Anxiety and Depression Score (HADS), Impact of Events Scale (IES), Peri-traumatic Dissociative Experiences Questionnaire conducted upon patient discharge from ICU and at 90 days	Descriptive and inferential statistical analysis	39.1% of relatives provided informal care for patients. At discharge 72.2% relatives reported anxiety symptoms and 25.7% reported depressive symptoms. This reduced to 40.4% and 14.9% at 90 days respectively. 32% reported taking anxiolytics/antidepressants at 90 days which they weren't before. Only 17% reported receiving specific care from psychiatrist or psychologist.	Study conducted in France, in patients with COPD who have chronic health needs and other co-morbidities, which may not represent typical ICU patients in other countries. There was very high loss to follow up (about 50%) which was explained and accounted for but nevertheless may impact the reliability of the findings.
Lemiale et al. 2010	To evaluate HRQOL in relatives of patients 90 days after ICU discharge or death.	284 relatives	Quantitative: Multi-centre, prospective, cohort, cross-sectional study in France	Simplified Acute Physiology Score II, ECOG/WHO Performance Status Scale, on recruitment, SF-36 and HADS at 90 days' post ICU discharge	Descriptive and inferential statistical analysis	At 90 days, 35.9% relatives reported taking anxiolytics or antidepressants. 49.3% reported anxiety and 20.1% reported depression. The physical component of the SF-36 was normal but the mental component showed substantial impairments	No baseline HRQoL measured. High patient mortality in study group therefore relatives' experiences will differ depending on ongoing caring responsibilities.
Ågård et al. 2014	To describe the influence of critical illness on patients and their partners in relation to rehabilitation, healthcare consumption and employment during the first year after ICU discharge.	18 patient and partner dyads	Quantitative: Multi-centre, retrospective, cohort, cross-sectional study across 5 ICUs in Denmark	Data collected from hospital charts and population registers and interviews at 3 and 12 months post ICU discharge	Descriptive statistical analysis	12 months after patient discharge, partners' employment status minimally affected. Partners' sick leave increased in 12 months following ICU stay. Some partners reported physical problems	Outcome measures were not made explicit within the report. Studied a small, heterogeneous population with varied rehabilitation needs within the specific cultural context of Denmark and their unique welfare system.
Andresen et al. 2015	To explore PTSD in family caregivers of	83 relatives	Quantitative:	Caregivers' sociodemographic	Descriptive and inferential	At 60 days, 22.89% of caregivers met criteria for PTSD. Incidence of PTSD	Study was conducted in single centre, with a short follow-up

	ICU patients and examined relationship between PTSD and specific patients' conditions and relatives' psychological characteristics		Single centre, prospective, cohort, cross-sectional study in Chile	variables, State Trait Anxiety Symptoms questionnaire, Short Form of the Composite International Diagnostic Interview scale and Posttraumatic Stress Disorder Checklist, version S (PCLS) were assessed at admission to ICU, 2-4 days and 60 days post-admission	statistical analysis	positively correlated with high levels of anxiety and depression in family at time of ICU admission. Effect was more pronounced in older patients with higher APACHE II scores, who were receiving mechanical ventilation and whose length of stay exceeded 2 days. Higher educational level is inversely correlated with PTSD	period, utilising self-reported checklists which are open to subjective bias.
Choi et al. 2014	To describe self-reported fatigue in caregivers of ICU survivors	47 Patient-caregiver dyads	Quantitative: Single centre, prospective, cohort, cross-sectional study in Canada	SF-36 Vitality subscale, CES-D 10, Brief Zarit Burden Interview-12, Caregiver Health behaviour scale, Pittsburgh Sleep Quality Index, Modified Given Symptom Assessment Tool at 2 weeks, 2 and 4 months after ICU discharge.	Descriptive and inferential statistical analysis	43-53% of caregivers reported clinically significantly fatigue across all time points although did improve over time. Participants reporting fatigue also reported increased depressive symptoms, burden, health risk behaviours and sleep quality and patient's symptom burden	Single- centre study with a high loss to follow-up due to patient death. There was a relatively short follow-up time and the SF-36 vitality score does not thoroughly evaluate fatigue compared with other more in-depth scales.
Choi et al. 2011	To describe lifestyle restrictions and distress among caregivers of chronically critically ill patients	69 Patient-caregiver dyads	Quantitative: Single centre, prospective, cohort, cross-sectional study in Canada	Changes in Role Function (CRF), modified Revised Memory and Behaviour Problems Checklist, Health Assessment Questionnaire (HAQ) at 1 and 6 months after ICU discharge	Descriptive and inferential statistical analysis	CRF reduced from 1 to 6 months after discharge. Caregiver's distress and patient's problem behaviours did not change over 6 months. The most commonly reported restriction was restricted social life and personal recreation.	There was a large loss to follow-up due to participants reporting "feeling overwhelmed". Therefore, those withdrawing were potentially those experiencing greatest lifestyle restriction and distress. The study sample was predominantly white and had a short follow-up period

Choi et al. 2012	To examine the trajectories of depressive symptoms in caregivers of critically ill adults from intensive care unit admission to 2 months post- ICU	50 caregivers, 47 patients	Quantitative: Single centre, prospective cohort, cross-sectional study in US	Shortened CES-D, Brief Zarit Burden interview-12, caregiver health behaviour, ADL and instrumental activities of daily living at ICU admission, ICU discharge and 2 months post-ICU discharge	Descriptive and inferential statistical analysis	Identified two trajectory groups: those who had clinically significant depressive symptoms that persisted at 2 months and those who had fewer depressive symptoms which further ameliorated at 2 months. High trajectory group reported greater burden and more health risk behaviours throughout	Single centre study with a short follow up time. There was no baseline for depressive symptoms available. There was a high loss to follow-up and therefore a small sample size in the end. Study utilised self-report scales which are open to bias
Choi et al. 2016	To describe changes in sleep quality in family caregivers of ICU survivors from the patients' ICU admission until two months post-ICU discharge	28 caregivers	Quantitative: Single centre, prospective, cohort, cross-sectional study in US	Pittsburgh Sleep Quality Index [PSQI], SenseWear Armband™ objective sleep/wake variables measurements, CES-D10, Brief Zarit Burden Interview-12, at ICU admission, 2 weeks and 2 months post ICU discharge	Descriptive and inferential statistical analysis	53.6% pf caregivers reported poor sleep quality across all time points. Worse sleep reported by care-givers who were employed and a non-spouse	This was a single centre study which had a small sample size of limited diversity with a large loss to follow-up.
Hwang et al. 2014	To explore anxiety and depression symptoms among families of adult intensive care unit survivors immediately following brief length of stay	106 caregivers	Quantitative: Single site, prospective, cohort, cross-sectional study in the US	HADS scale upon patient discharge	Descriptive and inferential statistical analysis	Prevalence of anxiety and depression symptoms in relatives of patients with a brief length of stay in ICU (<48hrs) is not significantly different to those relatives of patients with a stay in ICU of greater than 48 hours	Study was conducted in a single site with a small sample size for comparison with other groups
McAdam et al. 2012	To compare levels of PTSD, anxiety, and depression during and 3 months after ICU discharge in family members of patients at high risk for dying and to determine if differences were	41 relatives	Quantitative: Single site, prospective, cohort, cross-sectional, study in the US	Impact of Event Scale-Revised (IES-R), HADS measured at 3-5 days after patient admission and 3 months' post patient death or ICU discharge	Descriptive and inferential statistical analysis	PTSD anxiety and depression scores were significantly lower at 3 months' after than during the experience. Scores did not significantly differ between family members of patients who died and family members of patients who survived. Among the total sample, 44% had significant anxiety, and 27% were depressed.	This study had a high loss to follow up with a small heterogeneous sample which lacked power to make comparisons between groups

	related to the patient's outcome.						
Sundararajan et al. 2014	To determine the prevalence and predictors of symptoms of PTSD in relatives of an Australian critically ill population	63 relatives	Quantitative: Single-site, prospective, cohort cross-sectional study in Australia	HADS, IES-R, SF-36, family satisfaction survey at 90 days' post-discharge from the ICU	Descriptive and inferential statistical analysis	41.27% had PTSD symptoms at 90 days. Anxiety score was predictive of PTSD symptoms. Other variables such as ICU outcomes (survival or death), the non-availability of medical insurance, educational level, and gender, involvement in decision-making, willingness of staff to answer questions, information and time given by ICU staff and satisfaction with emotional support, patient health status were not associated with PTSD symptoms	This single site study had a relatively small sample of relatives of patients who had survived ICU and those who died. There therefore may be variance in the ongoing care giving responsibilities.
van den Born-van Zanten et al. 2016	To describe the level of caregiver strain and posttraumatic stress-related symptoms in relatives of ICU survivors	94 caregivers	Quantitative: Single-centre, prospective cohort, cross-sectional study in The Netherlands	Dutch version of the validated Caregiver Strain Index (CSI), Trauma Screening Questionnaire (TSQ) and the Caregiver Strain Index (CSI) at 3 months' post ICU discharge.	Descriptive and inferential statistical analysis	21% of the caregivers reported high levels of strain. 6% reported severe strain. PTSD-related symptoms were seen in 21% of the caregivers. The mean time spent on caregiving was 10 hours per week. One quarter of the relatives had reduced their hours of gainful employment prior to hospital admission and that 2% had completely stopped working.	This single site study was not to power for correlational analyses. No baseline assessment of psychological status was conducted. Self-report measurement tools were utilised.
Van Pelt et al. 2007	To describe 1-year longitudinal outcomes and depression risk for caregivers of critical illness survivors and compare depression risk between caregivers of patients with and without pre-ICU admission functional dependency	169 caregivers	Quantitative: Single site, prospective, cohort, cross sectional study in the US	CES-D Scale, ES-D, Activity Restriction Scale, reduction in employment collected at 2,6 and 12 months after initiation of mechanical ventilation	Descriptive and inferential statistical analysis	33.9% of all caregivers at risk of depression at 2 months, reducing to 22.8% at 12 months however difference not statistically significant. Depression risk higher in carer-givers of patients with pre-ICU functional dependence however, not significantly so. Increase risk in carers of patients with increased age and those using paid assistance. Reduction in employment high- only 28% employed at two months. Activity Restriction Scale was high. Caregivers spent nearly 6hrs/day caring for their	Although published in 2007, the data for this single site study was collected in 1999 and therefore may not reflect today's situation. There was a large loss to follow up and large amount on missing data

						family member at 2 months with no significant reduction at 12 months	
Wintermann et al. 2016	To investigate patient and family-related risk factors for posttraumatic stress and reduced Health-related Quality of Life in family members of patients with chronic critical illness	83 relative-patient dyads	Quantitative: Single site, prospective, longitudinal cohort, observational and cross-sectional study in Germany	The Posttraumatic Stress Scale-10 and the EQ-5D-3L up to six months after transfer from an acute hospital.	Descriptive and inferential statistical analysis	15.7% of family members demonstrated clinically significant symptoms of PTSD. Time following ICU discharge and the patients' diagnosis of PTSD were independently associated with PTS in family members. Family members with higher PTS reported lower HRQL. There appeared to be no significant	Single site, small study. PTSS-10 is a self-report scale rather than a formal diagnostic tool. Also, cross-sectional data rather than longitudinal. Optimum PTSD symptomology occurs at 3-months but data collected at up to 6 months
McPeake et al. 2016	To explore the impact of critical care survivorship on caregivers.	36 caregivers	Quantitative: Single site, retrospective, cohort, cross-sectional study in Scotland	IES-R, HADS, Carer Strain Index (CSI), and the Insomnia Severity Index (ISI) 4-20 weeks' post ICU discharge or up to 3 years	Descriptive and inferential statistical analysis	53% of caregivers suffered significant strain. Poor quality of life in the patient was significantly associated with higher caregiver strain (P= .006). Anxiety was present in 69% of caregivers. Depression was present in 56% of caregivers, with a significant association between carer strain and depression. ISI scores higher in caregivers reporting carer strain. 44% of caregivers were required to make work adjustments and 39% stated that they had experiences financial burden during the period of critical illness and recovery.	There was a great variability in time since ICU discharge (4 weeks-3 years) when data was collected. As data was retrospectively collected there was no baseline measurement of psychological health. Study only used self-report scales.
Warren et al. 2016	To identify whether families of traumatic brain injury (TBI) patients in the ICU experience psychological differences as compared with non-TBI patients' family members.	82 relatives	Quantitative: Single site, retrospective, cohort, cross-sectional study in the US	The Patient Health Questionnaire 8-Item measured depression, the Primary Care PTSD Screen measured symptoms of posttraumatic stress conducted at baseline, upon ICU admission, and at three months after patient discharge	Descriptive and inferential statistical analysis	48.7% were families of those with TBI, 51.2% were families of those without TBI. At baseline, 39% of the total sample (33% non-TBI, 45% TBI, p= 0.28) screened positive for depressive symptoms and 24.3% (26% non-TBI, 23% p= 0.69) were positive for PTS symptoms. At 3 months 20% (28% TBI, 12% non-TBI p=0.08) reported depressive symptoms and 17% (25% TBI, 10% non-TBI, p= 0.07) screened positive on the PC-PTSD. A significant difference was reported between the	This single site study had a relatively small sample with large loss to follow up. Pre-existing psychological status was not assessed and there was great heterogeneity of the non-TBI group

						groups at 3 months, with family members in the non-TBI group showing a significant decrease in depression and PTS symptoms.	
Wolters et al. 2014	To describe the impact of an acute illness with intensive care unit (ICU) admission on the physiological and social well-being of former ICU patients and their families	88 relatives	Quantitative: Single site, retrospective, cohort, cross-sectional study in The Netherlands	TSQ, CSI, Caregiver task questionnaire three months after patient discharged from ICU	Descriptive statistical analysis	15% of family members reported PTSD. 23% of family members were positive for possible carers overburden.	This small single site study reported lots of missing data for both the TSQ and the CSI which was not accounted for.
Dithole and Thupayagale-Tshweneaga 2013	To explore the incidence of PTSD in spouses, at six months after their relative's discharge from an ICU.	28 spouses	Mixed Methods: Prospective, single centre, cohort, cross-sectional design with qualitative interviews in Botswana	PTSD Checklist Specific Scale and face-face interview conducted at 6 months post-ICU discharge	Descriptive statistical analysis and Colaizzi's framework	57.1% of spouses reported PTSD symptoms at 6 months. Qualitative themes were sleep disturbances, emotional instability, and fear	This study was a very small convenience sample in a single centre in Botswana. No baseline data was collected.