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Title: The expressed support needs of families of adults who have survived critical illness: a thematic synthesis

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**Abstract:** Background: Surviving critical illness can result in ongoing psychological, physical and cognitive impairments for both survivors and families. During the time from the critical illness through to the period of adaptation back to community living, family and survivor's needs change. Objectives: This systematic review aimed to provide an in-depth insight into the expressed support needs of families of adults who survived an admission to intensive care unit and returned to a home environment. It also aimed to explore how these needs change over time, and what support provisions families perceived to be helpful.

Methods: This was a systematic review using thematic synthesis methodology. Predefined searches were conducted in CINAHL, Medline, PsychINFO, SocIndex, EMBASE, Academic Search Complete, EThOS and OpenGrey to locate studies published in English from 2000. Two reviewers screened each study against the inclusion criteria. Quality appraisal was undertaken using Joanna Briggs Institute tools. Extracted data were managed in Nvivo12® and analysed to identify descriptive and analytical themes. The Timing it Right Framework was used to frame changes in need across the recovery continuum.

Results: Twenty-nine studies were included, 22 qualitative, six quantitative and one mixed methods. Five key family needs were identified across the recovery continuum: for security; to make sense of the situation; finding a balance; holding everything together; and for trust.

Discussion: Families found the following interventions helpful: written information; care coordination and navigation; input from intensive care staff after discharge to support continuity; and provision of family support groups. Although there are similarities between the needs of families and survivors, there are sufficient differences to warrant the development of processes to identify and address family need throughout the recovery continuum.

Conclusion: More research is required to develop a tool to better identify the needs of families across the recovery continuum, identify gaps in current service provision, and design interventions to meet these needs.

Study registration: CRD42019136883 (PROSPERO)

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**Title:**

The expressed support needs of families of adults who have survived critical illness: a thematic synthesis.

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Leanne Aitken: Conceptualisation, Validation, Supervision, Writing – Review & Editing

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|----------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|
| Randomised (and quasi-randomised) controlled trial             | CONSORT – Consolidated Standards of Reporting Trials                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                       |
| Qualitative studies                                            | COREQ: Consolidated criteria for reporting qualitative research                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                       |
| Systematic Review of Controlled Trials                         | PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                       |
| Study of Diagnostic accuracy / assessment scale                | STARD Standards for the Reporting of Diagnostic Accuracy studies                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                       |
| Observational cohort, case control and cross sectional studies | STROBE <b>S</b> trengthening the <b>R</b> eporting of <b>O</b> bservational Studies in <b>E</b> pidemiology                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                       |
| Quasi experimental / non-randomized evaluations                | TREND - Transparent Reporting of Evaluations with Non-randomized Designs                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                       |
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**ENTREQ checklist (Enhancing transparency in reporting the synthesis of qualitative research)**

| No. Item                      | Guide questions/description                                                                                                                                                                                                                                                                                                                                                                    | Reported on page #             |
|-------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|
| 1. Aim                        | State the research question the synthesis addresses                                                                                                                                                                                                                                                                                                                                            | 1, 4                           |
| 2. Synthesis methodology      | Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)                                                                  | 4-6                            |
| 3. Approach to searching      | Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved)                                                                                                                                                                                        | 4-5                            |
| 4. Inclusion criteria         | Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)                                                                                                                                                                                                                                                                 | 4                              |
| 5. Data sources               | Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources | 4-5                            |
| 6. Electronic Search strategy | Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)                                                                                                                                                          | 5<br>Supplementary materials I |
| 7. Study screening methods    | Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)                                                                                                                                                                                                                                          | 5, 7                           |
| 8. Study characteristics      | Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions)                                                                                                                                                                                                        | 8, 10-11                       |
| 9. Study selection results    | Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development)        | 7                              |
| 10. Rationale for appraisal   | Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings)                                                                                                                                               | 5, 9                           |
| 11. Appraisal items           | State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting)                                                                                                    | 5, 9                           |
| 12. Appraisal process         | Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required                                                                                                                                                                                                                                                                             | 5                              |
| 13. Appraisal results         | Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale                                                                                                                                                                                                                                           | 9,<br>Supplementary materials  |
| 14. Data extraction           | Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a                                                                                                                                                               | 5-6                            |

|                          |                                                                                                                                                                                                                              |       |
|--------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
|                          | computer software)                                                                                                                                                                                                           |       |
| 15. Software             | State the computer software used, if any                                                                                                                                                                                     | 6     |
| 16. Number of reviewers  | Identify who was involved in coding and analysis                                                                                                                                                                             | 6     |
| 17. Coding               | Describe the process for coding of data (e.g. line by line coding to search for concepts)                                                                                                                                    | 6     |
| 18. Study comparison     | Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary)                                            | 6     |
| 19. Derivation of themes | Explain whether the process of deriving the themes or constructs was inductive or deductive                                                                                                                                  | 6     |
| 20. Quotations           | Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation                                                  | 13    |
| 21. Synthesis output     | Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct) | 12-20 |

**Abstract:**

*Background:* Surviving critical illness can result in ongoing psychological, physical and cognitive impairments for both survivors and families. During the time from the critical illness through to the period of adaptation back to community living, family and survivor’s needs change.

*Objectives:* This systematic review aimed to provide an in-depth insight into the expressed support needs of families of adults who survived an admission to intensive care unit and returned to a home environment. It also aimed to explore how these needs change over time, and what support provisions families perceived to be helpful.

*Methods:* This was a systematic review using thematic synthesis methodology. Predefined searches were conducted in CINAHL, Medline, PsychINFO, SocIndex, EMbase, Academic Search Complete, EThOS and OpenGrey to locate studies published in English from 2000. Two reviewers screened each study against the inclusion criteria. Quality appraisal was undertaken using Joanna Briggs Institute tools. Extracted data were managed in Nvivo12® and analysed to identify descriptive and analytical themes. The Timing it Right Framework was used to frame changes in need across the recovery continuum.

*Results:* Twenty-nine studies were included, 22 qualitative, six quantitative and one mixed methods. Five key family needs were identified across the recovery continuum: for security; to make sense of the situation; finding a balance; holding everything together; and for trust.

*Discussion:* Families found the following interventions helpful: written information; care coordination and navigation; input from intensive care staff after discharge to support continuity; and provision of family support groups. Although there are similarities between the needs of families and survivors, there are sufficient differences to warrant the development of processes to identify and address family need throughout the recovery continuum.

*Conclusion:* More research is required to develop a tool to better identify the needs of families across the recovery continuum, identify gaps in current service provision, and design interventions to meet these needs.

Study registration: CRD42019136883 (PROSPERO)

**Keywords:** critical care, family, care-givers, social support, critical care outcomes.

#### **What is already known about the topic?**

- Critical illness has physical, cognitive and psychological consequences for survivors and their families
- Survivors' needs change across the recovery continuum
- Families frequently provide care and support to survivors throughout the illness and recovery journey

#### **What this paper adds**

- Families' support needs also change across the recovery continuum and include the need for security, the need to make sense of the situation, the need to find a balance, the need to hold everything together, and the need for trust in healthcare professionals
- Whilst survivors and family members often have overlapping needs, the need to hold everything together and the need for trust in healthcare professionals is unique to family members
- Families found the following interventions helpful: written information; care coordination and navigation; input from ICU staff after discharge to support continuity; and provision of family support groups

## 1. Introduction

Increasing numbers of individuals are surviving critical illness that involved an admission to an intensive care unit (ICU) (King *et al.*, 2019). Whilst surviving to ICU discharge was once used as a measure of success, there is growing awareness of the public health challenge associated with survivorship (Desai, Law and Needham, 2011; Kean *et al.*, 2017).

Surviving ICU can lead to a combination of short- and long-term complications. Physical impairments occur in over half of survivors and include neuromuscular weakness, decreased respiratory function and impairments in activities in daily living (Desai, Law and Needham, 2011). Psychological impairments, such as depression, anxiety and post-traumatic stress disorder (PTSD), are also common and affect up to 62% of survivors (Rawal, Yadav and Kumar, 2017). Cognitive impairments, such as memory and attention deficits can affect three-quarters of survivors at hospital discharge (Desai, Law and Needham, 2011). These impairments are collectively known as Post Intensive Care Syndrome (PICS) (Needham *et al.*, 2012). There are many risk factors for PICS including age, pre-ICU functioning, presence and duration of ICU delirium, severity of illness, impaired glucose regulation, sepsis, heavy sedation, delusional memories of ICU, agitation, and duration of ventilation (Desai, Law and Needham, 2011). PICS symptoms have been found to last from months to years (Rawal, Yadav and Kumar, 2017).

Experiencing an ICU admission can also have a significant psychosocial impact on family members, with up to 30% of family members displaying increased levels of anxiety, depression and PTSD (Davidson, Jones and Bienvenu, 2012; McPeake *et al.*, 2016; Rawal, Yadav and Kumar, 2017). These impairments are known as PICS-family (PICS-F). Risk factors include younger age, female sex, lower education, being the spouse, having comorbidities, or a history of anxiety, depression or severe mental illness (Inoue *et al.*, 2019; Lee *et al.*, 2019).

The evidence base on the support needs of patients surviving critical illness is increasing. For example, King *et al.* (2019) conducted a scoping review of the qualitative literature and identified patients' informational, emotional, instrumental, appraisal and spiritual needs across the recovery journey, which they subsequently mapped against the Timing it Right framework (Cameron and Gignac, 2008), to describe how these needs changed as survivors transitioned from intensive care to the home environment. Interventions developed to support survivors after critical illness have included the provision of written information (Davidson *et al.*, 2013; Desai, Law and Needham, 2011) and post-ICU clinics, post-ICU rehabilitation and peer support groups (Schofield-Robinson *et al.*, 2018).

The support needs of family members are also important as families frequently provide ongoing care and support throughout the illness and recovery journey (Nelderup and Samuelson, 2020). Despite increased awareness of PICS-F, searches of relevant databases suggest that to date, no synthesis of the support needs of family members exists.

The aim of this systematic review was to provide insight into the expressed support needs of families of adults who have survived an admission to ICU and who return to a home environment, and to explore how these needs change over time. This will enable interventions to be designed to reduce the incidence and severity of PICS-F. Within this review, family was defined as anyone who the patient identified as such, and will be referred to as ‘families’ or ‘family members’ throughout. The term ‘survivor’ is used to describe an adult who has survived a critical illness which involved admission to an ICU for any length of time.

## **2. Methods**

This qualitative systematic review follows the Joanna Briggs Institute (JBI) guidelines (Lockwood *et al.*, 2017) and reporting guidance from the Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) statement (Tong *et al.*, 2012). The protocol was registered with the PROSPERO database (ref: CRD42019136883).

### **2.1 Eligibility criteria**

Inclusion criteria included adult family of adults surviving admission to non-psychiatric ICUs with an explicit expression of need. All research designs (qualitative, quantitative or mixed-methods) were included, which fitted with the principles of a systematic and critical approach within thematic synthesis (Thomas and Harden, 2008). Papers published after 2000 were included to reflect improvements in critical care survival rates since the turn of the century (Desai, Law and Needham, 2011) and recognition of the ongoing challenges of recovery after critical illness (Davidson and Harvey, 2016). For pragmatic purposes, only studies with full text available without cost and published in English were included.

### **2.2 Information sources**

CINAHL, Medline, PsychINFO, SocIndex, EMBASE and Academic Search Complete were searched through EBSCOHost. Theses, conference papers and research reports not published in academic journals were searched through EthOS and Open Grey databases. Citation searching of included studies was undertaken to identify additional studies not captured during the search process (Tong *et al.*, 2012).

### 2.3 Search strategy

For maximum sensitivity, individual searches of each database using a list of search terms derived from the research objectives and including a combination of synonyms, truncations and the Boolean operators AND and OR, and subject headings, MeSH terms and thesaurus were conducted on 30/06/2019. The full search from Medline is included in Supplementary materials.

### 2.4 Study selection

A two-stage screening process was undertaken using Rayyan®, a software package for study screening and selection (Ouzzani *et al.*, 2016). Screening of title and abstracts was undertaken by two reviewers (KM and either CM or LMA) to identify studies matching the inclusion/exclusion criteria. Any discrepancies were resolved through consensus. Full-text copies of the remaining studies were retrieved and assessed for eligibility, again by two authors. Agreement for inclusion was determined by all authors in the case of conflict.

### 2.5 Quality appraisal

Assessment of study quality was undertaken using either the appropriate JBI Quality Appraisal (QA) tool (Lockwood *et al.*, 2017; Moola *et al.*, 2017) or the Mixed Methods Appraisal Tool (MMAT) (Hong *et al.*, 2018). The former was chosen as JBI was the only organisation providing tools for all study types except mixed methods studies. The MMAT was selected as it is one of very few QA tools for mixed methods studies. Where only one component of mixed methods studies (either quantitative or qualitative) met the inclusion criteria, QA was undertaken using the relevant JBI QA tool for that component. All studies, regardless of quality, were included in the review to ensure all relevant data were synthesised, however, the appraisals allowed identification and comment on the quality of each study and how this may have affected their contribution to the synthesis (Tong *et al.*, 2012).

To promote rigour, studies were initially independently appraised by KM, LMA and CM, with appraisals compared. Acceptable inter-rater reliability was achieved after four studies. Thereafter, KM undertook QA of all studies.

### 2.6 Data extraction and synthesis

Relevant data were extracted by KM into a custom-built Microsoft Access® database. This included study details (e.g. aims, context, methodology and findings) and quality assessment information. Findings included data related to need presented in the 'results' or 'findings' sections of the included studies. Indicative quotes and associated themes had to include explicit expression of need, not implied or extrapolated from data (e.g. satisfaction or "[intervention] was helpful" would not be

1 included). Where studies included support needs of survivors or families of non-survivors, they were  
2 included only if themes or indicative quotes were able to be identified and separated for each group.  
3

4 For quantitative studies or quantitative components of mixed methods studies, any data from the  
5 'results' section relating to the expressed needs of at least half of respondents were included for  
6 thematic coding. Some examples included needs rated as 'important' or 'very important' by 50% or  
7 more of respondents or where the average score on a Likert scale was 2 or higher (where 1 was  
8 'most important') from a possible 4. This was a pragmatic decision based on varied reporting of data  
9 in those studies. Data were exported to NVivo 12®, a software programme designed for supporting  
10 synthesis of qualitative data (QSR International, 2018).  
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17 Extracted data were analysed using thematic synthesis (Thomas and Harden, 2008). This comprised  
18 three stages: line-by-line coding of findings for each study; codes organised into descriptive themes;  
19 and further interpretation of descriptive themes to develop analytical themes. The initial line-by-line  
20 coding overlapped with the development of descriptive themes as the process of coding often  
21 identifies various levels within the translation of concepts from one study to another. The third stage  
22 relied on the individual insights and judgement of KM, and led to the generation of new themes, in  
23 consultation with CM and LMA.  
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## 31 *2.7 Organisational Framework* 32

33 To support the analysis of data pertaining to how the support needs of families change as the  
34 patient moves through various care environments, the authors drew on the Timing it Right (TIR)  
35 conceptual framework (Cameron and Gignac, 2008). This framework was originally developed to  
36 identify the changing needs of caregivers of people with stroke across different care environments.  
37 It comprises five different phases of caregiver support: event/diagnosis, stabilisation, preparation,  
38 implementation and adaption. The framework has since been used to examine the experiences of  
39 survivors of Acute Respiratory Distress Syndrome (Lee *et al.*, 2009) and structure the findings of the  
40 aforementioned scoping review of ICU survivors' needs (King *et al.*, 2019). The phases of the  
41 framework correspond to the usual critical illness recovery continuum: admission to ICU  
42 (event/diagnosis); transfer to and treatment on a ward (stabilisation); preparation for discharge  
43 (preparation); and discharge home (implementation and adaptation) (Lee *et al.*, 2009; King *et al.*,  
44 2019).  
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### 3. Results

#### 3.1 Search results

The literature search identified 6216 studies, of which 29 were included in the review (see PRISMA Flow Diagram – Figure 1) after removing duplicates and applying the inclusion and exclusion criteria.

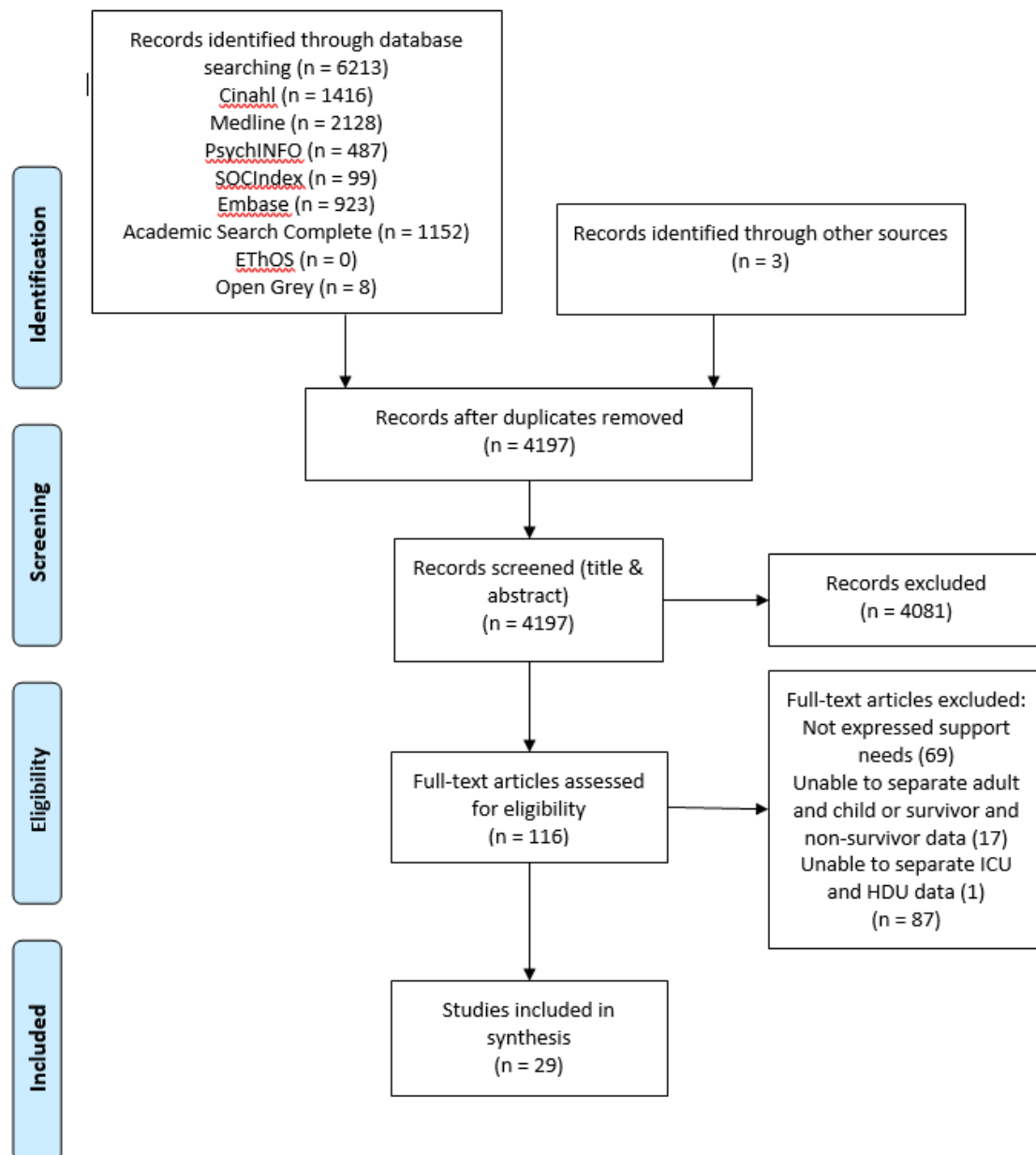


Figure 1. PRISMA Flowchart of study search, screening and selection

#### 3.2 Study characteristics

There were 22 qualitative studies, six quantitative studies and one mixed methods study (Table 1).

There were 700 participants in total; sample sizes ranged from six to 230, with Kirshbaum-Moriah, Harel and Benbishty (2018) not stating their sample size. Different sampling strategies included: convenience (n = 16), purposive (n = 8), theoretical (n = 2), snowball (n = 1) or self-identification (n = 1). Choi *et al.*, (2018) did not state the method of obtaining their sample population.

Studies were conducted in Sweden (n = 6), USA (n = 4), Canada (n = 3), Norway (n = 3), Australia (n = 2), and Colombia (n = 2). One study each was from Denmark, Greece, Iran, Israel, Taiwan and the UK. Two were undertaken across two countries (Denmark and Sweden, and UK and USA).

Qualitative studies used either thematic or content analysis (n = 12), grounded theory (n = 2), interpretive description (n = 2), phenomenological interpretive designs (n = 2), hermeneutic phenomenology (n = 2), framework analysis (n = 1), or descriptive case study methodology (n = 1).

The quantitative studies incorporated either cohort (n = 3) or cross-sectional (n = 3) designs.

Studies took place at either a single point or multiple points along the TIR continuum, up to two years post-hospital discharge (Table 1).

| First author     | Date | Event | Stabilisation | Preparation | Implementation | Adaptation |
|------------------|------|-------|---------------|-------------|----------------|------------|
| Auerbach         | 2005 |       |               |             |                |            |
| Chatzaki         | 2012 |       |               |             |                |            |
| Hart             | 2013 |       |               |             |                |            |
| Kirshbaum-Moriah | 2018 |       |               |             |                |            |
| Maxwell          | 2007 |       |               |             |                |            |
| Shorofi          | 2016 |       |               |             |                |            |
| Holm             | 2012 |       |               |             |                |            |
| Larsson          | 2013 |       |               |             |                |            |
| Keenan           | 2010 |       |               |             |                |            |
| Ågren            | 2009 |       |               |             |                |            |
| Czerwonka        | 2015 |       |               |             |                |            |
| Gallop           | 2015 |       |               |             |                |            |
| Gill             | 2016 |       |               |             |                |            |
| Haugdahl         | 2018 |       |               |             |                |            |
| Knudsen          | 2018 |       |               |             |                |            |
| Antonio          | 2018 |       |               |             |                |            |
| Chaboyer         | 2005 |       |               |             |                |            |
| Häggström        | 2014 |       |               |             |                |            |
| Herling          | 2019 |       |               |             |                |            |
| Paul             | 2004 |       |               |             |                |            |
| Aitken           | 2017 |       |               |             |                |            |
| Tsai             | 2015 |       |               |             |                |            |
| Choi             | 2018 |       |               |             |                |            |
| Comini           | 2016 |       |               |             |                |            |
| Engström         | 2008 |       |               |             |                |            |
| Frivold          | 2016 |       |               |             |                |            |
| Johansson        | 2004 |       |               |             |                |            |
| Tamayo Botero    | 2017 |       |               |             |                |            |
| Wallin           | 2013 |       |               |             |                |            |

Table 1: Study reported time periods according to Timing it Right Framework

### 3.3 Quality appraisal

Four studies were assessed as low quality, three medium, ten high, and 12 very high. Due to the range of potential scores associated with each different study type (between 8 and 17) scores were converted into percentages to allow better comparison and grouped accordingly. Very high-quality studies achieved a score of  $\geq 85\%$ , high-quality studies scored 70-84%, medium-quality 51-69% and low-quality  $\leq 50\%$  (Table 2). Full QA summaries are available in Supplementary materials.

| First Author<br>Year<br>Country | Approach                              | Primary aim of study                                                                                                                             | Sample | QA<br>score     | Data collection                                                |
|---------------------------------|---------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|--------|-----------------|----------------------------------------------------------------|
| Johansson<br>2004<br>Sweden     | Grounded<br>Theory                    | To generate a theoretical model about families' coping with an ICU survivor at home.                                                             | N=14   | 10/10<br>(100%) | Interviews 3-15 months after discharge                         |
| Paul<br>2004<br>UK              | Thematic<br>Analysis                  | To develop an evidence-based information booklet for patients and families preparing for transfer from ICU.                                      | N=7    | 9/10<br>(90%)   | Interviews on ward                                             |
| Auerbach<br>2005<br>USA         | Cohort                                | To assess families' satisfaction with needs met, acute stress disorder, perceptions of staff, optimism, and the relationships between these.     | N=40   | 1/11<br>(9%)    | Questionnaires on ICU & ward                                   |
| Chaboyer<br>2005<br>Australia   | Descriptive<br>Case Study             | To examine patient and family perceptions of ICU transfer, focusing specifically on those aspects of perceived as difficult or helpful.          | N=6    | 9/10<br>(90%)   | Focus groups 1 month after hospital discharge                  |
| Maxwell<br>2007<br>USA          | Mixed<br>Methods                      | Using the CCFNI, to explore differences between families' needs and perceptions of nurses, and how well needs were met.                          | N=20   | 10/17<br>(59%)  | Questionnaire in ICU                                           |
| Engström<br>2008<br>Sweden      | Thematic<br>Analysis                  | To describe how ICU survivors and families experience a post-discharge, follow-up visit to the ICU.                                              | N=9    | 8/10<br>(80%)   | Interviews 9-15 months after hospital discharge                |
| Ågren<br>2009<br>Sweden         | Grounded<br>Theory                    | To identify and conceptualise the needs of spouses of patients with complications of heart failure after cardiac surgery.                        | N=13   | 8/10<br>(80%)   | Interviews 3 weeks to 21 months after event                    |
| Keenan<br>2010<br>Canada        | Interpretive<br>Description           | To identify expressed needs of families or survivors of severe brain injury.                                                                     | N=25   | 7/10<br>(70%)   | Interviews on ward & on discharge from hospital                |
| Chatzaki<br>2012<br>Greece      | Cross-<br>sectional                   | To define families' needs, using the Critical Care Family Needs Inventory (CCFNI), in Crete, Greece.                                             | N=230  | 7/8<br>(87.5%)  | Questionnaire in ICU                                           |
| Holm<br>2012<br>Norway          | Phenomeno-<br>logical<br>Interpretive | To examine the experiences of partners of patients after cardiac arrest and subsequent ICU hypothermia treatment.                                | N=9    | 10/10<br>(100%) | Interviews 5-12 months after discharge                         |
| Hart<br>2013<br>USA             | Cross-<br>sectional                   | To explore family and nurse satisfaction with ICU visitation guidelines.                                                                         | N=104  | 3/8<br>(37.5%)  | Questionnaire on discharge to ward                             |
| Larsson<br>2013<br>Sweden       | Thematic<br>Analysis                  | To describe the hospital experiences of families of patients with cardiac arrest and subsequent ICU hypothermia treatment.                       | N=20   | 10/10<br>(100%) | Interviews on discharge from hospital                          |
| Wallin<br>2013<br>Sweden        | Thematic<br>Analysis                  | To describe families' support and information needs six months after the survival of cardiac arrest treated with therapeutic hypothermia in ICU. | N=20   | 8/10<br>(80%)   | Interviews 6 months after event                                |
| Häggström<br>2014<br>Sweden     | Mixed<br>methods                      | To investigate families' perceptions of quality of care during a patient's transfer from ICU to a general ward.                                  | N=65   | 7/10<br>(70%)   | Questionnaire 1-2 months after ICU discharge                   |
| Czerwonka<br>2015<br>Canada     | Framework<br>Methodology              | A pilot study to explore survivors' and families' needs throughout the recovery continuum using the Timing it Right framework.                   | N=7    | 8/10<br>(80%)   | Interviews 7 days and 3, 6, 12 & 24 months after ICU discharge |

|                                      |                                  |                                                                                                                                                  |                                        |                 |                                                                                        |
|--------------------------------------|----------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|-----------------|----------------------------------------------------------------------------------------|
| Gallop<br>2015<br>UK & USA           | Thematic<br>Analysis             | To explore the experiences and long-term impact of severe sepsis on survivors and their families.                                                | N=17<br>UK: N=10<br>USA: N=7           | 8/10<br>(80%)   | Interviews up to 12 months after ICU discharge                                         |
| Tsai<br>2015<br>Taiwan               | Cohort                           | To explore the changing needs of families of stroke patients and factors related to these up to three months after discharge home.               | N=60                                   | 5/11<br>(45%)   | Questionnaire on ICU discharge, hospital discharge, 2 weeks & 3 months after discharge |
| Comini<br>2016<br>Italy              | Cohort                           | To evaluate changes in families' burden and clinical and health-related quality of life outcomes over time for long-stay ICU survivors'.         | N=23<br>(stage 1)<br>N=16<br>(stage 2) | 6/11<br>(57%)   | Questionnaire on hospital discharge & 6 months later                                   |
| Frivold<br>2016<br>Norway            | Hermeneutic<br>Phenomenology     | To illuminate families' experiences of everyday life after a loved one's stay in an ICU.                                                         | N=9                                    | 9/10<br>(90%)   | Interviews 3-12 months after ICU discharge                                             |
| Gill<br>2016<br>Canada               | Thematic<br>Analysis             | To understand the experiences of ICU survivors and families, and identify improvement opportunities using a peer researcher approach.            | N=32                                   | 10/10<br>(100%) | Focus groups up to 24 months after ICU discharge                                       |
| Shorofi<br>2016<br>Iran              | Cross-sectional                  | To examine families' needs and the perceptions of nurses of these needs, using CCFNI.                                                            | N=80                                   | 6/8<br>(75%)    | Questionnaire in ICU                                                                   |
| Aitken<br>2017<br>Australia          | Mixed<br>methods                 | To elicit preferences of who wanted ICU diaries, what should be in them and in which format.                                                     | N=22                                   | 8/10<br>(80%)   | Interviews 3 to 5 months after ICU discharge                                           |
| Tamayo<br>Botero<br>2017<br>Columbia | Phenomenological<br>Interpretive | To understand the significance for families of caring for an individual at home after cardiovascular surgery.                                    | N=8                                    | 5/10<br>(50%)   | not stated                                                                             |
| Antonio<br>2018<br>Columbia          | Thematic<br>Analysis             | To understand the families' perspective of transition for patients discharged from ICU.                                                          | N=30                                   | 6/10<br>(60%)   | Interviews on ward                                                                     |
| Choi<br>2018<br>USA                  | Content<br>Analysis              | To longitudinally describe the varying challenges and needs of families of ICU survivors related to discharge home.                              | N=20                                   | 8/10<br>(80%)   | Interviews in ICU, and 2 weeks, 2 & 4 months after ICU discharge                       |
| Haugdahl<br>2018<br>Norway           | Hermeneutic<br>Phenomenology     | To explore families' experiences of long-term ICU patients' pathways towards survival .                                                          | N=13                                   | 9/10<br>(90%)   | Interviews 6-18 months after ICU discharge                                             |
| Kirshbaum-Moriah<br>2018<br>Israel   | Thematic<br>Analysis             | To investigate the experiences of family members participating in a nurse-social worker led ICU support group .                                  | Not stated                             | 9/10<br>(90%)   | Focus groups at home. Post-discharge period not stated                                 |
| Knudsen<br>2018<br>Denmark & Sweden  | Thematic<br>Analysis             | To explore families' experiences and coping strategies during the first six months after patient diagnosis of necrotising soft tissue infection. | N=25                                   | 9/10<br>(90%)   | Interviews 6 months after ICU discharge                                                |
| Herling<br>2019<br>Denmark           | Interpretive<br>Description      | To explore ICU survivors and families experiences of transition to hospital ward and identify ways to support.                                   | N=14                                   | 10/10<br>(100%) | Interviews up to 8 days after ICU discharge                                            |

Table 2: Summary of study characteristics

Weaknesses in the mixed method study included the qualitative component not answering the research questions and results not integrating qualitative and quantitative components. In cross-sectional studies, shortcomings included poor clarity around potential confounding factors and the absence of strategies to deal with confounding. No cohort studies were rated as high quality due to lack of clarity about whether follow-up was complete and what strategies were in place to address incomplete follow-up. Furthermore, no cohort studies included a comparison group without ICU admission. Within the qualitative studies, 14 had no clear identification of the influence of the researcher on the research and nine did not locate the researcher culturally or theoretically.

### *3.4 Results of synthesis*

Five key themes were identified: seeking security, making sense of the situation, finding a balance, holding everything together, and trust (Figure 2). Themes were dynamic with some interaction between aspects of each, however each theme is discussed in linear order. Indicative verbatim quotations are provided in table 3. Whilst including quotations from research participants has become standard practice in much qualitative research (Corden and Sainsbury, 2006) , in this review, one qualitative study (Paul, F., Hendry and Cabrelli, 2004) presented their findings without directly quoting participants.

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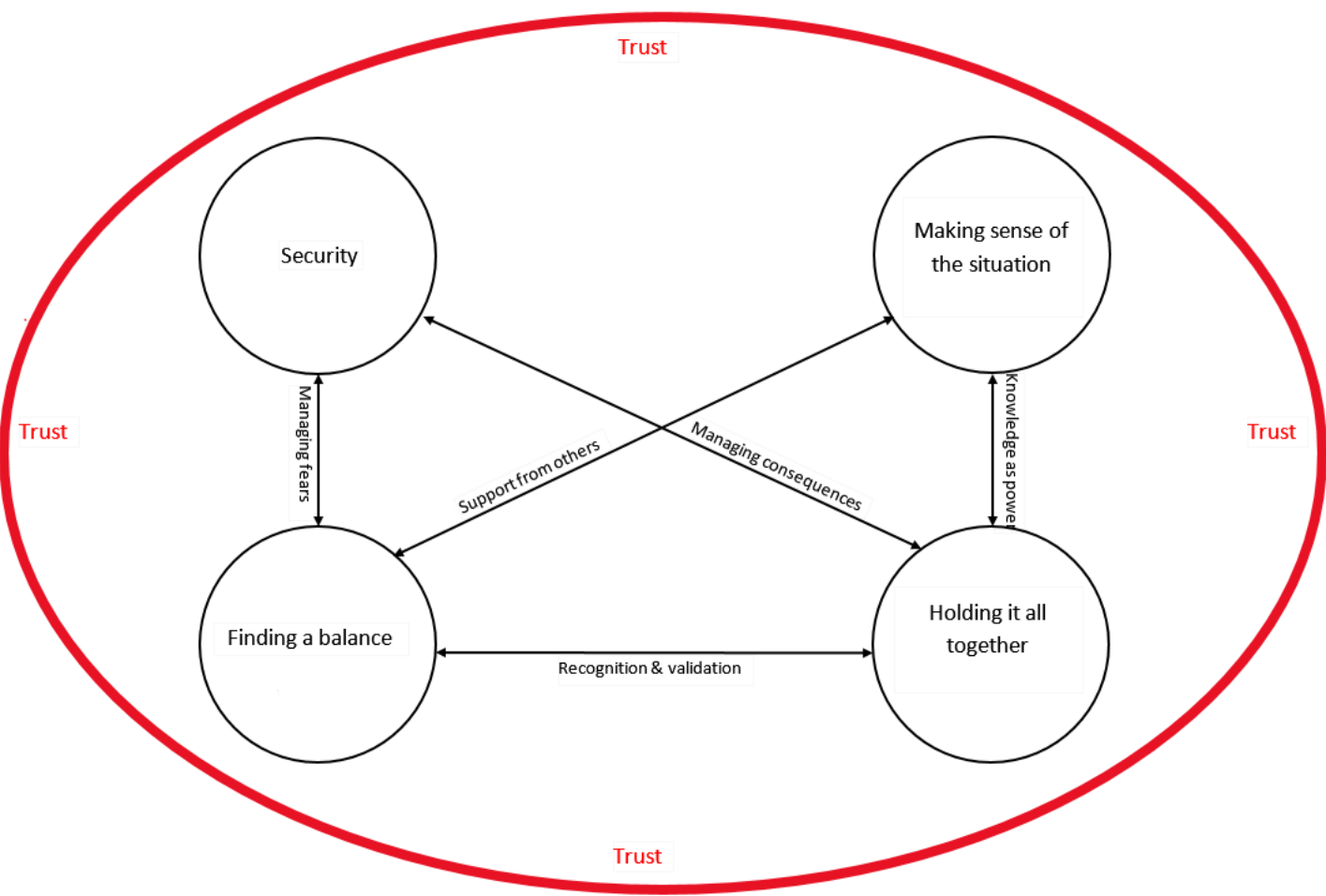


Figure 2: Graphical representation of key themes of family members' needs after critical illness

| Theme                         | Sub-theme                  | Indicative quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------|----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Seeking security              | Feeling safe               | <p><i>"It's one-on-one at ICU and on the ward you are just one in a million"</i>(pg.141) (Chaboyer et al., 2005).</p> <p><i>"we've had a battle with the District Nurses who should be here every day, only wanting to come every other day because of their costs, time and workload, etc., so it's just—it's not smooth sailing, is it?"</i>(pg.304) (Gallop et al., 2015)</p> <p><i>"The homecare nurse ... she came right over the next day ... after she left I knew everything would be okay"</i>(pg.245) (Czerwonka et al., 2015)</p>                                                                                                                                                                                                      |
|                               | Managing fears             | <p><i>"Are they sure that they are still going in the right direction? She still had infections that had not disappeared"</i>(pg.32) (Knudsen et al., 2018)</p> <p><i>"Is it acceptable to touch our loved one? If so how do we touch without disturbing the lines and wires? We are afraid of causing damage"</i> (pg.258) (Kirshbaum-Moriah, Harel and Benbenishty, 2018)</p> <p><i>"No one seems to know how long his condition is going to be the way it is or if it is ever going to be any different, if he's ever going to get better, or if he's just going to stay the same"</i>(pg.405) (Choi et al., 2018)</p>                                                                                                                         |
| Making sense of the situation | Knowledge as power         | <p><i>"most nurses offered explanations of procedures and equipment as they were working even without questions to prompt them"</i>(pg.374) (Maxwell, Stuenkel and Saylor, 2007)</p> <p><i>"Yes, we had visiting nurses and others...we almost had to instruct them on what to do...none of them knew what had been wrong with my mother when they came here, but of course, nobody knows (the disease)"</i>(pg.33) (Knudsen et al., 2018).</p>                                                                                                                                                                                                                                                                                                   |
|                               | Getting support            | <i>"talking with friends, a social welfare officer, psychologist or hospital chaplain was not always enough"</i> (pg.1643) (Wallin et al., 2013)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Finding a balance             | Being close                | <p><i>"They [the ICU staff] were wonderful, and I was allowed to be there as long as I wanted"</i>(pg.131) (Häggström, Asplund and Kristiansen, 2014)</p> <p><i>"He couldn't do anything himself- it was just terrible - nine weeks with one-on-one care and then he was put in a ward with six people!"</i>(pg.141) (Chaboyer et al., 2005)</p> <p><i>"When I wake up in the morning the first thing I do is see if she is alright"</i>(pg.245) (Czerwonka et al., 2015)</p> <p><i>"My mother stopped working and decided to take care of him all the time"</i>(pg.236) (Tamayo Botero, 2017)</p>                                                                                                                                                |
|                               | Recognition and validation | <i>"My kids wanted me to decorate the house for Christmas and I...didn't want to do that...my husband is in a hospital room and I'm in this beautiful home and all nicely decorated."</i> (pg.32) (Keenan and Joseph, 2010)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Holding it together           | Being the bridge           | <i>"I don't want to be a nag, but I want to try to give him a realistic picture of where he is at and where he is going"</i> (pg.405) (Choi et al., 2018)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|                               | Managing the consequences  | <p><i>"The fact that the insurance company has been there...because otherwise, financially speaking,...we don't know how we'd handle it."</i>(pg.33) (Keenan and Joseph, 2010)</p> <p><i>"[I'm still doing more than before], but now it's kind of getting easier because [my husband] is able to help me out now"</i>(pg.245) (Czerwonka et al., 2015)</p> <p><i>"Certainly the brother I knew doesn't exist anymore...whenever my brother comes out of it (coma), I will be meeting my brother all over again"</i>(pg.31) (Keenan and Joseph, 2010)</p> <p><i>"As the time has gone by, I shouldn't say their interest is less...I've indicated to them... 'please don't stop'...We need this support"</i>(pg.33) (Keenan and Joseph, 2010)</p> |
| Trust                         |                            | <p><i>"maybe it's mostly a question of how they care for the ill patient but it's so closely tied to how one is treated as a relative. I felt from the first moment that I was very secure in a way here because right from the start I got to be involved"</i> (pg.356) (Larsson et al., 2013).</p> <p><i>"The way they communicate with you. Those are all huge (emphasis) things that reduce the stress and involve you in the care"</i>(pg.32) (Keenan and Joseph, 2010)</p> <p><i>"We camped out for nine days—we took over the waiting room...We had no trust"</i>(pg.9) (Gill et al., 2016)</p>                                                                                                                                            |

Table 3: Indicative quotes to illustrate themes

### 3.4.1 Seeking security

Families felt uncertain and afraid due to the sudden change in their circumstances caused by the survivors' critical illness. As such, they sought security, a state of being free from danger of threat. Two subthemes were identified: feeling safe and managing fears.

#### 3.4.1.1 Feeling safe

When in the ICU, although afraid, families felt safe because the survivor was closely monitored with staff visibly present and responsive to signs of deterioration, and families were encouraged to be involved in decision-making (Maxwell, Stuenkel and Saylor, 2007; Agren *et al.*, 2009). Once discharged to the ward (stabilisation) this sense of safety frequently turned to one of abandonment as the survivor was seen as one of many, often in a room with other patients (Czerwonka *et al.*, 2015; Antonio *et al.*, 2018; Herling *et al.*, 2019). At the same time, families felt excluded from decision-making as health professions started to make decisions with the survivor alone (Chaboyer *et al.*, 2005; Czerwonka *et al.*, 2015; Herling *et al.*, 2019). This sense of abandonment usually decreased as families adjusted to lower levels of monitoring and survivors progressed in their recovery. In the weeks after discharge home (implementation), feelings of abandonment and insecurity often returned as families adjusted to being at home without the constant presence of health professionals. In some cases, this was exacerbated by perceptions of availability and accessibility of community services (Gallop *et al.*, 2015). Feelings of abandonment were lessened during periods of transition by early and obvious follow-up such as ICU staff visiting the survivor on the ward (Engström, Andersson and Söderberg, 2008; Häggström, Asplund and Kristiansen, 2014; Czerwonka *et al.*, 2015) and timely input by community nursing staff (Czerwonka *et al.*, 2015).

#### 3.4.1.2 Managing fears

Fears predominantly related to prognosis and not knowing what was happening or might happen. In ICU (event) families feared the survivor would die and worried this would happen when they were not at the bedside (Agren *et al.*, 2009). Once discharged from ICU (stabilisation), fear of dying shifted to a fear of relapse (Knudsen *et al.*, 2018). This fear continued for up to a year after discharge (Choi *et al.*, 2018). Fear of the unknown was highest during the first three stages (event, stabilisation and preparation) but decreased after discharge, although remaining present. In ICU (event), this fear often related to the unfamiliar physical environment (Kirshbaum-Moriah, Harel and Benbenishty,

2018). On the ward, fear of the unknown usually lessened once the survivor and family adjusted to the change of care setting and realised it was not as bad as anticipated (Häggström, Asplund and Kristiansen, 2014; Czerwonka *et al.*, 2015). During discharge planning (preparation) families expressed fears relating to not knowing how the survivor might manage at home (Wallin *et al.*, 2013; Choi *et al.*, 2018). Fear of the unknown incorporated the fear that the survivor would never fully recover (Choi *et al.*, 2018).

### 3.4.2 Making sense of the situation

The survivor's critical illness required family members to assume the role of caregiver. To make sense of the situation - to process and come to terms with changing family roles - they needed support and appropriate information. Two subthemes were identified: knowledge as power and getting support from others.

#### 3.4.2.1 Knowledge as power

Knowledge helped families understand what was happening and what might happen in the future (Auerbach *et al.*, 2005; Chatzaki *et al.*, 2012; Shorofi *et al.*, 2016). In ICU (event) and when stabilised on the ward, families wanted to know the prognosis and valued honesty from those looking after the survivor (Maxwell, Stuenkel and Saylor, 2007). As survivors moved towards and past discharge home, families' need for information shifted to needing to know the likely long-term effects.

Families felt access to information was greatest in the ICU with staff constantly available and responsive to questions (Agren *et al.*, 2009; Maxwell, Stuenkel and Saylor, 2007). On the ward, nurses were sometimes referred to as 'gatekeepers' of both information and access to doctors (Herling *et al.*, 2019). Poor access to information contributed to feelings of insecurity (Wallin *et al.*, 2013). Once the survivor moved to the ward, and then to home (stabilisation, implementation and adaptation), families reported different experiences, with some regarding community staff as knowledgeable (Czerwonka *et al.*, 2015) whilst others regarding them as less competent than those they encountered in ICU (Wallin *et al.*, 2013; Häggström, Asplund and Kristiansen, 2014). One area of frustration was lack of specialist knowledge on the survivor's condition (Knudsen *et al.*, 2018).

Families found that keeping written diaries or photographic records in ICU (Agren *et al.*, 2009; Aitken *et al.*, 2017; Knudsen *et al.*, 2018) or being provided with staff-completed diaries (Wallin *et al.*, 2013; Häggström, Asplund and Kristiansen, 2014) helped them make sense of the situation. They could refer to this material to aid their recall of information and events (Frivold, Slettebø and Dale, 2016). Families referred to the diaries on the ward and at home to help gauge recovery. When preparing for discharge and in the early stages of being back at home, families valued both the provision of

written information (Aitken *et al.*, 2017) and being able to talk alone to a nurse or doctor (Holm *et al.*, 2012; Czerwonka *et al.*, 2015).

#### 3.4.2.2 Getting support from others

Families needed support from others to help them make sense of the situation (Johansson, Fridlund and Hildingh, 2004; Agren *et al.*, 2009; Larsson *et al.*, 2013; Wallin *et al.*, 2013; Czerwonka *et al.*, 2015; Frivold, Slettebø and Dale, 2016; Tamayo Botero, 2017). Sometimes this support was from friends or other family members, at other times it was from religious figures, or members of the extended multidisciplinary team. The need for support was present along all stages of the TIR Framework; however, support from clinicians was considered especially important, particularly whilst in hospital (event, stabilisation and preparation) (Wallin *et al.*, 2013). Those who did not utilise healthcare-facilitated formal support services later wished they had (Keenan and Joseph, 2010).

#### 3.4.3 Finding a balance

Families needed to balance different, often competing, priorities throughout the continuum of the survivor's recovery. Two subthemes were identified: being close, and seeking recognition and validation.

##### 3.4.3.1 Being close

Families reportedly needed to be physically close to the survivor in ICU. When they were not with the survivor, they worried they might die alone or might wake to see only unfamiliar faces. Families wanted to remain within or close to the hospital so they could quickly attend if called upon (Agren *et al.*, 2009; Keenan and Joseph, 2010; Holm *et al.*, 2012). Closeness was facilitated by flexible visiting policies and comfortable waiting rooms with suitable seating, privacy and amenities (Auerbach *et al.*, 2005; Chatzaki *et al.*, 2012; Häggström, Asplund and Kristiansen, 2014; Maxwell, Stuenkel and Saylor, 2007; Shorofi *et al.*, 2016).

On the ward (stabilisation), particularly just after discharge from ICU when they were still making sense of the situation, families again felt the need to stay close to the survivor to ensure adequate monitoring and timely identification of signs of deterioration (Czerwonka *et al.*, 2015); (Chaboyer *et al.*, 2005; Häggström, Asplund and Kristiansen, 2014). This need decreased as the survivor became better able to identify and articulate their own needs (Chaboyer *et al.*, 2005).

Once discharged home (implementation), families once more felt the need for closeness due to an ongoing sense of responsibility for monitoring the survivor's wellbeing (Czerwonka *et al.*, 2015) and

1 coordinating their care, as well as providing assistance with activities of daily living (Johansson,  
2 Fridlund and Hildingh, 2004). As the survivor recovered and routines became established  
3 (adaptation), the need for closeness usually lessened (Wallin *et al.*, 2013; Czerwonka *et al.*, 2015;  
4 Choi *et al.*, 2018).  
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8 Across the TIR framework, the need for closeness often caused family members to suppress their  
9 own needs, which adversely impacted on their relationships with other family members, their ability  
10 to work or study, and their management of their own health (Johansson, Fridlund and Hildingh,  
11 2004; Agren *et al.*, 2009; Keenan and Joseph, 2010; Tamayo Botero, 2017). Some of those who  
12 suppressed their needs early in the process recognised that earlier acceptance of support may have  
13 enabled them to better balance competing demands (Keenan and Joseph, 2010; Frivold, Slettebø  
14 and Dale, 2016; Choi *et al.*, 2018). However, not everyone suppressed their own needs. As a result,  
15 some were able to find a balance earlier. One study found that during stabilisation families were  
16 already shifting their attentions back towards the wider family and their work commitments (Keenan  
17 and Joseph, 2010). By the time they were preparing for discharge, more families were less likely to  
18 suppress their own needs (Wallin *et al.*, 2013; Czerwonka *et al.*, 2015; Frivold, Slettebø and Dale,  
19 2016).  
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#### 22 3.4.3.2 Seeking recognition and validation 23 24

25 At the same time as needing to be close to the survivor, and despite often sacrificing their own  
26 routines, families also expressed a need to be recognised as individuals with their own lives and  
27 issues (Auerbach *et al.*, 2005; Chatzaki *et al.*, 2012; Häggström, Asplund and Kristiansen, 2014).  
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29 Across the TIR framework, the need for recognition could be met by the healthcare team taking an  
30 active interest in them and asking how they were coping (Auerbach *et al.*, 2005; Keenan and Joseph,  
31 2010; Wallin *et al.*, 2013; Frivold, Slettebø and Dale, 2016). The need for recognition and validation  
32 was especially apparent amongst those with health issues of their own (Chatzaki *et al.*, 2012) or with  
33 children (Agren *et al.*, 2009; Keenan and Joseph, 2010). However, the need for validation often  
34 resulted in families feeling guilty about putting their own needs before those of the survivor (Keenan  
35 and Joseph, 2010; Kirshbaum-Moriah, Harel and Benbenishty, 2018).  
36  
37

38 Some families found that as the survivor moved towards independence it was easier for them to find  
39 a balance (Czerwonka *et al.*, 2015). Acknowledging their own health needs and other responsibilities  
40 and accepting support from others helped this process and enabled families to find their inner  
41 strength and 'hold it together' (Johansson, Fridlund and Hildingh, 2004; Agren *et al.*, 2009; Frivold,  
42 Slettebø and Dale, 2016).  
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#### 3.4.4 Needing to hold it all together

Families talked about needing to hold everything together. Comprising some elements in common with needing security, making sense of the situation and finding a balance, this theme then draws on additional aspects and behaviours that allowed families to contain and control the new situation. Two sub-themes were identified: being the bridge, and managing the consequences.

##### 3.4.4.1 Being the bridge

Families took responsibility for sharing information and managing relationships between wider family and friends, particularly in ICU and shortly after discharge home. Where family dynamics were strained, family members found the bridging role more difficult (Keenan and Joseph, 2010; Kirshbaum-Moriah, Harel and Benbenishty, 2018).

If the survivor had sustained a significant brain injury, during event and stabilisation, and into preparation and implementation, families were the bridge between the survivor and professionals involved in their care. This was to ensure the survivor's wishes and previous activities or function were known (Keenan and Joseph, 2010; Frivold, Slettebø and Dale, 2016; Haugdahl *et al.*, 2018). Once on the ward (stabilisation), families also found themselves being the bridge by supporting the survivor to recall recent events (Engström, Andersson and Söderberg, 2008; Häggström, Asplund and Kristiansen, 2014; Frivold, Slettebø and Dale, 2016).

In all stages, families found themselves bridging communication from clinicians by supporting the survivor's rehabilitation - encouraging them to undertake activities to facilitate recovery. During implementation and adaptation families talked about the importance of reinforcing professional advice and pacing progress. Knowing what to expect as recovery progressed helped families undertake these bridging roles (Czerwonka *et al.*, 2015).

In addition to the above bridging activities, families were sometimes required to get involved in care tasks due to perceived or actual gaps in provision on the ward or access to services when home (Comini *et al.*, 2016; Tamayo Botero, 2017; Knudsen *et al.*, 2018). This was more prevalent in low- or middle-income countries (Tamayo Botero, 2017; Antonio *et al.*, 2018) but also found in high-income countries where specialist care was needed for uncommon conditions (Gallop *et al.*, 2015; Knudsen *et al.*, 2018).

##### 3.4.4.2 Managing the consequences

Critical illnesses had an impact on families' financial wellbeing in terms of loss of income and the costs of care. In relation to the former, during implementation and adaption, some family members

1 had stopping working (Tamayo Botero, 2017) and others had reduced their hours or retired early  
2 (Wallin *et al.*, 2013) because survivors had not returned to previous levels of function (Keenan and  
3 Joseph, 2010; Tsai *et al.*, 2015; Gill *et al.*, 2016; Choi *et al.*, 2018). In relation to the costs of care,  
4 families found dealing with insurance companies both challenging and helpful (Keenan and Joseph,  
5 2010).  
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10 Survivors' care needs also impacted on family members having to take on additional responsibilities  
11 at home (Czerwonka *et al.*, 2015). Families needed to manage relationship changes after the  
12 survivor's injury which sometimes affected personality and their role within the family (Keenan and  
13 Joseph, 2010; Knudsen *et al.*, 2018). The impact of critical illness also affected relationships with  
14 families or friends (Keenan and Joseph, 2010). This links to the need for validation experienced by  
15 families, with awareness of the need to be recognised for the role they were undertaking.  
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#### 21 *3.4.5 Needing trust*

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24 The need for trust in healthcare professionals was threaded throughout the aforementioned themes  
25 and had a significant impact on how families' believed their needs were perceived and met  
26 (Johansson, Fridlund and Hildingh, 2004; Chatzaki *et al.*, 2012; Holm *et al.*, 2012; Häggström,  
27 Asplund and Kristiansen, 2014; Shorofi *et al.*, 2016; Haugdahl *et al.*, 2018). Trust affected families'  
28 experience of transitions in care, their perception of information provided to them, and their  
29 awareness of the type and extent of formal support offered (Keenan and Joseph, 2010; Czerwonka  
30 *et al.*, 2015). This then affected their ability to cope, and meet their emotional needs (Frivold,  
31 Slettebø and Dale, 2016). Trust was affected by perceived staff characteristics of compassion,  
32 approachability, and competence and the positivity of family members (Auerbach *et al.*, 2005;  
33 Keenan and Joseph, 2010; Larsson *et al.*, 2013).  
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42 Trust affected families' need for security. If practitioners were trusted it helped manage negative  
43 emotions. Families experienced less abandonment because they trusted care would be provided  
44 (Larsson *et al.*, 2013). Where families had greater optimism, they had less unmet need (Auerbach *et*  
45 *al.*, 2005).  
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50 Consistent, appropriate information from approachable and knowledgeable clinicians facilitated  
51 trust and helped families make sense of the current situation (Chatzaki *et al.*, 2012; Holm *et al.*,  
52 2012; Häggström, Asplund and Kristiansen, 2014; Gill *et al.*, 2016; Shorofi *et al.*, 2016; Haugdahl *et*  
53 *al.*, 2018). The availability and provision of appropriate support from staff aided acceptance.  
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58 The presence of trust supported families finding a balance. Where families did not trust the staff,  
59 they were more likely to need physical closeness to the survivor when in hospital (Gill *et al.*, 2016).  
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1 With trust, families felt more able to focus on other responsibilities or allow formal care to be used,  
2 particularly when at home. It also allowed honest sharing of families' own needs to ensure they did  
3 not feel resentful or overwhelmed by expectations of their input into the survivor's care (Wallin *et*  
4 *al.*, 2013; Antonio *et al.*, 2018; Choi *et al.*, 2018).  
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8 If trust was present between those providing care and families, being the bridge between health and  
9 social care staff felt less onerous as families believed key information was freely shared to them and  
10 other professionals (Czerwonka *et al.*, 2015; Gill *et al.*, 2016). Trust helped reduce anxieties and  
11 stress and this allowed for managing consequences to seem less burdensome (Häggström, Asplund  
12 and Kristiansen, 2014; Frivold, Slettebø and Dale, 2016; Aitken *et al.*, 2017).  
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#### 17 **4. Discussion**

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19 In this qualitative systematic review of 29 studies involving 700 participants, five themes were  
20 identified. These themes included: seeking security, making sense of the situation, finding a balance,  
21 holding everything together, and trust. These themes are used to discuss how the support needs  
22 change over time in relation to survivors' recovery and highlight support provisions perceived by  
23 families to be helpful.  
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##### 29 *4.1 Differences in family and survivor needs over time*

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31 Many needs expressed by families remained present throughout the recovery continuum, but the  
32 detail of what was needed changed. In many cases, these family needs paralleled survivors' needs as  
33 identified by King *et al.* (2019), but some differences were found. Key similarities included the need  
34 for closeness throughout the recovery continuum and for psychological support although, for  
35 families, this was related to seeking support for the survivor above themselves (Azoulay *et al.*, 2017;  
36 Choi *et al.*, 2018; Ewens, Hendricks and Sundin, 2018). Both survivors and families had insecurity  
37 after discharge home but families also had this need during preparation, linked to feeling  
38 overwhelmed and unprepared for perceived responsibility for the survivor at home (Paul, Fiona and  
39 Rattray, 2008; Choi *et al.*, 2018; King *et al.*, 2019). Areas where survivors' needs differed from  
40 families included the need for information to make sense of the situation and their fears of not being  
41 able to communicate, related to being critically unwell and ventilated in ICU (King *et al.*, 2019).  
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53 For both families and survivors, the nature of identified formal healthcare support changed  
54 throughout the recovery continuum. It moved from needing staff with specialist skills for managing  
55 life supporting therapies to people that could help them manage rehabilitation and recovery on the  
56 ward, in long term rehabilitation facilities and at home (Lee *et al.*, 2009; Chiang, 2011; King *et al.*,  
57 2019).  
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Families often sublimated their own needs in ICU to those of the survivor (Verhaeghe *et al.*, 2005) and this extended across the recovery continuum. Focusing on survivors' needs may enhance closeness and help families manage fears, particularly in the early stages of recovery (Nelderup and Samuelson, 2020) but conflicts with the need for recognition of themselves as individuals with health problems or other responsibilities. As survivors became more independent families were able to regain their own independence with resumption of own work and leisure activities (Chiang, 2011; Czerwonka *et al.*, 2015). This freedom supported families with finding a balance between their own and survivors' needs.

The need to hold everything together was unique to families but was reflected from the survivors' perspective as they needed family to help them fill in the pieces from being critically ill and communicate with various professionals on their behalf (King *et al.*, 2019). Survivors were cognizant of the additional burdens their critical illness placed on families in providing care or due to financial constraints (Maley *et al.*, 2016; King *et al.*, 2019).

For families, trust played a key role in how they perceived the success of discharges from one care setting to another. This was not identified in the review of survivors' needs but feelings of being neglected or isolated, not accessing specialist post-discharge support due to worrying that staff would be too busy, and the needs related to discharges highlight the importance of this (King *et al.*, 2019). Trust is not a concept commonly used in the literature but studies identifying barriers and enablers to transfers identify communication, emotional support and information provision as key factors (de Grood *et al.*, 2018; Donaghy *et al.*, 2018; Gotlib Conn *et al.*, 2018). These are factors identified within this review as affecting trust within families.

#### 4.2 What families found helpful

All the specific interventions or services identified by families as helpful had good communication as a core principle. This supported families' trust and reduced anxieties about transfers from one care environment to another. Families identified that a lack of knowledge and insensitivity to patient needs from ward staff exacerbated experience of poor transfers (Ramsay *et al.*, 2014; Herling *et al.*, 2019). Interventions provided when highly dependent survivors when first admitted to wards from ICU (de Grood *et al.*, 2018; Gotlib Conn *et al.*, 2018) are affected by resource constraints, including staffing levels. This problem continues through the patient journey and results in lack of funding for appropriate follow up care, support and information after discharge, thus contributing to poor experiences and outcomes for survivors and their families (Donaghy *et al.*, 2018; Ewens, Hendricks and Sundin, 2018).

Families found diaries and other forms of written information useful throughout the TIR framework. It gave them something to refer back to, particularly when access to formal support decreased. Previous studies show that survivors and families do not always retain verbal information (Verhaeghe *et al.*, 2005). Research being undertaken on structured discharge documentation supports consistency of information provision (Bench, Day and Griffiths, 2013) and the relationship of this to recovery and reduction in PICS symptoms (Bench *et al.*, 2015). The most appropriate format and use for diaries remains unclear, with inconsistent evidence of benefit across both survivors and families (Barreto *et al.*, 2019; Garrouste-Orgeas *et al.*, 2019; Halm, 2019).

Four studies, all from either Canada or Sweden, highlighted requests from families for a care coordinator (Engström, Andersson and Söderberg, 2008; Wallin *et al.*, 2013; Czerwonka *et al.*, 2015; Gill *et al.*, 2016). Families struggle to navigate complex care pathways (Funk, Dansereau and Novek, 2019). The prolonged recovery associated with critical illness leads to increased healthcare resource use including higher risk of hospital readmission (Lone *et al.*, 2013; Hua *et al.*, 2015; Ewens, Hendricks and Sundin, 2018), particularly for those with multimorbidity and polypharmacy (Donaghy *et al.*, 2018). Nursing care coordinators have been used for people with other complex needs with positive outcomes including reduced hospital readmissions (Joo and Liu, 2017; Breen *et al.*, 2018). Availability of this role may vary dependent on healthcare provision as not all countries have well developed community health and social care services.

Input from ICU staff when discharged to the ward and then having planned appointments on hospital discharge reduced anxieties and increased security for families. It helped them feel less burdened by being the bridge between the survivor and their experiences. ICU Liaison Nurses, Outreach teams and post-discharge ICU visits have been introduced in many high-income countries in response to this need (Chaboyer, 2006; Mehlhorn *et al.*, 2014; Ramsay *et al.*, 2014; Jensen *et al.*, 2015). These have benefits of supporting knowledge exchange between ward and ICU nurses and improving quality of care (Häggström *et al.*, 2018). They reduce the risk of survivors developing PTSD (Jensen *et al.*, 2015) and readmission to ICU (Niven, Bastos and Stelfox, 2014).

The review highlighted examples of both formal and informal support groups for families and requests for groups like those offered to survivors. Support groups or group rehabilitation are available to survivors and can have beneficial effects on psychological recovery (Ramsay, 2011). As families often experience similar psychological disturbances to survivors (Elliott *et al.*, 2014), it would be logical to assume that family support provision would have similar outcomes. Numerous peer support models, both face-to-face and online, are being developed to facilitate recovery for

1 survivors and families (McPeake *et al.*, 2019). However, the plethora of approaches available and the  
2 limited evidence to support efficacy (Haines *et al.*, 2018) makes it difficult to recommend one model.  
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4 There is good knowledge of factors affecting transfers from ICU and the impact on survivors and  
5 families (Chaboyer, 2006; Bench *et al.*, 2015). Research is now shifting towards identifying ways to  
6 facilitate transfer from hospital-based care to home or long term care facilities, to improve  
7 outcomes for survivors (de Grood *et al.*, 2018). Family support facilitates survivor recovery (Maley *et al.*,  
8 2016; Frivold *et al.*, 2017). Strategies to support families during discharge home could improve  
9 survivor outcomes indirectly through reducing carer stress and improving coping alongside meeting  
10 identified family needs (Donaghy *et al.*, 2018; Gotlib Conn *et al.*, 2018).  
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#### 17 *4.3 Implications for research and practice*

18 The focus of current research on families' needs is predominantly on ICU and transfers to wards or  
19 how they perceive the needs of survivors (Paul, Fiona and Rattray, 2008; Donaghy *et al.*, 2018; King  
20 *et al.*, 2019). Because the support needs of families change throughout the recovery continuum, a  
21 tool to identify areas of greatest family need at various stages in the survivor's recovery would help  
22 target appropriate services at the appropriate time. Classifying what services were available has the  
23 potential to assist in identifying gaps in provision and aid establishment of new services to address  
24 unmet needs.  
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33 There is a need to build awareness and knowledge amongst non-ICU staff about potential issues  
34 affecting recovery for survivors and their families. This is already being undertaken amongst ward  
35 staff in some settings (Häggström *et al.*, 2018; Kauppi, Proos and Olausson, 2018) but there is a gap  
36 in research relating to out-of-hospital care providers. Some initial work on information sharing has  
37 already been undertaken with General Practitioners (GPs) but this work is not universal (Bench,  
38 Cornish and Xyrichis, 2016). However, survivors and their families may have contact with other  
39 health and care providers such as community nursing teams, community rehabilitation services and  
40 home carers, rather than with the GP. Identification of whether there may be issues with knowledge  
41 of these staff groups about caring for survivors of critical illness and their families is urgently needed.  
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50 There is already an identified need for interventions and services which reduce the incidence and  
51 severity of PICS and PICS-F. This is exacerbated by the global Covid-19 pandemic. Mortality rates are  
52 estimated between one and seven percent of confirmed cases (Vincent and Taccone, 2020) and has  
53 resulted in increased healthcare utilisation. This included a need for ICU care in 4-12% of infected  
54 people in Europe (Phua *et al.*, 2020; World Health Organization Europe, 2020). It is estimated that  
55 approximately 50% of patients will survive to ICU discharge (Phua *et al.*, 2020). In the context of  
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higher incidence of mental health issues in the general population resulting from the pandemic (Usher, Durkin and Bhullar, 2020), reduced family visiting and involvement in the ICU due to infection control measures, and increased numbers of survivors, interventions that support families throughout the recovery continuum to reduce the incidence and impact of PICS-F are more important than ever.

#### *4.4 Strengths and limitations*

This review covered the entire continuum from ICU to after discharge home. It was not restricted to a single care setting or transition between two specified periods of care. Further, a comprehensive and systematic approach using thematic synthesis methodology maximised the robustness of this review. However, it is noted that the nature of undertaking thematic synthesis involves individual interpretation of the evidence. This introduces a risk of bias due to the researcher applying their own beliefs and previous experience. Rigor was generated through regular discussion and critique of the emerging themes by all authors.

A wide search strategy was used to increase the likelihood of identifying appropriate studies. Risk of publication bias was reduced by ensuring searches included two commonly used grey literature databases (EThOS and OpenGrey). However, the restriction of data inclusion to those themes and quotes with expressed need risks missing other valuable data where the need is implied rather than explicit.

This review only included studies published in English language and available in full text. Only including English language publications risks missing other needs based on culture and different health care systems.

### **5. Conclusion**

Families have five needs throughout the recovery continuum: for security; to make sense of the situation; to find a balance; to hold everything together; and for trust. There are similarities between the needs of families and survivors but enough differences that tools to identify changing family need should be developed.

Families found the following interventions helpful: written information; care coordination and navigation; input from ICU staff after discharge to support continuity; and provision of family support groups. Some of these interventions are well established but more development of service provision and associated research is required to fill gaps in service provision for families of ICU

survivors. Interventions to increase awareness of families' needs in out of hospital environments  
may have benefit in reducing and addressing families' needs.

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None declared.

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