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REVIEW

What measures have been used to explore the outcomes of family members of critically ill patients: a scoping review

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Abstract

Background: Family members of critically ill patients are known to experience short and longer term challenges, including emotional and social problems. To undertake robust future interventional research to support this cohort, we undertook a comprehensive evaluation of the measures used in family outcome research to date.

Design: Scoping review. We searched Medline, PsycINFO, Scopus, CINAHL, and Web of Science (core collection) for articles published between 2000 and 2024 which examined the outcomes of family members of critically ill patients. Data on outcome measures, study design, and population characteristics were extracted from eligible studies.

Results: We reviewed 9873 abstracts and identified 388 eligible unique family member cohorts. Across these studies, there were 59 (15.2%) randomised control trials, 287 (74.0%) observational cohorts, 8 (2.1%) quality improvement programmes, and 34 (8.8%) non-randomised controlled interventional studies. Most research was undertaken in USA, Canada, and Europe ($n=264$, 67.5%). A total of 218 different outcomes measures were used across the studies included. In this review, 345 (89%) studies measured emotional or psychological outcomes, 85 (22%) measured family experience outcomes, 65 (17%) measured general functional status, quality of life or well-being outcomes, 35 (9%) measured environmental or social outcomes, and 10 (3%) measured cognitive outcomes.

Conclusions: We identified 388 studies which reported the outcomes of family members of critically ill patients. Over 200 different outcomes measures were utilised, exploring conceptual domains such as quality of life as well as psychological and social outcomes. The majority of studies were observational in nature with variable follow-up timelines. This review has highlighted that a core outcome measure set is essential to enable reliable, robust, and comparable interventional research in this area.

Keywords: Critical illness, Family, Outcome assessment, Scoping review, Caregivers

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Background

The provision of intensive care services and the number of people surviving a critical illness have increased steadily over recent decades [1, 2]. As a result, there is a greater understanding of the long-term challenges which survivors of critical illness face [3]. These challenges are complex and include physical, social, emotional, and cognitive issues [4, 5]. Psychological problems include anxiety, depression, and symptoms of Post-Traumatic Stress (PTSD). Physical challenges include chronic pain and mobility issues, whilst cognitive impairments in memory and executive functioning may affect almost half of survivors [6]. Ongoing impairments can have a significant impact for the individual as well as the healthcare system and society; up to 30% of survivors will need an unplanned hospital readmission in the 90 days following discharge and many will have significant ongoing social problems, such as reduced employment and increased dependency on state welfare [7–9]. Survivorship can also have a profound impact on the patient's close family and social network [10].

Family members of critically ill patients are also known to experience short- and long-term problems [11, 12]. These problems can be multi-dimensional and include social issues such as reduced employment and psychological problems such as Post-Traumatic Stress Disorder (PTSD) [8, 13]. In response to this evidence, professional organisations such as the Society of Critical Care Medicine have called for greater research in relation to patient and family outcomes [14] to ensure optimal care is delivered in a safe and effective manner. However, there is limited information or consensus on the outcomes and measures which should be examined in this research [15]. One step to address this is to develop a standardised group of outcome measure or a Core Outcome Measure Set.

Adopting a core and standardised set of outcomes in a particular research area has multiple benefits including enabling the comparison and synthesis of studies [16]. This approach also ensures that meaningful and relevant outcomes are incorporated into studies [17] and has been used in other areas in critical care, for example with survivors of Acute Respiratory Failure [3]. In creating a standardised set of outcomes, an important first step is an understanding and identifying the current tools and measures available, including the conceptual domains which they aim to cover [16]. A scoping review also helps determine the heterogeneity of reported outcomes; considered together with the views of key stakeholders (for example, family members, clinicians, and survivors) a scoping review underpins the establishment of candidate outcomes and domains for a Core Outcome Set (COS) [18].

To identify the current tools and measures used in research examining the outcomes of family members of critically ill patients, we undertook a comprehensive scoping review of published literature between 2000 and 2024.

Take-home message

Family members of critically patients are known to experience short and longer-term challenges. We reviewed 388 unique family member cohorts. A total of 218 different outcome measures were used to capture the outcomes of family members of critical care patients. A core outcome measure set could enable reliable, robust and comparable future interventional research in this area.

Methods

Study design

A scoping review was conducted, and the Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews (PRISMA-ScR) checklist was used to guide reporting [19] (electronic supplementary material 1). This approach was used as the purpose of scoping reviews is to map evidence on a topic and identify main concepts, theories, sources, and knowledge gaps in a systematic way [19]. This was a scoping review and involved no human participants; as such, no institutional ethical review was required.

Research question

What study measures have been used in research exploring the outcomes of family members of critically ill patients between 2000 and 2024?

The aim of this scoping review was to map the outcomes and measures which have been captured in the literature to understand the outcomes of family members of critically ill patients.

Identification of eligible studies

There were a broad range of terms used in the literature to describe our cohort of interest including family members, unpaid carers, informal carers, caregivers, and next of kin. We included cohorts, in line with previous definitions, who provided the majority of the financial, emotional, and physical support for the patient or the individual primarily responsible for caring for the patient on an unpaid basis [20]. We have utilised' family member' as an umbrella term throughout this manuscript. In addition to the concepts used to define the population, other search strategies included: mental health, psychological symptoms or stress, depression, anxiety, PTSD, employment, social work, welfare, strain, or burden.

We searched the databases Medline, PsycINFO, Scopus, CINAHL, and Web of Science (core collection) in May 2024 using keywords and medical subject headings (MeSH). We searched for articles published between 2000 and 2024. We choose a cut-off of 2000 as critical care practise changed in light of emerging data around for example long-term outcomes and practises related to sedation management, including the importance of family inclusion [21, 22]. The full search strategy is provided in electronic supplementary material 2. An experienced librarian (IK) designed and managed the search. All reference lists of included studies were searched for other potentially relevant studies. The search was limited to English-language publications.

Study selection

We included published studies which assessed the outcomes of family members or unpaid of critically ill patients. We included all articles examining outcomes across the critical care continuum, including those with outcomes during the critical care hospitalisation and after hospital discharge. All studies explored family member outcomes; only publications where family members of critically ill patients made up more than 50% of the study population were included, to ensure that the outcome measures collated were focussed on family members of critically ill patients.

We excluded studies which only assessed outcomes using qualitative methods (such as in-depth interviews with family members). We also excluded paediatric and neonatal populations, as their needs and experiences differ significantly. Specifically, the development of decision-making capacity, the role of parental support, and the impact of long-term sequelae on family functioning are unique to each group [23]. If a conference abstract was identified that appeared relevant, searches were made to identify a full manuscript; if no paper was found, the abstract was excluded. Commentaries, research protocols, case reports, literature reviews, and opinion pieces were also excluded.

Data abstraction

After de-duplication, two independent reviewers screened abstracts and full texts, with discrepancies resolved using consensus discussion (JM, VD, CB, PH, and FF). A third reviewer arbitrated conflicts when needed. All screening and data extraction activities were conducted using Covidence systematic review software [24].

Across the data extraction process, we noted several cohorts that had multiple publications associated with them. We included only one publication for each family cohort represented in the literature to enable representation of the literature to date. When multiple publications reported on the same family cohort, we grouped them into a single study to avoid double-counting outcomes. After merging these grouped studies under a primary reference, we systematically reviewed each publication to ensure that all reported outcomes were included in the analysis. This process was checked by two reviewers to ensure that no relevant data were missed.

Reviewers completed data extraction between September and December 2024. The reviewers met regularly to ensure a standardised approach to screening and data extraction.

For each eligible article, the following data were abstracted using a standardised data template which was piloted before use: publication year, study design, ICU population (for example, cardiac, neuro), population size, geographical location of study, and the outcome measurements used.

The conceptual domain of each measure was classified by two reviewers into one of the following pre-determined categories: cognition; general functional status, quality of life (QoL), or well-being; emotional/psychological; social and environmental; and family experience. These categories were derived through iterative discussion across the research team to identify broad

Table 1 Detailed description of definition of conceptual domains included in this analysis

Domain category	Description	Example
Cognition	The mental action or process of retrieving information	Memory, problem solving, or decision-making
General functional status or quality of life/well-being	The measure of overall health, comfort, or happiness of an individual	General health
Emotional/psychological	The measure of the strong feelings or states arising in the mind	Grief, burden, or anxiety
Social and environmental	The measure of factors relating to the surroundings or interaction with others	Social support, care roles, or ability to return to work
Family experience	The measure of events on family dynamics and relationships	Family needs or satisfaction

themes and thematic analysis of the outcome measures employed. A detailed description of each domain is provided in Table 1. Whilst some outcome measures could be classified under more than one conceptual domain (for example, sleep could be physical and psychological), to ensure clarity of reporting, we classified each outcome measure under one domain. Decisions around domain inclusion were discussed across the research team (including article review) for all measures included in this review.

Data synthesis

Study characteristics for categorical variables were summarised as percentages, and continuous variables as medians and interquartile ranges (IQRs). All descriptive statistics and plots were generated using R (version 4.3.2; R Core Team, Vienne, Austria).

To understand different populations and account for publication trends, we undertook several subgroup analyses. First, we explored publications related to COVID-19 cohorts given the significant change in hospital visitation and the subsequent potential impact on family members. To investigate the impact of COVID-19 as well as the publication of the Post-Intensive Care Syndrome-Family framework (PICS-F) in 2012 [12], we undertook an analysis to examine trends in outcome domains over three time periods based on study publication date. The time periods used were 2000–2012 (before the PICS-F framework), 2013–2020 (after the PICS-F framework and before COVID-19), and 2021–2024 (during/after COVID-19). A chi-squared test of independence was used to assess whether the proportion of studies reporting each domain differed significantly across the three time periods. Finally, we explored if there were any differences in the nature of outcomes for those publications which included bereaved family members, given the differences in experiences which this cohort of family members have.

Results

A total of 9937 nonduplicate citations were reviewed, of which 680 were selected for full-text screening (Fig. 1). Following review for inclusion by two independent reviewers, we found 410 eligible publications. Following review by two independent reviewers, a small number of publications which reported on the same family cohort were found. Following the identification of duplicate cohorts ($n=22$), 388 unique family cohorts were included in this analysis. Electronic supplementary material 3 provides a full reference list of the publications included in this review and electronic supplementary material 4 provides details of duplicate publications related to the same cohort of family members.

Study design and characteristics

Across the studies included, 59 (15.2%) were RCTs, 287 (74.0%) were observational cohort studies, 8 (2.1%) were quality improvement programmes and 34 (8.8%) were non-randomised controlled interventional study design. In total, 31 (8.0%) were related to COVID-19 populations, and 32 (8.2%) were studies of bereavement.

Of the 388 studies of unique family cohorts included, 71 (18.3%) were published before or during 2012 (before the PICS-F framework was published), 159 (40.1%) were published between 2013 and 2020 (after the PICS-F framework was published, and before COVID-19), and 158 (40.7%) during or after 2021 (during or after COVID-19). The overall median participant count was 90 (IQR: 54–170), with a median of 74 (IQR: 46–164) participants before or during 2012, 90 (IQR: 53–168) participants in studies published between 2013 and 2020, and 96 (IQR: 60–192) participants during or after 2021. A large proportion of research in this area was conducted in North America (n = 135, 34.8%) (Table 2).

Most studies ($n=239$) measured the outcomes of family members at one time point only. The median (IQR) time from critical care admission to the final outcome assessment was 0 months (0–3 months), with the longest follow-up time point being 48 months after critical care discharge. This indicates that outcomes were typically assessed only during the period of critical care or hospitalisation (0 months), with limited longitudinal follow-up assessments.

Outcome measures

Amongst the 388 eligible studies, 10 (2.6%) included at least one cognitive outcome; 65 (16.8%) included at least one general functional, QoL, or well-being outcome; 345 (88.9%) included at least one emotional/psychological outcome; 35 (9.0%) included at least one environmental or social outcome; and 85 (21.9%) included an outcome related to family experience. Overall, 254 (65.4%) studies measured a single domain and 134 (34.5%) measured two or more domains. Across these studies, 218 outcome measures were used.

The included outcome measures used a variety of different scales, including adjectival or Likert scales (i.e., unipolar or bipolar scales that uses descriptors along a continuum [25]) (67%), mixed scales (8%), dichotomous scales (6%), numerical rating scales (6%), visual analogue scales (6%), numerical scales (5%), and multiple-choice scales (2%). We were unable to assess the content of 2% of the measures used.

Psychological and emotional outcomes

In total, 345 (88.9%) publications included a psychological or emotional outcome measure, with a total of 127

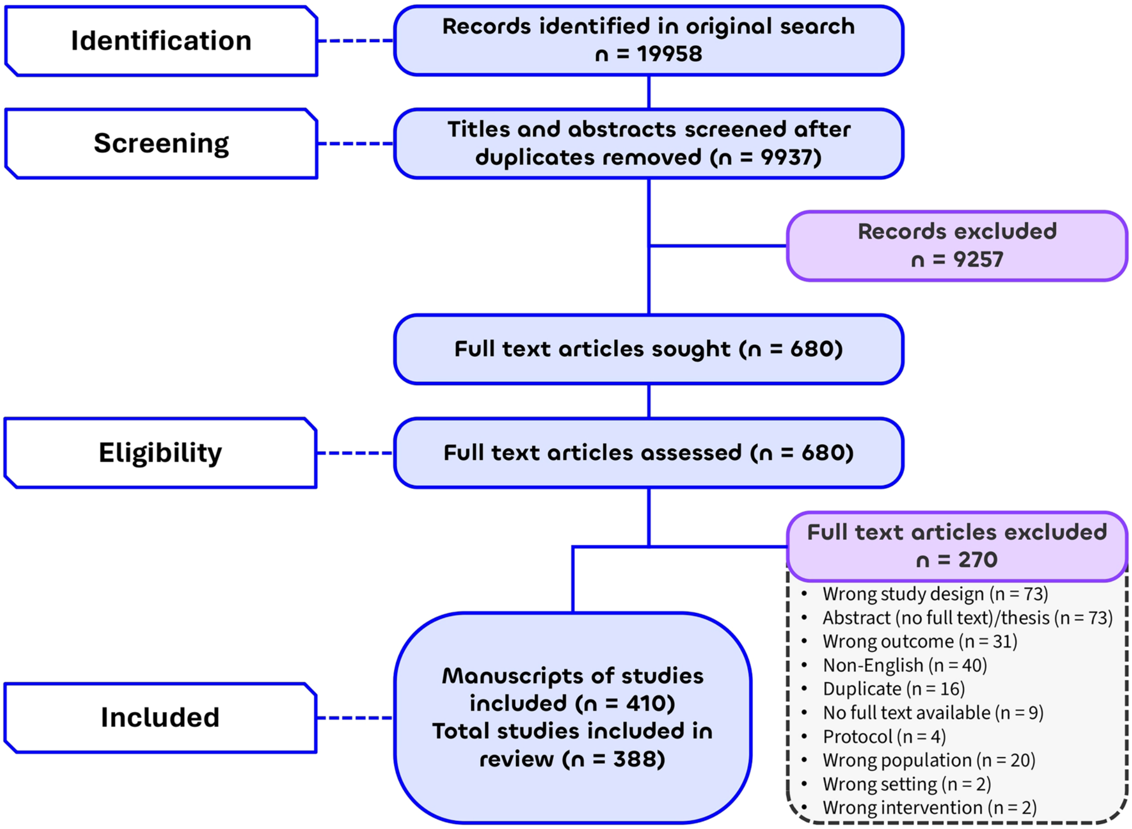

Fig.1 Flow diagram of study identification, screening, and inclusion process

outcome measures included. The most commonly utilised outcome measure was the Hospital Anxiety and Depression Scale (HADS) which was employed in 148 (38.1%) of studies [26]. PTSD was commonly measured, with 11 different outcomes measures utilised across 137 (35.3%) studies [27]. The most frequently utilised PTSD outcome measure was the Impact of Events Scale-Revised (IES-R), which was used in 91 (23.5%) studies (electronic supplementary material 5, Table 1).

Family experience

The final conceptual domain captured was family experience, which was included in 85 (21.9%) studies. In total, 25 different family experience outcome measures were used (electronic supplementary material 5, Table 2). The most common family experience outcome measure was the Critical Care Family Needs Inventory [28], employed in 30 (7.7%) studies, followed by the Family Satisfaction with the ICU Questionnaire in 27 (7.0%) studies [29].

General functional status, quality of life (QoL), or well-being

General functional ability, global QoL, and well-being measures were included in 65 (16.8%) eligible publications. In total, 32 different measures were used; the most common measure was the 36 Item Short Health Form which was used in 14 (3.6%) studies [30], followed by the EQ-5D which was used in 10 (2.6%) studies (electronic supplementary material 5, Table 3) [31].

Social and environmental outcomes

Social and environmental measures were captured in 35 (9.0%) studies. Across the eligible studies, 29 different outcome measures were included, which explored concepts such as return to employment and caregiving needs (electronic supplementary material 5, Table 4). The most commonly reported measure was the Medical Outcomes study Social Support Survey, which was used in 4 (1.0%) studies.

Table 2 Characteristics of included studies

Demographic		Total ($n = 388$)	Pre PICS-F framework publication (2000–2012) ($n = 71$)	Post PICS-F framework publication (2013–2020) ($n = 159$)	During and post COVID-19 (2021–2024) ($n = 158$)
Study design	Observational	287 (74.0%)	59 (83.10%)	116 (72.96%)	112 (70.89%)
	RCT	59 (15.2%)	4 (5.63%)	25 (15.72%)	30 (18.99%)
	Non- randomised intervention study	34 (8.8%)	8 (11.27%)	13 (8.18%)	13 (8.23%)
	Quality improvement programme	8 (2.1%)	0 (0.00%)	5 (3.14%)	3 (1.90%)
Median no. of participants (IQR)		90 (54—170)	74 (46—164)	90 (53—168)	96 (60—192)
Location of study	North America	135 (34.8%)	33 (46.48%)	66 (41.51%)	36 (22.78%)
	South America	25 (6.4%)	3 (4.23%)	13 (8.18%)	9 (5.70%)
	Europe	126 (32.8%)	24 (33.80%)	44 (27.67%)	58 (36.71%)
	Asia	85 (21.9%)	6 (8.45%)	28 (17.61%)	51 (32.28%)
	Africa	3 (0.8%)	0 (0.00%)	2 (1.26%)	1 (0.63%)
	Australia	12 (3.1%)	5 (7.04%)	4 (2.52%)	3 (1.90%)
	Cross-continental	2 (0.5%)	0 (0.00%)	2 (1.26%)	0 (0.00%)
Population type	Mixed general population	263 (67.9%)	55 (77.46%)	116 (72.96%)	92 (58.23%)
	ARDS	6 (1.6%)	1 (1.41%)	3 (1.89%)	2 (1.27%)
	Cardiac	19 (4.9%)	0 (0.00%)	1 (0.63%)	0 (0.00%)
	COVID-19	31 (8.0%)	4 (5.63%)	9 (5.66%)	6 (3.80%)
	Delirium	3 (0.8%)	1 (1.41%)	0 (0.00%)	0 (0.00%)
	Neuro (surgical/trauma)	22 (5.7%)	0 (0.00%)	0 (0.00%)	31 (19.62%)
	Sepsis	8 (2.1%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
	Other/speciality populations	4 (1%)	0 (0.00%)	1 (0.63%)	2 (1.27%)
	Study of bereavement	32 (8.3%)	2 (2.82%)	11 (6.92%)	9 (5.70%)
First assessment undertaken during critical care admission		342 (88.1%)	63 (88.73%)	145 (91.19%)	134 (84.81%)

IQR interquartile range, *RCT* randomised control study, *ARDS* acute respiratory distress syndrome

Cognitive outcomes

Across the 10 (2.6%) publications which included a cognition measure, we found six different measures which explored cognition in family members. The most commonly reported measure was the Cognitive and Affective Mindfulness Scale-Revised, which was used in 5 (1.3%) studies [29] (electronic supplementary material 5, Table 5).

Subgroup analysis

COVID-19: Since 2020, there have been 31 studies (8.0% of all studies in this field published since 2000) related to family outcomes in the context of COVID-19. In this cohort, 31 different outcomes measures were used. Compared to studies not related to COVID-19, there was a notable reduction in the proportion of COVID-19 studies measuring outcomes in the experience conceptual domain (3% versus 24%), and an increase in the COVID-19 studies measuring outcomes in the psychological or emotional conceptual domain (100% versus 88%).

Bereavement: We found 32 (8.2%) publications which included family members who had experienced bereavement. In this cohort, 23 different outcome measures were used. Five tools were used to measure grief in this cohort, with the Inventory of Complicated Grief measure used most frequently ($n = 8$, 25.0% of bereavement studies) (electronic supplementary material 5, Table 1) [32].

Trends over time: Table 3 provides details of the representation of conceptual domains in the literature before and after both the publication of the PICS-F framework in 2012, and the COVID-19 pandemic. A chi-squared test of independence found no significant association between conceptual domain and time period ($p = 0.17$),

Table 3 Frequency of conceptual domains by time period

Conceptual domain	Pre PICS-F framework publication (2000–2012) (*n* = 71)	Post PICS-F framework publication (2013–2020) (*n* = 159)	During and post COVID-19 (2021–2024) (*n* = 158)
Psychological or emotional	61 (85.9%)	136 (85.5%)	148 (93.7%)
Experience	18 (25.4%)	36 (22.6%)	31 (19.6%)
General functional status and QOL	12 (16.9%)	26 (16.4%)	27 (17.1%)
Environmental or social	11 (15.5%)	12 (7.5%)	12 (7.6%)
Cognitive	1 (1.4%)	8 (5%)	1 (0.6%)

suggesting that the measurement of conceptual domains did not vary significantly over time.

Discussion

This scoping review of measures employed to evaluate the outcomes of family members of critically ill patients identified 388 unique family cohorts between 2000 and 2024. As far as we can establish, this is the most comprehensive review of family outcomes in the critical care literature to date. We found that most studies were conducted in the Global North and the use of emotional and psychological measures was most common, with nearly 90% of cohorts including at least one such measure. Overall, we found 218 outcome measures that have been used to assess family member outcomes. This scoping review will inform the process of establishing a core outcome set for studies family members of critically ill patients, providing an overview of the existing research.

The number of different outcome measures used across the conceptual domains varied significantly. Unsurprisingly, the main conceptual domain captured was the psychological or emotional category. This finding likely reflects the Society of Critical Care Medicine's 2012 Post-Intensive Care Syndrome-Family (PICS-F) Framework, which included an emotional domain in isolation to represent the potential issues which family members might encounter across the patient illness trajectory [12]. However, evidence over the last decade highlights that the trajectory of family members and informal carers is more complex than previously understood, with impairments experienced across multiple domains [10, 33]. There is need to actively consolidate learning about family member outcomes and experience and revise the PICS-F framework accordingly.

The use of over 200 outcome measures reflects the pressing need to develop a set of standardised outcome measures in this field. National and international groups have endeavoured to articulate best practises to enable optimal outcomes from critical illness for both patients and their families. Organisations, including the Society of Critical Care Medicine, the European Society of Intensive Care Medicine, and the Intensive Care Society, have overwhelmingly recommended that researchers standardise the use of outcomes across studies of critically ill populations to enable the synthesis of consistent outcome data necessary for meta-analysis to facilitate comparison across interventions, to gain understanding of their relative effectiveness and cost-effectiveness, and ultimately to improve outcomes [14, 34, 35]. Family members and informal carers can play a vital role in the recovery of patients following discharge from critical care; improving survival rates and increasing prevalence of multimorbidity and complex care needs mean that their input is more important than ever [36, 37]. Yet, if the contribution of families to recovery is to be valued and optimised, understanding the impacts on those family members is also crucial. Given the significant impact family members can have on the patient, and indeed the impact critical illness can have on family members, it is key that standardised outcomes are available in this area to guide treatment decisions and understand the impact of intervention testing.

Core outcome measure sets help ensure consistency, comparability, and relevance of outcomes across studies, improving evidence synthesis and decision-making [38]. Most importantly, outcome measure sets ensure that researchers include outcomes which are meaningful to the public. This scoping review has identified a clear need for a core outcome set in this area, in addition to the identification of existing measures utilised in research over the last two decades. The next step is to understand if any conceptual domains are missing from those which have been identified in the review through robust stakeholder engagement [39]. Following this, the most important outcomes are identified through approaches, such as the Delphi technique, nominal group technique, or consensus meetings [40]. Measures are then identified with a subsequent assessment of quality (including validity and reliability). The final step is piloting this standardised set in practise to ensure acceptability and feasibility.

Despite the growing evidence of the social and economic problems experienced by both patients and family members during and after critical illness [41, 42], only

35 (9%) studies captured outcomes in this conceptual domain. Without empirical data in this area, it will be difficult to understand how improvements can be made. A revised core outcome measure set should consider the importance of this domain carefully, including ways in which social challenges can be captured in a meaningful way.

This comprehensive scoping review, encompassing over 400 studies, significantly advances the field of critical care recovery by synthesising a vast body of evidence, mapping the landscape to ensure that future research is meaningful for people involved. Our team included multi-disciplinary content and methodological experts, ensuring a thorough and robust review process. We employed a systematic search strategy which was executed by an experienced medical librarian and used duplicate screening for abstracts and full-text review, ensuring independent scrutiny of all included cohorts.

However, we acknowledge several limitations. Despite the systematic approach to literature inclusion, eligible studies might have been inadvertently excluded. To minimise this risk, all abstracts and articles were reviewed by two reviewers independently. A further limitation is that we excluded articles which were not in English, clearly influencing the interpretation of these results and perhaps responsible for our finding that most research had taken place in the Global North. We also only included studies where greater than 50% of cohort were family members of critically ill patients, as such we may have excluded outcome measures used in broader populations. This analysis did not include paediatric populations, future research should explore outcomes and outcome measures in this population. We did not include studies that assessed family outcomes using qualitative methods. Although we acknowledge that qualitative methods are important to the development of valid and reliable outcomes, we limited this review to include only quantitative outcomes, because they can be compared, reviewed, and aggregated. Finally, although determining the frequency of use of outcome measures is relevant for mapping prior research and the design a core outcome set, rigorous evaluation of psychometric properties and feasibility of implementing the outcome measure is a critical next step. This requires intensive exploration, utilising established methodology to ensure that this is done in an accurate and comprehensive manner [43].

In conclusion, significant heterogeneity exists in how the outcomes of family members of critically ill patients are measured in the literature between 2000 and 2024. We found that 218 outcome measures were used, more than half of which captured emotional and psychological outcomes. This review has highlighted that there is a need to establish a common outcome set for the evaluation of family members' outcomes to ensure effective and consistent measurement.

Supplementary Information
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Data availability
All data included in this review is publicly available.

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