Adult patient and carer experiences of planning for hospital discharge after a major trauma event: a qualitative systematic review

Jeanette Collins

Thesis submitted as fulfilment for the
award of Master of Clinical Science
The University of Adelaide and JBI
November 2021

Table of Contents

Acknowledgement

I would like to thank my primary supervisor Dr Lucylynn Lizarondo for her support and guidance throughout my attendance on the Masters of Clinical Science course and also Dr Kylie Porritt for agreeing to be part of my supervisory team part way through the course.

I also thank Ms Susan Taylor, my co-supervisor, who is also based in Perth. I am grateful for her expertise, contributions and continuous encouragement throughout my learning.

I would like to acknowledge Ms Elsie Patterson for her assistance with the critical appraisal of the specified papers. I appreciate the time she spent on reviewing the papers and her contributions in the ensuing discussion.

I would like to extend my thanks to the staff of the JBI and to Ms Vikki Langton, Librarian, and her colleagues at The University of Adelaide Library for fielding my questions in relation to search strategy, article retrieval and software support. Lastly, I would like to thank Ms Siew Siang Tay who undertook professional copyediting of this thesis in accordance with the Australian Standards of Editing Practice in a timely manner.

Thesis declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of The University of Adelaide and, where applicable, any partner institution responsible for the joint-award of the degree.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the library search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

This review fulfils the requirements for completion of a Master of Clinical Science degree for J. C.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Jeanette Marie Collins 1st November 2021

Abstract

Objective: The objective of this systematic review was to identify and synthesise the best available evidence on patient and carer experiences of hospital discharge planning after a major trauma event.

Introduction: Major trauma is an event that can affect anyone at any time in their lives despite their previous health status. Globally, it is a significant contributor towards disability, causing economic, social and emotional issues for the individual, carer and community. The transition from hospital to home after a traumatic event is an important stage for both patient and carer. The patient may be adjusting to a disability whilst attempting to settle into the community and participate in previous life roles. Their family members may have the increased responsibility of caring for their loved one, in addition to adopting life roles left unattended to by their injured relative.

Methods: The systematic review was conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence. Meta-aggregation was used to synthesise the evidence. The systematic review included qualitative studies that explored the experiences of adults (aged 18 to 65 years) and their carers related to hospital discharge planning following a major trauma event. Relevant studies were identified through a comprehensive search of relevant databases, including PubMed, Embase, Scopus, PsycINFO and CINAHL. Grey literature sources were also searched. JBI tools were used for methodological quality appraisal and data extraction. Extracted data were analysed and grouped into categories, from which a set of synthesised findings were developed, and which assisted in the creation of evidence-based recommendations for practice in discharge planning procedures following major trauma.

Results: Fourteen papers from 13 studies included data relating to patient and carer experiences of discharge planning (n= 389, 298 patients and 91 carers). A total of 49 findings were extracted and organised into ten categories. Four synthesised findings were developed from the categories: 1) Patients and carers feel generally unprepared to manage at home after discharge from hospital; 2) Early identification of patients' post discharge needs allows for appropriate referrals and supports to be organised prior to discharge; 3) Patients and carers value participation in the discharge planning process to facilitate an organised discharge from the hospital; 4) The timely presentation, delivery and relevancy of information impact how patients and carers manage their discharge.

Conclusion: The aggregation of findings from 14 published papers indicates that generally patients and carers do not have positive experiences in the discharge planning process following a major traumatic event. The synthesised qualitative data indicates that the application of patient- and family-centred principles will improve patient and carer participation and experiences of the discharge planning process. This approach will also provide skills to prepare patients for reintegrating successfully into the community. Future research is needed to investigate patient centred approaches in discharge planning for major trauma and neuro trauma patients and carers, and to investigate the viability of extending the trauma pathway from tertiary centres to the community.

Keywords

Patient experience; caregiver experience; discharge planning; major trauma; qualitative research

ConQual Summary of Findings table

Systematic review title: Adult patient and their carer experiences of planning for hospital discharge after a major trauma event: a qualitative systematic review					
Synthesised finding	Type of research	Dependability	Credibility	ConQual Score	Comments
1. Patients and carers feel generally unprepared to manage at home after discharge	Qualitative	Unchanged	Unchanged	High	Dependability: Unchanged. 5/7 publications scored 5/5 or 4/5. Of those which scored 4/5, two did not cite the researcher culturally or theoretically and two did not state the influence of the researcher on the study. The remaining 2 publications did not address the influence of the researcher or locate the researcher culturally. Credibility: Unchanged as 11 unequivocal (U) findings.
2. Early identification of patients' discharge needs allows for appropriate referrals and supports to be organised prior to discharge from hospital	Qualitative	Downgraded 1 level	Unchanged	Moderate	Dependability: Downgraded 1 level. 2/3 publications did not locate the researcher theoretically or culturally, or state the influence of the researcher on the study. Credibility: Unchanged. > 80% of unequivocal findings. 5 unequivocal (U) and 1 credible (C) findings.
3. Patients and carers value participation in the discharge planning process to facilitate an organised discharge from hospital	Qualitative	Unchanged	Unchanged	High	Dependability: Unchanged. 4/7 findings were extracted from publications that scored 5/5 or 4/5. The remaining 3 findings are from publications that did not locate the researcher culturally or theoretically, or report the influence of the researcher on the study Credibility: Unchanged. > 80% of unequivocal findings. 6 unequivocal (U) and 1 credible (C) findings
4. The timely presentation, language used and relevancy of information impact how patients and carers manage their discharge	Qualitative	Downgraded 1 level	Unchanged	Moderate	Dependability: Downgraded 1 level. 4/6 publications scored 3/5 as they did not locate the researcher theoretically or culturally, or report the influence of the researcher on the study. Credibility: Unchanged. > 80% of unequivocal findings. 11 unequivocal (U) and 1 credible (C) findings.

Abbreviations

TBI	Traumatic brain injury
SCI	Spinal cord injury
GCS	Glasgow Coma Scale
ASIA	American Spinal Injury Association
HRQoL	Health related quality of life
DALY	Disability life adjusted year
ISS	Injury Severity Score
WHO	World Health Organisation
SDM	Shared decision-making
HL	Health literacy
TeamSTEPPS	Team Strategies and Tools to Enhance Performance Patient Safety
OT	Occupational Therapist
VSTR	Victorian State Trauma Registry
VOTOR	Victorian Orthopaedic Trauma Outcomes Registry,
CT	Computerised Tomography
PTA	Post Traumatic Amnesia

List of tables

List of figures

Thesis structure

This thesis is organised into four chapters. The following is a brief outline of the purpose of each chapter.

Chapter 1: Introduction

The first chapter explores the concept of major trauma, which is discussed and defined within the context of current literature and how it relates to this systematic review. Discharge planning is considered a routine process but there is little awareness among healthcare professionals of the effects of poor discharge planning on patient and carer success at home. The importance of patients and carers receiving adequate hospital discharge planning is introduced, with discussion over how this process can affect the success of the patient and carer coping after discharge. Literature on the common factors contributing to poor discharge planning are listed, along with the social, medical and economic consequences when this process is lacking. As patients and carers who have experienced major trauma often experience life changing events, the value of and participation in beneficial discharge planning is investigated as a rationale for undertaking this systematic review.

The role of evidence-based healthcare is presented along with a discussion about the role of systematic reviews in research and in progressing healthcare delivery. The author's interest in the research topic is revealed, indicating the motivation for this research.

Chapter 2: Methods

The Methods chapter explains the research process in accordance with JBI methodology for qualitative systematic reviews. The inclusion criteria consisting of participants, phenomena of interest, context and types of studies are introduced, and the steps involved in the search strategy, study selection and critical appraisal are detailed. The data extraction process is explained, followed by the introduction of the meta-aggregation as an approach to data synthesis. Finally, the method for assessment of confidence in the systematic review findings is discussed.

Chapter 3: Results

The systematic review search results are documented alongside the methodological quality and characteristics of the relevant studies. The results of the meta-aggregation process are presented, including the synthesised findings, categories and findings with verbatim illustrations.

Chapter 4: Discussion and conclusion

An overview of the synthesised findings is discussed in the context of existing evidence and published literature regarding discharge planning relating to major trauma. The strengths and weaknesses of this systematic review are identified and debated. In this final chapter, conclusions drawn from the outcomes of the review are reported, along with recommendations for practice and future research.

Chapter 1: Introduction

This thesis presents a systematic review conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence, with meta-aggregation as the method of synthesis. The objective of the review was to explore the experiences of patients and carers during the hospital discharge planning process after they experience a major traumatic event.

Background

Major trauma is a leading cause of disability in the adult population, with far-reaching effects not only for the person and family involved but also local communities and society.[1] In 2016-2017, approximately 8400 people in Australia sustained an injury recorded as major trauma, with blunt trauma accounting for 95% of these injuries, and 44% of these injuries resulting from road and 'off-road' incidents.[2] As the general population is growing older, low falls (from standing and <1m) account for an increasing proportion of major trauma.[3] Other causes of major injury include high falls (>1m), pedal cyclist, pedestrian accidents and drownings.[4] The World Health Organization (WHO) uses the disability-adjusted life year (DALY) to measure the impact of disease and injury on the population. In 2019, road injury cost the global community 79,116 DALYs, followed by falls at 38,216,[5] demonstrating to different degrees the heavy impact of trauma on patients, their carers and healthcare systems.

Major trauma can cause different types of injuries, including burns, fractures, injuries to specific body parts (e.g. chest, abdomen, brain) that may affect the functioning of multiple body systems (e.g. neurological, respiratory).[6] Major trauma is also typically associated with admission to intensive care units for mechanical ventilation, serious injury to two or more body systems, and urgent surgery to address intracranial, intrathoracic or intra-abdominal injuries.[7] Major trauma to the central nervous system, such as traumatic brain injury (TBI) and spinal cord injury (SCI), often results in slower physical and cognitive recovery [8] and poorer functional outcomes [4] compared to other organ injuries, due to the limited ability of neural tissue to regenerate itself. A combination of brain and spinal injuries due to trauma further limit an individual's recovery from injury.[9]

The Injury Severity Score (ISS) [7] is one of the most commonly used scoring systems for trauma severity. The ISS has a range of 0-75 and is calculated by adding together the three highest squared scores from the Abbreviated Injury Scale (AIS). The AIS is a method of coding and rating sustained injuries where each injury is coded based on an internationally determined dictionary and injuries are rated between 1 (minor injury) to 6 (injury incompatible with life). The higher the ISS, the more severely a person is injured. However, if a person is given a AIS score of 6 in one body region, they automatically receive an ISS of 75.[10] Historically, there has been a lack of international agreement over what ISS score constitutes a major trauma. The European Trauma Registries indicates an ISS>16,[1,11] while the Australian Trauma Registry [6] stipulates an ISS >12, as major trauma. The Glasgow Coma Scale (GCS)[12] and the American Spinal Injury Association (ASIA) Impairment Scale[13] are also universally used to ascertain the severity of injury, however, they are specific to traumatic brain and spinal cord injury, respectively. As the definition of major trauma for research purposes is inconsistent, the authors of this paper decided to use one or more of the above-mentioned trauma severity measures to determine the presence of major trauma in study participants. The acceptable score for presence of major trauma by each trauma severity measure is explained in Chapter 2 under the 'Inclusion criteria' section.

Due to advances in trauma medicine, fatalities are decreasing which results in a greater number of survivors who experience persistent and ongoing disabilities.[14] This does challenges not only the survivor and carer but also the community and health care systems which are required to support the survivor's ongoing needs.[15] In a recent qualitative study, trauma survivors expressed an interruption to their daily routine and concerns for their futures. There was ongoing anxiety regarding pain, disability, mobility, work, housing and accommodation, social activities and finance up to three years post injury.[16] Major trauma also impacts on quality of life, with patients scoring below their pre-injury health-related quality of life (HRQoL) status at 24 months post injury, using a standardised scale.[17] Patients who experienced major trauma reported consistently low HRQoL three to four years post injury, with only 20% describing no presence of disability at this milestone post incident.[18,19] Self-perceived presence of disability has been shown to be present up to 15 years post injury, indicating the long-lasting effects of trauma past the initial admission and treatment.[20]

Informal or family caregivers play a significant role in the recovery of a major trauma survivor.[21] Sudden injury of a relative and the subsequent hospital admission often results in psychological distress and crises occurring within a family,[21] often leaving carers with limited time to adjust.[22] Due to limited resources available through health and local government systems, families are obliged to accept responsibility of providing care for their injured relative.[23,24] Leishout et al.[22] report that approximately two thirds of care for TBI survivors is provided by informal carers, mostly mothers. The responsibility of being a carer for individuals with complex social, emotional and financial needs posts major trauma, whilst balancing their own home and work commitments can be immense for the family caregiver.[22,25]

The provision of care to an injured relative is not without consequences to the carer's health,[26] relationships,[23] and home and work commitments.[25] This, in turn, may affect a carer's ability to provide enough quality care to their relative.[23] Charlifue et al.[25] identify that family carers feel 'on-call' most of the time as they attend to needs of their relative. As a result, there is a high incidence of psychological issues (e.g. depression, anxiety), carer burden and poor quality of life in family caregivers of individuals post major trauma.[22-27] Leishout et al.[22] report that family caregivers often report feelings of 'unpreparedness' for the carer role and do not associate themselves with this feeling until approximately three years after their relative's initial injury.

Discharge from hospital to home is a key stage for any patient in their recovery process. It is a complex transition that places patients at a 25% increased risk of encountering an adverse event such as medical deterioration resulting in hospital readmission.[28,29] Different tasks need to be coordinated between in-patient and community providers to ensure that patients receive adequate education and information to function effectively over the transition period.[30] Qualitative studies on patient and carer experiences in discharge planning from a variety of medical specialties identify themes such as lack of patient and carer preparation for discharge,[31] limited patient participation in the discharge planning process,[32] insufficient and inadequate provision of information pertaining to discharge advice,[31] and poor communication between tertiary and primary healthcare professionals.[31] As a result, patients and carers often experience anxiety and a feeling of abandonment after discharge.[32] Several qualitative studies have focused on major trauma patient and carer experiences of discharge planning, with study results reflecting those experiences from non-trauma specialities.[8,33,34,35,36,37] Most major trauma survivors have experienced an unexpected and abrupt event which impacts both their long-term physical, psychological health,[38] and financial wellbeing.[39] Family members are thrust into the caring role due to the lack of formal services available to care for patients with high care needs,[22] resulting in social isolation[27] and increased occurrences of depression[24] and carer stress.[25] This group of people have complex needs which increase their vulnerability during the discharge process and beyond.[40] As a comprehensive overview of these experiences is lacking in the literature, it is important that this research be conducted in order to understand how this stage of recovery is experienced and perceived by trauma patients and their carers in order to form recommendations for future service planning, clinical practice and research.

A preliminary search of PubMed, *JBI Evidence Synthesis* and the Cochrane Library identified two systematic reviews related to discharge planning. Picenna et al.[41] updated a qualitative systematic review originally conducted by Parkes and Sheppard[42] on the experiences of patients with an acquired brain injury (ABI) being discharged from an in-patient to a community setting. The review included patients (and carers) with an ABI as a result of stroke, brain tumours, infection, poisoning, lack of oxygen and degenerative disease, and discarded any papers that included patients with other injuries. Picenna et al.[41] identified 10 papers from nine qualitative studies that met the inclusion criteria of the paper. The authors included papers focusing on participants with ABI only excluding those papers with trauma related brain injuries. The second systematic review was an update of a systematic review on the effectiveness of discharge planning[43] for all types of patients discharged from hospital, irrespective of age, gender or condition, and included quantitative research only. The authors did not include any qualitative studies and therefore did not explore patient and carer experiences which this current systematic review focuses on. This thesis therefore aims to address these gaps by evaluating the best available qualitative evidence on patients' and carers' experiences of discharge planning after a major traumatic event by employing the JBI systematic review methodology.

Systematic review objective

The objective of this systematic review was to identify and synthesise the best available qualitative evidence on patient and carer experiences of hospital discharge planning after a major trauma event. It is hoped that the findings will provide an evidence base to guide policy and practice.

Evidence-based healthcare and the role of systematic reviews

As healthcare delivery develops and advances, there is an increasing emphasis on applying evidence to practice.[44] Sackett et al.[45] acknowledges the growing importance of and interest in evidence-based practice initially within the field of medicine. They provide a practical definition: 'evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about care of individual patients'.[45(p.71)] Sackett et al.[45] and Dawes et al.[4] consider that evidence is both clinical expertise developed over a professional's career and the best external evidence. External evidence comprises relevant clinical research which is scientifically based and client centred. Evidence-based practice is centred on addressing individual patients' predicaments, rights and preferences,[45] and recommends that those receiving care contribute towards decisions regarding their care.[44]

Sackett et al.[45] state that a clinician's expertise will decide whether the external evidence applies to an individual patient's situation but does not elaborate on the ability of the health professionals to assess the quality of evidence. Dawes et al.,[44] argue for health professionals to not only regularly access current research evidence to guide decision-making in healthcare delivery but have the ability to judge the quality of the research. They suggest that health professionals should be able to gain, assess, apply and integrate new knowledge. Training in such skills should be routinely included in all university health science curricula and available to health professionals currently working, with the aim of evidence-based practice being immersed in daily health service delivery.

Evidence-based practice and adequate clinical decision making requires access to the best available, current, valid and relevant research evidence.[44] However, with the increasing volume of research publications, accessing evidence-based practice has been perceived as a complex and challenging process as research is not always presented in a manner that is easily digestible and the time required to access and appraise research is often beyond what is available for busy healthcare practitioners.[44] Both Sackett et al.[45] and Dawes et al.[44] support the value of systematic reviews where the results of several studies are appraised and synthesised to produce evidence to guide practice. Traditionally, literature reviews amalgamate the outcomes of different research publications on a topic but as this approach follows no strict methodology, they are subjective, often relying on the author's knowledge, experience and preferences.[46] Also, literature reviews are challenging to replicate as they have no process to guide their formulation. Systematic reviews differ to literature reviews as they 'offer a ready and rigorous solution for decision makers to navigate their way to the best available evidence to inform their decision-making'.[47] (p.133) Systematic reviews are governed by strict methodologies and feature a clearly articulated objective and question, set of inclusion and exclusion criteria, a comprehensive search strategy to identify all relevant published and non-published studies, appraisal of these studies, analysis of extracted data, and presentation and synthesis of findings.[46] In essence, systematic reviews attempt to uncover all evidence, report data not theory, contain explicit and exhaustive reporting, and are conducted to the same rigour and standards as primary research.[46]

Originally, systematic reviews investigated questions on effectiveness which analysed quantitative data. However, as Munn et al.[48] explain, health professionals often have research questions that cannot be addressed by traditional quantitative methodologies. Sackett et al.[45] indicate that best external evidence should not be limited to randomised trials and meta-analyses but involve the search of the best external evidence from many different sources to answer the clinical question at hand. As a result, different systematic review methodologies have evolved and been accepted to support the various types of questions that emerge in evidence-based healthcare. JBI has developed stringent methodologies to guide the different types of evidence syntheses, including those of qualitative data. These methodologies are published in the JBI Manual of Evidence Synthesis.[49] Hall and Harvey[50] postulate that qualitative research allows in-depth investigation of certain research questions that a quantitative approach cannot answer. Draper[51] explains that one strength of qualitative research is its ability to understand patterns of human behaviour and how these influence health management, identify priorities and needs relevant to particular social and cultural contexts, and inform the design and implemention of interventions appropriate to the context. Qualitative research inherently has its roots in ontology (the study of being) and epistemology (understandings of the nature of knowledge),[52] and concentrates on participant narratives to deliver evidence in the form of meaning and understanding to investigate appropriate research questions. Ultimately qualitative research compliments[50] the objectivity and empiricism found in quantitative research.[51,53]

The question pertaining to this systematic review investigates the quality and nature of patient and carer experiences of discharge planning and what this means to them, therefore it is best addressed by applying a qualitative systematic review methodology.

Researcher's perspective and interest in the topic

I chose my research topic as I have an interest in the hospital discharge process and the need to embed evidence-based practices. I have previously worked as a hospital-based allied health professional and have contributed towards the discharge planning process for patients. I now work in an Early Supported Discharge service that rehabilitates patients, often with major traumatic injuries, in their home post hospital discharge. Adult patients who have experienced major trauma are vulnerable as they often have long-lasting physical, psychosocial and cognitive disabilities that prevent them from engaging in their previous life roles.[11] They are often reliant on family to assist them to succeed at home, a role which the family member is often obligated to undertake without the necessary healthcare skills or aptitude.

The International Centre for Allied Health Evidence based at the University of South Australia suggests that discharge planning can involve a range of organisational activities, which are usually instigated in hospital and continue into the community, in order to ensure that appropriate post-discharge supports are in place in a timely and effective manner.[56]

In reality, there are increasing financial constraints preventing delivery of adequate discharge planning in preparation for the transition from hospital to home. In many countries, facilitating early discharge of patients is used as a strategy to reduce costs and ease bed management pressures.[57] This may be beneficial for the hospital system, however, by reducing length of stay, the patient and carer have decreased exposure to health professional expertise and may be at risk of readmission as health needs and discharge information may not have been addressed.

There is a growing policy focus on collaboration between healthcare professionals and consumers to ensure that healthcare delivery is client centred. The National Safety and Quality in Healthcare Service (NSQHS) Australia has developed standards[58] to reflect this. The Partnering with Consumers Standard[58] discusses the benefits for consumers to participate in healthcare planning, design and delivery, and provides guidance for this approach to be implemented in practice. The Medication Safety Standard[58] and the Communication for Safety Standard also encourage partnerships between clinicians and consumers to minimise risks to patients and consumers. One aspect is to acknowledge that patients are partners in their own care, which implies that patients are empowered and have influence over their healthcare. Today, as the average length of hospital stay is decreasing, there is potentially less opportunity for clinicians and consumers to engage in shared communication, planning and decision-making.

Rather than investigating clinicians’ perspectives on their role in discharge planning, I was interested in patients’ and their carers’ experiences of the process, with a specific focus on major trauma patients. As a health professional, I was eager to gain insights into the pre-discharge planning that patients and their carers receive, and how their experiences of this process assist them to cope at home. Specifically, I was interested to investigate whether information is adequate, and whether the delivery and format affect how patients and carers understand and use this information. I was keen to explore the amount of collaboration between patients, carers and health professionals in the discharge planning process, and what impact this has on the patient and carer experience.

This chapter has presented background information on the topic of this systematic review. It has also introduced and discussed the importance of evidenced-based healthcare and the role of systematic reviews in this process.

Chapter 2: Methodology and methods

Chapter 2 describes the methods followed in relation to criteria for study inclusion, search strategy, study selection, critical appraisal of studies, and data extraction and synthesis.

Research design

The research design chosen was a systematic review of qualitative evidence which followed the JBI method of qualitative synthesis. A systematic review is a form of secondary research that integrates and synthesises all available evidence relating to the research question. The JBI approach to systematic reviews of qualitative evidence uses meta-aggregation as a distinct process to synthesise available evidence into synthesised findings. Meta-aggregation is an approach that was devised by a working group of qualitative research specialists in response to the growing awareness that qualitative research can provide relevant and meaningful outcomes to guide healthcare delivery.[52] The approach has been described as sensitive to the nature and traditions of qualitative research while being aligned with the process of systematic reviews.[52] Meta-aggregation is grounded in the qualitative traditions of pragmatism and Husserlian transcendental phenomenology in that the emphasis is on producing practical outcomes that can guide healthcare policy in a manner that where knowledge is developed in an unbiased way.[52] The focus of meta-aggregation therefore is not on reinterpreting qualitative data presented, rather it is to integrate the data to produce outcomes.[52]

One aim of meta-aggregation is not to reinterpret the original authors' research but to combine the findings from each included paper into a whole. Findings are defined as 'a verbatim extract of the author's analytic interpretation'.[54 (p.4)] which should be accompanied by an illustration which is 'a direct quotation of a participant's voice, fieldwork observation or other data'.[54 (p.4)] Similarly themed findings are then grouped into categories and finally similarly themed categories are amalgamated into synthesised findings. Lockwood et al.[52] state that synthesised findings are statements that can establish an acceptable basis for recommendations for practice.

This systematic review was completed in line with the JBI methodology for qualitative systematic reviews,[52] referring to an *a priori* published protocol (PROSPERO CRD42019138431),[59] in order to produce the highest level of evidence on the review topic and to create practical statements to guide service delivery.

Criteria for considering studies for inclusion in the systematic review

Participants

This systematic review considered studies that included adult patients aged between 18 and 65 who had sustained an injury following an acute major trauma event, and any studies related to family carers of the aforementioned group. The age limit for inclusion in this systematic review was ≤65 years old as adults below this age are more likely to participate in paid work and have more parental and financial responsibilities than people in their senior years due to having dependants. In such instances, major trauma could potentially affect their engagement in their life roles, resulting in increased reliance on family carers. The presence of major trauma was indicated by one or more of three trauma severity measure scores detailed below. To be considered, the study must have indicated the inclusion of patients with major trauma (i.e. identified by using one of the trauma severity assessments and defined by the relevant acceptable score, as listed below):

- ISS of >12[1]
- Major traumatic central nervous system injury (defined as Glasgow Coma Scale <13,[12] or ASIA Impairment Scale A or B,[13] or other clear definitions).

This review was restricted to studies that included major cases of trauma since these are considered more likely to result in long-term disability than minor cases (e.g. limb fracture).

Phenomena of interest

This review included studies that explored the experiences of patients and their family carers in the pre-discharge planning process. These experiences included those related to patients' and carers' readiness for discharge, their support requirements and involvement (or lack of) in the discharge planning process, information provision from in-patient healthcare practitioners, and their met and unmet needs.

Context

The context was discharge from inpatient hospital care (emergency department, trauma unit, acute ward or in-patient rehabilitation unit) following an admission precipitated by a major traumatic event back to an unsupervised community setting (e.g. patient's previous residence or residence of a relative). Studies where participants were discharged to residential care or nursing homes were excluded because participants would receive daily supervision from paid health professionals.

Types of studies

This review considered qualitative studies including but not limited to phenomenology, grounded theory, ethnography, action research and qualitative descriptive studies. Only studies published in English were eligible for inclusion in this review, with no publication date restrictions.

Search strategy

A three-step search strategy was employed to identify published and unpublished studies. Firstly, an initial search of MEDLINE was conducted. Text words in the title and abstract of identified articles were analysed, and index terms used to describe the article were utilised to identify keywords and increase relevance to the topic. A second search strategy was developed, employing all keywords and index terms, and this was adapted for each database. Each database was searched from its inception to the date 7th September 2019 to ensure all pertinent articles were included. This search was updated on 25th June 2020. A full search strategy for each database is available in the Appendix I.

Information sources

The final search strategy was applied to the following databases: PubMed (National Library of Medicine), Embase (Elsevier), Scopus (Elsevier), CINAHL (via EBSCO), PsycINFO (via Ovid) to locate published articles. The databases Worldwidescience.org, ProQuest (via EBSCO) and Google Scholar were searched for both published and unpublished articles.

Study selection

All relevant references were uploaded to and collated in EndNote X9.1.1 bibliographic software (Clarivate Analytics, PA, USA). The references were then uploaded into Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia) for screening. Duplicates were removed and all titles and abstracts were scanned to exclude papers not matching the inclusion criteria. It was difficult to identify whether some papers matched the systematic review inclusion criteria of population (age, severity and type of injury sustained) and context (discharge planning from hospital or rehabilitation centre to a patient's home) from information presented in their titles and abstracts, hence the large number of papers screened at the full text stage. Full text articles were obtained for the remaining studies and assessed against inclusion criteria. Full text studies that did not meet the inclusion criteria and reasons for exclusion are presented in Appendix II. Eligible studies for inclusion were uploaded into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI) (JBI, Adelaide, Australia).[55]

Assessment of methodological quality

Eligible papers were critically appraised by two independent reviewers (JC, EP) for methodological quality using the standardised JBI Critical Appraisal Checklist for Qualitative Research (Appendix III).[55] . Each paper was appraised independently by the two reviewers allocating a 'yes', 'no' or 'unclear' response to each of the ten questions. For questions 1 to 5, some papers explicitly described the study design in relation to the research methodology, however this explanation was lacking in some papers. Data presented in these papers were clearly descriptive, so it was decided between reviewers to classify these studies as 'qualitative descriptive', as described by Sandelowski.[60] In relation to Criterion 9, if there was no clear reporting of ethics approval, it was rated 'unclear'. Any discrepancies were resolved between reviewers through discussion until agreement was achieved, therefore consultation with a third reviewer was not required. No study was excluded based on methodological quality, however the quality of the study was accounted for in the interpretation of findings and recommendations.

The purpose of critical appraisal of the included studies was to assess their methodological quality and to provide information to determine their level of dependability, according to the ConQual approach.[54] The answers from questions 1 to 5 of the critical appraisal checklist were recorded and used to assess the dependability of each research paper.

Data extraction

Qualitative data were extracted by the primary reviewer (JC) using the JBI Qualitative Data Extraction Tool (Appendix IV) from JBI SUMARI.[55] Data extracted included population details, study methods, specific objectives, phenomena of interest, and outcomes of significance to the review objectives. Findings were identified by repeatedly reading the results section of the included papers. A finding for this review was considered to be a verbatim excerpt of the author's interpretive text (i.e. themes or subthemes) with a supporting quotation of participant voice (i.e. illustration).

For some papers, findings were extracted at the theme level, whereas for other papers findings were presented at the sub-theme level. Extraction of findings at the theme level was done in papers with research objectives closely aligned to the topic of discharge planning in major trauma. For papers which covered broader topics of patient and carer experiences of their hospital stay after major trauma, relevant findings were extracted at the sub-theme level.

All findings were assigned one of three levels of credibility according to the following criteria:

- Unequivocal (U) – findings accompanied by an illustration that is beyond reasonable doubt and therefore not open to challenge
- Credible (C) – findings accompanied by an illustration lacking a clear association with it and therefore open to challenge
- Not supported (NS) – findings not supported by data.[52]

Data synthesis

Data synthesis was conducted using the meta-aggregative approach. Qualitative research findings were pooled using JBI SUMARI.[55] The process involved reading the extracted unequivocal and credible findings multiple times to assemble groups of findings based on similarity of meaning, and then creating a set of statements that represented this process (i.e. included findings were grouped to form categories). Categories containing similar themes were then subjected to synthesis to develop a comprehensive set of synthesised findings that could form a basis for evidenced-based practice. Results are presented as synthesised findings, and each synthesised finding is underpinned by multiple categories which emerged from the findings of individual studies.

Assessment of confidence in findings

The synthesised findings of this systematic review were graded according to the ConQual[54] approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings. A Summary of Findings includes all major elements of the systematic review and details how the ConQual score is created. Each synthesised finding is presented, along with the type of research informing it, with scores for dependability and credibility, and the overall ConQual score.

Munn et al.[54] describe the ConQual approach as a basis to establish quality and confidence in qualitative systematic review findings. This approach specifically examines the presence of dependability and credibility. Dependability is established if the research process is logical, traceable and clearly documented, that is, the research methodology is deemed to address the research question being asked.[54] Credibility is determined by the level of congruence between the study data and the author's interpretation of it,[54] and establishes a level of 'plausibility'.[52] It is determined by the author's interpretation of verbatim participant text and the meaning derived from it.

Dependability is determined by the results of five questions within the critical appraisal process which address the relationship between research methodology and the research question, and data collection and data analysis. The last two of the five appraisal questions concerning dependability relate to whether the researcher has stated their cultural or theoretical position, and explained their influence over the research. The JBI critical appraisal checklist is presented in Appendix III.

Credibility is rated by the number of each level of findings within a synthesised finding, with credibility being downgraded when there is a higher presence of credible and unsupported findings.[54] Dependability and credibility scores of synthesised findings are combined to produce the Summary of Findings for the systematic review. This is presented in a table format for ease of understanding by health professionals and demonstration of transparency of the ConQual process.[54]

Chapter 3: Results

This chapter provides an overview of the results identified by the systematic review. This includes methodological quality of the studies and their characteristics. The findings of the systematic review are categorised and presented as synthesised findings.

Search results

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram[64] (Figure 1) shows the process of study identification, screening and examination of the papers for review. The PRISMA diagram shows that 11,978 papers were identified from the search process across a range of selected databases. Papers were imported into EndNote X9.1.1 bibliographic software (Clarivate, PA, USA) organised and then exported into Covidence software (Veritas Health Innovation, Melbourne, Australia). Covidence removed 3030 duplicates, leaving 8948 citations for reviewing of titles and abstracts against the inclusion criteria. A total of 233 citations were eligible for full text review; 219 studies were excluded, leaving 14 papers from 13 studies for inclusion in the review. One study elicited two published papers.[62,63] Eligible studies were then uploaded into JBI SUMARI[55] to assist with the synthesis process. Refer to Appendix V for characteristics of the included studies.

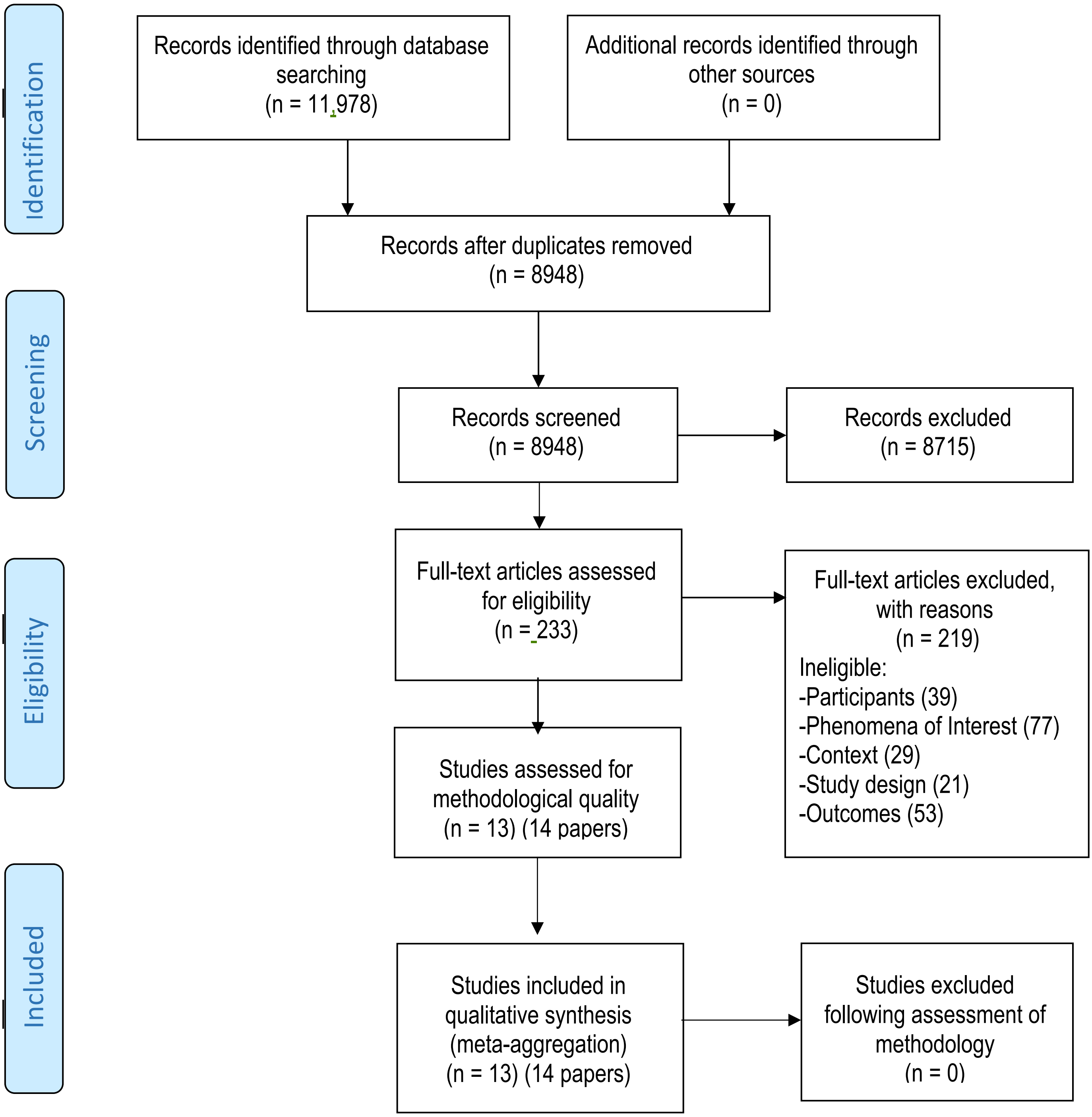


Figure 1: PRISMA flow diagram of search results, study selection and inclusion process[61]

Description of included studies

Methodological quality

Five out of 14 papers demonstrated congruence between their stated philosophical perspective and the research methodology employed (Q1).[36,64,65,66,34] All 14 papers demonstrated congruence between their research methodology and their research question/objectives (Q2).[33,34,36,62,-72] The 14 papers also demonstrated congruence between their research methodology and their data collection (Q3) and analysis of data (Q4).[33,34,36,62-72] Twelve[33,34,36,63-67,69-72] of the 14 papers demonstrated congruence between the research methodology and interpretation of their data (Q5), with two papers being unclear about their interpretation approach.[62,68] Only two papers[62,36] contained statements locating the authors culturally or theoretically (Q6). Four papers addressed the researchers' influence on the research (Q7).[36,64,65,67] Inclusion of participant contribution and voice was present in 13 papers (Q8),[33,34,36,62-69,71,72] with Kreitzer[70] being the exception as there were no verbatim illustrations supporting findings relevant to this systematic review. This paper, however, was included in this review as it met the inclusion criteria. Eleven[33,34,36,62-68,72] papers reported ethical research or approval from an appropriate body (Q9). All 14 papers were able to draw conclusions from their analysis and interpretation of data (Q10).[33,34,36,62-72] The results of the critical appraisal for the 14 included papers are presented in Table 1. Where papers presented findings without verbatim illustration, these were excluded from the meta-synthesis (Appendix VI).

Table 1: Critical appraisal results of eligible studies using the JBI critical appraisal too

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Abrahamson et al.. 2017[36]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Braaf et al. 2018[68]	U	Y	Y	Y	U	U	U	Y	Y	Y
Beaton et al. 2019[67]	U	Y	Y	Y	Y	U	Y	Y	Y	Y
Brauer et al. 2011[64]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Conti et al. 2016[65]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Gabbe et al. 2013[33]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Mbakile-Mahlanza et al. 2017[62]	U	Y	Y	Y	U	Y	U	Y	Y	Y
Mbakile-Mahlanza et al. 2015[63]	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Moore et al. 2017[71]	U	Y	Y	Y	Y	U	U	Y	U	Y
Paterson et al. 2001[34]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Sandström et al. 2019[72]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Yoshida 1994[69]	U	Y	Y	Y	Y	U	U	Y	U	Y
HeydariKhayat et al. 2020[66]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Kreitzer et al. 2019[70]	U	Y	Y	Y	Y	U	U	Y	U	Y

Y: yes; N: no; U: unclear[55]

Characteristics of included studies

The qualitative studies included within this review were conducted between 1994 and 2020, with eight conducted in the last five years. Three studies were undertaken in the USA,[64,70,71] two from Australia,[68,33] two from Canada,[34,69] one from Botswana resulting in two published papers, [62,63] and one each from Iran,[66] Italy,[65] New Zealand,[67] Sweden[72] and the United Kingdom.[36] Six studies focused on TBI participants,[34,36,62-64,71] two on SCI participants,[65,69] one on burns participants,[66] and the remaining four studies included participants affected by major trauma.[31,67,68,72] Sample sizes ranged from five to 120, comprising a total of 389 participants (298 patients and 91 carers). Most studies conducted interviews within a year post discharge. One study, Moore,[71] interviewed participants whilst they were still in-patients and the remaining studies conducted interviews post discharge, with participants reflecting on their experiences up to 22 years previously. Studies gathered a variety of perspectives from either patients, [33,66-69,75] or carers[62-65,71] or a combination of both patients and carers.[36,34]

Nine of the published papers were from studies that had employed a qualitative descriptive approach.[33,34, 62,63,67,68] Two papers were from studies that used a phenomenological approach,[65,66] one paper described a study that used critical realism[36] and one paper did not describe an approach to their qualitative research.[69] Data were collected by in-depth individual or focus group interviews. Qualitative analysis methods included: thematic analysis,[33,36,62,63,68] phenomenological,[65] Colazzi's descriptive phenomenological approach,[66] content analysis,[70,72] qualitative content analysis,[71] naturalistic enquiry[34] and grounded theory approach.[69] Appendix V describes the characteristics of the included studies.

Review findings

A total of 49 findings and their illustrations were extracted from the 13 studies included in this review. Of the 49 findings, 33 were unequivocal (U), four were credible (C) and 12 were unsupported (US). The 12 unsupported findings lacked illustrations and were therefore excluded from the meta-synthesis, as per JBI methodology for qualitative systematic reviews.[52] The excluded study findings without illustrations are listed in Appendix VI. The remaining 37 findings were organised into four synthesised findings comprising of 11 categories which reflect the phenomena of interest of this systematic review.

Synthesised finding 1: Patients and carers feel generally unprepared to manage at home after discharge

Patients and carers felt they were not adequately prepared to live in the community once discharged from supervised care. Between them, they did not feel they had the skills necessary to live effectively at home. This synthesised finding was derived from three categories comprising 11 unequivocal findings (see Table 2).

Category 1.1 Carers felt unprepared to address their relative's needs at home and did not anticipate the challenges that subsequently arose.

Carers felt unprepared to support their disabled relative to live at home and in the community on discharge. They expressed a lack of skills to support their relative's needs and poor confidence in the caring skills they had supposedly acquired from education provided to them. After hospital discharge, the carers' observations of patients' participation in activities and their abilities to address patients' needs were below their expectations. The findings indicate that even though some carers felt they received adequate education and information from the in-patient health professionals, there were still patient care needs that could not be predicted. In hindsight, they wished they had requested for and had access to psychological services. This category is supported by four unequivocal findings.

> Finding 1: Carers: element of surprise that things were not as anticipated (U)
>
> *"He had a couple of weekend visits but that still wasn't somehow really enough to prepare us."* 36 (p.1689)

Finding 2: Carers: difficulty coping with the transition home and unforeseen challenges that arose (U)

> *"I was ready to go home, but mentally I was not prepared. I thought great we are going home and she is going to return home. The reality is she got home and realised how much she wasn't able to do. Rather than what she could, now it was, I can't get out of bed and I can't go to the kitchen and I can't do things I used to be able to do. It was an emotional hit. Physically she was ready. Truthfully, emotionally she was too because she was going to face that hurdle sooner or later. I should have prepared myself better for it."* 64 (p.125)

Finding 3: Carers: felt inadequately prepared to handle their injured relative (U)

> *"He went there with a brain injury and at some point had that operation, went to ICU and we were told his vocal cords were hurt. He then had a tracheostomy inserted and this was a new thing to us. They then called us in to practise dealing with it before their eyes to know if we would cope once he has been discharged. But before we even knew this foreign object on his neck and how to deal with it, they discharged him. We wondered what it would be like at home, we were not ready at all, they should have told us the chances were high in the next month for him to be discharged so that we could get to be emotionally prepared."* 63 (p.951)

Finding 4: Carers: support seeking experienced by caregivers as they are not ready to accept the situation and afraid of possible mistakes within their relationships (U)

> *"I also think that greater support should be provided for us psychologically. Sometimes we do not have enough answers to what they [SCI survivors] have asked us or we do not know how to treat or cope with some behaviors, or even we do not know where we can insist with them."* 65 (p.163)

Category 1.2 Carers expressed they had little understanding of their relative's needs prior to discharge. Advice from health professionals was unsatisfactory when sought.

Carers reported concerns and poor understanding of how to care for their relatives after discharge and posed questions to the health professionals to seek clarification and support. Their concerns were belittled, leaving them questioning themselves and the health professionals. This category is supported by two unequivocal findings..

Finding 1: Carers: concerned about taking him home [patient] with little understanding about how to care for him (U)

> *"We didn't know what we were going to do with his wound like that, but they said it didn't matter because the skull was closed. He had a clot of blood and I was scared that it would rot and cause an infection."* 62 (p.562)

Finding 2: Carers: feeling ill-prepared for discharge with little understanding of the patient's needs post discharge (U)

> "We asked some things early on, because we wanted to, maybe, try to make some plans… Initially, the doctor says to me, 'Well, I can't give you any kind of a timetable. I'm setting you up for a real disappointment if things don't go that way.' So that was fine. But, it's just – we didn't know [about the consequences of a TBI]. And if we had known, I think I'd have been a little bit more prepared for it." 71 (p.6)

Category 1.3 Patients felt inadequately prepared for discharge, reporting that rehabilitation did not focus on addressing issues that may arise in the community.

Patients also felt unprepared for discharge following their hospital admission, reporting that rehabilitation was not always client centred. Therapy and education occurred in the hospital where skilled assistance was available, and the environment was designed to accommodate the needs of people with a disability. Some patients reported a lack of awareness and understanding by in-patient health professionals of the different skills required for them to effectively participate at home and in the community, in comparison with the hospital environment where often the environment was designed for people with a disability. Patients felt they had to re-learn skills to live at home and in the community, sometimes without access to the support and skills of health professionals. Patients felt mentally unprepared for discharge even though they had progressed well in rehabilitation. This category is supported by five unequivocal findings.

Finding 1: Patients: implications not sufficiently explored nor issues addressed (U)

> *"Nobody prepared me for home…Nobody said, 'Well, what are you going to do when you get there?' …. I just needed a bit more guidance on how it was going to be"* 36 (p.1688)

Finding 2: Patients: independence on the ward… was not the only concern (U)

> *"You have to get out there. You have got to, because it is, ah, you get so much of a hospital mentality that you um… you are in for a real shock when you get outside [laughs]. [I ask, 'What is a hospital mentality?']. Everything is accessible and everything is easy. It is all right there for you. And all the doors are wide, everything is at the right level. You never run into a washroom that you cannot get into. That sort of thing."* 69 (p.101)

Finding 3: Patient: lack of physical preparation for the outside world (U)

> *"A greater focus of being independent on the ward. Nursing was doing a lot of things they should not. They actually should been forcing me to. I was still getting assistance in ADL [activities of daily living] a week before I was discharged, but I could do it."* 69 (p.101)

Finding 4: Patients: lack of social preparation regarding interacting with people (U)

> *"…I wanted to talk to people who had been injured for a longer period of time to find out, like, what is it really like? Like, what is it like when you leave the hospital? How do people react to you? How do you answer questions when people say, 'How do you go to the bathroom?', when they say, 'Can you have sex? Can you have children? Are you ever going to get married?' And there was not anybody around because most of the people in --- were newly injured and did not have the life experiences or the social experience to say how things would be."* 69 (p.102-03)

Finding 5: Patients: transfers often had to be re-learned (U)

> *"When we learned to do car transfer at ----, you do the one on the passenger side, so you transfer over… Now, I always go in on the driver side. I never go on, never, never, on the passenger side. That is just an inconvenience I think. Because they [rehab] said, 'You do*

> *not want to get out in traffic.' But I do, anyways. I have to get in on the [driver] side. I am not about to park 3 feet away [from the curb] so that I can get out on the passenger side."* 69 (p.102)

Table 2: Synthesised finding 1: Patients and carers feel generally unprepared to manage at home after hospital discharge

Findings	Categories	Synthesised finding
Carers: element of surprise that things were not as anticipated (U) Carers: difficulty coping with the transition home and unforeseen challenges that arose (U) Carers: felt inadequately prepared to handle their injured relative (U) Carers: support seeking experienced by caregivers as they are not ready to accept the situation and afraid of possible mistakes within their relationships (U)	Carers generally felt unprepared to address their relative's needs at home and did not anticipate the challenges that subsequently arose.	Patients and carers feel generally unprepared to manage at home after hospital discharge
Carers: concerned about taking him home with little understanding about how to care for him (U) Carers: feeling ill-prepared for discharge with little understanding of the patient needs post discharge (U)	Carers expressed they had little understanding of their relative's needs prior to discharge. Advice from health professionals was unsatisfactory when sought.	
Patients: implications not sufficiently explored nor issues addressed (U) Patients: independence on the ward… was not the only concern (U) Patients: lack of physical preparation for the outside world (U) Patients: lack of social preparation regarding interacting with people (U) Patients: transfers often had to be re-learned" (U)	Patients felt inadequately prepared for discharge, reporting that rehabilitation did not focus on addressing issues that may arise in the community.	

U = Unequivocal – findings accompanied as an illustration that is beyond reasonable doubt and therefore not open to challenge
C = Credible – findings accompanied by an illustration lacking a clear association with it and therefore open to challenge

Synthesised finding 2: Early identification of patients' post discharge needs allows for appropriate referrals and supports to be organised prior to discharge from hospital

Patients and carers felt that their needs for community services were not identified promptly in their inpatient admission. When these needs were assessed, community referrals were not consistently instigated nor information about community supports explicitly explained. In such cases, patients and carers felt abandoned by the healthcare services after discharge. This synthesised finding was derived from two categories comprising six findings, five unequivocal and one credible (see Table 3).

Category 2.1 Patients did not receive adequate advice regarding community services to assist with managing their recovery after discharge, leaving them uncertain about who to contact.

Patients reported a lack of information regarding the ongoing management of their health issues and recovery post discharge. Once discharged, they were uncertain about which organisation to approach for clarification and support. This category is supported by three unequivocal findings.

Finding 1: Patients: expressed that they were uncertain about who to obtain information from (U)

> *"I came out of rehab on a very strong course of medication, and I really didn't know who I should be speaking to about that… I wasn't sure I needed it anymore but couldn't get a definitive answer anywhere on that."* [68 (p.6)]

Finding 2: Patients: …some sought clarification about the role of the general practitioner (GP) (U)

> *"It was never properly explained to me the role in my recovery of the (name of hospital) versus my local doctor. And it was only down the track I discovered that it was my local doctor who had taken the handover in terms of… overseeing my recovery. That was never made clear to me."* [68 (p.6)]

Finding 3: Patients: counselling/psychological services and the contact details, should have been provided at discharge (U)

> *"As I was leaving the hospital, or before I was discharged, something could have been said about some kind of counselling or just some kind of number to contact."* 68 (.p5)

Category 2.2 Patients and carers expressed a feeling of neglect by the health system post discharge. They attempted to manage their recovery without the support of health professionals.

Patients and carers felt forgotten and unsupported after they had been discharged from hospital. Patients felt confused and disorientated as they missed the supervised care and dedicated rehabilitation they had received in hospital. Patients were motivated to continue their rehabilitation and attempted to continue rehabilitation unsupervised, however they were uncertain about who to approach for advice. Some felt that community services did not possess the specialist skills required to support them at home. It was believed this situation could have been avoided if the hospital team had identified patients' needs early, instigated community referrals and educated the patients and carers regarding these actions. This category is supported by three findings, two unequivocal and one credible.

Finding 1: Patients: complained about the hospital-based caring. (U)

> *"…hospital discharge means 'being forgotten by the health care system'…"* 66 (p.5)

Finding 2: Patients: did not understand how to appropriately progress their recovery… (U)

> *"… when I came out of hospital they were going to send me to a physio place where I stayed on the premises… but that didn't come to fruition … and I found myself probably going to gym by myself or perhaps swimming by myself, and not sure what I was doing."* 68 (p.7)

Finding 3: Carers: the importance of the Spinal Cord Unit (SCU) for caregivers even after discharge (C)

> *"I would like the home care staff provided by the National Health Service to come to the SCU in order to be trained. In this way there would be fewer complications and problems."* 65 (p.163)

Table 3: Synthesised finding 2: Early identification of patients' post discharge needs allows for appropriate referrals and supports to be organised prior to discharge from hospital

Findings	Categories	Synthesised finding
Patients: expressed that they were uncertain about who to obtain information from (U) Patients: some sought clarification about the role of the general practitioner (GP) (U) Patients: counselling/psychological services and the contact details, should have been provided at discharge (U)	Patients did not receive adequate advice regarding community services to assist with managing their recovery after discharge, leaving them uncertain about who to contact.	Early identification of patients' post discharge needs allows for appropriate referrals and supports to be organised prior to discharge
Patients: complained about the hospital-based caring. (U) Patients: did not understand how to appropriately progress their recovery… (U) Carers: the importance of the Spinal Cord Unit for caregivers even after discharge (C)	Patients and carers expressed a feeling of neglect by the health system post discharge. They attempted to manage their recovery without the support of health professionals	

U = Unequivocal – findings accompanied as an illustration that is beyond reasonable doubt and therefore not open to challenge
C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge

Synthesised finding 3: Patients and carers value participation in the discharge planning process to facilitate organised and timely discharge from the hospital.

Patients and carers valued involvement in and contributing towards the discharge planning process. Collaboration with the healthcare professionals in planning for home was meaningful and rewarding, however, this not always present, causing confusion and frustration. Patients and carers also perceived poor collaboration and communication within the multidisciplinary team, which resulted in them receiving mixed messages regarding discharge planning. This synthesised finding was derived from two categories comprising eight findings, seven unequivocal and one credible (see Table 4).

Category 3.1 Patients and carers had mixed experiences of collaboration with health professionals regarding discharge planning, with some patients/carers describing positive relationships whereas others expressed dissatisfaction.

Patients and carers had mixed experiences of working with the health professionals. They often felt excluded from decisions on discharge planning which often resulted in unanticipated and disorganised experiences, however, there were some positive relationships. But there were occasions where discharge continued despite the possibility of failure due to patients being unwell and inadequate home environments. This category is supported by five unequivocal and one credible finding.

Finding 1: Failure to consult patients early in the discharge planning process (U)

> *"So it seems like you're going along, you're doing your rehab, you're attending, you're making progress and then all of a sudden they'll come to you and say okay, you'll be finishing up in a couple of weeks – that's it… it seems a lot like they don't engage the patient very well."*[68] (p.9)

Finding 2: …caregiver reported getting information about discharge from a board (U)

> *"They wrote on the board up there that in order for him to be discharged, he would have to have his restraints removed, and get the thing off his neck."*[71] (p.4)

Finding 3: Carer tried to negotiate with staff but was overruled (U)

> *"He came home at 8 o'clock by ambulance and it was just the worst night of our life. He couldn't breathe… He was in pain. He was distraught. He'd got pleurisy. He'd got two infected drain sites. His leg got cellulitis in it and an infection. He needed a hospital bed … he was already getting a pressure sore on the base of his spine… There was just nothing in place. They literally just threw him out one night and that was it. There was no care or compassion."* 36 (p.1688)

Finding 4: Lack of shared understanding between themselves and the healthcare professionals (U)

> *"They [healthcare professionals] said it would take time for me to come back to my previous state and that I needed a long hospital stay. Then suddenly without any dialogue whatsoever, they had planned [to send] me home. To a home undergoing renovations. I told them it wouldn't be possible to manage there, without a toilet or anything."* 72 (p.3)

Finding 5: Given little information at discharge regarding ongoing medical needs (C)

> *"… Even from discharging her, she was not given sick leave, I had to ask if she can be given one that's how she ended up getting one."* 62 (p.562)

Finding 6: Strong collaboration between caregivers, health professionals and patients (U)

> *"I felt integrated and fully participant in the decision-making process. I loved the happiness and optimism of health care professionals."* 65 (p.163)

Category 3.2 Poor communication amongst health professionals regarding discharge planning negatively impacted the patient and carer experience of this process.

Patients and carers perceived poor communication amongst health professionals in relation to discharge planning. This disorganisation negatively affected the care received by patients and reduced the likelihood of their involvement and influence in the process. This category is supported by two unequivocal findings.

Finding 1: Alarmed at the thought of caring without adequate resources, which may have been eased through referral to allied health to assist with discharge planning (U)

> *"There was a bit of… we'll just push you out the door and you can go home… because (my husband) wouldn't have been able to look after me and there was the conversation of, is there anyone at home that can look after you and I was like well not really… if I'm in trouble he's not really going to be there to help me out. I explained to them my house… is… old… and I've got pets, toilet outside, awkward little steps and stuff, and at that stage I was still sleeping sitting up in the hospital bed because I couldn't lie flat, but they wouldn't listen and discharged me anyway."* [67 (p.19)]

Finding 2: Staff did not adequately consult them, preparations were disorganized (U)

> *"They weren't talking to each other. It just got very confusing and, in the end, I got myself into such a state… …Nobody had said to me, how do you feel about him coming home? Are you happy for him to come home?"* [36 (p.1689)]

Table 4: Synthesised finding 3: Patients and carers value participation in the discharge planning process to facilitate organised and timely discharge from hospital

Findings	Categories	Synthesised finding
Failure to consult patients early in the discharge planning process (U) Strong collaboration between caregivers, health professionals and patients (U) Caregiver reported getting information about discharge from a board (U) Carer tried to negotiate with staff but was overruled (U) Lack of shared understanding between themselves and the healthcare professionals (U) Given little information at discharge regarding ongoing medical needs (C)	Patients and carers had mixed experiences of collaboration with health professionals regarding discharge planning, with some patients/carers describing positive relationships whereas others expressed dissatisfaction	Patients and carers value participation in the discharge planning process to facilitate organised and timely discharge from hospital.
Alarmed at the thought of caring without adequate resources, which may have been eased through referral to allied health to assist with discharge planning (U) Staff did not adequately consult them, preparations were disorganized (U)	Poor communication amongst health professionals regarding discharge planning negatively impacted the patient/carer experience of this process	

U = Unequivocal – findings accompanied as an illustration that is beyond reasonable doubt and therefore not open to challenge
C = Credible – findings accompanied by an illustration lacking a clear association with it and therefore open to challenge

Synthesised finding 4: The timely presentation, language used and relevancy of information impact how patients and carers manage their discharge

Presentation of information to patients and carers was an important factor in the success of discharge planning. Patients and carers were not satisfied with how the information relating to their discharge was presented leaving them dissatisfied and confused. Reported issues included poor timing in regard to receipt of information, being overwhelmed with or lacking relevant information, experiencing meaningless jargon and dealing with contradictions and inconsistencies of content. This synthesised finding was derived from four categories comprising 11 unequivocal and one credible finding(see Table 5).

Category 4.1 Patients did not receive adequate information at an appropriate time to aid their recovery and discharge planning.

Patients and carers felt they did not receive adequate information on how to manage injuries and hospital discharge. Patients wanted to receive more education and clearer information on how to care for themselves. Carers also wanted more information on the management of their injured relative. Patients and carers indicated that information was not forthcoming from the health professionals and they had to ask questions to actively seek clarification. This category is supported by four unequivocal findings.

Finding 1: Lack of timely information in a format that respondents [participants] found helpful (U)

> *"It's not black and white. If it's in black and white, even though the injured one may not be able to understand it, but at least they have got a perception of what's wrong with them. And if that's the case then they can – like now, in my case – I can now adjust to what I know, whereas before I didn't know anything so I couldn't adjust myself to it."* 36 (p.268)

Finding 2: An important gap in information transmission resulting in several misunderstandings (U)

> *"A definite step forward should be made regarding the two basic steps of hospitalization, that is, diagnosis communication and discharge management. I think that communication aspects should be more implemented by all professionals."* 65 (p.163)

Finding 3: They [family] remained confused about the injured person's prognosis, services and various health professionals involved (U)

> *"No one even tried to sit down with me and explain what could happen, what she might be like. Nothing, nothing."* 34 (p.50)

Finding 4: Discharge was a stressful time… many felt ill prepared for it as a result of insufficient information (U)

> *"When they send you home, I think just your whole world's been turned upside down and any instruction or anything like that that you're given, you just don't remember at all."* 33 (p.150)

Category 4.2 Patients and carers were sometimes overwhelmed by the amount of information. The realisation of their traumatic circumstance reduced their capacity to attend to information provision.

Some patients and carers commented they received too much information, limiting their ability to process it. Their retention of information was impacted by the shock of being involved in a traumatic situation and the realisation of taking on new and additional caring responsibilities. Patients, carers and doctors also had different priorities in terms of information requirements, resulting in misinformation. This category is supported by three unequivocal findings.

Finding 1: "information overload" as a factor in one's inability to recall information (U)

"… couldn't take in any more… it is too much." 34 (p51)

Finding 2: Unable to give full attention to what discharge information health professionals are teaching (U)

"One man described how he was unable to "really hear" what the nurse was teaching because he was concentrating on how he and his children 'were going to survive this thing'." 34 (p.50)

Finding 3: Health professionals do not always share what is important in the injured person's recovery. (U)

"… you land up having to hear about something that isn't even on your agenda. And you forget what they've said as soon as it has been said." 34 (p.5)1

Category 4.3 Patients and carers did not understand the language used by the healthcare professionals.

Patients and carers did not understand the medical terms and technical jargon used to describe injuries and what to expect in relation to their recovery. Patients and carers did not understand the context and background of the language used by healthcare professionals, making it meaningless to them. This category is supported by one credible and two unequivocal findings.

Finding 1: Caregivers had difficulty defining commonly used words in discharge instructions (C)

… "primary care" … "arousable" … "well healed" 71 (p.5)

Finding 2: They [caregivers] were confused by the formatting, lack of description or overly technical language used (U)

"I still don't know… in this one, in that case, if those things happen, if they would want you to call? Call the clinic or [someone else]? [They should] specify who they should call." 71 (p.5)

Finding 3: Patients reported not understanding information (U)

"I suppose just a bit more of an overall understanding of what was (surgically) happening. So, a bit more information, just of a general nature rather than specific medical sort of speak, just, I suppose in layman's terms." 68 (p.6)

Category 4.4 The content of information provided to patients and carers was varied, resulting in them feeling confused.

Patients and carers often received inconsistent or conflicting information regarding their health care which resulted in them feeling confused. Healthcare professionals delivered over-complicated information making it difficult for the recipients to understand, resulting in poor processing of it. This category is supported by two unequivocal findings.

Finding 1: Contradictory information given by health professionals (U)

> *"If you can't trust them to give you the straight goods, then you don't listen when they talk to you."* 34 (p.51)

Finding 2: Inconsistency in written information left patients unclear (U)

> *"The discharge summaries, the one I got from (name of rehabilitation) and one I got from (name of hospital) are completely different in explaining what happened and what I can do now."* 68 (p.7)

Table 5: Synthesised finding 4: The timely presentation, language used and relevancy of information impact how patients and carers manage their discharge

Findings	Categories	Synthesised finding
Lack of timely information in a format respondents [participants] found helpful (U) An important gap in information transmission resulting in several misunderstandings (U) They [family] remained confused about the injured person's prognosis, services and various health professionals involved (U) Discharge was a stressful time… many felt ill prepared for it as a result of insufficient information (U)	Patients did not receive adequate information at an appropriate time to aid their recovery and discharge planning	The timely presentation, delivery and relevancy of information impact how patients and carers manage their discharge
"information overload" as a factor in one's inability to recall information (U) Unable to give full attention to what discharge information health professionals are teaching (U) Health professionals do not always share what is important in the injured person's recovery. (U)	Patients and carers were sometimes overwhelmed by the amount and relevancy of information. The realisation of their traumatic circumstance reduced their capacity to attend to information provision	
Caregivers had difficulty defining commonly used words in discharge instructions (C) They [caregivers] were confused by the formatting, lack of description or overly technical language used (U) Patients reported not understanding information (U)	Patients and carers did not understand the language used by the healthcare professionals	
Contradictory information given by health professionals (U) Inconsistency in written information left patients unclear (U)	The content of information provided to patients and carers was varied resulting in them feeling confused	

U = Unequivocal – findings accompanied as an illustration that is beyond reasonable doubt and therefore, not open to challenge
C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge

Chapter 4: Discussion and conclusion

This chapter expands on the results of the systematic review by listing the research findings and discussing the data in relation to current literature on discharge planning after major trauma. Strengths and limitations of the review are presented, along with recommendations for practice and suggestions for future research.

Discussion

The purpose of this systematic review was to identify, evaluate and synthesise all available qualitative studies on adult and carer experiences of discharge planning following a major traumatic event. Fourteen papers from 13 studies were included after a comprehensive search process and assessment of methodological quality. The findings of this review indicated that patients and carers value participation in discharge planning but generally do not have a positive experience of the process. The first synthesised finding related to the level of readiness for discharge and demonstrated that neither patient nor their carers perceived they were adequately prepared for discharge from the inpatient setting/ward/services. The focus of rehabilitation was often not on individual requirements, and the responsibility of caring for their loved one seemed overwhelming and was not acknowledged or addressed. The second synthesised finding, early identification of support requirements, indicated that participants felt unsupported after discharge due to lack of knowledge on community resources and referrals, which they felt should have been highlighted early in their admission. The third synthesised finding described patient and carer participation in discharge planning to facilitate organised and timely discharge from hospital. There was perceived poor collaboration in the discharge planning process not only between health professionals and patients and carers but also between staff members, creating further risk of dissatisfaction and failure to address patient and carer needs. Information delivery was the fourth synthesised finding. The timing, relevancy and language used to present information was below patient and carer expectations, resulting in confusion and frustration. Some patients and carers felt overwhelmed with the amount of information while others were left confused about the medical jargon used and the brevity of information on the medical status of patients and discharge planning options. In the following paragraphs, each synthesised finding is discussed in relation to current research evidence to further support and define recommendations for practice.

The first synthesised finding revealed that trauma patients and carers did not feel adequately prepared or ready for discharge from hospital even though they had undergone rehabilitation or an extended hospital stay to assist with recovery. The period after a major traumatic event is extremely significant for both patients and carers. Following major trauma, patients experienced a huge sense of loss as their bodies and future aspirations had been impacted by a life-changing event.[67, 72-74] Gotlib Conn et al.[8] reveal that a large proportion of major trauma patients live with life altering disabilities such as loss of limbs, spinal cord injury, traumatic brain injury and post-traumatic stress disorder. Uleberg at al.[11] found that most major trauma patients take approximately two years to resume their pre-injury level of activity, with reliance on medical benefits in the interim. The medical management of these complex injuries, combined with feelings of vulnerability, and unfamiliarity with and expectations of health services,[40] place major trauma patients at a high risk of failure with hospital discharge.[8]

The discharge process itself has a much more significant impact on the success of the discharge than physical factors such as a change in the environment. It involves adjustment to a different health status, level of function, change in roles and role identity, and new expectations after a life-changing event.[75,76] The pressure of uncertainty at discharge also exists for the caregiver as often healthcare support services transition beyond the acute care episode.[64] Their family caregivers have a shift in responsibility as they become a link to social networks and financial support, and adopt important life roles on behalf of the patient.[67] Caregivers appreciate education from healthcare professionals and the opportunity to learn practical skills to care for their loved ones prior to discharge and consider discharge a challenge when this preparation does not occur.[75] The experiences of major trauma patients and carers in discharge planning are similar to those of other types of hospital patients. Lutz et al.[77] recommend the need for educating stroke caregivers prior to discharge, along with identifying of caregiver capacity to address patient needs. This enables carers to improve their readiness for discharge. Lapum et al.[78] indicate that often it is the health professionals' perspective of a patient's level of participation in activities that determines the discharge readiness of cardiac surgery patients rather than discussions with patient and carer. Mitchell et al.[79] highlight that carers of patients discharged from any hospital speciality worry about readiness for discharge. One of their study participants stated, 'you don't know what you don't know',[79(p.5)] indicating that health professionals have a role in preparing patients and carers for discharge. Given the significant changes imposed on the patient and family carers because of the major trauma, it is understandable that major trauma patients and carers do not feel prepared or ready for hospital discharge despite their satisfaction with the care and rehabilitation received during the hospitalisation.[37,80]

Considering that major trauma patients and their carers will likely encounter intense emotions, such as fear, anger, frustration, guilt and despondence,[38] it is important for inpatient healthcare professionals to recognise these emotional reactions and prepare patients and carers for discharge using evidence-based approaches.[38] There is an increasing amount of literature that supports the development of positive coping strategies for neurotrauma patients and their carers, such as resilience, hope and spirituality, to promote healthy life adjustments and satisfaction.[16,81,82]

Practical approaches to assist major trauma patients and their carers to foster positive coping strategies prior to inpatient discharge have been identified.[16,81] Patients find that setting achievable short-term goals with therapists enables them to succeed, reinforcing a sense of confidence in overcoming their disability.[81] Short term goals assist patients to focus on the day-to-day changes in their lives, rather than looking ahead to the future, which encourage them to live in the 'present' and establish realistic expectations.[16,81] Engaging in and maintaining a goal-based approach in therapy assists patients to enhance their readiness for discharge.[83] Giving patients the opportunity to compare their own performance with others, including participation in peer support, has a positive effect on patient self-efficacy, whilst observation of fellow patients' performance can empower patients to focus on and achieve rehabilitation goals.[81] Peer support can give them a sense of being socially connected and camaraderie in a time where patients and carers feel isolated.[21] Another technique, that is, engendering a sense of 'feeling useful'[81 (p.1049)] and patient participation in self-identified meaningful activities[84] in a familiar context, increases their motivation to engage in therapy. [73,85] Engaging in activities where patients contribute towards the outcome or assist others in achieving their gorals can reinforce a feeling of being valued.[81] It is recommended that TBI[84] and SCI[73] patients participate in life activities in a relevant context during rehabilitation as it is beneficial for them to apply what they have learnt during recovery in real world situations, helping them to feel prepared for their transition to the community.

Discharge home that is carefully planned and coordinated can be pivotal to enhancing patient and carer awareness, adjustment to injury and development of a new sense of self-identity.[86] It is therefore important for major trauma patients and carers to have access to clinical psychology services to support them through this important stage of their recovery.[40,65,66,83,87] Psychology services should be available not only to facilitate the patient's recovery, address the patient's and carer's experiences of a traumatic event or to support them whilst navigating health services,[91] but also to assist in the development of positive coping skills.[16]

The second synthesised finding focussed on early identification of patient and carer requirements for discharge to enable relevant referrals and supports to be arranged. This review revealed that there was a lack of information on the ongoing management of injury and prevention of secondary complications in the community provided to major trauma patients and their carers. Early identification of patients' and carers' post discharge needs allows for a care plan to be formulated and information provided. Often there are unmet needs in service provision, making it challenging for patients and carers to navigate the discharge to home smoothly.[79]

Literature on effective discharge planning recommends early and holistic assessment of patients' and carers' post discharge needs so that plans can be put in place in a timely manner whilst reducing delays and the risk of readmission.[89] Gonçalves Bradley et al.[43] state that commencing discharge planning early in a patient's admission can reduce healthcare costs. Hospital discharge is in itself a time of uncertainty for both trauma patients and carers as they transition to community living, therefore not receiving timely and relevant information on ongoing support services and referrals can leave them feeling frustrated,[86] lonely,[65] let down,[90] vulnerable[8] and abandoned.[88]

Patients and carers prefer continuous, seamless care in the transition from hospital to home, ideally with the same health professionals already involved in their care as this creates trust and provides the needed reassurance.[79] There is an emphasised need for continuity of care where individualised care plans provide timely exchange of information between all in-patient and community health professionals involved in the patient's care, including contact details for inpatient health professionals that are knowledgeable about their situation and accountable for them in the discharge process.[79,91] There is evidence supporting the importance of the role of specialist trauma nurses and case managers as integral members of the inpatient trauma pathway. They assist with prompt inpatient allied health referrals and early discharge planning, making apositive impact on patient and health service outcomes.[92,93]

In some situations, where people have sustained work or transport-related injuries, compensatory systems providing financial and health support have been established by local and national governments,[94] however, there are some trauma patients with major injuries who are not eligible to be supported by these services. Gotlib Conn et al.[8] acknowledge this shortfall and introduces the concept of trauma care navigation as a possible solution. A case manager or the specialist trauma nurse, if funded, could support major trauma patients and carers through their illness journey, regardless of their eligibility for insurance schemes or outreach teams. 'Patient navigators are trained health providers who integrate patient information, facilitate access to system-wide services and offer therapeutic care continuity where fragmentation exists.'[8(p.101)] The trauma navigator model has the potential to address a variety of issues experienced by patients and carers, such as identification of high risk patients and their needs early in hospital admission,[95] medication management,[32] assessment of emotional well-being on and after discharge,[87] and acting as a point of contact for patient and carer questions regarding their ongoing care via follow-up phone calls.[68]

Community service providers feel poorly resourced to care for trauma patients due to their inability to access relevant information from the trauma centres.[8,90] Naylor et al.[91] emphasise the need for individualised care plans that record relevant information on patient care to aid exchange of information between in-patient and community health professionals involved in a patient's care. Trauma navigators could be best placed to act as an intermediary between tertiary and primary healthcare professionals to facilitate information exchange, transfer of care plans and provision of advice on the optimal management of the patient.[68] Other positive initiatives, such as the Center for Trauma Survivorship,[88] support patients after discharge by providing links with dedicated multidisciplinary trauma teams. In a study conducted by Livingstone et al.,[88] patients attended appointments at a tertiary facility for thorough assessment by the team and were provided with a team contact phone line providing potential 24-hour access. The focussed team approach enabled linkages with appropriate facility departments to address patient and carer concerns, resulting in improvements in managing patients' mental health and trauma symptoms. Subsequently, emergency department attendance by their cohort was reduced.

Patient and carer value participation in the discharge planning process to facilitate organised and timely discharge from hospital was the third synthesised finding. Even though some patients and carers felt part of a collaborative process, their contribution towards discharge planning decisions was often lacking. This resulted in patients and carers losing trust and confidence in the health professionals involved in the discharge planning. Patients and carers also perceived poor collaboration between health professionals which had a negative impact on their experiences of discharge planning.

There is evidence to demonstrate that poor collaboration between patients, carers and healthcare professionals is detrimental to patients' safety and satisfaction.[32] Limited opportunity for patients to contribute to their care results in them feeling more vulnerable,[40] like an 'object of care'. [74 (pg. 589)] Unger et al.[73] describe that SCI patients fight for control not only as they have lost mastery of their body, life roles and ability to make choices but also against healthcare professionals as they are perceived to be directing their rehabilitation and discharge planning. Where patients are disengaged from the decision-making process, they are unaware how and why plans are made.[90]

Zakzesky et al.[83] found that some patients described their own role as 'responding to the actions of the team',[83(p,237)] indicating a passive stance rather than being equal collaborative partners in care provision. When patients adopt a passive role in their care, discharge lacks context and is considered as a random set of events that needs to be resolved prior to their discharge. Some studies attribute poor patient and carer collaboration in discharge planning to organisational culture which healthcare professionals have limited ability to affect.[8,32] However, when patients are given the opportunity to take control or participate in their care, they are more likely to feel empowered and adopt an active role in discharge planning.[83]

Shared decision-making (SDM) is one aspect of patient centred care that promotes a collaborative relationship between patients, carers, and health professionals. It is defined as an 'approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences'.[96(p.5146)] Shared decision-making aims to support patient autonomy by creating good relationships, respecting both individual competence and interdependence on others.[97] Tonelli and Sullivan[98] stress that for a decision to be shared, it should be a consensus between all the agents sharing in the decision. Therefore, SDM is not just between the healthcare professional and patient but can involve other stakeholders such as the patient's carer.

Where trauma patients are unable to contribute to discharge planning due to their disabilities or being overwhelmed by their traumatic experience, it is invaluable for their carers to liaise with healthcare professionals.[72] In these situations, the position and role of the carer as an 'expert' on behalf of the patient should be recognised and encouraged by healthcare professionals.[7] Establishing a partnership with carers is likely to have a positive effect on patients.[72,79] Zakzesky et al.[83] emphasise the positive effects of carer support on the patient during the discharge planning process as they can absorb information, provide emotional and physical support, and advocate on behalf of the patient. Carers often have to learn new skills to support their injured loved ones at home,[22] often skills and responsibilities that are not covered by formal care services.[26] It is therefore imperative that carers are considered stakeholders in any shared decisions on discharge planning.

Kaslow et al.[99] discuss the need for SDM within the discharge planning process as it is a stage of uncertainty in a patient's recovery and it ensures that delivery of care is consistent with priorities of both the patient and family. The authors provide practical suggestions to aid patient and carer participation in the discharge planning process. They advocate open discussions between patients, carers and healthcare professionals about post-discharge needs in order to establish a documented care plan detailing out-patient appointments, training and education options, and inpatient team contacts for use during discharge if patient questions arise.

The benefits of adopting an SDM approach in the care of trauma patients are well supported. Lindberg et al.[100] indicate that participants in their study stressed the importance of being given the opportunity to join discussions where they could express opinions and feelings. Unger et al.[73] highlight that participants enjoyed being considered an equal in the therapeutic relationship. Other studies demonstrate that patients who actively contribute towards rehabilitation and discharge planning decisions can exert feelings of control which they had previously found lacking. Collaboration also empowers patients and carers to take an active role in facilitating discharge.[83,85] The opportunity to contribute towards shared decision-making has also improved self-conceptualisation among TBI patients who experience cognitive and behavioural disabilities.[101]

Findings within the third synthesised finding described that patients and carers perceived poor collaboration between different healthcare professionals participating in the discharge planning process. This often negatively affected the patients' and carers' experience of the discharge planning process.

Interprofessional collaboration is an evidence-based approach designed to improve communication and collaboration within healthcare professional teams and has been identified as a beneficial tool in enabling the delivery of patient centred care.[99,102] Reeves et al.[103] describe interprofessional collaboration as "the process by which health and social care professional groups work together to positively impact care". [103] (p.7) The process involves regular interactions and negotiations between health professional groups that value the expertise and contributions various disciplines bring to patient care.[103] Wei et al.[102] argue that collaboration amongst health professionals creates a synergy that provides efficient, safe and high-quality services. The process can be negatively affected by imbalances of authority within disciplines, limited awareness of others' roles and responsibilities, and poor professional boundaries,[103] but when applied successfully it is beneficial to patient outcomes. Improving collaboration and communication during discharge planning refines care delivery and enhances patient and staff satisfaction.[104,105] One approach that can assist with the implementation of interprofessional teamworking is TeamSTEPPS.[106] It is a program that can address team challenges such as hierarchy and provide team members with effective communication skills. Strategies within the program include standardised handover formats, daily briefings in relation to patient management, simulation of communication methods in real-work scenarios and communication tools designed to voice concern without emotion. Scotten et al.[105] investigated the introduction of the TeamSTEPPS approach for discharge planning on a paediatric unit in the USA. The interprofessional team, which included patients and carers, identified and selected which TeamSTEPPS tools to utilise, reflecting ownership of the strategy. One tool used was the Transitional Care Model that identified patients at high risk of readmission and flagged them for routine telehealth follow-up post discharge. This study demonstrated that patients and carers were very satisfied with telehealth follow-ups as they had easy access to healthcare professionals and received answers without needing to travel or spend time at hospital appointments.

The fourth synthesised finding pertained to discharge information provision. Patients and carers often felt disappointed with the timely presentation, language used and relevancy of information leaving their communication requirements unfulfilled. This systematic review highlighted that patients and carers received too little or too much information, indicating that information requirements were specific to each set of people. Patients require specific and individualised information about their injuries and discharge plans ensuring it is delivered in a clear and simple way.[35] Poor communication at multiple levels is a significant barrier to successful discharge of trauma patients.[88] Patients and carers must navigate complex and unfamiliar language, deal with missing or inconsistent information whilst attempting to integrate information from numerous and diverse health professionals regarding their injuries and future management. This can be a cause of non-compliance to advice which can be associated with unplanned re-admission and preventable adverse events.[68] Goldsmith et al.[35] suggest that one of the reasons for poor patient understanding of health-related information is low health literacy among trauma patients.

Health literacy (HL) is gaining recognition as a crucial determinant of patient outcomes.[107] Health literacy is commonly cited as an individual's ability to read and understand health information and apply this information to, and subsequently make, healthcare related decisions.[108] It is a multifaceted approach that includes healthcare professionals, patients, carers and other supporting organisations. Low HL is a surprisingly common occurrence in developed countries, such as the USA, Europe and Australia,[107] with low HL in trauma patients being comparable to other patient groups.[109] Trauma patients and carers with low HL often have a limited understanding of their injuries, face challenges with compliance to advice, and are generally not satisfied with physician communication.[71] It is therefore how healthcare professionals and institutions deliver information needs to be addressed to ensure that it is understandable and practical for patients and carers.[110] Rajah et al.[107] reveal that healthcare professionals themselves often have a poor understanding or knowledge of HL and therefore often over-estimate patients' and carers' level of health literacy. In view of this, Rajah et al.[107] further indicate that HL education for healthcare professionals is required and when provided could improve their recognition and understanding of patient and carer HL. In their study, Roodbeen et al.[111] found that palliative care healthcare professionals do not recognise the term health literacy but acknowledge that they encounter the effects of low health literacy in their patients on a daily basis. This study and others advocate the need of healthcare professionals to engage in HL training to raise their awareness of the subject, and to learn and apply effective communication strategies such as 'teach back' and 'chunk and check'.[107,110,111] Integration of patient learning styles into information delivery can also enhance compliance with advice and improve patient understanding and satisfaction.[110]

There are different factors that can support HL within the cohort of trauma patients. Early identification of low HL in patients and carers using standardised HL tools allows for modification of communication strategies.[109] Multi-modal communication approaches such as video, audio and written formats can accommodate differences in the patient's and carer's learning style and level of HL, and have proven to be beneficial.[68] Adoption of the talk-back approach where patients and carers demonstrate their understanding of information by repeating what they have been told to healthcare professionals is a useful tool to gauge assimilation of important information and has been recommended in the literature.[8,16,79,109] Engaging healthcare professionals such as GPs[68] or trauma nurses[67,109] for community follow-up have been recognised as being advantageous in ensuring better patient understanding of important information.

Moore et al.[71] introduce the concept of capacity building in HL for carers as part of their preparation for caring for patients. Coffey et al.[112] explain that carers are thrust into the role with no time to prepare and are frequently overwhelmed by the novel demands of their role. Carers benefit from having their learning needs identified promptly and then addressed through formal training, whether this is in relation to novel specialised health tasks or management of emotional symptoms.[71]

Goldsmith et al.[35] stress that meeting the information needs of trauma patients at discharge may be time consuming and challenging, particularly in busy and acute environments, however the time taken to ensure that their personal information needs are addressed can improve patient outcomes and potentially prevent rehospitalisation and associated costs.

This systematic review has highlighted that patients and carers who have experience major trauma do not consistently have positive experiences of their hospital discharge planning process. Areas of refinement in existing practices along with the adoption of patient and family centred approaches have been identified and recommended, aimed at easing the transition of patients to their home and reducing the risk of adverse events. It is hoped that the outcomes of this systematic review will influence healthcare professional awareness of patient and carer experiences to better inform a new model and affect positive change in healthcare delivery. Specific recommendations for practice will be expanded in the ‘Conclusion’ section below.

Strengths of the review

This systematic review was performed according to the *a priori* protocol and employed a rigorous methodological approach, as described in the JBI Reviewers Manual.[55]

This is the first systematic review to investigate patient and carer experiences of discharge planning post major trauma. Previous systematic reviews focused only on quantifying the effectiveness of discharge planning and did not explore patient/carer experiences which are equally important in informing health service delivery. Investigating qualitative data on this subject has highlighted that gathering, exploring and understanding the opinions and perspectives of patients and carers regarding their experience of the discharge planning process are important to ensuring gold-standard healthcare delivery.

This review also established a practical definition of the term Major Trauma in the context of Traumatic Brain Injury and Spinal Cord Injury which had been previously lacking in the literature. Previously, there here was little global consensus of how to classify the different levels of trauma severity, therefore it was necessary to explore this topic to assist in formulating the inclusion criteria for this review.

Limitations of the review process

Despite an extensive literature search of eight databases (five for published literature and three for unpublished literature), the amount of qualitative evidence on this topic was limited. Although a systematic search was conducted and all efforts made to locate and identify relevant studies, there is a possibility that some studies may have been missed. Screening of articles was conducted by one of the reviewers only (JC), with validation by other reviewers (LL, KP) if required, therefore relevant studies may have been erroneously excluded, potentially contributing to selection bias. This systematic review only included articles that were written in English, potentially excluding appropriate articles published in other languages.

Limitations of included studies

The papers included in the systematic review had limitations which should be highlighted. Most primary studies did not explicitly report the methods and qualitative methods employed. The use of a qualitative descriptive design was presumed where clarity was lacking. The majority of the primary study authors did not present their cultural and theoretical orientations, making it difficult to evaluate how their beliefs and values influenced their research.

There was variability in the contexts of the studies relating to the discharge planning experiences of major trauma patients and their carers, with some taking place in acute wards versus rehabilitation centres. There were possible differences in the way patients were involved in the discharge planning process. For example, for patients in acute wards had significantly less time for discharge planning to occur, whereas for patients in rehabilitation centres experienced extensive discharge planning which occurred over an extended period. Furthermore, some studies gathered evidence from community-based participants who reflected on their discharge planning experience up to 20 years previously. Participant recollection of events may have altered in the time between discharge and data collection.

Conclusion

To the authors' knowledge, this is the first qualitative evidence synthesis investigating patient and carer perspectives of discharge planning post major trauma. The aggregation of findings from 14 published papers indicates that patients and carers generally do not have positive experiences in discharge planning after major trauma. Four synthesised findings emerged: (1) Patients and carers feel generally unprepared for to manage at home after discharge from hospital; (2) Early identification of patients' post discharge needs allows for appropriate referrals and supports to be organised prior to discharge; (3) Patients and carers value participation in the discharge planning process to facilitate an organised discharge from hospital; and (4) The timely presentation, delivery and relevancy of information impacts how patients and carers manage discharge.

Findings of this systematic review reveal that even though some patients and carers were satisfied with the collaborative relationship they shared with their health professionals, the cohort was generally not satisfied with their experiences of the discharge planning process. Both patients and carers felt that their needs and expectations for the transfer home had not been comprehensively identified and addressed. Collaboration between patients, carers and healthcare professionals was not consistent, resulting in poor information provision, leaving patients and carers confused and unsupported.

Implications and recommendations for practice

JBI is committed to the transfer and implementation of research evidence in healthcare policy and practice as this has been highlighted to be an important part of evidence-based practice.[44] Therefore, each JBI systematic review methodology advises provision of recommendations for practice based on evidence to guide healthcare professionals.

Grades are used to classify recommendations for practice, based on the strength of the evidence. Grade A recommendations are considered 'strong' as there is adequate literature to support the proposition whereas Grade B recommendations are considered 'weak' or 'conditional'.[113] The following points present recommendations for practice when facilitating discharge planning with patients and carers after major trauma …

- Patients and carers should receive education on coping skills, such as hope and resilience, and have access to peer support to assist to them adjust to the effects of their injuries and reintegrate into the community. Education can be delivered by any member of the healthcare team who have received formal training on how to teach the adoption of coping skills. (Grade A)

- Patients and carers should be referred to psychological services on discharge from hospital after major trauma. Psychological services can reinforce the application of positive coping strategies when patients and cares face unexpected challenges and need to rely on their own resources to address them. (Grade A)
- Patients and carers should have the opportunity to acquire and apply skills learnt in an environment or context that is meaningful and relevant to them, e.g. home environment or local community. This enables them to hone their skills and familiarises them with their environment prior to hospital discharge. (Grade A)
- Patients' care should be governed by a trauma management pathway, where relevant. This will assist in early identification of individual patient and carer discharge needs so these can be addressed prior to discharge. Patients should be assigned a trauma pathway healthcare professional to provide support and advocacy services throughout their hospital admission and ideally continue after discharge. (Grade B)
- On discharge, patients should have received a written individualised care plan containing relevant information on medication, hospital contacts and community-based referrals. (Grade B)
- Patients and carers should be invited to participate in shared decision-making in regard to their healthcare. This empowers patients and carers to direct their care and ensures that care remains relevant to the individual. An example of shared-decision making is the setting and regular review of short-term rehabilitation goals. (Grade A)
- Healthcare teams should adopt interprofessional teamwork strategies, such as standardised handover formats, daily briefings and simulation of scenarios, as contained is TeamSTEPPS. These strategies promote effective communication and assist in providing discharge planning that is organised, prepared and collaborative (Grade A)
- Healthcare professionals should be trained in health literacy skills to enable them to be sensitive towards and understand the information needs and learning style of patients and carers. This should influence the provision of individualised discharge information that is presented in an easily accessible format for patients and carers. (Grade A)

Adopting these recommendations will assist patients and their carers in managing the transition from hospitalised care to the community whilst aiming to reduce the long-term impact of the trauma on their reintegration into previous life roles.

Implications and recommendations for research

During the conduct of this systematic review, several areas for potential research were highlighted and are listed below:

- Even though different patient centred approaches have been introduced in the 'Discussion' section of this systematic review, there is limited research into the effects of employing them in the discharge planning process in any hospital specialty. Further research in this area could investigate the frequency of adoption of the approaches and the perceived worthiness of their application.
- There is limited global consensus on the definition of the levels of trauma using specific measures. It would be advantageous for organisations to collaborate in order to standardise definitions of trauma severity.
- This systematic review investigated major trauma patient and carer perspectives of hospital discharge planning. It would be interesting to investigate health professionals' perceptions and experiences of engaging with patients and carers in the discharge planning process.
- Gaps in the trauma pathway have been identified by reviewing current literature. Research into the merits and financial costs of extending trauma care pathways from tertiary centres into the community could be investigated
- Review of current literature indicates limited employment of interprofessional strategies in trauma care. It may be beneficial to identify the factors that facilitate or inhibit the implementation of interprofessional teamwork principles in trauma patient management.

Conflict of interest

The author declares no conflict of interest.

References

1. Ringburg AN, Polinder S, van Ierland MC, Steyerberg EW, van Lieshout EM, Patka P, et al. Prevalence and prognostic factors of disability after major trauma. J Trauma. 2011;70(4):916-22.
2. Cameron PA, Fitzgerald MC, Curtis K, McKie E, Gabbe B, Earnest A, et al. Over view of major traumatic injury in Australia – Implications for trauma system design. Injury. 2020;51(1):114-21.
3. Kehoe A, Smith JE, Edwards A, Yates D, Lecky F. The changing face of major trauma in the UK. Emerg Med J. 2015;32(12):911-5.
4. Gabbe BJ, Simpson PM, Cameron PA, Ponsford J, Lyons RA, Collie A, et al. Long-term health status and trajectories of seriously injured patients: A population-based longitudinal study. PLoS Med. 2017;14(7):e1002322.
5. Global Health Estimates 2020: Disease burden by Cause, Age, Sex, by Country and by Region 2000-2019. Geneva: World Health Organisation; 2020. [cited 2021 October 19]. Available from: https://www.who.int/data/global-health-estimates
6. Australian Trauma Quality Improvement (AusTQIP) Collaboration (2018). Australian Trauma Registry, Management of the Severely Injured in Australia. 1 July 2016 to 30 June 2017. Alfred Health, Melbourne, Victoria [cited 2021 October 19]. Available from: http://ATR_Annual+Report_16-17_FA3_lowres_spreads.pdf
7. Baker SP, O'Neill B, Haddon Jr W, Long WB. The Injury Severity Score: A method for describing patients with multiple injuries and evaluating emergency care. J Trauma. 1974;14(3):187-96.
8. Gotlib Conn L, Zwaiman A, DasGupta T, Hales B, Watamaniuk A, Nathens AB. Trauma patient discharge and care transition experiences: Identifying opportunities for quality improvement in trauma centres. Injury. 2018;49(1):97-103
9. Garlanger KL, Beck LA, Cheville AL. Functional outcomes in patients with co-occurring traumatic brain injury and spinal cord injury from an inpatient rehabilitation facility's perspective. J Spinal Cord Med. 2018;41(6):718-30.

10. The Trauma Audit andfile:///Users/jeanettecollins/Downloads/ATR_Annual+Report_16-17_FA3_lowres_spreads.pdf Research Network. The Injury Severity Score (ISS). Salford, UK. 2021 [cited 5 Apr 2021]. Available from: https://www.tarn.ac.uk/Content.aspx?c=3117

11. Uleberg O, Pape K, Kristiansen T, Romundstad PR, Klepstad P. Population-based analysis of the impact of trauma on longer-term functional outcomes. Br J Surg. 2019;106(1):65-73.

12. Teasdale G, Jennett B. Assessment of coma and imparied consciousness. A practical scale. Lancet. 1974;13;2(7872):81-4.

13. Kirschblum S, Waring WP 3rd. Updates for the International standards for neurological classification of spinal cord injury. Phys Med Rehabil Clin N Am. 2014;25(3):505-17.

14. Haagsma JA, Graetz N, Bolliger I, Naghavi M, Higashi H, Mullany EC, et al. The global burden of injury: incidence, mortality, disability-adjusted life years and time trends from the Global Burden of Disease study 2013. Inj Prev. 2016;22(1):3-18.

15. Van Beeck EF, Larsen CF, Lyons RA, Meerding WJ, Mulder S, Essink-Bot ML. Guidelines for the conduction of follow-up studies measuring injury-related disability. J Trauma. 2007;62(2):534-50.

16. Braaf S, Ameratunga S, Ponsford J, Cameron P, Collie A, Harrison J, et al. Traumatic injury survivors' perceptions of their future: a longitudinal qualitative study. Disabil Rehabil. 2020;42(19):2707-2717..

17. Havermans RJM, Lansink KWW, de Munter L, de Jongh MAC. Relationship between health status and functional outcome during two years after a severe trauma. Injury. 2020;51(12):2953-61.

18. Fleischhacker E, Trentzsch H, Kuppinger D, Meigel F, Beyer F, Hartl WH. Long-term changes of patient-reported quality of life after major trauma: The importance of the time elapsed after injury. Injury. 2018;49(2):195-202.

19. Haider AH, Herrera-Escobar JP, Al Rafai SS, Harlow AF, Apoj M, Nehra D, et al. Factors Associated With Long-term Outcomes After Injury: Results of the Functional Outcomes and Recovery After Trauma Emergencies (FORTE) Multicenter Cohort Study. Ann Surg. 2020;271(6):1165-73.

20. Wad MS, Laursen T, Fruergaard S, Morgen SS, Dahl B. Survival and health related quality of life after severe trauma − a 15 years follow up study. Injury. 2018;49(2):191-4.

21. Newcomb AB, Hymes RA. Life Interrupted: The Trauma Caregiver Experience. J Trauma Nurs. 2017;24(2):125-33.

22. Lieshout K, Oates J, Baker A, Unsworth CA, Cameron ID, Schmidt J, et al.. Burden and Preparedness amongst Informal Caregivers of Adults with Moderate to Severe Traumatic Brain Injury. Int J Environ Res Public Health. 2020;17(17): 6386..

23. Conti A, Clari M, Nolan M, Wallace E, Tommasini M, Mozzone S, et al.. The Relationship Between Psychological and Physical Secondary Conditions and Family Caregiver Burden in Spinal Cord Injury: A Correlational Study. Top Spinal Cord Inj Rehabil. 2019;25(4):271-80.

24. DeDios-Stern S, Lee EJ. Blame, coping, and psychosocial outcomes in caregivers of individuals with brain injury. Rehabil Psychol. 2017;62(3):353-62.

25. Charlifue SB, Botticello A, Kolakowsky-Hayner SA, Richards JS, Tulsky DS. Family caregivers of individuals with spinal cord injury: exploring the stresses and benefits. Spinal Cord. 2016;54(9):732-6.

26. Bonsu K, Kugbey N, Ayanore MA, Atefoe EA. Mediation effects of depression and anxiety on social support and quality of life among caregivers of persons with severe burns injury. BMC Res Notes. 2019;12(1):772.

27. Manskow US, Sigurdardottir S, Roe C, Andelic N, Skandsen T, Damsgard E, et al. Factors Affecting Caregiver Burden 1 Year After Severe Traumatic Brain Injury: A Prospective Nationwide Multicenter Study. J Head Trauma Rehabil. 2015;30(6):411-23.

28. Pinelli V, Stuckey HL, Gonzalo JD. Exploring challenges in the patient's discharge process from the internal medicine service: A qualitative study of patients' and providers' perceptions. J Interprof Care. 2017;31(5):566-74.

29. Couturier B, Carrat F, Hejblum G. A systematic review on the effect of the organisation of hospital discharge on patient health outcomes. BMJ Open. 2016;6(12):e012287.

30. Waring J, Bishop S, Marshall F. A qualitative study of professional and carer perceptions of the threats to safe hospital discharge for stroke and hip fracture patients in the English National Health Service. BMC Health Serv Res. 2016;16:297.

31. Ameratunga S, Abel S, Tin Tin S, et al. Children admitted to hospital following unintentional injury: perspectives of health service providers in Aotearoa/New Zealand. BMC Health Serv Res. 2010;10:333-341

32. Hesselink G, Flink M, Olsson M, Barach P, Dudzik-Urbaniak E, Orrego C, et al. Are patients discharged with care? A qualitative study of perceptions and experiences of patients, family members and care providers. BMJ Qual Saf. 2012;21 Suppl 1:i39-49.

33. Gabbe BJ, Sleney JS, Gosling CM, Wilson K, Hart MJ, Sutherland AM, et al. Patient perspectives of care in a regionalised trauma system: lessons from the Victorian State Trauma System. Med J Aust. 2013;198(3):149-52.

34. Paterson B KB, Gmiterek. 'They never told us anything': Post discharge instruction for families of persons with brain injuries. Rehab Nursing. 2001;26(2):48-53.

35. Goldsmith H, McCloughen A, Curtis K. The experience and understanding of pain management in recently discharged adult trauma patients: A qualitative study. Injury. 2018;49(1):110-6.

36. Abrahamson V, Jensen J, Springett K, Sakel M. Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study. Disabil Rehabil. 2017;39(17):1683-94.

37. Nunnerley JL, Hay-Smith EJ, Dean SG. Leaving a spinal unit and returning to the wider community: an interpretative phenomenological analysis. Disabil Rehabil. 2013;35(14):1164-73.

38. Wiseman T, Foster K, Curtis K. The experience of emotional wellbeing for patients with physical injury: A qualitative follow-up study. Injury. 2016;47(9):1983-9.

39. Ioannou L, Cameron PA, Gibson SJ, Ponsford J, Jennings PA, Georgiou-Karistianis N, et al. Financial and recovery worry one year after traumatic injury: A prognostic, registry-based cohort study. Injury. 2018;49(5):990-1000.

40. Kellezi B, Earthy S, Sleney J, Beckett K, Barnes J, Christie N, et al. What can trauma patients' experiences and perspectives tell us about the perceived quality of trauma care? a qualitative study set within the UK National Health Service. Injury. 2020;51(5):1231-7.

41. Piccenna L, Lannin NA, Gruen R, Pattuwage L, Bragge P. The experience of discharge for patients with an acquired brain injury from the inpatient to the community setting: A qualitative review. Brain Inj. 2016;30(3):241-51.

42. Shepperd S, Lannin NA, Clemson LM, McCluskey A, Cameron ID, Barras SL Discharge planning from hospital to home. Cochrane Database of Systematic Reviews. 2013 Jan 31;(1): CD000313

43. Goncalves-Bradley DC, Lannin NA, Clemson LM, Cameron ID, Shepperd S. Discharge planning from hospital. Cochrane Database Syst Rev. 2016;27(1):CD000313.

44. Dawes M, Summerskill W, Glasziou P, Cartabellotta A, Martin J, Hopayian K, et al. Sicily statement on evidence-based practice. BMC Med Educ. 2005;5(1):1.

45. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. BMJ. 1996;312(7023):71-2.

46. Aromataris E, Pearson A. The Systematic Review: An overview. Am J Nurs. 2014;114(3):53-8.

47. Aromataris E, Fernandez R, Godfrey CM, Holly C, Khalil H, Tungpunkom P. Summarizing systematic reviews: methodological development, conduct and reporting of an umbrella review approach. Int J Evid Based Healthc. 2015;13(3):132-40.

48. Munn Z, Stern C, Aromataris E, Lockwood C, Jordan Z. What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. BMC Med Res Methodol. 2018;18(1):5.

49. Lockwood C, Porritt K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, et al. Chapter 2: Systematic Reviews of qualitative evidence. In: Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis JBI 2020. [Cited 2021 October 17]. Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-03

50. Hall R, Harvey LA. Qualitative research provides insights into the experiences and perspectives of people with spinal cord injuries and those involved in their care. Spinal Cord. 2018;56(6):527.

51. Draper AK. The principles and application of qualitative research. Proc Nutr Soc. 2004;63(4):641-6.

52. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179-87.

53. Pearson A. Balancing the evidence: incorporating the synthesis of qualitative data into systematic reviews. JBI Reports. 2004;2(2):45-64.

54. Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of qualitative research synthesis: the ConQual approach. BMC Med Res Methodol. 2014;14(1):108.

55. Aromataris E, Munn Z, (Editors). JBI Manual for Evidence Synthesis. JBI, 2020. [cited 2021 October 17] Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-01

56. Evidence ICoAH. Discharge Planning Project. [Internet]. Adelaide (Aus): University of South Australia; [Cited 2021 October 17. Available from: https://www.unisa.edu.au/research/Allied-Health-Evidence/Projects/Quality-Care1/DCP/

57. OECD iLibrary. Health at a Glance 2019: OECD Indicators [Internet]. Paris. 2019.[Cited 2021 October 17]. Available from: https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-2019_4dd50c09-en

58. National Safety and Quality Health Service Standards. In: Australian Commission on Safety, and Quality. 2nd ed. Sydney: ACSQHC. 2017. p.13-21

59. Collins J, Lizarondo L, Porritt K. Adult patient and/or carer experiences of planning for hospital discharge after major trauma: a qualitative systematic review protocol. JBI Evid Synth. 2020; 18(2):341-347

60. Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health. 2010;33(1):77-84.

61. Moher D, Liberati A, Teztlaff J, Altman DG. Preferred Reporting Items for Systematic Review and Analyses: The PRISMA Statement. PLoS Med. 2009;6(7): e1000097.

62. Mbakile-Mahlanza L, Manderson L, Downing M, Ponsford J. Family caregiving of individuals with traumatic brain injury in Botswana. Disabil Rehabil. 2017;39(6):559-67.

63. Mbakile-Mahlanza L, Manderson L, Ponsford J. The experience of traumatic brain injury in Botswana. Neuropsychol Rehabil. 2015;25(6):936-58.

64. Brauer J, Hay CC, Francisco G. A retrospective investigation of occupational therapy services received following a traumatic brain injury. Occup Ther Health Care. 2011;25(2-3):119-30.

65. Conti A, Garrino L, Montanari P, Dimonte V. Informal caregivers' needs on discharge from the spinal cord unit: analysis of perceptions and lived experiences. Disabil Rehabil. 2016;38(2):159-67.

66. HeydariKhayat N, Ashktorab T, Rohani C. Home care for burn survivors: A phenomenological study of lived experiences. Home Health Care Serv Q. 2021;40(3):204-217.

67. Beaton A, O'leary K, Thorburn J, Campbell A, Christey G. Improving patient experience and outcomes following serious injury. N Z Med J. .. 2019;132(1494):15-25.

68. Braaf S, Ameratunga S, Nunn A, Christie N, Teague W, Judson R, et al. Patient-identified information and communication needs in the context of major trauma. BMC Health Serv Res. 2018;18(1):163.

69. Yoshida KK. Institutional impact on self concept among persons with spinal cord injury. Int J Rehabil Res. 1994;17(2):95-107.

70. Kreitzer N, Bakas T, Kurowski B, Lindsell CJ, Ferioli S, Foreman B, et al. The Experience of Caregivers Following a Moderate to Severe Traumatic Brain Injury Requiring ICU Admission. J Head Trauma Rehabil. 2020;35(3):E299-E309..

71. Moore M, Kiatchai T, Ayyagari RC, Vavilala MS. Targeted areas for improving health literacy after traumatic brain injury. Brain Inj. 2017;31(13-14):1876-81.

72. Sandström L, Engstrom A, Nilsson C, Juuso P. Experiences of suffering multiple trauma: A qualitative study. Intensive Crit Care Nurs. 2019;54:1-6..

73. Unger J, Singh H, Mansfield A, Hitzig SL, Lenton E, Musselman KE. The experiences of physical rehabilitation in individuals with spinal cord injuries: a qualitative thematic synthesis. Disabil Rehabili. 2019;41(12):1367-83.

74. Lefebvre H, Pelchat D, Swaine B, Gélinas I, Levert MJ. The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. Brain Inj. 2005;19(8):585-97.

75. Uhrenfeldt L, Fegran L, Aagaard H, Ludvigsen MS. Significant others' experience of hospitalized patients' transfer to home: A systematic review and meta-synthesis. Z Evid Fortbild Qual Gesundhwes. 2018;139:1-9.

76. Weber L, Voldsgaard NH, Holm NJ, Schou LH, Biering-Sorensen F, Moller T. Exploring the contextual transition from spinal cord injury rehabilitation to the home environment: a qualitative study. Spinal Cord. 2021;59(3):336-46.

77. Lutz BJ, Young ME, Creasy KR, Martz C, Eisenbrandt L, Brunny JN, et al. Improving Stroke Caregiver Readiness for Transition From Inpatient Rehabilitation to Home. Gerontologist. 2017;57(5):880-9.

78. Lapum JL, Fredericks S, Liu L, Yau TM, Retta B, Jones VM, et al. Facilitators and Barriers of Heart Surgery Discharge: Patients' and Nurses' Narrative Accounts. J Cardiovasc Nurs. 2016;31(4):350-6.

79. Mitchell SE, Laurens V, Weigel GM, Hirschman KB, Scott AM, Nguyen HQ, et al. Care Transitions From Patient and Caregiver Perspectives. Ann Fam Med. 2018;16(3):225-31.

80. Boschen KA, Tonack M, Gargaro J. Long-term adjustment and community reintegration following spinal cord injury. Int J Rehabil Res.. 2003;26(3):157-64.

81. Dibb B, Ellis-Hill C, Donovan-Hall M, Burridge J, Rushton D. Exploring positive adjustment in people with spinal cord injury. J Health Psychol. 2014;19(8):1043-54.

82. Jones KF, Simpson G, Briggs L, Dorsett P, Anderson M. A study of whether individual and dyadic relations between spirituality and resilience contribute to psychological adjustment among individuals with spinal cord injuries and their family members. Clin Rehabil. 2019;33(9):1503-14.

83. Zakzesky D, Klink K, McAndrew N, Schroeter K, Johnson G. Bridges and Barriers: Patients' Perceptions of the Discharge Process Including Multidisciplinary Rounds on a Trauma Unit. J Trauma Nurs. 2015;22(5):232-9.

84. Sullivan CT, Gray MA, Williams GP, Green DJ, Hession CA. The use of real life activities in rehabilitation: the experience of young men with traumatic brain injuries from regional, rural and remote areas in Australia. J Rehabil Med. 2014;46(5):424-9.

85. Sand A, Karlberg I, Kreuter M. Spinal cord injured persons' conceptions of hospital care, rehabilitation, and a new life situation. Scand J Occup Ther.. 2006;13(3):183-92.

86. Turner BJ, Fleming J, Ownsworth T, Cornwell P. Perceived service and support needs during transition from hospital to home following acquired brain injury. Disabil Rehabi. 2011;33(10):818-29.

87. Sleney J, Christie N, Earthy S, Lyons RA, Kendrick D, Towner E. Improving recovery-Learning from patients' experiences after injury: a qualitative study. Injury. 2014;45(1):312-9.

88. Livingston DH, La Bagnara S, Sieck D, Yonclas P, Castellano C, Cho C, et al. The Center for Trauma Survivorship: Addressing the great unmet need for posttrauma center care. J Trauma Acute Care Surg. 2020;89(5):940-6.

89. Goodman H. Discharging patients from acute care hospitals. Nurs Stand. 2016;30(24):49-57.

90. Kimmel LA, Holland AE, Hart MJ, Edwards ER, Page RS, Hau R, et al. Discharge from the acute hospital: trauma patients' perceptions of care. Aust Health Rev. 2016;40(6):625-32.

91. Naylor MD, Shaid EC, Carpenter D, Gass B, Levine C, Li J, et al. Components of Comprehensive and Effective Transitional Care. J Am Geriatr Soc. 2017;65(6):1119-25.

92. Walter E, Curtis K. The role and impact of the specialist trauma nurse: an integrative review. J Trauma Nurs. 2015;22(3):153-69.

93. Liu SI, Curren J, Leahy NE, Sobocinski K, Zambardino D, Shikar MM, et al. Trauma Response Nurse: Bringing Critical Care Experience and Continuity to Early Trauma Care. J Trauma Nurs. 2019;26(4):215-20.

94. Spittal MJ, Grant G, O'Donnell M, McFarlane AC, Studdert DM. Development of prediction models of stress and long-term disability among claimants to injury compensation systems: a cohort study. BMJ Open. 2018;8(4): e020803.

95. Groene RO, Orrego C, Sunol R, Barach P, Groene O. "It's like two worlds apart": an analysis of vulnerable patient handover practices at discharge from hospital. BMJ Qual Saf. 2012;21 Suppl 1(Suppl_1):i67-75.

96. Elwyn G, Coulter A, Laitner S, Walker E, Watson P, Thomson R. Implenting shared decision making in the NHS. BMJ. 2010;341:c5146.

97. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd AA, Kinnersley P, et al. Shared Decision Making: A model for clinical practice. J Gen Intern Med. 2012;27(10):1361-7.

98. Tonelli MR, Sullivan MD. Person-centred shared decision making. J Eval Clin Pract. 2019;25(6):1057-62.

99. Kaslow NJ, Dunn SE, Henry T, Partin C, Newsome J, O'Donnell C, et al. Collaborative patient- and family-centered care for hospitalized individuals: Best practices for hospitalist care teams. Fam Syst Health. 2020;38(2):200-8.

100. Lindberg J, Kreuter M, Taft C, Person LO. Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. Spinal Cord. 2013;51(11):834-7.

101. Knox L, Douglas JM, Bigby C. "I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury. Disabi Rehabil. 2017;39(22):2250-60.

102. Wei H, Corbett RW, Ray J, Wei TL. A culture of caring: the essence of healthcare interprofessional collaboration. J Interprof Care. 2020;34(3):324-31.

103. Reeves S, Pelone F, Harrison R, Goldman J, Zwarenstein M. Interprofessional collaboration to improve professional practice and healthcare outcomes. Cochrane Database Syst Rev. 2017;6(6):CD000072.

104. Lobchuk M, Bell A, Hoplock L, Lemoine J. Interprofessional discharge team communication and empathy in discharge planning activities: A narrative review. J Interprof Educ Pract. 2021; 23(7):100393.

105. Scotten M, Manos EL, Malicoat A, Paolo AM. Minding the gap: Interprofessional communication during inpatient and post discharge chasm care. Patient Educ Couns. 2015;98(7):895-900.

106. Clapper TC. TeamSTEPPS® is an effective tool to level the hierarchy in healthcare communication by empowering all stakeholders. J Commun Healthc. 2019;11(4):241-4.

107. Rajah R, Ahmad Hassali MA, Jou LC, Murugiah MK. The perspective of healthcare providers and patients on health literacy: a systematic review of the quantitative and qualitative studies. Perspect Public Health. 2018;138(2):122-32.

108. Sørensen K, Van den Brouke S, Fullam J, Doyle J, Pelikan J, Slonska Z, et al. Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health. 2012; 25:12-80.

109. Weinberg JA, Shehada MZ, Chapple KM, Israr S, Jones MD, Jacobs JV, et al. The health literacy of hospitalized trauma patients: We should be screening for deficiencies. J Trauma Acute Care Surg. 2019;87(5):1214-9.

110. Kim MY, Oh S. Nurses' Perspectives on Health Education and Health Literacy of Older Patients. Int J Environ Res Public Health. 2020;17(18):6455.

111. Roodbeen R, Vreke A, Boland G, Rademakers J, van den Muijsenbergh M, Noordman J, et al. Communication and shared decision-making with patients with limited health literacy; helpful strategies, barriers and suggestions for improvement reported by hospital-based palliative care providers. PLoS One. 2020;15(6):e0234926.

112. Coffey NT, Cassese J, Cai X, Garfinkel S, Patel D, Jones R, et al. Identifying and Understanding the Health Information Experiences and Preferences of Caregivers of Individuals With Either

Traumatic Brain Injury, Spinal Cord Injury, or Burn Injury: A Qualitative Investigation. J Med Internet Res. 2017;19(5):e159.

113. JBI Levels of Evidence and Grades of Recommendation Working Party. Supporting document for the JBI levels of Evidence and Grades of Recommendation. JBI. 2014 [cited 18 July 2021]. Available from: https;//joannabriggs.org/sites/default/files/2019-05/JBI%20Levels%20of%20Evidence%20SupportingDocuments-v2.pdf

Appendix I: Search strategy

PubMed

ID	Query
1	multiple trauma[mh] OR major trauma [tiab] OR trauma [tiab] OR traumatic brain injur* [tiab] OR brain injuries, traumatic [mh] OR burns [mh] OR burn[tiab] OR burns [tiab] OR spinal cord injuries [mh] OR spinal cord injur* [tiab] OR trauma, nervous system [mh] OR neurotrauma [tiab]
2	Plannings, discharge [tiab] OR Patient discharge [mh] OR Hospital discharge [tiab] OR rehabilitation centers [mh] OR rehabilitation [tiab] OR Neurological Rehabilitation [mh] OR neurorehabilit* [tiab] OR Patient education [mh] OR patient education [tiab] OR caregiver [mh] OR caregiver* [tiab]
3	Qualitative research [mh] OR qualitative [tiab] OR Personal narratives [mh] OR Narration [mh] OR Narrat* [tiab] OR Patient experience* [tiab] OR patient satisfaction [mh] OR Satisfaction, patient [tiab] OR patient attitude* [tiab] OR Grounded theory [mh] OR Grounded theory [tiab] OR Phenomenolog* [tiab] OR case report [mh] OR Case report* [tiab] OR Descript* [tiab] OR Ethnograph* [tiab]
4	1 AND 2 AND 3
5	Limited to papers published in English

Embase

ID	Query
1	‘multiple trauma’/de OR ‘trauma’:ti,ab OR ‘major trauma’:ti,ab OR ‘traumatic brain injury’/de OR ‘traumatic brain injur*’:ti,ab OR burn/de OR ‘burn’:ti,ab OR ‘burns’:ti,ab OR ‘spinal cord injury’/de OR ‘spinal cord injur*’:ti,ab OR ‘nervous system injury”/de OR ‘neurotrauma’:ti,ab
2	Hospital discharge/de OR ‘hospital discharge’:ti,ab OR ‘patient discharge’:ti,ab OR ‘discharge plan*’:ti,ab OR ‘rehabilitation centre’/de OR ‘rehabilitation cent*’:ti,ab OR ‘rehabilitation’:ti,ab OR ‘neurorehabilitation’/de OR ‘neurological rehabilit*’:ti,ab OR ‘Patient education’/de OR ‘patient education’:ti,ab OR caregiver/de OR caregiver*:ti,ab
3	‘Qualitative research’:ti,ab OR ‘qualitative*’:ti,ab OR Patient satisfaction/de OR ‘Satisfaction, patient’:ti,ab OR ‘personal experience’/de OR ’personal experience*’:ti,ab OR Narrative/de OR ‘narrat*’:ti,ab OR ‘patient attitude’/de OR ‘patient attitude*’:ti,ab OR ‘Grounded theory’/de OR ‘Grounded theory’:ti,ab OR phenomenology/de OR ‘Phenomenolog*’:ti,ab OR ‘case report’/de OR ‘Case report*’:ti,ab OR descriptive research/de OR ‘Descript*’:ti,ab OR ‘ethnography’/de OR ‘Ethnograph*’:ti,ab
4	1 AND 2 AND 3
5	Limited to papers published in English

PsycINFO

ID	Query
1	Trauma.sh OR multiple trauma.ti,ab OR major trauma.ti,ab OR traumatic brain injury.sh OR traumatic brain injur*.ti,ab OR spinal cord injuries.sh OR spinal cord injur*.ti,ab OR burns.sh OR burn.ti,ab OR burns.ti,ab OR nervous system injur*:ti,ab OR neurotrauma:ti,ab
2	Hospital discharge.sh OR hospital discharge.ti,ab OR discharge planning.sh OR discharge plan*.ti,ab OR rehabilitation centers.sh OR rehabilitation cent*.ti,ab OR rehabilitation:ti,ab OR patient discharge.ti,ab OR neurorehabilitation.sh OR neurorehabilit*.ti,ab OR client education.sh OR patient education.ti,ab OR client education:ti,ab OR caregiver.sh OR caregiver*.ti,ab
3	Qualitative methods.sh OR qualitative*.ti,ab OR narrative analysis.sh OR narrat*.ti,ab OR personal narrat*.ti,ab OR client satisfaction.sh OR patient satisfaction.ti,ab OR client attitudes.sh OR patient attitude*.ti,ab OR phenomenology.sh OR phenomenolog*.ti,ab OR ethnography.sh OR ethnograph*.ti,ab OR grounded theory.sh OR grounded theory.ti,ab OR case report.sh OR case report*.ti,ab
4	1 AND 2 AND 3
5	Limited to papers published in English

Scopus

ID	Query
1	“major trauma” OR “nervous system injur*” OR “traumatic brain injur*” OR burn OR burns OR “spinal cord injur*” OR “trauma*”
2	“Hospital discharge” OR “patient discharge” OR “discharge plan*” OR “rehabilitation cent*” OR “Patient education” OR “caregiver”
3	“qualitative*” OR Narrat* OR “Patient satisfaction” OR “patient attitude*” OR “Grounded theory” OR Phenomenolog* OR Ethnograph* OR “Case report”
4	1 AND 2 AND 3
5	Limited to papers published in English

CINAHL

The search for unpublished studies in relevant websites

ID	Query
1	(TI “Traumatic brain injur*” OR AB "traumatic brain injur*") OR MH Brain injuries OR (TI”brain traum*” OR AB “brain traum*”) OR MH Burns OR (TI burn OR AB burn) OR (TI burns OR AB burns) OR MH Spinal Cord Injuries OR (TI "spinal cord injur*" OR AB "spinal cord injur*") OR MH Multiple Trauma OR TX “multiple trauma” OR MH trauma OR (TI traum* OR AB traum*) OR (TI “major trauma” OR AB “major Trauma”) OR (TI “nervous system injur*”:OR AB “nervous system injur*”) OR (TI “neurotrauma” OR AB “neurotrauma”)
2	MH Discharge planning OR (TI “Discharge Plan*” OR AB “Discharge Plan*”) OR AB “Transfer, Discharge”) OR MH Patient Discharge OR TI ”Patient Discharge” OR AB “Patient discharge”) OR MH Rehabilitation centers OR (TI ”Rehabilitation Cent*” OR AB “Rehabilitation Cent*”) OR (TI rehabilitation OR AB rehabilitation) OR (TI “neuro rehabilit*” OR AB “neuro rehabilit*”) OR MH patient education OR (TI “patient education” OR AB “patient education”) OR MH caregivers OR (TI “caregiver*” OR AB “caregiver*”)
3	MH qualitative methods OR (TI “qualitative*” OR AB “qualitative*”) OR MH narrative analysis OR (TI “narrat*” OR AB ”narrat*”) OR MH patient satisfaction OR (TI “patient satisfaction” OR AB “patient satisfaction”) OR MH patient experience OR (TI ”patient experience” OR AB “patient experience”) OR MH patient attitudes OR (TI “patient attitude*” OR AB “patient attitude*”) OR MH phenomenological research OR (TI “phenomenolog*” OR AB phenomenolog*”) OR MH ethnographic research OR (TI”ethnograph*” OR AB “ethnograph*”) OR MH descriptive research OR (TI ”descript*” OR AB “descript*”) OR (TI “case report” OR AB “case report”) OR MH grounded theory OR (TI “grounded theory” OR AB “grounded theory”)
4	1 AND 2 AND 3
5	Limited to papers published in English

WorldWideScience.org

ID	Query
1	"discharge plan*" AND ("major trauma" OR "traumatic brain injur*" OR "spinal cord injur*") AND ("qualitative*" OR "patient experience*" OR "patient satisfaction" OR “caregiver*”)
2	Limited to papers published in English

ProQuest Dissertations and Theses Databases

ID	Query
1	"discharge plan*" AND ("major trauma" OR "traumatic brain injur*" OR "spinal cord injur*") AND ("qualitative*" OR "patient experience*" OR "patient satisfaction" OR “caregiver”)
2	Limited to papers published in English
3	First 20 pages

Google Scholar

ID	Query
1	"discharge plan*" AND ("major trauma" OR "traumatic brain injur*" OR "spinal cord injur*") AND ("qualitative*" OR "patient experience*" OR "patient satisfaction" OR “caregiver*”)
2	Limited to papers published in English, pdf,
3	First 20 pages

Appendix II: Studies ineligible at full-text review

Reason for exclusion: Ineligible population

Paediatric population

Books

Allen ME. Effectiveness and outcomes of adding therapeutic behavioral services to an existing treatment plan for children in crisis [dissertation]. [Sacremento] California State University 2010. 85 p

Kiser L Strengthening family coping resources: Intervention for families impacted by trauma. 1st ed. Philadelphia Routledge; 2015. 294 p

Journals

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Armstrong-James L, Cadogan J, Williamson H, Rumsey N, Harcourt D	Using Photo-Elicitation to Explore Families' Experiences of Burn Camp	Journal of Family Nursing	2019	25	1	81-108
DeWitt K	The experience of getting well as described by adolescents recovering from trauma: a phenomenological perspective	Rehabilitation Nursing Research	1993	2	1	p10-16
Donoghue K, Stead R	Consumer evaluation of a head injury assessment and rehabilitation unit	Paediatric Nursing	2002	14	10	p20-3
Gan C, Gargaro J, Kreutzer JS, Boschen KA, Wright FV	Development and preliminary evaluation of a structured family system intervention for adolescents with brain injury and their families	Brain Injury	2010	24	4	651-663
Gan C, Wright, FV	Development of the family needs questionnaire - pediatric version [FNQ-P] - phase I	Brain Injury	2019	33	5	623-632
Gauvin-Lepage J Lefebvre H	Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals	Brain Injury	2010	24	9	1087-1097
Gauvin-Lepage J, Lefebvre H, Malo D	Resilience in Families with Adolescents Suffering From Traumatic Brain Injuries	Rehabilitation Nursing	2015	40	6	368-77
Gebhardt MC, McGehee LA, Grindel CG, Testani-Dufour L	Caregiver and nurse hopes for recovery of patients with acquired brain injury	Rehabilitation Nursing	2011	36	1	p3-12
House LA, Russell HF, Kelly EH, Gerson A, Vogel LC	Rehabilitation and future participation of youth following spinal cord injury: caregiver perspectives	Spinal Cord	2009	47	12	882-6

Robert R, Berton M, Moore P, Murphy L, Meyer W, Blakeney P et al.	Applying what burn survivors have to say to future therapeutic interventions	Burns	1997	23	1	50-4

Patient population

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Aggar C, Pryor J, Fisher M	Partners' experiences of caregiving and perceptions of inpatient rehabilitation following catastrophic injury	International Journal of Therapy & Rehabilitation	2017	24	6	255-262
Au EH, Holdgate A	Characteristics and outcomes of patients discharged home from the Emergency Department following trauma team activation	Injury	2010	41	5	465-9
Bergman K	Discharge Instructions for Concussion: Are We Meeting the Patient Needs?	Journal of Trauma Nursing	2016	23	6	327-333
Freeman T	Assessing the role of formal and informal caregivers in the current tertiary healthcare system: Factors influencing care roles and satisfaction with care		2005		NR02639	341
Gotlib Conn L, Zwaiman A, DasGupta T, Hales B, Watamaniuk A, Nathens AB	Trauma patient discharge and care transition experiences: Identifying opportunities for quality improvement in trauma centres	Injury	2018	49	1	97-103
Herrmann LL, Deatrick JA	Experiences and Perceptions of Hospitalization and Recovery of Older Adults and Their Caregivers Following Traumatic Brain Injury: "Not Knowing"	Research in Gerontological Nursing	2019			p1-12
Hironobu S, Kaoruko T, Naohisa K, Sashika H, Takada K, Kikuchi N	Rehabilitation needs and participation restriction in patients with cognitive disorder in the chronic phase of traumatic brain injury	Medicine	2017	94	4	p1-12
Jackson BS	The dilemma of the hasty discharge	The Journal of nursing administration	1996	26	6	p7-9
Jacobs VM, Lamb M	Informational needs of post-surgical patients following discharge		1995		MM01868	155
Kimmel LA, Holland AE, Hart MJ, Edwards ER, Page RS, Hau R et al.	Discharge from the acute hospital: trauma patients' perceptions of care	Australian Health Review	2016	40	6	625-632
Leith KH, Phillips L, Sample PL	Exploring the service needs and experiences of persons with TBI and their families: the South Carolina experience	Brain Injury	2004	18	12	1191-208
McGrath PM, Mink BP	The experience of family caregivers within the acute care hospital setting: An institutional ethnography		2014		3633881	214

Munce SEP, Webster F, Fehlings MG, Straus, SE, Jang E, Jaglal SB	Meaning of self-management from the perspective of individuals with traumatic spinal cord injury, their caregivers, and acute care and rehabilitation managers: an opportunity for improved care delivery	BMC Neurology	2016	16		11
Newcomb AB, Hymes RA	Life Interrupted: The Trauma Caregiver Experience	Journal of Trauma Nursing	2017	24	2	125-133
Oyesanya TO, Arulselvam K, Thompson N, Norelli J, Seel RT	Health, wellness, and safety concerns of persons with moderate-to-severe traumatic brain injury and their family caregivers: a qualitative content analysis	Disability and Rehabilitation	2019			p1-11
Phillips L	Let's get moving: Improving discharge time	Nursing Management	2017	48	9	36-38
Piccenna L, Lannin NA, Gruen R, Pattuwage L, Bragge P	The experience of discharge for patients with an acquired brain injury from the inpatient to the community setting: A qualitative review	Brain Injury	2016	30	3	241-51
Porto A, Anderson L, Kalinich T, Deane KC, Vogel LC, Zebracki K	Understanding transition for youth with spinal cord injury: Youth and caregiver perceptions	Journal of Spinal Cord Medicine	2019			p1-7
Sleney J, Christie N, Earthy S, Lyons RA, Kendrick D, Towner E	Improving recovery-Learning from patients' experiences after injury: a qualitative study	Injury	2014	45	1	312-9
Van Horn E, Mishel M	Loss of resources and depressive symptoms after traumatic injury	Southern Online Journal of Nursing Research	2009	8	3	163
Warren N, Walford K, Susilo A, New PW	Emotional Consequences of Delays in Spinal Rehabilitation Unit Admission or Discharge: A Qualitative Study on the Importance of Communication	Topics in Spinal Cord Injury Rehabilitation	2018	24	1	54-62

Clinician perspective

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Doser K, Norup A	Family needs in the chronic phase after severe brain injury in Denmark	Brain Injury	2014	28	10	1230-7
Guilcher SJT, Everall AC, Patel T, Packer TL, Hitzig SL, Lofters AK	Medication adherence for persons with spinal cord injury and dysfunction from the perspectives of healthcare providers: A qualitative study	J Spinal Cord Med	2019	42	sup1	215-225
John JT, Block L, Stein A, Vasile E, Barilla-LaBarca ML	Caring for Patients with Physical Disabilities: Assessment of an Innovative Spinal Cord Injury Session That Addresses an Educational Gap	Am J Phys Med Rehabil	2019	98	11	1031-1035
Lambert J	Meeting the emotional needs of a patient	Rehabilitation nursing : the official journal of the Association of Rehabilitation Nurses	1999	24	4	141-142

Machado WC, Silva VM, Silva RA, Ramos RL, Figueiredo NM, Branco EM et al.	Hospital discharge of patients with disabling neurological injury: necessary referrals to rehabilitation	Cien Saude Colet	2016	21	10	3161-3170
Sabet FP, Tabrizi KN, Saadat S, Khankeh HR Abedi HA, Danial Z	Perception from barrier and facilitator for providing early rehabilitation care for RTI victims	Trauma Monthly	2015	20	3	No pagination specified

Reason for exclusion: wrong phenomena

Wrong intervention

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Amsters D, Duncan J, Field V, Smales A, Zillmann L, Kendall M, Kuipers P	Determinants of participating in life after spinal cord injury - advice for health professionals arising from an examination of shared narratives	Disability and Rehabilitation	2018	40	25	3030-3040
Bäckström J, Willebrand M, Sjöberg F, Haglund K	Being a family member of a burn survivor , Experiences and needs	Burns Open	2018	2	4	193-198
Baker A, Barker S, Sampson A, Martin C	Caregiver outcomes and interventions: a systematic scoping review of the traumatic brain injury and spinal cord injury literature	Clinical Rehabilitation	2017	31	1	45-60
Bernet M, Sommerhalder K, Mischke C, Hahn S, Wyss A	"Theory Does Not Get You From Bed to Wheelchair": A Qualitative Study on Patients' Views of an Education Program in Spinal Cord Injury Rehabilitation	Rehabilitation Nursing	2019	44	5	247-253
Braaf SC, Lennox A, Nunn A, Gabbe BJ	Experiences of hospital readmission and receiving formal carer services following spinal cord injury: a qualitative study to identify needs	Disability and Rehabilitation	2018	40	16	1893-1899
Costa MC, Rossi LA, Lopes LM, Cioffi CL	The meanings of quality of life: interpretative analysis based on experiences of people in burns rehabilitation	Revista Latino-Americana de Enfermagem	2008	16	2	252-9
Dibb B, Ellis-Hill C, Donovan-Hall M, Burridge J, Rushton D	Exploring positive adjustment in people with spinal cord injury	Journal of Health Psychology	2014	19	8	1043-54
Fitts MS, Bird K, Gilroy J, Fleming J, Clough AR, Esterman A et al.	A Qualitative Study on the Transition Support Needs of Indigenous Australians Following Traumatic Brain Injury	Brain Impairment	2019	20		137-159
Harms L	After the accident: Survivors' perceptions of recovery following road trauma	Australian Social Work	2004	57	2	161-174

McPherson KM McNaughton H, Pentland B	Information needs of families when one member has a severe brain injury	International Journal of Rehabilitation Research	2000	23	4	295-301
Papadimitriou C, Stone DA	Addressing existential disruption in traumatic spinal cord injury: a new approach to human temporality in inpatient rehabilitation	Disability and Rehabilitation	2011	33	21-22	2121-33
Zakzesky D, Klink K, McAndrew N, Schroeter K, Johnson G	Bridges and Barriers: Patients' Perceptions of the Discharge Process Including Multidisciplinary Rounds on a Trauma Unit	Journal of Trauma Nursing	2015	22	5	232-9

Not discharge planning

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Ågård AS, Egerod I, Tønnesen E, Lomborg K	Struggling for independence: A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge	Intensive and Critical Care Nursing	2012	28	2	105-113
Abou-Abbass H, Bahmad H, Ghandour H, Fares J, Wazzi-Mkahal R, Yacoub B et al.	Epidemiology and clinical characteristics of traumatic brain injury in Lebanon: A systematic review	Medicine (Baltimore)	2016	95	47	e5342
Abreu BC, Zhang L, Seale G, Primeau L, Jones JS	Interdisciplinary meetings: investigating the collaboration between persons with brain injury and treatment teams	Brain Injury	2002	16	8	691-704
Adams D, Dahdah M	Coping and adaptive strategies of traumatic brain injury survivors and primary caregivers	NeuroRehabilitation	2016	39	2	223-37
Aitken LM, Chaboyer W, Jeffrey C, Martin B, Whitty JA, Schuetz M et al.	Indicators of injury recovery identified by patients, family members and clinicians	Injury	2016	47	12	2655-2663
Akturk S, Akturk U	Determining the spiritual well-being of patients with spinal cord injury	Journal of Spinal Cord Medicine	2018			p1-8
Albright KJ, Duggan CH, Rahman RO	Motherhood in the context of spinal cord injury	Topics in Spinal Cord Injury Rehabilitation	2009	15	1	43-58
Alexander JL, Willems EP	Quality of life: some measurement requirements	Archives of Physical Medicine and Rehabilitation	1981	62	6	261-5
Alexiewich D	Evaluation of a videotape: orientation of patients to rehabilitation	SCI Nursing	1990	7	2	p31-3
Allison LA	Life care planning for individuals with spinal cord injuries: outcomes and considerations		2007		Ph.D.	452 p-452 p

Alve YA, Bontje P, Begum S	Intra- and interpersonal agency: Resuming occupational participation among persons with spinal cord injury after discharge from in-patient rehabilitation	Scandinavian Journal of Occupational Therapy	2019			p1-14
Ames H, McAlister L, Holmes SA	Interdisciplinary counselling sessions to promote post sci adjustment	Journal of Spinal Cord Medicine	2016	39	5	600
Amir D	A song is born: Discovering meaning in improvised songs through a phenomenological analysis of two music therapy sessions with a traumatic spinal-cord injured young adult	Music Therapy	1990	9	1	62-81
Angel S, Kirkevold M, Pedersen BD	Rehabilitation after spinal cord injury and the influence of the professional's support (or lack thereof)	Journal of Clinical Nursing	2011	20	11-Dec	1713-22
Angel S, Kirkevold M, Pedersen BD	Rehabilitation as a fight: a narrative case study of the first year after a spinal cord injury	International Journal of Qualitative Studies on Health & Well-Being	2009	4	1	28-38
Angel S, Kroll T	Placing rehabilitation and recovery after spinal cord injury into a biographical context: a U.S. versus Danish case comparison	Journal of Neuroscience Nursing	2012	44	6	298-306
Arima T, Noguchi T, Mochida J, Toh E, Konagai A, Nishimura K	Problems of long-term hospitalised cervical spinal cord injury patients in university hospitals	Paraplegia	1994	32	1	19-24
Armstrong J, Ager A	Perspectives on disability in Afghanistan and their implications for rehabilitation services	International Journal of Rehabilitation Research	2005	28	1	87-92
Armstrong TW, Williamson MLC, Elliott TR, Jackson WT, Kearns NT, Ryan T	Psychological distress among persons with upper extremity limb loss	British Journal of Health Psychology	2019	24	4	746-63
Arulselvam K, Oyesanya T, Thompson N, Seel R, Gordon C, Pavel M et al.	Exploring use of Technology in Persons with TBI and Their Caregivers: A Qualitative Content Analysis...2017 ACRM/American Congress of Rehabilitation Medicine Annual Conference 23-28 October, Atlanta, GA	Archives of Physical Medicine and Rehabilitation	2017	98	10	e68-e68
Arya S, Xue S, Embuldeniya A, Narammalage H, da Silva T, Williams S et al.	Coping strategies used by traumatic spinal cord injury patients in Sri Lanka: a focus group study	Disability and Rehabilitation	2016	38	20	2008-15
Ashworth F, Clarke A, Jones L, Jennings C, Longworth C	An exploration of compassion focused therapy following acquired brain injury	Psychology and Psychotherapy	2015	88	2	143-62
Barnett BS, Mulenga M, Kiser MM, Charles AG	Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi	Burns	2017	43	3	602-607
Boschen KA, Tonack M, Gargaro J	Long-term adjustment and community reintegration following spinal cord injury	International Journal of Rehabilitation Research	2003	26	3	157-64

Brennan Morrey RD, Quintana S	The relationship of hope, goal setting, goal commitment, and functional attainment among medical rehabilitation inpatients		2009		3400081	223
Brown P, Harmiss M, Schomer K, Johnson K	A systematic review of reviews to evaluate the evidence supporting interventions for people with traumatic brain injury	Archives of Physical Medicine and Rehabilitation	2010	91	10	e7
Calder A, Badcoe A, Harms L	Broken bodies, healing spirits: road trauma survivor's perceptions of pastoral care during inpatient orthopaedic rehabilitation	Disability and Rehabilitation	2011	33	15-16	1358-66
Caplan B	Staff and patient perception of patient mood	Rehabilitation Psychology	1983	28	2	67-77
Carlozzi NE, Kallen MA, Hanks R, Hahn EA, Brickell TA, Lange RT et al.	The TBI-CareQOL Measurement System: Development and Preliminary Validation of Health-Related Quality of Life Measures for Caregivers of Civilians and Service Members/Veterans with Traumatic Brain Injury	Archives of Physical Medicine and Rehabilitation	2019	100	4s	S1-s12
Carlozzi NE, Kratz AL, Sander AM, Chiaravalloti ND, Brickell TA, Lange RT et al.	Health-related quality of life in caregivers of individuals with traumatic brain injury: development of a conceptual model	Archives of Physical Medicine and Rehabilitation	2015	96	1	105-13
Chamberlain DJ	The experience of surviving traumatic brain injury	Journal of Advanced Nursing	2006	54	4	407-17
Charlifue SB	Partners of men with spinal cord injury: an exploration of stress, depression and burden		2004		Ph.D.	191 p-191 p
Charlifue SB, Botticello A, Kolakowsky-Hayner SA, Richards JS, Tulsky DS	Family caregivers of individuals with spinal cord injury: exploring the stresses and benefits	Spinal Cord	2016	54	9	732-6
Checklin M, Fernon D, Soumilas J, Stephens D	What is it like to have your loved one with a severe brain injury come to rehabilitation? The experiences of significant others	Disabil Rehabil	2020	42	6	788-797
Chen HY, Boore JR	Living with a relative who has a spinal cord injury: a grounded theory approach	Journal of Clinical Nursing	2009	18	2	174-82
Chen HY, Boore JR	Living with a spinal cord injury: a grounded theory approach	Journal of Clinical Nursing	2008	17	5a	116-24
Christensen J, Langberg H, Doherty P, Egerod I	Ambivalence in rehabilitation: thematic analysis of the experiences of lower limb amputated veterans	Disability and Rehabilitation	2018	40	21	2553-2560
Chuang CH, Yang YO, Kuo LT	Finding a Way to Cope: A Qualitative Study of the Experiences of Persons with Spinal Cord Injury	Journal of Neuroscience Nursing	2015	47	6	313-9

Ciccia AH, Threats T	Role of contextual factors in the rehabilitation of adolescent survivors of traumatic brain injury: emerging concepts identified through modified narrative review	International Journal of Language and Communication Disorders	2015	50	4	436-51
Cicerone KD	Participation as an outcome of traumatic brain injury rehabilitation	Journal of Head Trauma Rehabilitation	2004	19	6	494-501
Ciofi-Silva CL, Rossi LA, Dantas RS, Costa CS, Echevarria-Guanilo ME, Echevarria-Guanilo ME et al.	The life impact of burns: the perspective from burn persons in Brazil during their rehabilitation phase	Disability and Rehabilitation	2010	32	6	431-7
Claydon JH, Robinson L, Aldridge SE	Patients' perceptions of repair, rehabilitation and recovery after major orthopaedic trauma: a qualitative study	Physiotherapy	2017	103	3	322-329
Claydon J, Maniatopoulos G, Robinson L, Fearon P	Challenges experienced during rehabilitation after traumatic multiple rib fractures: a qualitative study	Disability and Rehabilitation	2018	40	23	2780-2789
Cleveland LG	Momentum: A model for motivation in rehabilitation for individuals with traumatic brain injury		1998		Ph.D.	380 p-380 p
Clifton S	Grieving my broken body: an autoethnographic account of spinal cord injury as an experience of grief	Disability and Rehabilitation	2014	36	21	1823-9
Coffey NT, Cassese J, Cai X, Garfinkel S, Patel D, Jones R et al.	Identifying and Understanding the Health Information Experiences and Preferences of Caregivers of Individuals With Either Traumatic Brain Injury, Spinal Cord Injury, or Burn Injury: A Qualitative Investigation	Journal of Medical Internet Research	2017	19	5	e159
Coffey NT, Weinstein AA, Cai C, Cassese J, Jones R, Shaewitz D et al.	Identifying and Understanding the Health Information Experiences and Preferences of Individuals With TBI, SCI, and Burn Injuries	J Patient Exp	2016	3	3	88-95
Collis Pellatt G	Patients and professionals' views of the patient's role in spinal cord injury rehabilitation	British Journal of Neuroscience Nursing	2006	2	4	190-197
Daugherty CE	Brain Injury Survivors: Narratives of Rehabilitation and Healing	Issues in Mental Health Nursing	2011	32	3	189-189
Dunpath T, Chetty V, Van Der Reyden D	The experience of acute burns of the hand - patients perspectives	Disability and Rehabilitation	2015	37	10	892-8
Dyck DG, Weeks DL, Smith CL, Shaw M	Multiple family group intervention for spinal cord injury: Quantitative and qualitative comparison with standard education	J Spinal Cord Med	2020		Jan-21	p1-11
Eady K, Moreau KA	Observing the influence of the physical environment on family involvement in a rehabilitation setting	Families, Systems, & Health	2018	36	4	493-506

Guldager R, Willis K, Larsen K, Poulsen I	Nurses' contribution to relatives' involvement in neurorehabilitation: Facilitators and barriers	Nurs Open	2019	6	4	1314-1322
Guldager R, Willis K, Larsen K, Poulsen I	Relatives' strategies in subacute brain injury rehabilitation: The warrior, the observer and the hesitant	Journal of Clinical Nursing	2019	28	1-Feb	289-299
Juguera Rodríguez L, Pardo Ríos, M, Castillo Hermoso M, Pérez Alonso N, Leal Costa C, Díaz Agea JL	Impact of simulation-based learning on family caregivers during the rehabilitation period of individuals with spinal cord injury	Spinal Cord	2020	58	1	95-105
King G, Nalder E, Stacey L, Hartman LR	Investigating the adaptation of caregivers of people with traumatic brain injury: a journey told in evolving research traditions	Disabil Rehabil	2020		21-Feb	p1-15
Kreutzer JS, Marwitz JH, Godwin EE, Arango-Lasprilla JC	Practical approaches to effective family intervention after brain injury	Journal of Head Trauma Rehabilitation	2010	25	2	113-20
Lucke KT, Coccia H, Goode JS, Lucke JF	Quality of life in spinal cord injured individuals and their caregivers during the initial 6 months following rehabilitation	Quality of Life Research	2004	13	1	97-110
Palimaru AI, Cunningham WE, Dillistone M, Vargas-Bustamante A, Liu H, Hays RD	Preferences of adults with spinal cord injury for widely used health-related quality of life and subjective well-being measures	Journal of Spinal Cord Medicine	2019	42	3	298-309
Pape T, Weaver J, Papadimitriou C, Kot T, Guernon A, Ford P et al.	No One Listens to Me: Working with Caregivers to Listen to Their Caring Experiences	Archives of Physical Medicine and Rehabilitation	2019	100	10	e102-e103
Reeder JM, Cain AO	Families coping with serious injury		1990		9027993	177
Rintala DH, Holmes SA, Fiess RN, Courtade D, Loubser PG	Prevalence and characteristics of chronic pain in veterans with spinal cord injury	Journal of Rehabilitation Research and Development	2005	42	5	573-583
Silver J, Ljungberg I, Libin A, Groah S	Barriers for individuals with spinal cord injury returning to the community: a preliminary classification	Disabil Health J	2012	5	3	190-6
Stenberg M,Stålnacke BM, Saveman BI	Family experiences up to seven years after a severe traumatic brain injury: family interviews	Disabil Rehabil	2020			p1-9
Turner B, Fleming J, Cornwell P, Worrall L, Ownsworth T, Haines T et al.	A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers	Brain Injury	2007	21	11	1119-30

Reason for exclusion: wrong setting

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Barclay L, McDonald R, Lentin P	Social and community participation following spinal cord injury: a critical review	International Journal of Rehabilitation Research	2015	38	1	p1-19
Bjornshave Noe B, Bjerrum M, Angel S	The influence of clarification and threats on life situation: patients' experiences 1 year after TSCI	Spinal Cord Ser Cases	2017	3		17006
Carson P	Investing in the comeback: parent's experience following traumatic brain injury	Journal of Neuroscience Nursing	1993	25	3	165-73
Carson PP	Head injury survivorship: the family experience		1992		PH.D.	218 p-218 p
Christiaens W, Van de Walle E, Devresse S, Van Halewyck D, Benahmed N, Paulus D et al.	The view of severely burned patients and healthcare professionals on the blind spots in the aftercare process: a qualitative study	BMC Health Services Research	2015	15		302
Degeneffe CE, Green R, Jones Cl	Service Use and Satisfaction Following Acquired Brain Injury: A Preliminary Analysis of Family Caregiver Outcomes	Rehabilitation Research, Policy & Education	2016	30	4	421-428
Dickson A, Ward R, O'Brien G, Allan D, O'Carroll R	Difficulties adjusting to post-discharge life following a spinal cord injury: an interpretative phenomenological analysis	Psychology, Health & Medicine	2011	16	4	463-74
Dwyer KJ, Mulligan H	Community reintegration following spinal cord injury: Insights for health professionals in community rehabilitation services in New Zealand	New Zealand Journal of Physiotherapy	2015	43	3	75-85
Eliacin J, Fortney S, Rattray NA, Kean J	Access to health services for moderate to severe TBI in Indiana: patient and caregiver perspectives	Brain Injury	2018	32	12	1510-1517
Joseph C, Wahman K, Phillips J, Nilsson Wikmar L	Client Perspectives on Reclaiming Participation After a Traumatic Spinal Cord Injury in South Africa	Physical Therapy	2016	96	9	1372-80
Jumisko E, Lexell J, Soderberg S	The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives	Disability and Rehabilitation	2007	29	19	1535-43
Kitter B, Sharman R	Caregivers' support needs and factors promoting resiliency after brain injury	Brain Injury	2015	29	9	1082-1093
Knox L, Douglas JM, Bigby C	"I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury	Disability and Rehabilitation	2017	39	22	2250-2260
Knox L, Douglas JM, Bigby C	'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI	Brain Injury	2015	29	6	745-57

Kratz AL, Sander AM, Brickell TA, Lange RT, Carlozzi NE	Traumatic brain injury caregivers: A qualitative analysis of spouse and parent perspectives on quality of life	Neuropsychological Rehabilitation	2017	27	1	16-37
Lennox, A, Gabbe B, Nunn A, Braaf S	Experiences With Navigating and Managing Information in the Community Following Spinal Cord Injury	Top Spinal Cord Inj Rehabil	2018	24	4	315-324
Manns PJ, May LA	Perceptions of issues associated with the maintenance and improvement of long-term health in people with SCI	Spinal Cord	2007	45	6	411-9
Mbakile L, Ponsford J, Manderson L	The experience of traumatic brain injury in Botswana	Neurorehabilitation and Neural Repair	2012	26	6	712-713
McIntyre M, Ehrlich C, Kendall E	Informal care management after traumatic brain injury: perspectives on informal carer workload and capacity	Disabil Rehabil	2020	42	6	754-762
Murray CM, Van Kessel G, Guerin M, Hillier S, Stanley M	Exercising Choice and Control: A Qualitative Meta-synthesis of Perspectives of People with a Spinal Cord Injury	Archives of Physical Medicine and Rehabilitation	2019	100	9	1752-1762
Nalder E, Fleming J, Cornwell P, Foster M	Linked lives: The experiences of family caregivers during the transition from hospital to home following traumatic brain injury	Brain Impairment	2012	13	1	108-122
Nunnerley JL, Hay-Smith, EJ Dean SG	Leaving a spinal unit and returning to the wider community: an interpretative phenomenological analysis	Disability and Rehabilitation	2013	35	14	1164-73
Rone Wilson K	Trying to make it through: The experience of African American caregivers of youth with traumatic brain injury. A grounded theory study	Dissertation Abstracts International Section A: Humanities and Social Sciences	2009	70	3-A	842
Rotondi AJ, Sinkule J, Balzer K, Harris J, Moldovan R	A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers	Journal of Head Trauma Rehabilitation	2007	22	1	14-25
Sharif FA, Mottaghi M	A study of experiences of traumatic families after releasing from hospital: A qualitative research	Annals of Tropical Medicine and Public Health	2018		1.2 Special Issue	SP33
Talbot LR, Levesque A, Trottier J	Process of implementing collaborative care and its impacts on the provision of care and rehabilitation services to patients with a moderate or severe traumatic brain injury	J Multidiscip Healthc	2014	7		313-20
Turner BJ, Fleming JM, Ownsworth TL Cornwell PL	The transition from hospital to home for individuals with acquired brain injury: A literature review and research recommendations	Disability and Rehabilitation	2008	30	16	1153-1176

Vissers M, van den Berg-Emons R, Sluis T, Bergen M, Stam H, Bussmann H	Barriers to and facilitators of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre	Journal of Rehabilitation Medicine	2008	40	6	461-7
Walker W, Wright J, Danjoux G, Howell SJ, Martin D, Bonner S	Project Post Intensive Care eXercise (PIX): A qualitative exploration of intensive care unit survivors' perceptions of quality of life post-discharge and experience of exercise rehabilitation	J Intensive Care Soc	2015	16	1	37-44

Reason for exclusion: wrong study design

Authors	Title	Journal	Published Year	Volume	Issue	Pages
Albright KJ, Duggan CH, Epstein MJ	Analyzing trauma narratives: introducing the Narrative Form Index and Matrix	Rehabilitation Psychology	2008	53	3	400-411
Arango-Lasprilla JC, Quijano MC, Aponte M, Cuervo MT, Nicholls E, Rogers HL et al.	Family needs in caregivers of individuals with traumatic brain injury from Colombia, South America	Brain Injury	2010	24	7-Aug	1017-26
Arango-Lasprilla JC, Lehan TJ, Stevens LF, Diaz Sosa DM, Espinosa Jove IG	Balancing act: The influence of adaptability and cohesion on satisfaction and communication in families facing TBI in Mexico	NeuroRehabilitation	2012	30	1	75-86
Bayley EW, Carrougher GJ, Marvin JA, Knighton J, Rutan RL, Weber BF	Research priorities for burn nursing: rehabilitation, discharge planning, and follow-up care	Journal of Burn Care and Rehabilitation	1992	13	4	471-6
Belciug MP	Patients' perceptions of the causes of their success and lack of success in achieving their potential in spinal cord rehabilitation	International Journal of Rehabilitation Research	2012	35	1	48-53
Bergman K, Maltz S, Fletcher J	Evaluation of moderate traumatic brain injury	Journal of Trauma Nursing	2010	17	2	102-8
Bishop LJ, Walters LB	Family matters: The role of the family in medical decision-making with competent patients		1998		9920546	514
de Goumoëns V, Didier A, Mabire C, Shaha M, Diserens K	Families' Needs of Patients With Acquired Brain Injury: Acute Phase and Rehabilitation	Rehabil Nurs	2019	44	6	319-327
Goldsmith H, McCloughen A, Curtis K	Using the trauma patient experience and evaluation of hospital discharge practices to inform practice change: A mixed methods study	Journal of Clinical Nursing	2018	27	7-Aug	1589-1598

Greenwald BD, Rigg JL	Neurorehabilitation in traumatic brain injury: does it make a difference?	Mount Sinai Journal of Medicine: A Journal of Translational and Personalized Medicine	2009	76	2	182-189
Hall R, Harvey LA	Qualitative research provides insights into the experiences and perspectives of people with spinal cord injuries and those involved in their care	Spinal Cord	2018	56	6	527
Hannold EM	Using veterans' perspectives to enhance rehabilitation outcome measures: value of qualitative methods	Journal of Rehabilitation Research and Development	2008	45	1	p6-8
Hanson KT, Carlson KF, Friedemann-Sanchez G, Meis LA, Van Houtven CH, Jensen AC et al.	Family caregiver satisfaction with inpatient rehabilitation care	PloS One	2019	14	3	No Pagination Specified
Harvey LA, Chu J, Bowden JL, Quirk R, Diong J, Batty J et al.	How much equipment is prescribed for people with spinal cord injury in Australia, do they use it and are they satisfied 1 year later?	Spinal Cord	2012	50	9	676-81
Herrera-Espińeira C, Rodríguez del Aguila M d M, Rodríguez del Castillo M, Valdivia AF, Sánchez IR	Relationship between anxiety level of patients and their satisfaction with different aspects of healthcare	Health Policy	2009	89	1	37-45
Jackson PD, Biggins MS, Cowan L, French B, Hopkins SL, Uphold CR	Evidence Summary and Recommendations for Improved Communication during Care Transitions	Rehabilitation Nursing	2016	41	3	135-48
Malec JF	Ethics in brain injury rehabilitation: existential choices among western cultural beliefs	Brain Injury	1993	7	5	383-400
Matter B, Feinberg M, Schomer K, Harniss M, Brown P Johnson K	Information needs of people with spinal cord injuries	Journal of Spinal Cord Medicine	2009	32	5	545-54
Noreau L, Noonan VK, Cobb J, Leblond J, Dumont FS	Spinal Cord Injury Community Survey: Understanding the Needs of Canadians with SCI	Topics in Spinal Cord Injury Rehabilitation	2014	20	4	265-276
Wyndaele JJ	Improve efficiency of spinal cord rehabilitation by reducing length of stay while maintaining or improving patient outcomes	Spinal Cord	2013	51	2	87
Wyndaele JJ	Spinal cord management. Looking into attitude and knowledge of caregivers and patients	Spinal Cord	2009	47	9	649

Reason for exclusion: wrong study focus

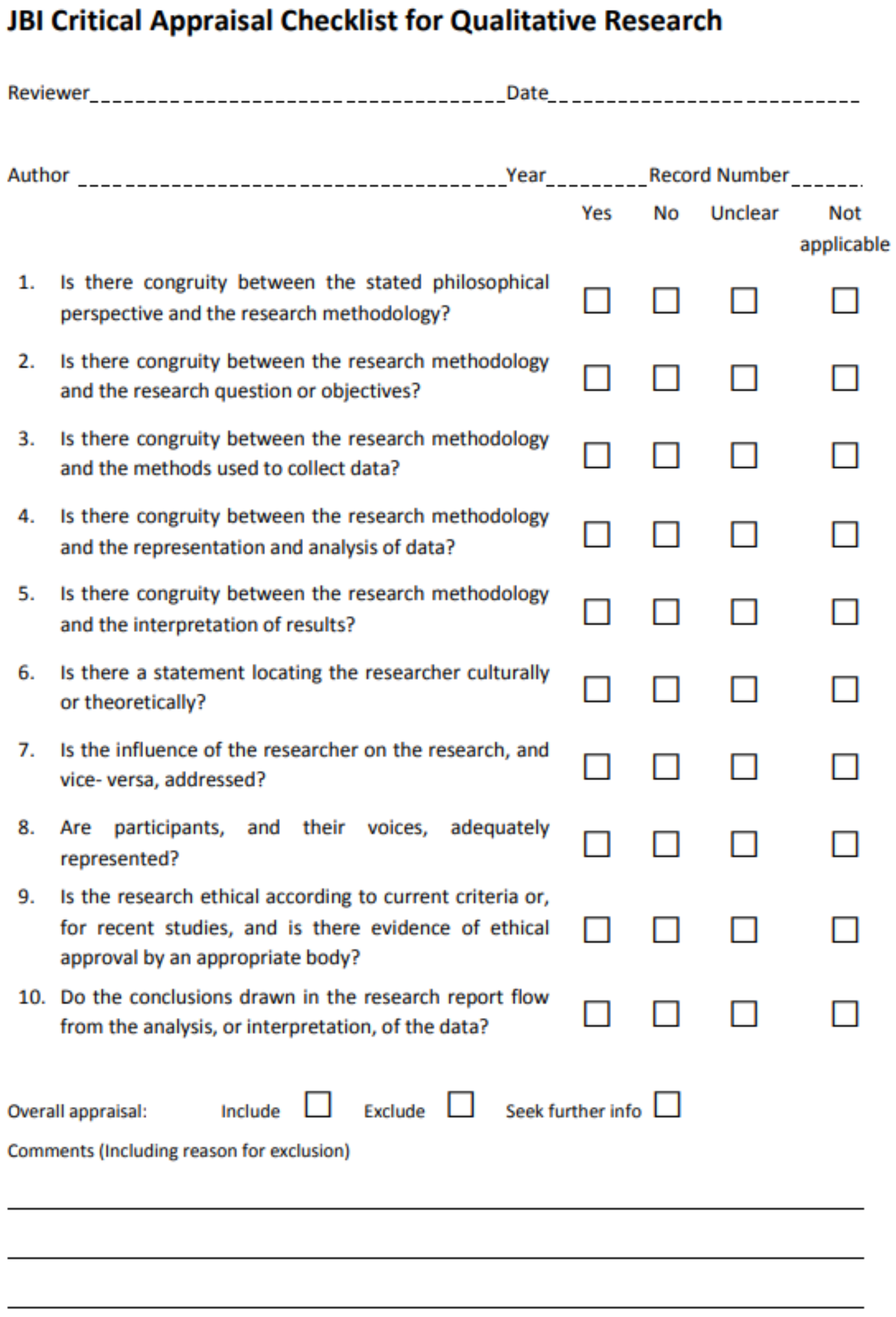
Authors	Title	Journal	Published Year	Volume	Issue	Pages
Andreoli A	Balancing risk-taking and safety among patients, families, and clinicians during transitions in care from brain injury rehabilitation		2010		MR72841	157
Bond C	Traumatic brain injury: help for the family	RN	2002	65	11	60-66; quiz 67
Braaf S, Ameratunga S, Ponsford J, Cameron P, Collie A, Harrison J et al.	Traumatic injury survivors' perceptions of their future: a longitudinal qualitative study	Disability and Rehabilitation	2019			p1-11
Bradford AN, Mackenzie E	Life interrupted: The orthopedic trauma caregiver experience		2012		3533299	307
Brice RG, Brice A	Recovery from a Subarachnoid Hemorrhage: Patient and Spouse Perspectives	Communication Disorders Quarterly	2017	38	2	119-128
Fleming J, Sampson J, Cornwell P, Turner B, Griffin J	Brain injury rehabilitation: the lived experience of inpatients and their family caregivers	Scandinavian Journal of Occupational Therapy	2012	19	2	184-93
Foster M, A Shelley, Fleming J	Unmet health and rehabilitation needs of people with long-term neurological conditions in Queensland, Australia	Health & Social Care in the Community	2015	23	3	292-303
Fraas MR	Narrative Medicine	Topics in Language Disorders	2015	35	3	210-218
Gan C, Gargaro J, Brandys C, Gerber G, Boschen K	Family caregivers' support needs after brain injury: a synthesis of perspectives from caregivers, programs, and researchers	NeuroRehabilitation	2010	27	1	p5-18
Garrino L, Curto N, Decorte R, Felisi N, Matta, E, Gregorino S et al.	Towards personalized care for persons with spinal cord injury: a study on patients' perceptions	Journal of Spinal Cord Medicine	2011	34	1	67-75
Glintborg C, Hansen TG	Bio-psycho-social effects of a coordinated neurorehabilitation programme: A naturalistic mixed methods study	NeuroRehabilitation	2016	38	2	99-113
Goldsmith H, McCloughen A, Curtis K	The experience and understanding of pain management in recently discharged adult trauma patients: A qualitative study	Injury	2018	49	1	110-116
Goyata SL, Rossi LA	Nursing diagnoses of burned patients and relatives' perceptions of patients' needs	International Journal of Nursing Terminologies and Classifications	2009	20	1	16-24
Graff HJ, Christensen U, Poulsen I, Egerod I	Patient perspectives on navigating the field of traumatic brain injury rehabilitation: a qualitative thematic analysis	Disability and Rehabilitation	2018	40	8	926-934
Grossenbacher NL	The trauma of spinal cord injury on the adolescent	Occup Ther Health Care	1985	2	3	79-90

Gullick JG, Taggart SB, Johnston RA, Ko N	The trauma bubble: Patient and family experience of serious burn injury	Journal of Burn Care and Research	2014	35	6	e413-e427
Gupta N	Lack of adequate care post spinal cord injury - a case report	Spinal Cord Ser Cases	2019	5		22
Gupta N, Raja K	Expectations of persons with paraplegia regarding their care in India: a qualitative study	Spinal Cord Ser Cases	2017	3		17042
Halpin SJ, Rakotonirainy R, Chamberlain MA, O'Connor RJ	Trauma rehabilitation in a teaching hospital in Antananarivo, Madagascar: current provision and patients' perspectives	Disability and Rehabilitation	2019			p1-7
Illman NA, Crawford S	Late-recovery from "permanent" vegetative state in the context of severe traumatic brain injury: A case report exploring objective and subjective aspects of recovery and rehabilitation	Neuropsychological Rehabilitation	2018	28	8	1360-1374
Jagnoor J, Bekker S, Chamania S, Potokar T, Ivers R	Identifying priority policy issues and health system research questions associated with recovery outcomes for burns survivors in India: a qualitative inquiry	BMJ Open	2018	8	3	e020045
Jannings W, Pryor J	The experiences and needs of persons with spinal cord injury who can walk	Disability and Rehabilitation	2012	34	21	1820-6
Juguera Rodriguez L, Pardo Rios M, Leal Costa C, Castillo Hermoso M, Perez Alonso N, Diaz Agea JL	Relatives of people with spinal cord injury: a qualitative study of caregivers' metamorphosis	Spinal Cord	2018	56	6	548-559
Kanmani TR, Raju B	Caregiver's Psychosocial Concerns and Psychological Distress in Emergency and Trauma Care Setting	Journal of Neurosciences in Rural Practice	2019	10	1	54-59
Lefebvre H, Pelchat D, Swaine B, Gélinas I, Levert MJ	The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum	Brain Injury	2005	19	8	585-597
Lucke KT, Martinez H, Mendez TB, Arevalo-Flechas LC	Resolving to go forward: the experience of Latino/Hispanic family caregivers	Qualitative Health Research	2013	23	2	218-30
Man DW	Family caregivers' reactions and coping for persons with brain injury	Brain Injury	2002	16	12	1025-37
Marklund N, Bellander BM, Godbolt AK, Levin H, McCrory P, Thelin EP	Treatments and rehabilitation in the acute and chronic state of traumatic brain injury	Journal of Internal Medicine	2019	285	6	608-623
May L, Day R, Warren S	Perceptions of patient education in spinal cord injury rehabilitation	Disability and Rehabilitation	2006	28	17	1041-9
McDermott GL, McDonnell AM	Acquired brain injury services in the Republic of Ireland: experiences and perceptions of families and professionals	Brain Injury	2014	28	1	81-91

Nalder E, Fleming J, Cornwell P, Shields C, Foster M	Reflections on life: experiences of individuals with brain injury during the transition from hospital to home	Brain Injury	2013	27	11	1294-303
O'Reilly K	Women's experience of traumatic brain injury -- a narrative review	Journal of the Australasian Rehabilitation Nurses' Association (JARNA)	2018	21	1	19-19
Rossi LA, Vila Vda S, Zago MM, Ferreira E	The stigma of burns Perceptions of burned patients' relatives when facing discharge from hospital	Burns	2005	31	1	37-44
Saban KL, Hogan NS, Hogan TP, Pape TL	He Looks Normal But ... Challenges of Family Caregivers of Veterans Diagnosed with a Traumatic Brain Injury	Rehabilitation Nursing	2015	40	5	277-85
Sand A,Karlberg I, Kreuter M	Spinal cord injured persons' conceptions of hospital care, rehabilitation, and a new life situation	Scandinavian Journal of Occupational Therapy	2006	13	3	183-92
Sansonetti, D, Nicks RJ, Unsworth C	Barriers and enablers to aligning rehabilitation goals to patient life roles following acquired brain injury	Australian Occupational Therapy Journal	2018	65	6	512-522
Savage I, Egan M	Women Family Members' Experiences of Involvement in Adult Inpatient Traumatic Brain Injury Rehabilitation	Open Journal of Occupational Therapy (OJOT)	2018	6	3	p1-12
Scheel-Sailer A, Post MW, Michel F, Weidmann-Hugle T, Baumann Holzle R	Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury-A qualitative interview-based study	Health Expectations	2017	20	5	1133-1142
Stayt LC, Venes TJ	Outcomes and experiences of relatives of patients discharged home after critical illness: a systematic integrative review	Nursing in Critical Care	2019	24	3	162-175
Strandberg T	Adults with acquired traumatic brain injury: experiences of a changeover process and consequences in everyday life	Social Work in Health Care	2009	48	3	276-297
Turner BJ, Fleming J, Ownsworth T, Cornwell P	Perceived service and support needs during transition from hospital to home following acquired brain injury	Disability and Rehabilitation	2011	33	10	818-29
Turner B, Fleming J, Ownsworth T, Cornwell P	Perceptions of recovery during the early transition phase from hospital to home following acquired brain injury: a journey of discovery	Neuropsychological Rehabilitation	2011	21	1	64-91
Van de Velde D, Bracke P, Van Hove G, Josephsson S, Devisch I, Vanderstraeten G	The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home	Disability and Rehabilitation	2012	34	6	491-502
Van De Velde D, Bracke P, Van Hove G, Josephsson S, Vanderstraeten G	Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home	International Journal of Rehabilitation Research	2010	33	4	346-355

Wallace SE, Evans K, Arnold T, Hux K	Functional brain injury rehabilitation: survivor experiences reported by families and professionals	Brain Injury	2007	21	13-14	1371-84
Webster J, Taylor A, Balchin R	Traumatic brain injury, the hidden pandemic: A focused response to family and patient experiences and needs	South African Medical Journal	2015	105	3	195-8
Whalley Hammell K	Experience of rehabilitation following spinal cord injury: a meta-synthesis of qualitative findings	Spinal Cord	2007	45	4	260-74
Whiffin CJ, Bailey C, Ellis-Hill C, Jarrett N, Hutchinson PJ	Narratives of family transition during the first year post-head injury: perspectives of the non-injured members	Journal of Advanced Nursing	2015	71	4	849-59
Whiffin CJ, Ellis-Hill C., Bailey C, Jarrett N, Hutchinson PJ	We are not the same people we used to be: An exploration of family biographical narratives and identity change following traumatic brain injury	Neuropsychological Rehabilitation	2019	29	8	1256-1272
Wimberly EP	Story telling and managing trauma: health and spirituality at work	Journal of Health Care for the Poor and Underserved	2011	22	3 Suppl	48-57
Wondolowski EL	A phenomenological inquiry into the family members' experience of having an adult member with a traumatic brain injury within the first three years	Dissertation Abstracts International Section A: Humanities and Social Sciences	2016	76	9-A(E)	No Pagination Specified
Wongvatunyu S, Porter EJ	Mothers' experience of helping young adults with traumatic brain injury...including commentary by Reid-Arndt S	Journal of Nursing Scholarship	2005	37	1	48-56
Zeilig G, Weingarden H, Laufer R, Brezner A, Navon M	Terror and rehabilitation of two family members with spinal cord injury	Israel Medical Association Journal	2002	4	7	563

Appendix III: Critical appraisal checklist



JBI Critical Appraisal Checklist for Qualitative Research

Reviewer_____________________________________Date___________________________

Author _____________________________________Year_________Record Number______

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

____

____

____

Appendix IV: Data extraction tool

JBI QARI Data Extraction Tool for Qualitative Research

Reviewer ______________________ Date ______________________

Author ______________________ Year ______________________

Journal ______________________ Record Number ______________________

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors conclusions

Comments

Complete Yes ☐ No ☐

Findings	**Illustration form Publication (page number)**	**Evidence**		
		Unequivocal	**Credible**	**Unsupported**

Extraction of findings complete Yes ☐ No ☐

Appendix V: Characteristics of included studies

Study citation	Methods for data collection and analysis	Country	Phenomenon of interest	Setting	Participants	Description of main results
Abrahamson et al.[36]	Semi structured interviews for data collection Thematic analysis carried out by two researchers	UK	Explore the experiences of patients and their carers of the transition home during the first month post discharge. What gaps and difficulties did patients and carers encounter in service provision during this period.	In-patient rehabilitation to community	10 patients and 9 carers Adults aged >18 admitted to a neuro-rehabilitation unit with severe TBI (GCS<8), loss of consciousness for 24 hours, post traumatic amnesia of seven or more days Carers were identified by participants as their main source of practical and emotional support	Many respondents expressed dissatisfaction with the discharge process and delays in community services. Respondents were unclear about the role of community therapy teams and limited therapy due to staff shortages.
Beaton et al.[67]	Qualitative descriptive Semi structured interviews Thematic analysis	New Zealand	Explore injured patients' experiences of care to identify areas for improvement in routine service delivery from surgical reams in the transition from inpatient to community-based care.	Transition from inpatient to community-based care, up to 12 months post discharge	17 participants - 8 patients (5 female, 3 male, up to 12 months post discharge), 8 nominated key support people, 1 nominated health professional (OT) Inclusion - aged 16 and above, ISS 8 or above, blunt trauma, Waikato Hospital as acute care provider, Waikato district domicile patient	Perceived issues and limitations in the patient care pathway following serious injury, especially relating to access to psychosocial services, the high level of reliance on key support people, inadequate communication and information provision, and lack of preparedness for discharge and coordination of post-discharge care.
Braaf et al.[68]	Qualitative descriptive Semi structured telephone interviews. Data analysed using thematic analysis	Australia	Explore seriously injured patients' perceptions of communication with and information provided by health professionals in their first 3 years following injury.	Major trauma survivors from discharge and into the community	65 patients Eligibility - patients aged 17 and above and registered with the Victorian State Trauma Registry. ISS of >12. 65 participants.	Discharge to home after a prolonged inpatient stay was described as stressful. Many seriously injured people found accessing, using and understanding

	using a framework approach				Exclusion - patients with severe traumatic brain injury or spinal cord injury who have been studied elsewhere and non-English speaking patients	injury and recovery information in the health care system challenging. Engaging with many health professionals from various specialties with different communication styles resulted in varied effectiveness in communication. Difficulty coordinating information from different sources and unmet information needs persisted for many.
Brauer et al.[64]	Phenomenological design Semi-structured interviews for data collection. Thematic analysis	USA	Gain insight into the continuum of occupational therapy services provided for individuals with TBI and gather inputs from such individuals' caregivers regarding their perspectives on the lived experience of TBI in relationship to received OT services.	Continuum of care - acute to community settings	4 families with a child between 17-33 years of age who sustained a severe TBI 5 family members contributed to the interviews; all family participants were considered the primary caregivers with their child living at home	Overall lack of a continuum, with most challenges occurring during acute care and the transition into services and life after inpatient rehabilitation.
Conti et al.[65]	Phenomenological design Semi structured interviews Analysis using a qualitative phenomenological methodology	Italy	Explore the situation of informal caregivers of persons with SCI when discharged home from a SCI unit, in relation to needs, emotional experiences, difficulties and subsequent reactions to discharge.	Final phase of hospitalisation and at 6 months from discharge	11 caregivers (8 females and 3 males) Inclusion - first-degree kinship caregivers, aged 18 years and old; patients had Modified Barthel Index score of 60 or lower, Italian speaking and living at home	Lack of communication by health professionals and unclear information on diagnosis and path to follow. Discharge was an important moment in the recovery pathway. While there is a desire to return home and gain autonomy, there is also fear and concern for clinical, logistic and organisational issues. Caregivers feel like they are the conduit between the assisted person and the outside world. The carers' needs are second to the assisted person's needs.

Gabbe et al.[33]	Qualitative descriptive design In-depth semi structured interviews Thematic analysis to identify important groupings	Australia	Explore injured patients' experiences of trauma care to identify areas for improvement in service delivery.	In-patient to community State Trauma (VSTR) and Orthopaedic Outcome (VOTOR) Registries used to identify participants. Interviews during reviews at 12 or 24 months	120 patients (60 male and 60 female) Inclusion - registered on either VSTR or VOTOR, blunt trauma patients, patients at least 12 or 24 months post injury, aged 18 and above, Transport Accident Commission compensable or non-compensable, received definitive care at an adult Major Trauma Service	Poor communication between patients and service providers. Patients felt that there was stark contrast between their experience of recovery and clinician prognosis. Transition from acute hospital to either rehabilitation or community was challenging. Lack of coordinated care between acute and community services
HedariKhayat et al.[66]	Phenomenological design Face-to-face semi-structured interviews Colazzi's descriptive phenomenological analysis	Iran	Explore the lived experiences of burn survivors after a 6-month period of home care following hospital discharge.	Community setting after discharge from hospital for care of burns to the body	16 patients (10 female and 6 male); adults aged between 18-58 years old	Participants described the home care follow-ups as ‘rehabilitation in the process for life’. Home care follow-ups were a necessity in the burn care system.
Kreitzer et al.[70]	Qualitative descriptive design Semi structured interviews Content analysis	USA	Determine the unmet needs and concerns, burden and description of health-related quality of life issues of informal caregivers of patient who survive a moderate to severe TBI.	Level one trauma centre and quaternary referral centre for neurotrauma	18 carer/patient dyads Caregivers defined as an English-speaking unpaid individual involved in assisting the survivor with ADL (activities of daily living) or medical tasks Moderate to severe TBI (GCS score of 3-13 at time of recruitment) Exclusion - Patients could not be pregnant or prisoners	The importance of major issues changed over time. Caregiver needs varied widely after six months. Topics amenable to early intervention included difficulty accessing appropriate healthcare providers and ancillary services after discharge from hospital, and problems related to early communication from care teams.

					Excluded carers of patient in whom the family was planning to withdrawal of life-sustaining treatment	
Mbakile Mahllanza et al. 2015[63]	Qualitative descriptive design Semi-structured interviews Grounded theory approach to analyse data	Botswana	Explore the experiences of acquired brain injury in individuals with TBI, their caregivers and healthcare professionals in Botswana. The experiences of treatment practices received by individuals with TBI following their injury and their caregivers' experiences within the healthcare system and the local community.	Majority of participants recruited throughout patient clinics. Minority recruited as in-patients	71 participants - 26 men (n=16) and women (n=10) with moderate to severe TBI, 18 caregivers (83% women), 27 health care workers Moderate TBI classified as PTA 1-7 days, abnormal CT scan, GCS 9-12 Severe TBI classified as PTA > 7 days, abnormal CT scan and GCS 3-8	Many individuals and carers had little education and knowledge about TBI. Communication was characterised by inadequate or a total lack of information given to those injured and their caregivers. Most patients were dissatisfied with their inpatient care, especially post hospital care. Patients, caregivers and their families accepted the complex nature of life post hospital and tackled it with resilience.
Mbakile Mahlanza et al. 2017[62]	Qualitative descriptive design Semi-structured interviews Thematically analysed and triangulated	Botswana	Explore the experiences of caregiving for individuals with TBI in Botswana. Examine the levels of caregiver anxiety and depression and their association with functional outcome in their TBI relative.	Community based and patients had TBI at minimum of 6 months and maximum of 15 years	18 carers (15 female and 3 male). Aged between 23 to 70 Inclusion - caregivers of patients who had Post Traumatic Amnesia of more than one day, abnormal CT and GCS of 3-12 Exclusion - patients with mild TBI, not citizens of Botswana or had other neurological problems concurrent with TBI	Caregiving created a significant burden. Most injured participants exhibited medical, physical, cognitive, behavioural and/or emotional difficulties, and were mainly dependent on their caregivers. Spouse caregivers experienced more depression and anxiety. Caregiving impeded by lack of information from the healthcare system.
Moore et al.[71]	Qualitative descriptive design	USA	Explore with caregivers the specific communication patterns that lead to improved	Large urban, Level 1 trauma centre	23 carers of 22 persons hospitalised	Carers reported being confused about different aspects of patients' care and

	In-depth semi-structured interviews Qualitative content analysis		understanding of TBI and patient needs, pattern of caregiver understanding of health information and strategies to improve preparation for caregiving (capacity building).		Female participants (83%) with an average age of 44 years; racially and ethnically diverse; carers for patients with moderate to severe TBIs	were not empowered or prepared for caregiving post-discharge. Discharge instructions and commonly used medical words were difficult for caregivers to understand.
Paterson et al.[34]	Qualitative descriptive design Semi-structured interviews lasting 45 to 60 minutes Data analysed using thematic analysis approach	Canada	'What constraints do you perceive regarding the provision of rehabilitative healthcare services?'	Community based patients between 10-24 months post injury	8 survivors of severe TBI, 7 family caregivers, 4 groups (5-8 in each group) of health professionals. Classification of severe or moderate TBI defined as at least one hour of unconsciousness and at least 24 hours of altered consciousness Patients 18 and above, ability to speak and understand English and in a non-comatose state when discharged	The way information, including its timing, amount, consistency and relevance, was presented to families was significant in determining whether families listened to and remembered discharge information. Families might misinterpret or not recall information given to them before their loved one was discharged even if it was delivered clearly and with sensitivity. Readiness of family members for information might be greatest when they confronted a new or unfamiliar situation, rather than before discharge, when the reality of caring for the person at home seemed distant.
Sandström et al.[72]	Qualitative descriptive design Semi-structured interviews Qualitative content analysis	Sweden	Explore the experiences of suffering multiple trauma.	Participants were gathered by searching the intensive care registry at a midsize hospital in northern Sweden	9 patients (6 men & 3 women), age 21 – 81 diagnosed with multiple trauma (2 or more lesions in at least two different body parts caused by accidents where the injuries may affect one or more body systems and pose a risk individually or together constitute a life-threatening condition)	The time after injury was uncertain for the participants and led to feelings of being lost. There was ambivalence between satisfaction with the received care and dissatisfaction related to not being taken seriously. Patients strived to get their life back on track, a way back to normal life from their injuries.

						Lack of shared understanding between participants and those who provided care for them. Their needs not taken into consideration by service providers. Unsure who to turn to for advice regarding treatment and recovery, especially post-discharge.
Yoshida[69]	No research design identified Semi-structured interviews Grounded theory approach was used to analyse data	Canada	Illustrate how the physical rehabilitation institutional process has consequences for self-concept among persons with traumatic SCI.	Community dwelling adults post inpatient Spinal Rehabilitation Unit	35 patients (28 men and 7 women); mean age at injury was 22; mean time living in the community was 9 years.. The study group was derived from contacts with the physio and occupational therapy departments and newsletter requests	Participants became aware, during inpatient rehabilitation or soon after, of the limited scope of 'independence' that was developed during their rehabilitation. Rehabilitation professionals must be sensitive and open minded to the needs and concerns of persons they serviced. Interactions with other individuals who were living out in the community with an SCI could greatly assist individuals in rehabilitation to prepare for the physical and social outside world.

Footnotes: TBI: traumatic brain injury, SCI: spinal cord injury, OT: Occupational Therapist, VSTR: Victorian State Trauma Registry, VOTOR: Victorian Orthopaedic Trauma Outcomes Registry, ISS: Injury Severity Score, CT: Computerised Tomography, GCS: Glasgow Coma Scale, PTA: Post Traumatic Amnesia

Appendix VI: Excluded study findings without illustrations

Abrahamson et al.[36]	
Finding	Respondents felt the final discharge home was relatively smooth (Not supported)
Illustration	Illustration not available
Finding	respondents raised concerns about unidentified and/or unmet need (Not supported)
Illustration	Illustration not available
Beaton et al.[67]	
Finding	Lack of preparedness for discharge (Not supported)
Illustration	Illustration not available
Finding	Ensure more specific discharge information and preparation is provided for patients and key support people before discharge from hospital (Not supported)
Illustration	Illustration not available
Braaf et al.[68]	
Finding	Many patients described wanting more information prior to their discharge home (Not supported)
Illustration	Illustration not available
Finding	Inconsistent information typically related to hospital discharge times. Confusion subsequently occurred regarding who or what information to believe (Not supported)
Illustration	Illustration not available
Kreitzer[70]	
Finding	*Coping for home* Indeed, this unmet need was the commonly brought up at all time points, mentioned by caregivers in 37 separate interviews (Not supported)
Illustration	Illustration not available
Mbakile-Mahlanza et al.[62]	
Finding	Caregivers received little information from the healthcare system and this impacted on the quality of care they could provide to their family member (Not supported)
Illustration	Illustration not available
Moore et al.[71]	
Finding	Caregivers universally reported confusion about some aspect of the discharge plan (Not supported)
Illustration	Illustration not available
Finding	Caregivers also reported confusion with medication management instructions (Not supported)
Illustration	Illustration not available
Paterson et al.[34]	
Finding	They [family] described how many healthcare practices are foreign and daunting to them and that they were often confused by the roles of various healthcare professionals (Not supported)
Illustration	Illustration not available
Yoshida[69]	
Finding	What is being suggested by some of the participants, is that they are being rehabilitated not only *within* a rehabilitation setting, but more importantly *for* a rehabilitation setting (Not supported)
Illustration	Illustration not available