“Socio-ecological factors supporting resilience in trauma recovery”

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Submitted in fulfilment of the requirements of
the degree of Doctor of Philosophy
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

(Signed)
Dedication

This thesis is dedicated to my family, Alan and Nicholas.

You have both enabled me to fulfill my long-held ambition to obtain my PhD.

Thank you for your support and patience.
Abstract

Background

Injury mortality rates have declined in many countries largely because of the development of sophisticated Trauma and injury prevention systems and improved patient care. However the morbidity following severe traumatic physical injury is increasingly recognized as an important public health matter. Little is known about injury recovery patterns and associated causes once patients are discharged home to their communities. Here, prevention activities are targeted at the secondary and tertiary levels in community settings, aiming to reduce or eliminate impairment and disability, minimize suffering and pain, and maximize quality of life for irremediable conditions.

Studies show that factors in patients’ socio-ecological environments contribute to poor outcomes. Socioeconomic disadvantage, blue collar jobs, and low levels of family, social and community support frequently appear as significant covariates in inception cohort studies of trauma patients. The socio-ecological model is a well-recognized framework for activating prevention strategies. For trauma patients their ‘eco-system’ incorporates resilient and healthy caregivers and families, supportive social networks and community and rehabilitation services. It also encompasses a neighborhood, defined by economic, social and physical properties that provide access to resources, enabling trauma recovery.

Variations in individuals’ resilience and in their resilient resources might explain why some people experience better outcomes compared to others, after suffering the same type of adversity. Resilience is rapidly becoming a factor of interest in trauma rehabilitation. It is a positive, protective quality, amenable to
interventions, and bolstered by social and environmental factors. Resilience promotion, in rehabilitation could potentially, support people and families exposed to severe trauma.

The over-arching aim of this thesis is to develop a program of research that investigated ‘resilience’ as part of the trauma patients’ socio-ecological system. Firstly, resilience at the community level was examined by synthesizing the research evidence of the effectiveness of socio-ecological resilience rehabilitation programs on the outcomes of people sustaining traumatic physical injuries. Secondly, a form of ‘neighborhood’ resilience characterized by the physical, social and economic aspects of patient’s neighborhoods were analysed in relation to rurality and short-term patient outcomes. And finally, resilience was examined in a cohort of primary informal caregivers of patients sustaining severe traumatic musculoskeletal injuries.

Methods
A systematic review was conducted to identify the effectiveness of multifaceted community socio-ecological rehabilitation programs aimed at fostering resilience. Twenty-one studies were retrieved and reviewed (11,904 participants). The results of 19 randomised intervention studies of moderate to high methodological quality were then pooled using a random-effects meta-analysis. Mean differences for continuous outcomes and risk ratios for outcomes including return to work (RTW), self efficacy and stress reduction were calculated.

To examine the influence of factors characterizing neighborhood resilience on trauma patients’ outcomes, data were accessed from the Gold Coast University Hospital Trauma Registry. A cross-sectional study design was employed, and geocoding methods enabled the creation of two area-level explanatory variables describing relative Socioeconomic Disadvantage, and remoteness from services.
These variables were linked to individual patients represented on the Trauma Registry, along with data items including age, injury severity, anatomical region, discharge disposition, number of comorbidities, injury mechanism, postcode of injury occurrence, and the first provider of care.

From this study sample, the association of these two neighborhood indices with inpatient outcomes was analysed using a retrospective cohort design. Outcome variables were acute length of stay days (ALSD) and inpatient mortality. Step-wise multivariable negative binomial regression and proportional hazards regression analyses were conducted, adjusting for age, injury severity, mechanism and comorbidity and sites of injury.

Finally, a prospective cohort study was designed to examine resilience in primary, informal caregivers of severe musculoskeletal trauma patients. Patient and caregiver dyads were recruited, shortly after the injury event and followed up three months later. Resilience was measured, using the Connor Davidson resilience scale (CD-RISC 10). Primary outcomes were caregiver burden and quality of life measured respectively, using the Caregiver Strain Index and the Short Form Version 12 (SF-12) Health Survey.

Results

**Resilience based community rehabilitation:** Resilience rehabilitation programs significantly increased the likelihood of RTW (OR 2.09 95% CI 0.99-4.44 \( p=0.05 \)), decreased the time taken to RTW (Mean difference -7.80, 95% CI -13.16 - -2.45 \( p=<0.001 \)), and increased levels of self-efficacy (Mean difference 5.19, 95% CI 3.12 - 7.26 \( p<0.001 \)). Favourable RTW outcomes resulted from programs involving workplace support \( p<0.001 \) compared to programs without this support. Positive
RTW outcomes were more common in people with musculoskeletal or orthopedic injuries compared with brain injuries ($p=0.02$).

**Neighborhood resilience:** 1025 patients were available for analysis, of which 77% were male. The mean age was 45 (SD 19.46) and median ISS was 17 (IQR=12). Increasing relative socioeconomic disadvantage was statistically significantly, and positively associated with remoteness of residence ($\chi^2=41.61, p<0.001$) remoteness of injury location ($\chi^2=19.73, p<0.001$), and number of comorbidities (KW H Statistic=11.26, $p=0.01$). Of those who received initial care from a regional hospital, there is a significant and positive trend according to increased likelihood of being disadvantaged category compared with those treated at the major trauma center ($\chi^2=14.14, p=0.003$). After adjusting for age, sex, injury severity and remoteness of injury location, a positive gradient of increasing disadvantage according to geographical remoteness of residence was evident, with a six fold increase in the odds of being in the most disadvantaged category, compared to the least disadvantaged (OR 6.21, 95% CI 3.07-12.57, $p<0.001$).

Based on the above cohort of trauma patients, increased hazard of inpatient mortality was found for age group (75+), (HR 3.53, 95% CI 1.77-7.11 $p=0.003$), higher ISS (HR 5.27, 95% CI 2.78-10.02, $p<0.001$), and injury mechanisms related to intentional self-harm or assault (HR 2.72, 95% CI 1.48-5.03, $p=0.001$). Increased risk for longer ALSD was evident for: older age, namely 65-74 (RR 1.37, 95% CI 1.10-1.83), head injury (HR 1.36 95% CI 1.15-1.62, $p<0.001$), extremity injuries (RR 1.62 95% CI 1.36-1.94 $p<0.001$), higher ISS (RR 2.05, 95% CI 1.76-2.39, $p<0.001$), and discharge to rehabilitation facility (RR 1.75 95% CI 1.43-2.14, $p<0.001$).

**Caregiver resilience:** Fifty-three (77%) eligible patient/carer dyads participated, with an attrition rate of 28%. At baseline, caregiver resilience was statistically significantly
(p<0.05) associated with their physical health, community support and family resilience. Significant reductions from baseline were found at follow up, for levels of resilience, mental health, physical exercise and community support. In multiple regression models, caregiver resilience independently predicted lower caregiver burden (β= -0.74, p=0.008) and higher levels of patient physical health and function (β= -0.69, p=0.003).

**Conclusion**

Trauma patients recover in a highly contextual environment where family, community and neighborhood factors are integral to successful patient outcomes. These studies showed that strategies aimed at addressing the public health burden of trauma disability should target the multiple and interacting layers of patients’ socio-ecological environment ensuring that all have capacity to support resilient recovery after severe traumatic injuries.
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Acknowledgement of published papers included in the thesis

Included in this thesis are four manuscripts that have been prepared for publication. The manuscripts are presented in Chapters 4, 5, 6 and 7 (Results).

In all of these papers, I was the first author. I conceived the question and the design of each study, conducted most of the analysis and drafted and revised the papers for submission.

In addition to my supervisors, some co-authors were medical students who were doing extra-curricular research training. Other co-authors were either academic colleagues or members of the Trauma Service.

Appropriate acknowledgements of those who contributed to the research but did not qualify as authors are included in each paper.

My contribution to each co-authored paper is outlined at the front of the relevant chapter.

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Chapter 1: Introduction

This chapter introduces the theoretical framework for the thesis and the rationale for undertaking the research. The public health impact of non-fatal trauma is discussed in the context of the increasing prevalence of non-fatal trauma morbidity and inequalities in outcomes. Socio-ecological-based resilience theories are then examined, specifically in relation to trauma patients’ socio-ecological systems. Following this, three main program areas of research for the thesis are outlined: resilience in rehabilitation, resilience in informal caregivers, and resilience in neighbourhoods. The aims and hypotheses for four studies are then presented and some important key terms defined.

Background and Significance of the Study

Public health impact of trauma

The millions of deaths that result from injuries worldwide represent only a small fraction of those who survive their traumatic injuries and experience disability. As more people survive and are discharged home, the burden of non-fatal traumatic injury increases, reflected by the increased use of health care services, in addition to lost productivity in wages and substantial social costs. However, the burden of non-fatal traumatic injury on the productivity of adult patients of working age, on caregivers, on families, and on the community at large has not been well described or quantified.

Traumatic injuries and their aftermath are not shared equally across all population groups. In this sense, injury severity, low-income blue-collar work, and the number of injuries are associated with poor longer-term function, health-related quality of life (HRQoL), and occupational re-integration. Contextual factors also account for variations in trauma recovery statistics. Social and family support are reportedly positive predictors of injury outcome for traumatic brain injured (TBI) patients.
Further, characteristics of patients’ neighbourhoods, such as geographic remoteness from services or socioeconomic disadvantage, also influence trauma outcomes, particularly where injuries have occurred in very remote locations.\textsuperscript{12–14}

Our current understanding of factors affecting adverse trauma outcomes is limited by the disparate ways in which prognostic factors and outcomes have been studied.\textsuperscript{7} Predictors are often analysed as covariates in models of outcomes, with little detail about their mechanism of action, i.e. how each either promotes or impedes positive outcomes. Hence many studies in the trauma literature report prognostic factors such as the presence or absence of ‘social support’, ‘family support’, or ‘socioeconomic disadvantage’. Without more detailed study of these factors, secondary and tertiary prevention strategies are limited. In addition, there is substantial heterogeneity in the outcomes assessed and the instruments used for evaluation.\textsuperscript{15,16} The clinical consensus is that patient-reported HRQoL is the outcome of over-arching importance, along with patients’ experience and satisfaction with health care and occupational re-engagement.\textsuperscript{17,18}

Much of what is currently known about outcome patterns and causal factors in trauma comes from patients sustaining serious neuro-trauma, such as spinal cord injuries (SCI) and TBI. However, there is comparatively less focus on patients with severe musculoskeletal traumatic injury or injury to the soft tissue, muscle, and/or bone. Traumatic musculoskeletal injuries are the cause of the majority of hospitalisations as a result of injury, and trauma to the pelvis and limbs in particular account for substantial physical, psychological, and work disability up to five years after severe injury.\textsuperscript{19}

\textbf{Socio-ecological systems theories}

Inequalities in trauma outcomes are a public health concern, and solutions will most likely be found in patients’ communities. However, generating an evidence base from
which to inform policy directions for health conditions such as trauma disability, which has multiple interacting causes, requires a departure from using traditional evaluation methods at the individual level. Instead, a systems approach is required, where public health action is aimed at components in the system rather than at individuals. This socio-ecological model of health prevention is important to the theory and practice of public health prevention, recognising that an individual’s social and physical environment provides the capacity for positive health behaviour. For trauma patients, important components are families, friends, the primary informal caregiver, community services, and the physical environment represented by ‘place’ of residence.

**Resilience Theory**

Not all people succumb to the adverse effects of traumatic injury, and therefore identifying who does well and why is of clinical interest. As such, resilience theory is rapidly claiming an important position in the trauma research literature, where most studies are of trauma patients sustaining severe TBI or SCI. Resilience is universally understood as a form of positive adaptation in the face of adversity and is therefore seen as a protective quality in individuals. It is of interest to clinicians who help patients manage chronic, disabling conditions. Most agree that it is not a fixed personal trait but is characterised by personal qualities that can be modified over time, including self-efficacy, optimism, a sense of mastery and coping, and an ability to handle stress. Based on studies of changes in brain size, neural networks, neurotransmitters, and adrenal steroid hormones following adversity in children, biological and genetic factors are also thought to relate to resilience. However, the research of the specific biological or genetic factors to target in studies of resilience is not yet conclusive.
Resilience is also conceptualised in terms of the relationship between individuals and their broader social environments, where numerous social, physical, and community resources provide the capacity for reliance to be increasingly enabled. This concept is consistent with the socio-ecological models of public health described above. In this sense, families, communities, and neighbourhood features are important ‘resilient resources’. For example, resilient families appear to have problem-solving and communication skills, cohesion, social support, financial stability, and a smaller family structure.

With regard to community resilience, there is general agreement on some key, common elements that, once again, incorporate adaptation to adversity and the various qualities required to enable this adaptation. Elements of community resilience have been studied for health outcomes and include a capacity to be economically robust, healthy, and connected to strong and effective communication networks. Resilient communities have access to quality health care and to a high level of other community resources, while safe neighborhoods and healthy living infrastructures are also important factors.

In this multi-faceted socio-ecological context, resilience has not been studied in trauma survivor populations. Elements such as social support and self-efficacy have been empirically highlighted in meta-analyses to be key components of resilience and can possibly promote functional recovery, work participation, and HRQoL after trauma. It is also possible that vocational support and family support systems can bolster resilience, while area-level indices of social and economic disadvantage have been associated with a higher risk of trauma mortality and psychosocial stress—for example, remoteness from services is associated with higher trauma mortality.

There are several ‘red flags’ to note when undertaking any study involving resilience. As a complex, multi-faceted construct, there is no current consensus with regard to its
form of measurement. Methodological approaches therefore differ across many studies, and our understanding of the role of this complex construct on trauma rehabilitation is indeterminate. Resilience research should, at a minimum, recognise the common domains that are understood as evidence of resilience, i.e. the personal and contextual factors described above.\textsuperscript{31}

Some published methodological guidelines exist that enable standardised approaches to resilience research and can facilitate comparison of the construct on health outcomes among different trauma populations.\textsuperscript{41,42} For example, there is consensus that longitudinal designs are warranted to study adaptation to adversity. While the notion of ‘adversity’ is subjective, it can be more objectively described as a negative life circumstance that is known to be statistically associated with adjustment difficulties.\textsuperscript{27} Psychometric instruments have been developed to measure personal resilient qualities, which therefore support repeated measures of resilience over time. Resilience has also been measured in ways that relate to trajectories of levels of specific symptoms associated with the adversity. Such measures are somewhat subjective, defining a proxy measure of resilience according to individuals who can maintain ‘stable’ or even ‘better than expected’ responses to adversity over time. For example, pre-defined responses (for example levels of depression) to adversity (e.g. traumatic injury) are measured at baseline and at follow-up time points, while mediating factors, such as environmental factors, are accounted for in analyses. In this sense, maintenance of stable or improved levels of this symptoms would be seen as a ‘positive resilient response’.\textsuperscript{42}

\textit{The social ecology of resilience in trauma recovery—gaps in knowledge}

Studying resilience in trauma patients’ socio-ecological systems could improve our understanding of why trauma outcomes vary, in addition to also helping to identify
potential points in the system that will promote the best possible outcomes. The following section describes the trauma survivors’ socio-ecological system and proposes areas for study that could optimise recovery.

**The patient**

At the heart of this system—the innermost layer—are severely injured trauma patients. These patients will, for the most part, have sustained serious, multiple traumatic physical injuries to two or more body systems, which could be blunt force (over 90% of injuries) or penetrating in nature.

All patients will have survived their injuries long enough to be admitted for at least 24 hours at the tertiary referral trauma centre (TRTC). This hospital—the Gold Coast University Hospital—provides trauma care for severely injured patients across two state borders, including the wider population in the designated catchment area of South East Queensland (SE QLD) and patients injured in the mostly regional areas of northern New South Wales (NSW). Both states have advanced trauma services, with well-developed rural and regional referral networks.

The catchment area for injury admissions includes people living in major cities in SE QLD (68%), with the remainder largely coming from inner regional areas of the catchment area in both states, of which most (71%) are from northern NSW, which is predominately classified as regional or rural in terms of proximity to services. So, for some of these rural patients (around 30%), transferal to the TRTC will involve care at a regional hospital in order to stabilise their injuries.  

Around three quarters of patients will be male, with an average age of 50, whereas the average age for females is 44. While in hospital, around 70% of patients will spend some time (around three to four days) in an intensive care unit, and some will undergo
surgery. All patients spend an average of eight to nine days in acute care for pain management. This is where physiotherapy, occupational therapy, social work, and other services (if needed) commence. Some patients are referred to the Rehabilitation Response Team, a shared care model of medical and allied health services that delivers rehabilitation in the acute setting for 3 to 14 days.

A small percentage (around 6%) will die in hospital, yet most (over 70%) will be discharged home, with the remainder sent to other acute care hospitals, rehabilitation centres, or correctional facilities. Once discharged home, either to their rural or urban places of residence, they will come under the care of the general practitioner who oversees community-based rehabilitation. Depending on the patient’s age and the type and severity of injuries sustained, this could involve additional psychology, physiotherapy, or occupational therapy services. Rurality of residence will also influence the nature and accessibility of the rehabilitation services offered.

As discussed above, studies highlight that many severely injured trauma patients exhibit significant disability and impaired quality of life some years after their injury. It is not known how effective rehabilitation services are in different contexts and how many patients are working or fulfilling their potential.

**Families and informal caregivers**

Many severely injured patients require a period of informal care after discharge, and therefore families and informal caregivers are an integral part of the patient’s ecosystem—they play a vital role in facilitating patients’ physical and psychological recovery and improving their health-related quality of life. Caregiving does not have a market value, yet the replacement cost of caregivers in Australia is estimated to be around $60.3 billion, with demand expected to outstrip supply by 2025.44
Identifying the factors that enable caregivers to adapt to adversity is also of economic importance.

Because of the acute and unpredictable nature of traumatic injuries, individuals charged with most of the caregiving responsibilities (i.e. the primary informal carer) often find themselves unprepared for this task. There is now a vast amount of research literature on caregivers, illustrating that providing care over prolonged periods of time adversely affects caregivers’ economic productivity and psychological and physical health.\textsuperscript{20–23} In this regard, the social costs they bear are substantial and probably represent a significant proportion of the injury burden.\textsuperscript{4}

Caregiver burden is a measure often reported in studies to describe carers’ response to the multi-faceted impact of caring, and it is predicted by low levels of social support, the severity of patients’ functional status and pre-existing depression, poor coping, perceived patient distress, and health outcomes.\textsuperscript{45} However, other outcomes important to caregivers, such as their quality of life, beyond the burden of caregiving have been comparatively less studied.

Not all caregivers struggle with their task, and notable variations in the way caregivers respond and adapt to their role are evident.\textsuperscript{46} Caregiver resilience could conceivably be protective against burden and the adverse physical and psychological outcomes of caregiving. This has not been studied in trauma, although research on Alzheimer’s patients suggests that caregiver resilience can moderate caregiver burden.\textsuperscript{47} The impact of resilience on global measures of caregivers’ quality of life is not known, and is therefore an important area to explore, given that the health and function of caregivers could impact upon patient recovery. In this regard, few trauma studies have evaluated the impact of caregiver resilience as a positive protective factor on patient outcomes.
**Community health services including rehabilitation programs**

The next important component of the patient's socio-ecological system is community-based rehabilitation services. When patients are well enough to be discharged from hospital, they are often referred to rehabilitation services, which focus on increasing patients’ independence and function and returning them to as much of their previous ability as possible.

Of interest is whether multi-component rehabilitation programs targeting socio-ecological factors can improve resilience and the long-term physical, functional, and psychological health outcomes in trauma populations. Research evidence suggests that individual behavioural changes are unlikely to be sustained unless health programs target one or more factors in the person’s socio-ecological environment. For trauma patients, this involves targeting families and caregivers, peer and social networks, the workplace, community health services, and cultural and spiritual influences, all of which are thought to enhance resilient behaviours such as coping, social integration, stress mitigation, and self-efficacy.

People who have survived acute traumatic injury experience difficulties returning to work. In this regard, frequency and duration of work disability are objective indicators of the economic and social impact of injury. Furthermore, returning to work suggests successful rehabilitation and functional recovery. Identifying strategies that help people return to work (RTW) after major trauma is therefore important. Observational research shows that peer and workplace support can predict participation outcomes in people with TBI, and integrating supportive relationships into the rehabilitation process can promote resilience in patients with acquired brain injuries.

Collating the literature on the effects of socio-ecological rehabilitation programs on outcomes post-injury, such as RTW, could help to identify the key components for
resilience and resilient outcomes. At present, there is no synthesised information of the evidence relating to the effectiveness of these multi-dimensional rehabilitation programs on acute trauma recovery.

**Neighbourhood prosperity and the physical environment**

The next ecological system is the patients’ neighbourhood of residence, an emerging area of public health concern, given that more patients are surviving serious trauma to hospital admission and are being discharged back to their place of residence. Here, the social, structural, environmental, and economic factors that characterise peoples’ ‘place of residence’ could be important for influencing recovery. Resilient communities have been studied in the context of disaster readiness, and the qualities that generally define a resilient community can shed light on the nature and reasons for variations in health outcomes in communities. Resilience-based research at the neighbourhood level is in its infancy; however, quantitative research from New Zealand on neighbourhood characteristics in relation to mortality rates suggests that it incorporates measures of socioeconomic deprivation, population density, and geographical and environmental factors, all of which are associated with health outcomes.

Understanding how severely injured people are characterised by their place of residence could ultimately assist in developing appropriate types of rehabilitation programs for injury survivors. In Australia, there is an over-representation of hospitalised, injured people from socioeconomically disadvantaged backgrounds. In this regard, low levels of income and education, blue-collar work, and unemployment are strong indicators of individual disadvantage and are associated with higher rates of mortality. Notably, a person’s socioeconomic status (SES) is influenced by a myriad of social and environmental factors, all interacting with one’s biology and genes to shape behaviour, examples of which include the quality of housing and the built
environment, social networks, occupational exposure, and the availability of services or resources that provide education or promote safety. These neighbourhood socioeconomic environments are thought to be more powerful than individual factors in predicting injury mortality and morbidity. Therefore, the potential for a ‘place’ to be a risk factor to all of its inhabitants, as opposed to just some, has prompted concerns that unless contextual factors are addressed, individual risk and inequalities will fester.

Rurality or remoteness of residence from services is another contextual factor strongly associated with socioeconomic dimensions of ‘place’. Rates of traffic-related injuries are more common in rural areas when compared to urban areas, and rural residents typically have relatively poorer access to health services when compared to their urban counterparts, in addition to having higher levels of risk behaviours—including occupational and physical risk—and higher rates of disease and injury. Patterns of injury are also different for rural residents when compared to urban residents, often involving serious incidents such as firearms, farming, mining, or natural environmental factors.

Measures of ‘residential remoteness’ are not routinely factored into studies of social and economic variations in injury outcomes. Furthermore, neither indices of relative disadvantage nor remoteness are captured in trauma registries, which for the most part contain data aimed at monitoring the quality of acute trauma care.

Therefore, understanding the magnitude and nature of these variations on trauma-specific outcomes could assist in developing programs for enhancing long-term outcomes for injury survivors.
Theoretical Framework: Socio-Ecological System Supporting Resilience in Trauma Outcomes

Based on existing literature from this chapter and Chapter 2, a resilient ‘eco-system’ for severely injured trauma patients is proposed that incorporates resilient and healthy caregivers (and families), supportive social networks, and community and rehabilitation services that have proven efficacy in promoting positive rehabilitation outcomes, such as patient quality of life or occupational re-engagement. It also encompasses a form of neighbourhood resilience that is positively associated with health and is defined by its social and physical properties, including population density, accessibility to general services, prosperity, connectedness, and accessibility to valuable resources for health promotion and prevention.

These factors form the theoretical framework for this thesis, as outlined in Figure 1.

Figure 1. Socio-ecological systems for resilient trauma outcomes
**Significance of This Research**

A vast amount of research data exists on the importance of socio-ecological factors for promoting health and health outcomes, yet there remains a lack of empirical evidence in the trauma space as to which factors are effective in changing health behaviours or outcomes in injured patients.

The role of resilience in injury recovery and rehabilitation is gaining traction but is not yet clearly understood. This chapter has outlined a sound rationale and theoretical framework for researching socio-ecological factors and resilience on trauma outcomes using public health principles. Underpinning this thesis is the hypothesis that a network of social and ecological factors—in addition to the patients’ individual or personal characteristics—can influence resilient adaptation or ‘better than expected’ trauma outcomes. These explanatory factors are complex and interacting, extending beyond the patient’s core qualities to their external environments, with some lying in the networks that patients are most closely nested within.

A program of research into the social ecology of resilience and severe multi-trauma outcomes is therefore proposed for three main areas:

1. Resilience and Rehabilitation
2. Resilience and Neighbourhoods
3. Resilience and Informal Caregivers

**Aims and Hypotheses**

The aims and hypotheses of this thesis, drawn from a comprehensive review of the literature, are as follows:
Study 1: Effectiveness of Resilience-Based Rehabilitation Programs

Aim: The aim of this study was to quantify, for injured adult patients, the effectiveness of rehabilitation programs that target socio-ecological systems and examine resilient outcomes.

Hypothesis 1: Socio-ecological resilience rehabilitation programs after severe traumatic injuries result in improved outcomes, including quality of life, stress mitigation, reduced time to return to work, and increased self-efficacy, when compared to programs providing standard care.

Study 2: Resilient Communities for Trauma Patients

Aims: This study had two aims, the first of which was to develop methods, using geocoded residential address data, for linking a robust multifaceted index of neighbourhood disadvantage and an index of geographic remoteness to individual, severely injured patients on the trauma registry. The second aim was to quantify the relationship between relative socioeconomic disadvantage and remoteness of residence for severe, acutely injured adult patients admitted to a TRTC over a four-year period.

Hypothesis 2: For severe, hospitalised trauma patients, there is a significant and positive relationship between neighbourhood disadvantage and remoteness of residence, independent of patient factors including injury severity, comorbidity, and age.

Study 3: Resilient Communities and Trauma Outcomes

Aim: The aim of this study was to evaluate the independent effects of neighbourhood-relative socioeconomic disadvantage and remoteness of residence on morbidity and mortality outcomes for severe, acutely injured adult inpatients.
**Hypothesis 3:** Dimensions of ‘place’ of residence defined by neighbourhood socioeconomic disadvantage and remoteness predict hospital outcomes for severely injured, hospitalised patients in a TRTC independent of patient factors such as age, injury severity, and comorbidity.

**Study 4: Resilient Informal Caregivers and Caregiver and Patient Outcomes**

**Aim:** The aim of this study was to quantify changes in caregiver resilience, quality of life, and socio-ecological factors during the acute phase of caring for patients with severe traumatic musculoskeletal injuries, and to evaluate the independent role of a standard, valid resilience metric on caregiver burden and carers’ and patients’ quality of life.

**Hypothesis 4:** In a prospective cohort study sample of informal caregivers of patients with severe multiple musculoskeletal traumatic injuries:

- Caregiver resilience (defined by individual and ecological factors) is significantly decreased from baseline;
- Caregiver resilience is independently protective of caregiver burden;
- Caregiver resilience is independently and positively associated with physical and mental function; and
- Caregiver resilience is independently and positively associated with patient physical and mental health function.

**Definitions of Terms**

Key terms used throughout this thesis are defined conceptually and operationally as follows:
**Acute Traumatic Physical Injury** involves damage to the body’ or body tissue caused from the rapid transfer of an external energy source to a person at levels that are above the threshold for tissue damage or the loss of essential components for living, such as oxygen and heat. The main energy forces causing traumatic injury are classified as either penetration or blunt force, but other forces involving shearing, blasting, thermal, or chemical forces can also cause injury. This definition acknowledges the role of biomechanics (forces and effects) in injury, the presence of an acceptable threshold, and the application of an external force of energy (the cause) that exceeds that threshold on musculoskeletal tissue (outcome).

A **Tertiary Trauma Referral Centre (TRTC)** is a hospital, otherwise defined as a ‘Level 1 trauma centre’, that provides the definitive level of specialised trauma care to moderate to severely injured patients with multiple traumatic injuries. Such a centre has a multi-disciplinary structure with the staff and resources necessary to provide specialised trauma care to patients. It encompasses regional trauma services and delivers trauma services at several levels, ranging from acute resuscitation to sub-surgery, rehabilitation education, and prevention.

**Non-fatal/long-term injury outcomes.** In this thesis, non-fatal injury is used interchangeably with ‘long-term outcomes’ to describe patients who have survived their injury to the point of hospital discharge. There is currently no standard definition for the appropriate timescale for measurement of outcomes after hospital discharge.

**Socio-ecological systems** represent the relationship a person has with social systems and their environment. The socio-ecological model succinctly captures the specific components in the microsystem closest to the individual that are important to their lives, in addition to addressing the bi-directional relationship between the different levels of these contextual forces. The models involve balancing traditional biomedical
concepts of individual risk with components in the broader social and environmental context, including the community. Each component or system is described succinctly, there is a hierarchy of levels and factors within the system, and methods of defining it can be identified.

Socio-ecological systems important for severe trauma survivors include their families and informal caregivers; social networks; community health services, including rehabilitation, allied health, and general practitioners; and their place of residence, characterised by its relative wealth and geographic and physical attributes.

**Resilience** is conceptualised—for individuals studied in this thesis—in terms of a patient’s individual characteristics incorporating resilient qualities such as coping and self-efficacy. External factors, such as social, physical, and community resources that provide the capacity for reliance to prosper are studied. The underlying focus of the present thesis is on the patients’ eco-system, and the ecological features studied in depth are the informal caregiver, community-based rehabilitation services, and the patient’s neighbourhood of residence.

Resilience is conceptualised as positive adaptation in the face of (personal or physical) adversity. In this thesis, ‘adversity’ refers to the acute, severe, traumatic injury event, and its impact upon on patients and their caregiver is examined in separate studies. ‘Positive adaptation’ refers to the maintenance of resilience measures or health symptom measurements after trauma or statistically and clinically significant improvements of these measures from baseline.

For this study, resilience is measured in two main ways, as informed by the literature—first, by a range of individual characteristics measured in psychometric scales such as the Connor Davidson Resilience Scale (CD-RISC), and second by measures of
trajectories of individuals’ psychological or physical health symptoms after adversity.\textsuperscript{27,28,41,42} Further, socio-ecological factors bolstering resilience are analysed as mediators in this process.

\textbf{Structure of the Thesis}

This thesis consists of eight chapters. Chapter 1 has briefly outlined the background and significance of the study, along with the research aims and hypotheses. Chapter 2 will present a critical review of the literature, including the public health burden of severe traumatic injury, inequalities in injury outcomes, and socio-ecological systems relevant for resilient adaptation after severe trauma. By so doing, research gaps and factors within these sociological systems are identified for study, including the informal caregiver, rehabilitation programs, socioeconomic status, and remoteness of patients’ place of residence.

Chapter 3 provides a comprehensive description of the methods for each study, including the research design, study sample and setting, procedures, data analysis, and ethical considerations. Chapters 4–7 respectively outline the research results of the four studies, while Chapter 8 summarises and integrates the findings, in addition to also discussing the studies’ limitations and implications for clinical practice and further studies and providing recommendations for promoting research into enhancing resilience for severely injured multiple trauma patients.
References


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Chapter 2: Literature Review

Introduction
This chapter expands on many of the concepts introduced in Chapter 1. It opens with a discussion of the epidemiological considerations for trauma outcome research, including definitions, coding, classification of injury severity, and outcome measurement. The current state of surveillance systems in Australia, including the capacity for longer-term outcome surveillance, is also examined.

Following this, the public health burden of non-fatal severe traumatic injury and inequalities in trauma outcomes are discussed, at which point the principles of socio-ecological systems theories for addressing complex public health problems are examined. Further, the known factors associated with trauma outcomes are outlined and gaps in knowledge identified.

Resilience theory is then appraised, including definitions and methodological consideration for trauma research and the incorporation of socio-ecological factors into study designs of resilience. Further, the current evidence base of resilience in trauma research is detailed in relation to trauma patients’ socio-ecological systems.

Finally, gaps in the current knowledge base are identified, which form the basis of the program of research undertaken in this thesis.

Traumatic Physical Injury: Case Definitions, Codes, Classification Systems, and the Role of Social and Environmental Factors

Developing an operational case definition of ‘traumatic injury’ for epidemiological research is challenging because of the many complex processes involved in its
causation. For example, a person could be involved in a car accident and sustain no pathological damage. Similarly, a person could present at hospital with bruising but with no history of any physical or mechanical assault to the body. Accepted epidemiological injury definitions therefore include the cause and outcome.¹

Dr William Haddon, known as the ‘father of injury epidemiology’, developed frameworks for understanding injury aetiology and strategies for interventions and prevention and helped facilitate a standard definition of ‘injury’ by doing so. Haddon described the temporal circumstances underlying motor vehicle crash injuries, drawing parallels with the infectious disease epidemiological triad of ‘environment’, ‘host’, and ‘agent. In doing so, he identified important strategies for injury prevention.²

The injury is defined by the crash sequence, which considers the circumstances of the crash prior to the event occurring, during the crash, and after the crash.

Table 1 outlines a hypothetical example of the matrix in relation to a motor vehicle accident. The accident involved an elderly female driver in a rural area who had been driving and drinking heavily and was unable to adequately respond to an oncoming motorbike rider after swerving to avoid hitting a kangaroo.

The matrix also describes how the crash sequence involves an interaction of the human factors (the ‘host’), the vehicle (‘agent’), and the physical and sociocultural environment (the ‘environment’). Haddon’s model has played a significant role in conceptualising the complex and multi-factorial nature of injury causation, including factors beyond the vehicle itself pre-injury and the nature of the crash. In this regard, the model shows the complex interaction of individual, social, and environmental factors that are involved with a traumatic motor vehicle injury and its aftermath.
## Table 1. Analysis of a motor vehicle accident using Haddon’s Matrix*

<table>
<thead>
<tr>
<th></th>
<th>Human Factors (Car driver)</th>
<th>Motor Vehicle</th>
<th>Physical Environment</th>
<th>Social and Economic Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-event</strong></td>
<td>Fatigue</td>
<td>Older car</td>
<td>Rural area</td>
<td>Socially acceptable culture for older-age drinking</td>
</tr>
<tr>
<td></td>
<td>Alcohol</td>
<td>Unregistered/not serviced regularly</td>
<td>Rainy, foggy evening</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bald tyres</td>
<td>Oil leak on road</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Faulty brakes</td>
<td>Uneven road surface/pot holes++</td>
<td></td>
</tr>
<tr>
<td><strong>Event</strong></td>
<td>Not wearing a seatbelt</td>
<td>No airbag</td>
<td>Oncoming motorbike; on the wrong side of road, having swerved to miss a kangaroo</td>
<td>Remoteness from services</td>
</tr>
<tr>
<td></td>
<td>Using a mobile phone at the time of the crash</td>
<td></td>
<td></td>
<td>Inexperienced regional medical staff administering intermediate trauma care for multiple internal injuries and uncontrolled haemorrhage</td>
</tr>
<tr>
<td><strong>Post-event</strong></td>
<td>Older lady</td>
<td>Isolated rural road</td>
<td>Infomral caregiver (husband) elderly and sick</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cognitively impaired</td>
<td>MB rider deceased at scene</td>
<td>Inadequate and inaccessible multidisciplinary rehabilitation programs in rural areas</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hearing deficits depressed, which worsens after injury (PTSD)</td>
<td>Car driver unconscious</td>
<td>Poor social support systems</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delayed emergency response</td>
<td>Ineffective medical management of ongoing depression</td>
<td></td>
</tr>
</tbody>
</table>

*Adapted by author (KEH), from Holder, 2001*  

A combination of codes from the International Classification of Diseases (ICD) are commonly used for research purposes to define the various pathologies related to injury. The 2017 ICD-10-CM codes for ICD injury and poisoning are vast and implicate the role of an external cause in defining an injury. In this regard, an external cause is defined as an environmental event, circumstance, or condition that was the
cause of injury. Wherever there is a principal diagnosis of traumatic injury, an external cause should be recorded. For injuries, the principal diagnosis is identified within the ICD-10 AM range of S00-T179 or T79.

For epidemiological research in the traumatic injury area, a valid definition relevant to the research question is important. Too often, research describes proxy definitions such as ‘ambulance attendances’, ‘ED attendances’, or ‘hospitalisations’. Counting hospital attendances for minor or moderate injuries will be biased according to factors related to health service access and admission procedures. However, this is less important for counting moderate to major injury cases, where there is a high probability of hospital admission.

**Injury Severity**

Severity scores are also used to define the injury case for epidemiological research and for triage and prognostic estimations. Many severity-scoring tools have been developed and are mostly used to predict mortality. The Abbreviated Injury Scale (AIS) was the first of these scales, but it did not describe overall severity for a patient who had multiple injuries. The Injury Severity Score (ISS) was developed for this purpose and is commonly used in epidemiological research today, particularly for studies of injury mortality. The ISS is an ordinal scale ranging from 1 to 75 and is computed by combining the nine AIS body regions into six categories (head or neck, face, chest, abdominal or pelvic contents, extremities or pelvic girdle, and external structures). The ISS calculation reflects the sum of the highest AIS scores for the three most severely injured body regions and is the most commonly used severity score in clinical and epidemiological studies of injury.

Table 2 illustrates how the ISS is calculated based on AIS scores:
Table 2. Example—Calculation of the Injury Severity Score

<table>
<thead>
<tr>
<th>Region</th>
<th>Injury Description</th>
<th>AIS</th>
<th>ISS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head and neck</td>
<td>Small subdural haematoma</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Face</td>
<td>Nil</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Chest</td>
<td>Flail chest</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Abdomen</td>
<td>Minor liver laceration</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ruptured spleen</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Extremity</td>
<td>Fractured femur</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>External Structures</td>
<td>No injury</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

ISS = 66
(16+25+25)

A shortcoming of the ISS is that it does not consider more than one injury per body region, which is problematic when there are multiple, severe injuries confined to a single body region. In addition, if there are several body regions affected by injury, then the ISS is forced to consider a second less severe injury in another region rather than consider the more severe injuries in the one region. In this regard, the ISS is the most commonly utilised severity score, but it may underestimate severity and not adequately predict outcomes for blunt force injury or for non-fatal outcomes where physical, psychological, family, and social functioning are important considerations.

Due to the deficiencies of the ISS, a number of attempts have been made to improve the coding system: for example, the Trauma Injury Severity Score incorporates physiological data and the International Classification of Diseases Based Injury Severity Score (ICISS) additionally attempts to rectify the shortcomings of the ISS by factoring in survival risk ratios for the number of each patient’s injuries. The New Injury Severity Score (NISS) was developed to overcome some of the limitations of
the ISS and is the sum of squares of the AIS scores of a patient’s three most severe injuries, irrespective of body region. The NISS is thought to take a more comprehensive account of multiple injuries in the same body region, particularly musculoskeletal injuries, while preserving the main components of the AIS. In addition, the NISS performs in a way that is more consistent with the surgeon’s instinct—as the number of injuries increase, so does the likelihood of death, even if these injuries occur in the same anatomical area.7

In Australia, most major traumatic injuries (around 90%) are caused by blunt force. Such injuries often result in multiple organ failure and are relatively more complicated to manage when compared to single penetrating injuries. For survivors, blunt force injuries resulting mainly from traffic accidents are more likely to result in longer-term functional complications, such as neurological and musculoskeletal deficiencies and physical and cognitive disabilities.9,10

Musculoskeletal Trauma
A significant amount of outcome and rehabilitation research in the trauma field is devoted to neuro-trauma, namely TBI and SCI. Musculoskeletal or orthopaedic trauma (injury to the soft tissue, muscle, and/or bone) burden is relatively understudied, while being the cause of most hospitalisations for injury. These types of injuries mostly result from traffic accidents10 and are associated with ongoing pain and disability.9 Those affected include younger adults, particularly those under 45 years old, who are at the productive stage of their lives.11 Traumatic musculoskeletal injuries are associated with prolonged physical dysfunction and psychological disorders, pain, and delayed time to return to work, particularly in patients with lower extremity trauma.12–14 One study reported that, after excluding TBI and SCI injuries from its cohort of patients, severe trauma to the pelvis and limbs accounted for 82%
of the overall disability scores and 90% of the moderate to severe disability scores five years post-injury.\textsuperscript{12} Musculoskeletal trauma also represents the large proportion of claims for compensation under traffic compensation system and workers compensation claims.\textsuperscript{9,13,15,16}

\textbf{Trauma Surveillance Systems}

Given the high costs of providing acute hospital injury care, establishing evidence of its effectiveness is important. In this regard, trauma registries provide information about the distribution and pattern of injuries and evidence of changes in acute patient outcomes. These registries typically collect information on patient demographics; the incident injury; and pre-hospital and in-hospital information, including intensive care stay, total length of stay, complications, and details of the acute care provided. A classification of injury severity is also calculated and entered onto the registry database.

In Queensland, injury information is currently collected by individual hospital centres, and trauma registries are repositories for information about patients for which they have provided care. A key feature of these registries is that they focus on injury-specific clinical information, with an emphasis on ease of data reporting so that the data can be analysed for quality of patient care, improvements in patient care, and reduction in mortality and morbidity from traumatic injury across the state.

The state-based Queensland Trauma Registry was established in 1998 and ceased being operational in 2012 after funding was withdrawn from the program. Shortly after this, planning commenced to establish a trauma registry at Gold Coast Health (GCH), and a Trauma Service Program was introduced at the new Gold Coast University Hospital in September 2013. The trauma service has an advisory committee and has recently received Level 1 trauma status, which means that it can
provide the full spectrum of care for critically injured patients, from resuscitation through to discharge and rehabilitation. It also provides research, education and fellowship training, trauma systems overview, quality improvement programs, data collection, prevention and outreach programs, trauma audit, and leadership responsibilities.

Trauma registries play an important role in guiding prevention activities. There is currently no standard or routine approach to collecting information about trauma outcomes beyond the acute care setting. As evaluation shifts from acute settings to communities, research designs and methods will differ from those used for acute care outcomes, where registry and clinical information systems provide easily accessible and analysable clinical data. Psychosocial and other community-based contextual factors will be important for analysis, and multi-level epidemiological modelling methods are likely to be used. In addition, surveillance of longer-term outcomes therefore requires synthesising information about a wide range of services related to trauma care and developing methods for evaluating the integration and continuity of care in ways that are as objective as possible.

**Important Outcomes for Trauma Survivors**

Following the development of trauma centres and trauma registries, outcome assessment was largely based on ‘in-hospital’ measures, mortality, morbidity, and short-term health process measures. However, evaluating patterns and predictors of trauma outcomes for survivors in community settings requires analysis of different types of outcomes and methodological approaches.

In the trauma research literature, there is substantial heterogeneity of outcome definitions and instruments used for evaluation, while studies have collected outcome data at multiple time points following hospital discharge. A systematic
review of health outcome measures after trauma found that, of 34 studies, 38 different outcome measures were identified. Furthermore, 21 outcome measures were used only once and only five were used in three or more studies. Only 6% of all possible health impacts were captured. Current outcome instruments may not fully capture all important features for longer-term, severe poly-trauma that involve function in terms of self-care and daily activities in the community, at work, and with families.

Clinical consensus is that functional capacity, occupational re-engagement (RTW), and global estimates of quality of life are the outcomes of over-arching importance for patients, which have mostly been validated and used in trauma populations. The duration of work disability is a more objective estimate of functional recovery and is indicative of the economic and social impact of injury, although some caution should be exercised when describing it as a surrogate for functional recovery. Many existing methods of classifying RTW do not describe the complicated pathways of returning to work after injury, and the various work role scenarios that can result once employment has recommenced. For example, a simple RTW status measure does not describe whether the patient returned to their pre-injury work status, whether they continued to have disability, or whether their job description and work status changed as a result of disability. Hou et al. have analysed many dimensions of RTW status in a two-year follow up study of workers with traumatic limb injuries. Over 40% of the large cohort of injured patients reported an unsuccessful, non-sustained pattern of RTW.

Patient quality of life is generally a self-reported outcome. Examples of quality of life instruments commonly used in trauma research include the Short-Form 36 Health Survey (SF=36), the Short-Form 12 Health Survey (SF=12), the Functional Independence Measure (FIM), the Glasgow Outcome Scale (GOS), the Glasgow
Outcome Scale—Extended Scale (GOS-E),\textsuperscript{31} and the Euroquol Scale (EQ-5D).\textsuperscript{32} Other outcomes deemed important for measurement include social dependency and patient experience of care.\textsuperscript{17}

**The Public Health Burden of Non-Fatal Severe Injury**

The millions of deaths that result from injuries worldwide represent only a small fraction of those who survive their injuries and experience disability. Physical disabilities resulting from severe traumatic injury include physical and/or cognitive limitations due to neurotrauma, paralysis due to spinal cord trauma, and partial or complete amputation of limbs or physical limb deformation resulting in mobility impairments. Traumatic injuries account for 300 million disability-adjusted life-years (DALYs) and represent 11\% of the global burden of disease.\textsuperscript{33} It has been estimated that violence and injury account for about one quarter of the billion or so people who currently live with disabilities. The disproportionate impact on younger people means that this type of injury is also the leading cause of the loss of economically productive years of life.

In Australia, injuries are a major cause of death and disability and represent one of the five disease groups in Australia causing the greatest burden of ill health on society.\textsuperscript{34} Increasingly, more patients survive serious trauma and are discharged to their communities, and longitudinal epidemiological data provides evidence of ongoing significant health problems.\textsuperscript{35–38} For patients, persistent pain, impairments in functional status, depression, post-traumatic stress disorder (PTSD), poor quality of life, increased use of health services,\textsuperscript{39} and reduced work-related productivity are common.\textsuperscript{40–43} In addition, protracted functional impairment has been reported two years after injury,\textsuperscript{31} while a systematic review and meta-analysis of health-related quality of life after injury reported that impairments in mobility, physical function,
pain, and discomfort persist one year after injury, across a wide range of injury
types.18 Similar patterns for HRQL and functional outcomes have also been reported
elsewhere38 and show that only approximately 42% of people have recovered function
at 12 months, according to a GOS-E score of >6.

In addition to the direct health care costs of traumatic injuries, which are estimated to
exceed $3.4 billion,44 experiencing and surviving severe injury result in disrupted
support networks, reduced productivity, and significant societal costs.45 In this regard,
the annual cost of injury to the Australian economy has been estimated to be $18
billion, which is more than cardiovascular disease ($2.2 billion) and type 2 diabetes
($989 million) combined.44

Injury burden can be quantified using a measure of the number of healthy years of life
lost due to injury or disability (a ‘YLD’ measure). The YLD measure shows that
injuries in Australia rank in the top ten of non-fatal burden of disease, with males at
nearly three times the risk of health loss due to their injuries than females.34

Contributing factors to the calculation of this measure are largely related to the
patient’s characteristics, such as their functional outcomes, use of health services,
injury severity, and the extent of disability.46 As rates of injury survival and the
subsequent prevalence of chronic disability in the community increase, additional
psychosocial factors should be considered and quantified if the full public health
burden of non-fatal injuries is to be understood.

**Hospitalisations for injuries**

Information about the patterns and trends in injuries for patients admitted to hospitals
in Australia comes from hospital separation data, where ‘separation’ is used to define
an episode of care and can include death, discharge, or transferal to another hospital.47

There were 483,189 hospital separations due to injury and poisoning for public and
private hospitals in Australia from 2012 to 2013. Separations from hospital as a result of an injury generally account for around 6% of all separations from hospital due to any cause. About 16% of these separations are relatively severe, classified as a high threat to life; most injuries occur in older people (aged 65 and over), yet the largest proportion of injuries for males occur between the ages of 25 and 44.

Rates of injury increase with remoteness of residence and are higher for Indigenous people when compared to non-Indigenous people and are mostly caused by falls (around 40%) followed by other unintentional causes, including exposure to an inanimate force (32%) and transport accidents (12%). Although transport injuries accounted for 12% of all hospitalised injury cases in the period of 2012–13, nearly 80% of these occurred between the ages of 15 and 64. For all males experiencing traffic crash injuries, around 80% are represented in this age category. For severe trauma, about 10% of people die in hospital. For every in-hospital death, about six are discharged home to the community. Younger males are highly represented in non-fatal cases when compared to females.

**Inequalities in outcomes**

The impact of trauma is not shared equally across all population groups, and variations in outcomes reveal inequalities. Socioeconomically disadvantaged people are at higher risk of non-fatal injuries and are mostly likely to be affected in terms of poorer long-term physical and psychological disability, including return to work. Research in Australia and overseas also suggests that trauma recovery for patients with major musculoskeletal trauma is more protracted than expected, with disabilities persisting well beyond the first year of the injury event. These types of injuries mostly result from traffic accidents and affect younger adults, particularly those under 45, who are at an economically productive stage of their lives. Long-term
follow-up of people with multiple injuries highlights patterns of social deterioration and economic deprivation.23 Disability is reportedly exacerbated for those with pelvic or limb injuries when compared to abdominal or chest injuries.12 Pre-injury morbidity and difficulties accessing services are associated with poor function and quality of life in these patients.50,51 In addition, such injuries represent a large proportion of the claims for compensation under traffic compensation systems and workers compensation claims.9,13,52

**Socio-Ecological Systems Theory and Approaches to Prevention**

The public health challenges concerned with the increasing prevalence of non-fatal trauma morbidity are akin to many chronic, disabling conditions that are managed in the community—they exist within a complex eco-system. Based on existing research, it is clear that single solutions will fail to adequately address the complexity of traumatic disabilities.53

For many years, the social and ecological framework has informed the theory and practice of public health.54,55 In 1972, Uri Brofenbrenner, a Russian-born American psychologist, postulated that child development was influenced by the interaction of the individual with multiple layers of their eco-system. His model succinctly captures the specific components in the microsystem closest to the individual and important to their lives (e.g. churches, family, school, peers, and health services). The model also addresses the bi-directional relationship between the different components.56,57 Systems theory has been applied in areas related to public health prevention and policy, mainly in the chronic disease field,58 and is premised on the idea that many social and environmental factors interact with an individual’s biological and genetic factors to shape behaviour and health.54,55,59,60 These factors include families, social
networks, the workplace, features of the physical environment, and the broader economic and political landscape.

At the centre of the model are the individuals—their personal and biological characteristics, behaviours, attitudes, and preferences. At the next level, the social environment describes individuals or groups who have close relationships with the individual, such as family; friends; peers; schools; sporting, religious, or community groups; health service personnel; or work colleagues. The physical environment defines natural and man-made influences that either enable or disable social interactions or individual behavioural change, such as roads, transport, parks, housing, and community or health facilities. Access to services is important at this layer. Finally, policies from any level of government are important in terms of creating environmental change, workforce and urban planning, funding, and taxes. This level might include policies addressing inequalities in social and economic circumstances and cultural norms.

The model posits that multiple, external, and interacting forces influence health behaviour, which in turn influence individual outcomes.\textsuperscript{61} The messages emanating from the data are compelling; addressing differentials in risk and health assets at the individual level is important, in addition to economic, educational, and social disadvantage; and enhancing social relationships and community cohesion and preventing social isolation is also significant, as is ensuring employment security, safe housing, a healthy start to life, and access to important services.\textsuperscript{62}

Emanating from this structure are social capital theories, which acknowledge the importance of social networks and communities on individual health, while also placing great emphasis on \textit{behaviours and interactions} within and between these networks that are health promoting. Characteristics of social capital espoused by
Putnam\textsuperscript{63} include (1) community networks; voluntary, state, and personal networks; and community density; (2) civic engagement, participation, and the use of civic networks; (3) local civic identity—sense of belonging, solidarity, and equality with other members; (4) reciprocity and norms of cooperation, a sense of obligation to help others, and confidence in the return of assistance; and (5) trust in the community. These resources can either be directly connected to the person, such as their family and social networks, or via broader networks. Similarly, Kawachi\textsuperscript{64} describes social capital in terms of the resources available to members of tightly-knit communities, conceptualising it as an attribute of a collective, such as neighbourhoods, workplaces, or schools. Elsewhere, an Australian study has empirically identified eight distinct elements of social capital: participation in local community, neighbourhood connections, family and friend connections, work connections, proactivity in the social context, feelings of trust and safety, tolerance of diversity, and value of life.\textsuperscript{65,66} Social capital theories emphasise the links between the individual and community health and can facilitate a more comprehensive understanding of the broader social influences on health and disparities in health. They are ecological measures, and there is currently no accepted or valid measurement index to capture the complexity of this level of social and community engagement. Proxy measures have been used, e.g. valid and multi-faceted indices of relative social and economic disadvantage that capture, to some extent, the amount of neighbourhood resources and ability of residents to connect and interact with each other.

\textbf{Methodological approaches}

The term ‘eco-epidemiology’\textsuperscript{67} has been used to identify the study of traditional biomedical concepts of individual risk, with the broader social and environmental context, including the community, otherwise known as ‘ecological’ factors.\textsuperscript{61} Eco-
epidemiology is underpinned by principles that recognise the relationship between an individual and their external or ecological environment and the need to analyse contextual or ecological factors alongside variables operating at the individual level.

Careful definition of the units of analyses for the exposure and outcome parameters is required for statistical analyses of ecological variables. Exposures that characterise contextual factors such as ‘family cohesion’ or the ‘size of workplace social networks’ are ecological and are therefore defined at a group level. Measuring the ecological factors associated with resilience—which are psychosocial, multi-factorial, and inter-related—presents analytical challenges. The best way to analyse ecological or contextual forces on individual health outcomes requires a clear conceptual framework and multi-level statistical analyses.

Despite the vast research data available on the importance of socio-ecological factors for promoting health, there is a comparative lack of objective, empirical evidence as to which factors are most effective in changing health behaviours or outcomes in injured patients. As it becomes increasingly apparent that multi-dimensional factors can support resilience and predict longer-term outcomes of trauma, a more detailed analysis of the socio-ecological components of injury outcomes is warranted. In this regard, taking a systems approach to prevention can help us to better understand the relationships behind complex public health problems and to find the most efficient, effective and equitable solutions. Hence, understanding these relationships is an important prerequisite for studying resilience and implementing solutions.


**Predictors of Outcomes after Hospital Discharge**

**Patient and clinical factors**

Duration of hospital length of stay has been identified as a predictor of long-term disability.\(^7^1\) Longer length of stay and number of ICU days has also been reported as important for 6-month and 12-month functional recovery.\(^2^1,^2^2\)

Major ‘injuries to the extremities’ have been reported as a 6- and 12-month predictors of poor function and quality of life.\(^2^1,^2^2\) Anatomical site of injury might also be important in terms of predicting longer-term disability. In this regard, major ‘injuries to the extremities’ have been reported as a 6- and 12-month predictor of poor function and quality of life.\(^2^2\) Two years after major blunt force multiple injuries, approximately 41% of patients with injuries to the lower extremities, particularly at the ankle site, experience pain or impaired disability (compared to 16% of injuries to the upper extremity).\(^7^2\)

However, the prognostic importance of injury severity on longer-term outcomes, namely RTW, is unclear. Some studies have identified a significant, independent association between injury severity as a predictor of time off work for major trauma,\(^7^3,^7^4\) while others have found no significant associations in multivariate analyses.\(^^4^0,^7^5\) Measures of injury severity, typically collected in trauma registries and used for predicting short-term outcomes, may not be adequate predictors of longer-term outcomes.\(^7^6\) Instead, other descriptions of the extent and severity of injury may be more valid indicators of the likelihood of recovery.\(^7^5\) In addition, some studies suggest that the numbers of injuries are important to consider.\(^7^7\)

Although comorbidity prior to the injury event appears to be an important factor for long-term injury outcomes, its definition and measurement varies.\(^7^8\) Approximately 23% of Australians live with two or more diseases, and the prevalence of comorbidity
rises with age. For major comorbid chronic conditions, people living in low socioeconomic areas and in regional and remote areas are most affected. The most common chronic diseases contributing to comorbidity are arthritis, back pain, and cardiovascular disease. Diabetes is an emerging problem in younger people, as is smoking and alcohol dependence, the latter of which has been shown to be a common pre-existing condition in major injury patients.79

In a well conducted, prospective study of major injury patients and return-to-work outcomes, comorbidity emerged as a negative predictor.31 Similar associations with comorbidity have been reported in other studies.28,80 An Australian prospective research study of people sustaining multiple orthopaedic injury found that a measure of ‘self-reported chronic illnesses’ at baseline did not predict RTW, whereas a generic measure of ‘self-assessed pre-injury status’ did, wherein an evaluation of poorer health status was more likely to be associated with a longer time to RTW when compared to those with a good health status. A detailed analyses mapping four comorbidity indices to ICD-10 codes found that comorbidity predicts 12-month functional outcome in orthopaedic injury survivors.78 Having two or more chronic illnesses was significantly associated with poorer quality of life in terms of poorer function, pain, psychological function, and cognitive ability of the EQ-5D.51 Derrett et al.82 also reported that having two or more chronic conditions pre-injury compared to none predicted an increased risk of disability at 24 months post-injury. However, smoking, obesity, and hazardous alcohol use did not show similar findings.

Elsewhere, quality of life has been studied in trauma patients, yielding some interesting results. In one study,83 patients with moderate to severe trauma living in Hong Kong were tracked from baseline and monitored for functional recovery up to one year after injury. Outcomes were measured using two quality of life instruments,
the SF-36 for physical and mental health function and the GOSE for functional outcomes. At 12 months, only 19% had achieved a high functional outcome. After univariate analyses, significant predictors of long-term (12-month), poor quality of life were: age greater than 65, male, pre-injury health problems, admission to ICU, ISS, baseline, and six-month physical and mental health function scores. Contextual factors were not studied, and sampling was carried out by means of convenience sampling instead of consecutive sampling methods.

The study showed variations in quality of life over time according to injury type, where injuries to the extremities had a poorer outcome when compared to others, excluding spinal injuries. For each group, the proportion achieving an SF-36 physical function score greater than the population norm, in descending order, was as follows: abdomen (18.2%), head/neck (17.8%), thorax (16.3%), extremity (10.8%), and spine (0%), whereas the proportion achieving an MCS greater than the population norm was almost the reverse that of PCS: extremity (37.3%), thorax (32.6%), head/neck (30.9%), abdomen (27.3%), and spine (12.5%).

Hence, improvements in mental health function exceeded physical function, with over half of the cases exceeding the Hong Kong population norm for all injuries at six months. The authors speculated that awareness of surviving significant trauma could leave patients with a sense of mental well-being that is greater than the population as a whole. Patients with spinal trauma with lower levels of mental health function at one year may be due to an awareness of prolonged and possibly non-recoverable injury.

**Social, demographic, and economic factors**

Prospective cohort studies consistently report that risk factors for poor trauma outcomes are found in the patients’ broader socio-ecological environments. Most of
the evidence relates to occupational outcomes after injury. Studies of contextual factors on quality of life outcomes after traumatic injury are difficult to interpret because of the many different types of injury samples studied and the instruments used. A systematic review of the impact of road traffic injury on quality of life\textsuperscript{14} confirmed the findings of other studies—that participants recover over time but never reach levels compared with general population norms. Age, gender, low socioeconomic status and educational levels, blue-collar work, less social support, injury severity, injury type, and post-traumatic stress disorder were all associated with reduced quality of life.

Predictors of RTW outcomes are multi-factorial and are mostly grounded in psychosocial factors that involve social support; work support, including workplace rehabilitation; compensability; family support; general health; employment pre-injury;\textsuperscript{85} education;\textsuperscript{52} and low poverty status.\textsuperscript{29} In an early, seminal study of time to first return to work at 3, 6, 9, and 12 months post-injury, Mackenzie et al.\textsuperscript{29} studied patients admitted to a Level 1 trauma centre using ‘time to event’ analysis techniques and found significant associations (p<0.05) with physical impairment and the rate and extent of RTW. Cox proportional hazards regression modelling was used to show that the increased relative odds of RTW was statistically significantly predicted by younger age (18–34 years), higher education levels (university level), lower levels of poverty, physical work demands, and the availability of practical support.

Subsequent research supports these findings, i.e. that the factors prolonging work disability are not solely confined to the severity of physical impairment at the time of the injury. Again, elements of individual disadvantage have been identified, such as blue-collar work, poor social support, older age, and lower education, all of which are
important predictors in reducing the likelihood of successful work re-engagement\textsuperscript{31,52,85} and the receipt of workers’ compensation\textsuperscript{13,29,31,52,81}.

A systematic review of studies published between 1985 and 2009\textsuperscript{52} examined a number of prognostic factors for RTW after acute orthopaedic trauma. Reasonably strong evidence was found for years of education, where more years were associated with less time away from work; a moderate level of evidence was found for psychosocial factors, namely for self-efficacy as a factor influencing less time from work; and strong evidence was found for increased time off according to undertaking blue-collar work. Significantly, no studies in the review evaluated work-related factors such as work organisation, policy, or systems. The authors concluded that there was not enough evidence to reliably identify prognostic factors for RTW.

Other factors predictive of increased time off work included high initial pain intensity, older age, negative pain attitudes in relation to work, an orthopaedic injury to more than one body region, and an injury that required initial surgery. The probability of increased time off work was associated with socioeconomic disadvantage, older age groups, having a chronic condition, comorbidity, multi-trauma, and occupations involving trades, labour, and transport/production. The socioeconomic disadvantages were not fully explained by occupational status. Participants who reported high social functioning at two weeks post-injury and were in receipt of injury compensation had a 2.58 times increased rate of RTW when compared to participants in receipt of compensation who reported low social functioning.

Other studies have shown that seeking financial compensation is associated with poor injury recovery, suggesting that they are more likely to have delayed return to work and productivity.\textsuperscript{29,81} Gabbe et al.\textsuperscript{31} found that while most (89\%) patients return to their pre-injury workplace at six months, fewer were working in the same role.
Families and caregivers

Families and primary, informal caregivers are an integral part of the patients’ socio-ecological environment. They have the closest relationship with the injured patient and play a vital role in facilitating their physical, psychological recovery and improving their health-related quality of life. However, informal caregivers have not been studied extensively for some subgroups of injuries and are potentially an important prognostic factor for trauma recovery.

Informal caregivers are typically a family member or a friend of the person receiving care, and they usually reside in the same household as the care recipient. The person who provides the majority of care is known as the primary caregiver, and the type of care they provide can range from personal care (such as showering and support with eating), in-home supervision, transport, and help with shopping to the use of medical devices, therapeutic interventions, and wound management. An informal caregiver may support care provided by formal care providers, share care with other informal caregivers, or be the sole caregiver. Informal caregivers are not paid for the care they provide, although some caregivers receive government benefits.

Most of our information about caregiving in the injury field concerns caregivers of people with TBI or SCI. Here, research consistently shows that providing care to these patients has both short- and long-term impacts on psychological health and emotional functioning. Caregivers reportedly start to experience stress, burden, depression, and anxiety around three months injury, with symptoms lasting for one to seven years.

Of concern is that poor health resulting from caregiving could adversely affect a carer’s ability to provide safe, sustainable care for trauma patients; however, empirical evidence for this is somewhat conflicting. In this regard, early research on
older spinal cord patients suggests very little in the way of a relationship between the recipient and caregivers’ well-being and depression, whereas other studies highlight that for patients with severe TBI, family functioning and caregiver social support is associated with improved patient productivity and social integration. An inception cohort study of people sustaining TBI found that better family function pre-injury was associated with better patient participation outcomes. In a reasonably well conducted longitudinal study, the contribution of caregiver emotional and family functioning in relation to participation outcomes (home and social integration) in patients following post-acute rehabilitation for brain injury was investigated. While family functioning was found to be unrelated to participation outcomes, the extent of caregivers’ emotional distress was predictive of outcomes for the patients who entered the program early, i.e. within six months of injury.

**Resilience**

**Definition of resilience**
Most people experience an event that causes significant psychological trauma in their lifetimes; however, based on studies of relatively low incidence rates of post-traumatic stress in exposed individuals, most people recover psychologically. The notable variations in the ways in which people respond to similar stressful life events has led to an emerging interest in exploring the role of resilience in trauma recovery. The phenomenon of resilience is gaining much attention in injury outcome research because of its potential to harness positive features associated with recovery as opposed to ‘risk’ features. In this regard, resilience could explain variations in the ways in which people respond and adapt to significant adversity, which is applicable to trauma populations.
Resilience is no longer seen as a fixed, unchanging personality trait but as a process of positive adaptation in the face of adversity. In this thesis, positive adaptation is conceived as maintaining normal development and function (physical or psychological) or even having improved or ‘better than expected’ function after significant adversity. The ability to make sense of changed circumstances—and to maintain a continuity of meaning after crisis or challenge—is a key aspect of the resilience process for individuals. Resilience is positively associated with lower depression rates, better physical health, and lower burden and stress. Resilient factors directly associated with physical health are self-care, adherence to treatment, health-related quality of life, and physical outcomes.

**Resilient qualities**

Resilience theory has its origins in psychiatry and the study of children who appeared to thrive despite significant adversity in the lives. A systematic review of qualitative and quantitative resilience research of people with a range of physical illnesses points to features such as hope, hardiness, locus of control, acceptance of illness, and determination, while other qualities include having active coping strategies and spirituality. Busnik et al. have summarised a set of core skills equated with resilience, which include the ability to have a positive outlook, an even temperament, self-regulatory and communication skills, good problem-solving skills, and social perception. In addition, social support and self-efficacy have been empirically shown in a meta-analysis to be key components of resilience as well as key factors for promoting functional recovery, work participation, and quality of life.

**Social and environmental factors (resilience resources)**

Resilience is conceptualised in terms of the relationship between individuals and their broader social environment, where numerous social, physical, and community
resources provide the capacity for reliance to prosper. Evidence for the role of these contextual factors in shaping resilience is expansive, largely stemming from studies of environmental factors on childhood adversity. In general, however, the evidence base is relatively sparse and methodologically poor.

For severely injured patients, resilience can be fostered by resilient and cohesive families and caregivers and from peers, supportive social networks, the workplace, community, and rehabilitation services. A wide range of observational studies have examined the prognostic importance of resilience qualities such as coping, self-efficacy, self-esteem, optimism, social support, community re-integration, sense of control, and sense of coherence on psychological and physical health outcomes and quality of life. Further, resilience ‘traits’ have been associated with improvements in mental and physical health and well-being following spinal cord and mild traumatic brain injuries and multiple trauma. Resilience-based skills, such as an ability to control one’s environment, integrate with one’s community, develop health competence, and access family support and social support have predicted global outcome measures of well-being and physical function. Two longitudinal studies that specifically examined the prognostic role of resilience measurement scales in patients with spinal cord injury (SCI) and with mild TBI reported fewer depressive symptoms and improvements in quality of life in those with early, higher levels of resilience.

Research also shows that contextual factors promoting resilience, such as economic and family support, can predict participation outcomes in people with TBI. In this regard, families and social support systems are significantly important. In an Australian study of TBI patients, family support was a significant factor in predicting emotional well-being in the long term, i.e. beyond three months post-
injury. Social support networks dissipated over time, and family became important for this subgroup of injury patients, and this pattern may also apply to other injury groups. Integrating supportive relationships into the rehabilitation process and helping patients develop a sense of control and evaluate life meaning can promote resilience in patients with acquired brain injuries.124

High levels of social functioning and strong social relationships are important predictors of work re-engagement following injury.41,52 Other resilience-based predictors for this outcome include coping skills112 and community integration.125 A recent synthesis of systematic reviews of factors affecting return to work after injury identified resilience factors such as self-efficacy and optimism as important predictors,126 although other studies have found no association between the psychosocial factors related to resilience and the likelihood of returning to work.74,127

**Resilience: Measurement and Methods for Research**

The resilience construct is broadly defined and has been interpreted variously and applied differently amongst adults, children, and societies. In this regard, there is no consensus as to how it should be measured. For example, resilience has been studied as a predictive trait where positive qualities such as self-esteem, self-efficacy, or optimism are evaluated in relation to clinically defined outcomes after injury such as depression; quality of life; returning to work; increased productivity in the areas of school, work, and volunteerism; and managing daily tasks such as finances and self-care.92 Resilience has also been studied in the form of outcomes, including measures of positive adaptation, coping, maintaining function, pursuing goals, and increased social or community integration, with studies of such outcomes evaluating the predictive importance of factors related to the injury event, such as injury severity, comorbidity, age, family factors, or rehabilitation interventions.93 Resilience has also
been examined as a mediator of factors relating to the injury event and later life outcomes such as depression.\textsuperscript{94} This has led to great heterogeneity in study designs and measures and has stymied understanding of the benefits of resilience in health. However, if resilience theory is to inform prevention programs and policies for trauma patients, then research should use rigorous methodologies that generate the best possible evidence base for maximum utility, which should include the many disciplines involved in studying the biological, social, and environmental factors that make up resilience.

**Definition of adversity**

Despite these obstacles some common domains are accepted as evidence of resilience, as described above.\textsuperscript{49} Furthermore, there are methodological guidelines that standardise approaches to resilience research and enable comparison of resilient health outcomes in different populations.\textsuperscript{42,50} These relate to the components of ‘adversity’ and ‘positive adaptation’ in the definition of resilience. Studies should focus on people with similar levels of risk experiences where possible,\textsuperscript{93} and while the notion of ‘adversity’ is subjective, it can more objectively be described as a negative life circumstance known to be statistically associated with adjustment difficulties.\textsuperscript{106} The adverse event can be severe and chronic, or it can be as a result of acute events such as severe traumatic injury.\textsuperscript{128} In children, adversity might be described as relating to low birth weight, chronic illness, and exposure to violence or deprivation. In older people, adversity can be socioeconomic disadvantage, chronic painful disability, or other health challenges.\textsuperscript{129}

**Measurement**

A longitudinal design is warranted to study the temporal aspect of adaptation to adversity. The measurement of resilience should, where possible, encompass
personality traits, and psychometric instruments are available that capture qualities strongly associated with resilience, such as self-esteem, self-efficacy, a sense of control, and sense of coherence and optimism. Some of these instruments are reasonably robust but are rarely used in studies of resilience. In this regard, resilient traits have been studied in similar ways using isolated proxy measures such as self-esteem, self-efficacy, or optimism in relation to clinically defined outcomes after injury, such as depression or quality of life.

A systematic review of resilience measurement scales identified 19 resilience measures, most with very questionable reliability and validity in clinical populations. Three measures had adequate psychometric properties. Table 3 summarises these three measures and the psychometric properties of each one. Of these measures, the Connor–Davidson Resilience Scale (CD-RISC) has been validated in injury populations and is generally used in research studies to measure outcomes of resilience. Thus, the CD-RISC has acceptable psychometric properties and is acknowledged as a reliable measure of resilience.
Table 3. Measures of resilience with the most adequate psychometric properties*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Reference, year</th>
<th>Items</th>
<th>Factors measured</th>
<th>Psychometrics (strong)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resilience Scale (RS)</td>
<td>Wagnuld and Young, 1993 [33]</td>
<td>25</td>
<td>1. Personal competence</td>
<td>Content validity; internal consistency; construct validity</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Acceptance of life</td>
<td></td>
</tr>
<tr>
<td>Resilience Scale for Adults (RSA)</td>
<td>Friborg et al., 2003 [107]</td>
<td>37</td>
<td>1. Personal competence</td>
<td>Content validity; internal consistency; construct validity; test-re-test reliability</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Social competence</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>3. Family coherence</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>4. Social support</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>5. Personal structure</td>
<td></td>
</tr>
<tr>
<td>Connor Davidson Resilience Scale (CD-RISC)</td>
<td>Connor and Davison, 2003 [132]</td>
<td>25</td>
<td>1. Personal strengths</td>
<td>Content validity; interval consistency; construct validity; test-re-test reliability</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Strengthening effects of stress and adversity</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3. Secure relationships and positive acceptance of change</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4. Sense of personal control</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5. Spiritual influences</td>
<td></td>
</tr>
</tbody>
</table>

*Adapted from Neils-Strunjas et al., 2017 [124]

Resilience has also been defined in a number of injury studies according to the degree of stability of psychological symptoms after the event, thereby indicating positive psychological adjustment over time. For example, patterns of resilience can be described according to one’s ability, after a traumatic event, to maintain either psychological function, experience a decline in psychological function followed by recovery, or function in ways that improve from baseline. In this sense, resilience is ‘inferred’ by assuming that any specified health outcome remains stable after adversity or is ‘better than expected’. So, people who maintain, from baseline, reasonably low and stable levels of distress after trauma might be described as ‘resilient’. 
Studies of trajectories of symptoms post-acute traumatic injury have inferred varied patterns of resilient recovery. Using latent growth mixture models, four distinct forms of recovery trajectories were defined for psychological outcomes: ‘resilience’, ‘chronic’, ‘delayed’, and ‘recovering’ groups. The ‘low symptom’ group was defined as ‘resilient’, whereas the ‘high, increasing symptom’ group was defined as ‘chronic’. Using the resilient group as the reference group, logistic regression analysis showed that the ‘delayed’ group had a significantly lower number of years of education, higher coping self-efficacy at baseline, and injuries that were caused by human intention. The ‘chronic’ group was over seven times more likely to have injuries of human intention and anger at baseline. In this regard, early identification of the people likely to have a less stable pathway after injury, such as chronic or delayed recovery, could be important.

Other work by Bonnano identified similar trajectories for anxiety and depression in SCI patients, where a pattern of stable, low-level symptoms for each disorder was characterised with higher resilient qualities such as coping and positive appraisal (seeing SCI as a challenge more than a threat) and less quality of life problems over time when compared to the groups with less stable symptoms. Notably, the ‘resilient’ covariates in these models focused on personal resilient traits, and the role of ecological factors providing resilient capacity was not examined. In these analyses, resilient functioning was used as the ‘reference’ group, thereby disabling any ability to explore external factors associated with resilient function in this group.

Diverging patterns of ‘resilience’ over time, defined by levels of symptom intensity after a traumatic injury, have been studied elsewhere for mild TBI patients, supporting the theory that variations in resilient symptoms in individuals exist immediately following injury and that different patterns of response evolve over
These methods are consistent with the view expressed by Kendall and Terry that resilience involves adjustment and adaptation processes and should therefore be studied longitudinally. In this study, resilient symptoms are relatively common after major injury, and injuries that were violent, caused by humans and high levels of anger, appear to be related to adverse psychological recovery. The method acknowledges that resilience is a construct (i.e. is not a fixed trait) and has adaptive qualities.

However, an important shortcoming of the ‘inference’ approach is that any positive outcome after adversity could be attributed to resilience. For example, some researchers have stated that the absence of PTSD after trauma is a resilient outcome. Because these levels are defined by researchers and are subjective, studies using this method should ideally measure baseline (pre-adversity) symptoms and have a clear definition, specified a priori, of the level of adaptive or ‘better than expected’ response to the adversity that is expected. This could, for example, specify statistically significant and clinically important changes for ‘better than expected’ outcomes.

To address the notion that variations in resilience is a proxy for unmeasured variations in risk exposures, studies of resilience should also rigorously account for social and environmental factors—in addition to biological factors (where possible)—that promote or impede resilient outcome measures in study populations.

**Non-Fatal Severe Trauma Outcomes: Gaps in Knowledge**

Existing studies in the trauma outcome field have consistently highlighted factors in predictive models that point to patients’ socio-ecological systems that are known to support resilience. For the most part, generic descriptions of ‘social support’, ‘family support’, and ‘socioeconomic status’ have been analysed with little detailed, empirical
analysis of what lies beneath such elements. For example, research is fairly persuasive about the positive role of perceived social support on rehabilitation outcomes,136 yet the precise nature of the best form of support, whether it lies in networks proximal to the patient (e.g. families and caregivers) or more distal (e.g. work colleagues, health care workers, or other community resources) to the patient is not known.

Drawing on the literature review in Chapters 1 and 2, the following section identifies gaps in the research and outlines three main areas worthy of further study.

**Effectiveness of innovative socio-ecological rehabilitation programs after traumatic injuries**

Socio-ecological systems theory recognises that individual behavioural changes are unlikely to be sustained unless there are programs addressing broader social and environmental factors that provide capacity for change.137 Many rehabilitation programs and research studies of these programs focus on strategies to reduce impairments in functional limitations,122 while little research has been conducted into the association between protective factors and injury outcomes.

The multi-dimensional role of resilience-based rehabilitation approaches to injury recovery is gaining traction, but evidence is sparse and results are inconsistent. Researching the effectiveness of single components in a trauma patients’ complex rehabilitation eco-system is of limited use.53 Given that trauma recovery involves a complex interchange of disciplines involving the patient, family, peers, health, and workplace, there is surprisingly limited evidence for the effectiveness of a suite of multiple contextual factors on rehabilitation.

A meta-analysis of psychosocial interventions for people with chronic illnesses reported that including a spouse in interventions had positive effects on patient
depression and, to some extent, mortality.\textsuperscript{138} In one approach that is consistent with the dynamic and interacting features of the socio-ecological model of resilience enhancement, Schultz et al.\textsuperscript{139} reported on a three-armed intervention of caregiver and care recipient (SCI) dyads as the units of analysis. In this regard, caregiver and care-recipient dyads were randomly assigned to either a ‘caregiver only’ arm consisting of a multi-component intervention, a ‘dual-target’ arm targeting both carer and patient, and an ‘information only’ control condition for the caregiver only. The interventions targeted resilience training and found that, compared to the caregiver group only, the interventions administered to both patients and carers resulted in less depression, caregiver burden, and negative health symptoms. The findings support the socio-ecological systems theory of resilience and the need to examine the synergies between the carer and patient unit so as to better understand the ways in which to achieve optimal rehabilitation results.

Elsewhere, a randomised controlled trial of resilience training in patients after TBI found significant increases in resilience measures (using the CD-RISC Scale) and measures of psychological health. However, the intervention solely targeted the patient, providing education, skill building, and psychological support. Resilience training in military populations pre-deployment has been shown to have positive effects on anxiety and PTSD;\textsuperscript{140} however, programs in civilian populations including non-clinical populations\textsuperscript{141} and clinical populations\textsuperscript{142} have failed to find conclusive evidence of effectiveness.

Little is empirically known about the interacting role of socio-ecological factors that are thought to support resilience in the area of injury rehabilitation, particularly those most closely related to the patient and involved with recovery. Designing rehabilitation interventions based on resilience enhancement for injured patients
requires some understanding as to whether and which ecological components are important to injury recovery.

**Socio-ecological factors supporting resilience in informal caregivers**

**The caregiving role**

Informal primary caregivers have the closest relationship with the injured patient, and they can find themselves suddenly and unexpectedly charged with facilitating patients’ physical and psychological recovery and improving their health-related quality of life after serious trauma. Caregivers are not paid. They have no market value and are not, in the clinical sense, formally managed or cared for throughout the patients’ rehabilitation pathway.

Herein lies the adversity that informal caregivers face in any study of resilience. The poor health outcomes associated with caregiving and the relative lack of formal support or clinical recognition of the caregiver burden suggest that the study of resilience and resilience ‘resources’ in informal caregivers using a systems approach has merit. Furthermore, in the socio-ecological context, many epidemiological studies of outcomes for a diverse range of caregivers of non-injured patients show that both individual and broader, ecological factors are important in terms of understanding risk and protective factors for adverse caregiver outcome. Good family functioning, coping skills, feelings of control, and social support are all important in terms of promoting positive caregiver health and mediating caregiver burden.

Research about the role of caregiver and family resilience in supporting injured patients and improving rehabilitation prospects is sparse, mostly cross-sectional, and focuses on people supporting relatives with TBI or SCI. Most of the literature on caregiving has acknowledged the public health significance of the role and has
addressed patient factors that negatively impact on the caregiving role. However, few studies have extended this analysis to examine how the caregivers’ broader socio-ecological network (which includes the patient) supports caregiver resilience and health and how this could positively influence patients’ rehabilitation prospects in turn. This approach explicitly recognises that traumatic injury takes a toll on patients and their informal carers and that during rehabilitation, each will influence the other in positive or negative ways.

**Economic factors**

In Australia, about one in eight (2.86 million) people provide informal care, most of whom are aged between 25 and 64 and are female. Around half participate in the workforce, and their weekly median income is around 42% lower than for non-caregivers. Informal caregivers provided an estimated 1.9 billion hours of care in 2015, with the replacement value of informal care being estimated to be about AU$60.3 billion. In this regard, the contribution of informal caring is thought to be so great that no insurance scheme is likely to fully fund its replacement\textsuperscript{148,149} and that demand for informal care will significantly outstrip supply in the next ten years.\textsuperscript{150} More recently, simulation data on informal carers for the Australian population estimates the economic costs of lost labour force participation at AU$3.58 billion, with a projected 49% increase to AU$5.3 billion in 2030.\textsuperscript{151}

**Declining health**

Studies of caregivers outside of the trauma space show that providing care over prolonged periods of time adversely affects caregivers’ economic productivity and psychological and physical health.\textsuperscript{143,152,153} Caregiver burden is a measure often used in research to depict their response to the physical, psychological, social, and financial demands of caring for someone.\textsuperscript{154} Predictors of caregiver burden have been
extensively studied across health conditions and include low levels of social support, the severity of patients’ functional status\textsuperscript{155} and pre-existing depression, poor coping, and perceived patient distress.\textsuperscript{143} Caregiver burden is possibly an independent predictor of caregiver mortality,\textsuperscript{156} reduced self-care, and health prevention behaviors.\textsuperscript{157} However, other outcomes important to caregivers, such as their quality of life, beyond the burden of caregiving have been comparatively less studied, despite the association with adverse health outcomes.

Most of our information about caregiving in the injury field concerns caregivers of people with brain or spinal cord injuries. Extrapolation of the findings of general caregiver research and even across injury subgroups is not advised because of the diverse range in patients physical and cognitive needs and caregiving characteristics and responsibilities. Hence, relatively little is known about caregiving health for patients in other injury subgroups such as musculoskeletal trauma. Caregivers reportedly start to experience stress, burden, depression, and anxiety around three months post-injury, with symptoms lasting for one to seven years.\textsuperscript{158} In this regard, depression, anxiety, somatic function, and family disruption are common.\textsuperscript{159–161} In addition, other studies suggest that caregivers are also more likely to become vulnerable to physical illnesses.\textsuperscript{162}

\textit{Caregiver resilience measures}

A cross-sectional sample of a convenience sample of caregivers of patients with neurotrauma reported negative correlations between self-rated psychometric measures of resilience and caregiver burden.\textsuperscript{163} A longitudinal study examined the trajectories of depressive symptoms in caregivers for SCI patients. Here, resilience was inferred (i.e. not measured psychometrically) by the different levels of symptoms over one year, which were defined as ‘chronic’, ‘recovered’, and ‘resilient’.\textsuperscript{164} Resilient
caregivers of patients with spinal cord injuries reported less health complaints when compared to those with significantly less resilient qualities.\textsuperscript{164} In addition, the association with poor family function pre-caregiving and increased carer stress and burden has also been reported.\textsuperscript{145}

\textit{Patient factors}

In terms of patient factors, the severity of the patients’ injury does not appear to have a significant impact on caregivers health or caregiver burden.\textsuperscript{158,165} However, time since injury\textsuperscript{165} and long-term increased patient disability and impairment have been reported to be associated with increased caregiver burden.\textsuperscript{143} This association between long-term impairment and carer burden has been reported elsewhere.\textsuperscript{166} Further, the emotional and psychological state of the patient may be important. In this regard, based on data from a prospective multi-centre study of traumatic brain injured patients, Kreutzer et al.\textsuperscript{159} found higher levels of caregiver distress in relation to the degree of patients’ functional impairment and patients who drank excessive alcohol and were less satisfied with life.

\textit{Health service support}

The availability and adequacy of health service support for caregivers is not fully understood in the Australian context and possibly varies according to different types of injury. Qualitative research on carers of brain-injured patients residing in Queensland\textsuperscript{167} suggests that services are insufficient and inconsistent, while accessing services for resources is also problematic in some areas. Caregivers have been described as the ‘invisible patient’, and a clinical review of caregiver burden reports that physicians are not fully acknowledging their responsibilities to the caregiver, particularly in terms of addressing their health and well-being, their ability to undertake the caregiving role, and the need for additional support.\textsuperscript{143} Much of the
focus in primary care settings is on the patients’ pathway; however, there is little information available in Australia about how carers are assessed (if at all) and supported along this pathway. The extent of caregivers’ unmet needs in the primary health service setting might directly impact on the caregiving role, carers’ health, and patient outcomes.

**Work support**

Combining work and informal care is challenging. Qualitative research shows that caregiver stress at work is related to high levels of distractibility, worry, and an inability to effectively carry out work tasks.\(^{168}\) Further, caregivers are less likely to participate in the labour workforce and in social and community or physical activities.\(^{169}\) Many carers report changes in their weekly hours of work as a result of caregiving or that their caring role has resulted in taking time off from work. While research points to the importance of workplace social capital and supportive work environments in promoting workers’ health and increasing participation in the workforce,\(^ {170}\) little is known in Australia about how work organisations support informal carers and whether this influences their work participation. Research\(^ {171}\) on work outcomes for informal carers shows that a heavy care burden decreased the ability to successfully combine work and care responsibilities, while workplace support (by peers and supervisors) was associated with good work outcomes (defined by work/care balance and perceived need for job adaptation). The importance of social support at work and jobs with flexible working schedules has also been highlighted.\(^ {168}\) Thus, outcomes important to caregivers, such as their quality of life, beyond the burden of caregiving have been comparatively less studied, despite the association with adverse health outcomes.
Methods for research involving caregivers and patients

Ecological systems theories emphasise the importance of understanding interactions and synergies between individuals or groups. Studying patients and carers together enables a better understanding of the reciprocal relationship between patients and carers as well as ascertaining the parallel changes in both over time. A systematic review of the evidence for caregiver interventions (which can be applied to caregiver research more generally) recommended a framework to support the dyad approach.\textsuperscript{172}

The caregiver and patient should be studied concurrently and dual outcome measures obtained, which include those related to physical health, psychological health, economic status, and health care utilisation. In addition, baseline measures should include demographic factors, health status, economic status, health insurance, relationship type, and cultural norms.

Resilient neighbourhoods

Socioeconomic disadvantage features prominently and consistently as a predictor of poor health outcomes. Inequalities exist in trauma populations where, in Australia, there is an over-representation of people from socioeconomically disadvantaged backgrounds. For trauma research, this has mostly been evaluated in terms of an individual’s occupation and education. In this regard, being in a blue-collar occupation is a significant risk factor for non-fatal injury and injury severity, over and above factors such as educational attainment or income.\textsuperscript{173} Disadvantage is also associated with higher rates of risky behaviours, speeding, alcohol and drug intake,\textsuperscript{174–176} comorbidity,\textsuperscript{175,176} crash severity,\textsuperscript{177} and injury severity.\textsuperscript{175,177} As such, many of these individual factors are collected by trauma registries to monitor trauma care, assist with injury prevention, and control and identify areas for clinical and epidemiological research.
However, it has been long recognised that the *places* where people live, work, and socialise fundamentally influence their health and life expectancy. In this sense, an individual’s social and economic status is influenced by a myriad of social and environmental factors, all interacting with individual-level factors to shape behaviour.\textsuperscript{54,55,59,178} These contextual factors include family and social networks, occupational exposures, and availability of services or resources that provide education or promote safety.\textsuperscript{49,179} Often called ‘area-level’ or ‘neighbourhood’ factors, they encompass a community’s material wealth, which in turn influences the quality of housing and the built environment,\textsuperscript{49} including social connections\textsuperscript{41} and the availability of services or resources that provide education or promote safety.\textsuperscript{49,173,179}

After controlling for individual factors, neighbourhood factors have been shown to independently predict an individual’s health risk.\textsuperscript{179–181} Therefore, the potential for ‘place’ to be an exposure to all its inhabitants (as opposed to some) has prompted concerns that unless contextual factors are addressed, individual risk and inequalities will fester.\textsuperscript{182,183} These factors are not routinely collected by registries. Longer-term trauma outcome surveillance data on patients’ neighbourhoods could ultimately help to inform approaches to recovery and rehabilitation.

Community resilience is a term commonly used in studies of disaster response, but it is increasingly appearing in the research literature in relation to impoverished disadvantaged areas in an attempt to understand why positive outcomes appear to paradoxically prevail.\textsuperscript{184} While definitions of community resilience are very blurred, there is general agreement on some key, common elements that, once again, encompass systems theories and incorporate a process of adaptation. Elements of community resilience have been studied for human health outcomes,\textsuperscript{184} including its capacity to be economically robust, healthy, and connected with strong and effective
communication networks. Resilient communities have access to quality health care and to a high level of other community resources,\textsuperscript{185} while safe neighborhoods\textsuperscript{186} and healthy living infrastructure\textsuperscript{184} are also understood as being important.

A great deal of work has been carried out to capture the contextual properties of communities that best explain their relative social, economic, and geographic disadvantages in all their complexity. These indices are mostly derived from census tract variables and tend to measure the economic standing of a neighbourhood in terms of its median income, housing value, proportion of blue-collar work, and amount of school education.\textsuperscript{173} Other contextual factors of neighbourhoods include their racial and ethnic concentration; population density; average distance to and availability of various services, often defined as ‘remoteness,’\textsuperscript{187–189} and estimates of residential stability and family structure.\textsuperscript{173} An array of community-level factors closely aligned with these and the factors described above relating to community resilience are collected during the Australian Census and are summarised into an Index of Relative Social Disadvantage (IRSD).\textsuperscript{190} The IRSD is often analysed at an area level as an explanatory factor for either group-level or individual-level outcomes and has explained health differentials and influenced health policies.\textsuperscript{191}

However, the IRSD indices do not capture an important feature that is intrinsically related to social and economic disadvantage in Australia and trauma outcomes—rurality of residence and the positive gradient that exists between socioeconomic disadvantage and increasing remoteness from services. The time taken to receive definitive care following severe trauma is a critical factor influencing survival, and injuries occurring in rural and remote areas pose specific challenges in this respect. Compared to urban dwellers, rural residents have relatively poorer access to health services, higher levels of risk behaviours—including occupational and physical risk—
and higher rates of disease and injury (e.g. from farming, mining, and work or road accidents.)

Unsurprisingly, Australian research has highlighted an increased risk of injury mortality according to geographical remoteness. However, once patients reach hospital, the risk of death is not significantly different to that of their urban counterparts. In addition, patterns of injury differ according to place of residence, i.e. rural residents are more likely to be involved in serious incidents causing injuries—such as firearms, farming, mining, natural environmental factors, and road injuries—and are at least twice as likely to be admitted to hospital for injury when compared to urban residents.

Thus, multi-faceted measures of socioeconomic disadvantage, conceptualising a community’s collective wealth, have not been factored into many trauma outcome studies of remoteness from services. Thus, the extent to which socioeconomic disadvantage independently accounts for reported associations between remoteness and hospital trauma outcomes is unclear. In this regard, understanding how ‘neighbourhood’ prosperity and accessibility to resources influence trauma outcomes, as well as elements of social and economic disadvantage, remoteness of residence, injury location, and place of initial trauma care, need to be disentangled.

**Summary**

This chapter has highlighted that severely injured trauma patients who survive and are discharged home recover in a highly contextual environment. Methodological approaches to research in this area will be essentially different from those used to study acute, clinical inpatient outcomes from trauma and will involve partnerships between clinicians and community and public health professionals.
In addition, the key factors known to predict adverse outcomes have been outlined and discussed in the context of socio-ecological systems theories, with secondary and tertiary prevention strategies in mind. Further, resilience has been highlighted as an important and emerging factor of interest in trauma, with significant potential for the prevention of worsening disability and enabling optimal recovery. However, there are notable gaps in the literature in relation to the study of resilience. In this sense, it is unclear how effective resilience-based rehabilitation programs are for important patient outcomes. In addition, resilience in informal caregivers has not been extensively studied using the most appropriate methodology. Finally, neighbourhood factors defined by relative prosperity and accessibility to services could adversely affect patients’ outcomes in the short and long term. These factors are not currently incorporated in trauma surveillance systems and could therefore be important for the long-term surveillance and monitoring of patient outcomes.
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Chapter 3: Methods

Overview

This chapter describes the methods used to test each of the four study hypotheses in this thesis. For each study, the hypothesis is stated and the study design is identified. The study participants, the study area and study period are defined. Inclusion and exclusion criteria are specified, and the recruitment procedures are described. For each study, relevant data definitions and data items are provided, including independent and dependent variables. Details of the statistical analytical methods used to test each hypothesis are given.

Study 1

The aim of this study was to quantify, for injured adult patients, the effectiveness of rehabilitation programs that target socio-ecological systems and examine resilient outcomes.

Hypothesis

That socio-ecological resilience rehabilitation programs after traumatic physical injuries result in improved outcomes, including stress mitigation, reduced time to return to work, and increased self-efficacy compared to programs providing standard care.

Research Design

A systematic review and meta-analysis were identified as the most appropriate method to determine the efficacy of multi-dimensional rehabilitation programs targeting resilience in injured patients. The approach taken was based on the reporting
guidelines for systematic reviews (PRISMA).¹ The study protocol was registered and updated at the Prospero International Prospective Register of Systematic Reviews (Registration ID CRD42016043332) website: http://www.crd.york.ac.uk/PROSPERO

**Inclusion and Exclusion criteria**

Eligible studies were randomised controlled trials, with a clearly defined intervention and comparison group, and prospective follow up. Interventions used one or more components of the socio-ecological resilience framework as part of the rehabilitation process following acute traumatic injury. Interventions were aimed at preventing the development of new disorders, or worsening disabilities following injuries.

Studies were excluded if they were pilot studies, quasi-experimental, case reports, case series, case control studies, cohort studies, or studies analysing non-numerical data. Studies were also excluded if patient selection was based on an existing psychological condition, if the intervention was not part of the post-discharge rehabilitation process or was treating an existing disorder other than the injury, diagnosed either before or in the immediate aftermath of the injury.

**Search Strategy**

The search strategy was guided by the PICO framework². The population was defined as adult patients aged 18-70 years, who had sustained a physical injury, presented to a hospital or clinic for acute management of the injury, and recruited to the study during the rehabilitation phase for that injury. Studies of elite athletes, or active military personnel exposed to psychological and physical trauma were excluded.
Because of the many different qualities that encompass resilience and the current lack of a standard definition of ‘resilience training’ programs, a number of measures were taken at the design stage of the review, to minimise ambiguity. For example, theoretical models described in the literature guided decisions about the inclusion criteria for eligible interventions.\textsuperscript{3-6} These included interventions aimed at enhancing resilient qualities and skills in the patient, as described above, or their external support sources.\textsuperscript{7} Interventions were required to target \textit{at least one} component of the socio-ecological framework in the study design, such as the individual, their family members, primary caregivers, workplace or social support networks and community resources. Control participants were those receiving standard rehabilitation care, or who did not use any of the components in the resilience model described above.

Additional measures were taken to minimise subjective or self-reported outcomes, which, in un-blinded trials, can lead to biased results. The primary outcome therefore consisted of two objective and recommended measures of occupational re-integration, firstly the proportion of people who were working at the designated study follow up time point, following the injury event, and secondly as the average time in days taken to return to work following the injury event. Secondary outcomes were self-reported changes in resilient behaviors such as: changes in the mean differences of self-efficacy and stress levels.

Finally, the follow up time was restricted to 2 years after the acute injury event, thereby minimising the potential for cross-overs between groups and other long term, and unmeasured factors to contaminate the association under investigation. Where the intervention was delivered to the target patients and one or more other
groups (eg family or caregiver), the outcome measures were to include at least one concurrent outcome measure of the patient.

A research librarian advised on the database searches and worked with two authors to conduct the searches. Databases were searched for relevant studies published during the past 30 years (1986-2017): PubMed, Scopus, Proquest, Cinahl, Web of Science, Clinical Trials Database, and the Cochrane Central Register of Controlled Trials (CENTRAL). No limits were placed on language. The reference lists of the identified papers were also searched.

The search strategy was broadly defined to capture the different qualities associated with resilient adaptation following injury. The key words used to search literature included: “Wounds and Injuries" AND "Resilience, Psychological” OR "Adaptation, Psychological" and “Randomised Controlled Trial”. These key words were searched in the Title and Abstract and MeSH terms were used were possible. An example of one of the search strategies, using MeSH terms is described as follows:

Data collection and data management

Selection of studies

Potentially eligible articles were imported into an EndNote bibliographic reference management software program (EndNote X7 (Bld 11961), Copyright 1988-2016 Thomson Reuters). Duplicates were removed and the remaining abstracts were screened using pre-specified inclusion and exclusion criteria. The research team (KH, JS) met to assess and classify the abstracted papers. Articles labeled as potentially relevant were retrieved and the full text examined. Disagreement was resolved by discussing with a third reviewer (MW) wherever necessary. A pre-tested EXCEL spreadsheet form was used to extract data from the identified studies.

Data were retrieved from eligible articles as follows:

1. Study characteristics: year of study, study setting, demographics, nature and severity of the injury, study design and methodology, type and duration of resilience program, resilience measurement instrumentation, control or comparison group;

2. Outcomes: the proportion RTW, average days to return to RTW, self-efficacy, and stress.

3. Subgroup variables: Injury type (Spinal Cord injury (SCI), TBI and musculoskeletal or orthopedic), follow up time point (<6 months, >=6 months), socio-ecological components (social support, workplace support, community support) and resilient skills (self-efficacy and coping strategies) that were targeted in the intervention.

Assessment of methodological quality

The PEDro tool was used to classify the quality of the evidence.
The authors of all the original studies were contacted for missing data from the published reports. Data were received from one of these authors.

**Statistical analysis**

Data from RCTs were pooled using Comprehensive Meta-analysis software (*Comprehensive Meta-analysis*. Version 2. Englewood, NJ.: Biostat, n.d. Computer software.) For continuous outcomes, mean differences and standard deviations were extracted. For dichotomous outcomes, ‘return to work’ event rates were calculated and expressed as the proportion of patients working or employed at follow up.

The results were pooled using a random-effects meta-analysis, and mean differences for continuous outcomes including average taken to return to work, self-efficacy and stress, and risk ratios for binary outcomes including return to work, along with their 95% Confidence Intervals were calculated. We calculated 95% confidence intervals and two-sided \( p \) values for each outcome.

Heterogeneity for all studies was estimated based on the \( I^2 \) index. Low heterogeneity was defined as \( I^2 \) was less than 30%, moderate heterogeneity was \( I^2 \) was 30-49% and a high level of heterogeneity, was \( I^2 \) was 50% or more.

Subgroup analyses were performed to investigate heterogeneity across the different program components for the ‘RTW’ outcome. These subgroup factors focused on types of program components fostering resilience, follow up time points, and injury types. Sensitivity analyses were conducted to assess whether statistically significant results were due to a particular study, or studies. Publication bias was assessed using Egger Regression Analytical techniques.\(^{10}\)


**Study 2**

The first aim of this study was to develop methods, using geocoded residential address data, for linking a robust multifaceted index of neighborhood disadvantage, and an index of geographic remoteness to individual, severely injured patients on the Trauma Registry. The second aim was to quantify the relationship between relative socioeconomic disadvantage and remoteness of residence for severe, acutely injured adult patients admitted to a Tertiary Referral Trauma Centre, the Gold Coast University Hospital (GCUH) over a four-year period.

**Hypothesis**

That for severely injured, hospitalized trauma patients; there is a significant and positive relationship between area-level indices of disadvantage and residential remoteness of residence, independently of patient factors, including injury severity comorbidity and age.

**Research Design**

To describe the association between ecological variables, specifically ‘neighborhood disadvantage’ and ‘remoteness of residence’ in trauma survivors, a cross-sectional study design was chosen. For this analysis, patients were sourced from the Trauma Registry at the GCUH.

**Study setting**

The tertiary referral trauma center in this study is the GCUH based in South East Queensland (SE QLD). It is a Level 1 Trauma center that provides the highest level of total trauma care for patients, from prevention through to rehabilitation It also provides trauma care for severely injured patients across two State borders, including the wider population in the designated catchment area of SE QLD and patients injured...
in mostly regional areas of northern New South Wales (NSW). The catchment area for injury admissions includes people mostly living in the Gold Coast, where the hospital is based (68%). The remaining admissions are mostly from inner regional areas of the catchment area in both States, which is dominated by patients transferred from northern NSW (71%). The hospital does not routinely receive patients from remote or very remote locations according to standard criteria. Both States have advanced trauma services, with well-developed rural and regional referral networks.

**Participants and sampling**

Eligible adult injury cases were sourced from the Hospital’s Trauma Registry, and met the standard criteria for a major trauma event, defined by the injury mechanism, the pattern of injury and various clinical features. Eligible patients were aged over 18 years, and admitted to the Hospital for at least 24 hours, from January 2014 to December 2017. The Trauma Registry has well-defined data integrity processes that ensure data reliability and validity.

**Data collection**

**Place-related (Area level) variables**

Area level measures were developed using geocoded information about the patients’ residential address at the time of injury and Census Tract data sourced from the Australian Bureau of Statistics. The Australian Statistical Geography Standard (ASGS)\(^1\) provides a framework of statistical areas that are hierarchically organized according to population size, and thus enabling publication of data that is comparable. Statistical Area Level 1 (SA1) is the smallest building block used for many spatial analyses, representing an average of 400 people living within that Area. Area level
‘exposure’ of residential disadvantage and remoteness was assigned to everyone at the SA1 level. Figure 2 shows the AGSC Structure.

**Figure 2. The AGSC Structure for defining spatially comparable areas.**

![AGSC Structure Diagram]


**Index of Relative Socioeconomic Disadvantage**

Several community-level factors are collected during the Australian Census and summarised into an Index or Relative Social Disadvantage (IRSD).\(^2\) The IRSD was used as an area-level proxy measure for individual socio-economic status. This index is distinctly different from the remoteness measure, and depicts the relative wealth of a community, and its capacity to use its material and social resources and
participate in society. It is defined by 17 different pieces of information related to the economic and social conditions of people and households (Table 4).

**Table 4. Properties of the IRSD index**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Annual household income</strong></td>
<td>Less than $20,799</td>
</tr>
<tr>
<td>Employment</td>
<td>% Families with children under 15 years of age who live with jobless parents</td>
</tr>
<tr>
<td></td>
<td>% Employed people classified as ‘labourers’</td>
</tr>
<tr>
<td></td>
<td>% people in the labour workforce unemployed</td>
</tr>
<tr>
<td></td>
<td>% Employed people classed as machinery operators or drivers</td>
</tr>
<tr>
<td></td>
<td>% People classified as Low Skill Community and Personal Service workers</td>
</tr>
<tr>
<td>Internet connection</td>
<td>% Occupied private dwellings with no internet connection</td>
</tr>
<tr>
<td>Education</td>
<td>% people aged 15 years or over whose highest level of education is Year 11 or lower</td>
</tr>
<tr>
<td></td>
<td>% people aged 15 years and over who have no educational attainment</td>
</tr>
<tr>
<td>Household factors</td>
<td>% Occupied private dwellings paying rent less than $166/week.</td>
</tr>
<tr>
<td></td>
<td>% Occupied private dwellings with no car</td>
</tr>
<tr>
<td></td>
<td>% Occupied private dwellings requiring one or more extra bedrooms</td>
</tr>
<tr>
<td>Family structure</td>
<td>% one-parent families with dependent offspring</td>
</tr>
<tr>
<td></td>
<td>% People aged 15 or over who are separated or divorced</td>
</tr>
<tr>
<td></td>
<td>% People who do not speak English very well.</td>
</tr>
<tr>
<td>Health</td>
<td>% people aged &lt;70 who have a longer-term health condition or disability and need assistance</td>
</tr>
</tbody>
</table>

*Source: Socio-Economic Indexes for Areas (SEIFA) 2011. Canberra. ABS Catalogue no. 2033.0.55.001.*

The IRSD scores for each patient were based on the SA1 associated with their geocoded address. If street numbers were supplied, then the IRSD would be for the SA1 that spatially enclosed the coordinates for that street numbered address. If no street numbers were supplied, the IRSD would be coded for the SA1 that spatially
enclosed the coordinates for the midpoint for that street/locality. If no streets were supplied, then the IRSD code would be for the SA1 that spatially enclosed the coordinates of the locality midpoint. The IRSD scores for all SA1s were standardised to a distribution where the average equals 1000 and the standard deviation is 100. A low score indicates relatively greater rates of disadvantage in that area compared to other areas, and is characterized by many low-income families, people with little training and working in unskilled occupations. A high score indicates a relative lack of disadvantage according to these characteristics.

Figure 3 shows the methods for coding IRSD for a hypothetical patient, using resources provided by the Australian Bureau of Statistics (ABS).

Figure 3. Method for assigning IRSD scores to patients at the SA1 level

Geographical remoteness of residence

Rurality is mostly defined as ‘remoteness’, and for research purposes, is an unambiguous measure of geographical distance from major service centers. The ASGS structure was used to define remoteness of residence for the study sample. Geographic remoteness in this sense, describes the physical distance of a location from the nearest urban center, which is a proxy measure of the level of access to goods and services. For this study and the trauma catchment area, GCUH, the ‘major city’ is most likely to be the city where the Trauma Centre is located. Remoteness Areas (RAs) divide Australia and the States and Territories into 5 classes of remoteness based on their relative access to services. These RAs were derived from the Accessibility and Remoteness Index of Australia, (ARIA+)\(^1^\) ARIA+ is a continuous measure, based on road distance measurements from over 12,000 populated localities to the nearest Service Centers in five size categories based on population size. The ASGS structure defines 5 classes of remoteness by the following values: a value of ‘1’ defines Major cities of Australia, ‘2’ defines Inner Regional Australia, ‘3’ is Outer regional Australia, ‘4’ is Remote Australia and ‘5’ defines ‘Very Remote Australia. See Figure 4.
Figure 4. Remoteness categories for Australia

![Map of Australia showing remoteness categories]

Relative access to 5 different categories of services, defined for 12000 localities by the Accessibility and Remoteness Index of Australia …ARIA+

Figure 5 shows how the patients were grouped into RA categories

Figure 5. Method for grouping patients into remoteness categories at SA1 level

![Diagram showing the grouping process]

Increasing population size within Statistical Areas (SA)

IRSD score for each patient was assigned at this level
**Geographical location of injury site**

Postcode of injury location was used to create two variables, one describing the State in which the injury occurred (NSW or QLD) and the other describing the ASGS remoteness categories, (RA) as described above.

**First provider**

Details of the first hospital provider after the injury were recorded, as some patients were initially treated at a regional hospital before being transferred to definitive tertiary Trauma care.

**Individual patient factors**

Individual patient covariates for the study’s hypothesis included age, sex, injury severity and injury mechanism, number of comorbidities, and anatomical region of injury. Injuries were classified according to the Abbreviated Injury Scale (AIS)\(^{13}\)\(^{13}\)\(^{13}\) and injury severity was defined using the Injury Severity Score (ISS), an ordinal scale ranging from 1 to 75, reflecting the sum of the highest AIS scores for the three most severely injured body regions.

Information about the manner of injury was obtained from the Registry, which coded external causes of injury according to standard ICD 10 classifications, defined by the World Health Organisation. These include injury mechanisms (for example, motor vehicle, falls, self inflicted, assault), manner of injury (unintentional/self inflicted, assault, undetermined) and place of occurrence (for example, playground), and codes for causes of external injury. The mechanism of injury and number of comorbidities were derived from standard ICD-10 codes. Injury mechanism was divided into 4 groups detailing injuries caused by transport, falls, ‘other external causes’ and intentional causes. Details of the first hospital provider after the injury
were recorded, as some patients were initially treated at another hospital before being transferred to definitive tertiary Trauma care.

**Procedure and Ethics**

The study received full Ethics approval from the Human Research Ethics Committees of the Tertiary Hospital Trauma Registry, the affiliated University and the Public Health Act, from the Queensland Government (HREC/QGC/256).

**Data management**

Trauma Registry Staff were consulted about data items and definitions. The data set was explored for outlying variables, of which there were none. The Geocoding Company was consulted regarding the methods for assigning coordinates to the patients’ residential addresses. The patients were categorized into four groups, by their IRSD scores. Hence quartiles of relative socioeconomic disadvantage were defined, such that each quartile contained about 25% of the total patient population. IRSD was defined as an ordinal variable with 1-4 categories, ranging respectively from most to least disadvantaged. Comorbidity was defined according to the number of co-existing conditions according to standard ICD 10 codes. This was condensed into an ordinal variable consisting of three categories (no, 1 and <=2 comorbidities).

There were small numbers of cases in Remoteness categories 3,4 and 5 (N=26), hence these were combined with category 2. As this Trauma Centre does not receive patients from remote or very remote locations, the study population therefore offers a unique perspective of the role of rurality rather than remoteness on patient morbidity and mortality. Other variables were condensed to simplify analyses and enable a more meaningful clinical interpretation of the data output: age was
categorized into for groups, and the First Provider status was assigned as either ‘GCUH’ or ‘Regional/other’.

Table 5 shows the variables used in the bivariate and multivariate analyses

Table 5. Data item definitions for Study 2

<table>
<thead>
<tr>
<th>Variable</th>
<th>Type of Variable</th>
<th>Level of Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient variables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Confounding</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Gender</td>
<td>Confounding</td>
<td>Nominal</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>Confounding</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Injury severity</td>
<td>Confounder</td>
<td>Continuous</td>
</tr>
<tr>
<td>Ecological variables (‘Place’)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative socioeconomic disadvantage</td>
<td>Independent</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Remoteness (injury location)</td>
<td>Independent</td>
<td>Ordinal</td>
</tr>
<tr>
<td>First provider</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td>State of Injury</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td>Remoteness (residence)</td>
<td>Dependent</td>
<td>Ordinal</td>
</tr>
</tbody>
</table>

*Statistical analysis*

SPSS statistical software (IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp) was used for this analysis.

Exploratory analysis firstly determined the patients’ age, sex, and injury characteristics and area-level socio-demographic (IRSD) and geographical variables. Categorical variables were summarised using counts and percentages; continuous variables were described according to means and standard deviations (SD). For the bivariate analyses, independent t-tests were used where the variables were normally distributed. Chi-square ($\chi^2$) statistics were used to compare categorical variables. Where the variables were not normally distributed, non-parametric methods were used (Kruskall Wallis H Test, Mann Whitney U Test) and median values reported.
Binary logistic regression was performed to determine the relative odds (adjusted for age and sex) of sustaining injury based on remoteness of residence, injury, referring hospital and State of injury, where, for each factor, IRSD was the main explanatory variable. Similarly, multiple regression analyses were performed to evaluate the relationship between IRSD and the following dependent variables: the number of comorbidities and ISS, NISS. For each analysis, IRSD was forced into the model to help determine the relationship between IRSD, remoteness and patient and injury factors.

**Study 3**

This study aimed to evaluate the independent effects of neighborhood relative socioeconomic disadvantage and remoteness of residence on morbidity and mortality outcomes for severe, acutely injured adult inpatients.

**Hypothesis**

That dimensions of ‘place’ of residence defined by neighborhood socioeconomic disadvantage and remoteness independently predict hospital outcomes for severely injured, hospitalized patients in a Level 1 Trauma Centre, independently of patient factors such as age, injury severity and comorbidity.

**Research Design**

This study was a retrospective cohort study of adult injury cases hospitalised for >24 hours, in a Level 1 Trauma Centre in Australia, where the date of hospitalisation occurred any time after January 01 2014 and before December 31, 2017. The study used the same data set that addressed Hypothesis 2, Study 2, and most of the details about the study participants and the data sources are as for Study 2 unless otherwise specified.
Study Setting

See description for Study 2

Participants and Sampling.

See description for Study 2

Data Collection

See full description for Study 2 regarding the standard data items for analysis. Additional data items used for this analysis are described below. Additional patient covariates for this study included Glasgow Coma Score (GCS), discharge disposition for trauma survivors (home, or rehabilitation) and anatomical region of injury defined by the Abbreviated Injury Scale (AIS). Polytrauma was defined as AIS >2 in 2 or more AIS regions.

Outcome variables

The two outcomes for this study were death in hospital and the number of days spent receiving acute care, for patients who survived to hospital discharge. The acute length of stay days (ALSD) was coded according to standard criteria (https://meteor.aihw.gov.au/content/index.phtml/itemId/181162). In the injury context, ALSD represents care that provides definitive treatment of the injury, relieves symptoms or severity and protects against exacerbations or complications that are life threatening. It also includes surgical, diagnostic or therapeutic procedures. ALSD was the preferred measure of morbidity compared to hospital length of stay, as it excludes time spent in hospital receiving other forms of care such as rehabilitation, palliative care or mental health care, which could produce spuriously inflated estimates of time spent receiving trauma care.
**Procedure and Ethics**

As for Study 2.

**Data Management**

Data management for all data items was the same as described for Study 2.

For injury severity, a dichotomised measure was produced because of the relatively small number of deaths in the sample. A receiver operator curve (ROC) was plotted, based on the non-parametric distribution assumption, as values are non-normally distributed. Each measure of injury severity was plotted against hospital mortality status. The cut-off point for each measure was defined as the point that maximized the true positive rate of the statistical model whilst minimising the false positive rate. The Area under the Curve (AUC) for ISS was 78.6%, (95% CI 0.72.9-0.84.2, (p<0.001)).

As the numbers of patients in some of the categories for ‘injury mechanism’ were very small, the categories they were condensed in bivariate and multivariate analysis to prevent patient identification.

Table 6 shows the variables used in the bivariate and multivariate analyses.
Table 6. Data item definitions for Study 3.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Type of Variable</th>
<th>Level of Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient and Injury characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Confounding</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Gender</td>
<td>Confounding</td>
<td>Nominal</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>Confounding</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Injury severity</td>
<td>Confounder</td>
<td>Continuous</td>
</tr>
<tr>
<td>Injury mechanism</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td>AIS Region</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td>Glasgow Coma Score (GCS)</td>
<td>Confounder</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Discharge disposition</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td><strong>Area-level variables (Ecological)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First provider</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td>State of Injury</td>
<td>Confounder</td>
<td>Nominal</td>
</tr>
<tr>
<td>Relative socioeconomic disadvantage</td>
<td>Independent</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Remoteness (injury location)</td>
<td>Independent</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Remoteness (residence)</td>
<td>Independent</td>
<td>Ordinal</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute Length of Stay Days</td>
<td>Dependent</td>
<td>Continuous</td>
</tr>
<tr>
<td>In hospital mortality&gt;24 hours</td>
<td>Dependent</td>
<td>Nominal</td>
</tr>
</tbody>
</table>

**Statistical Analysis**

SPSS statistical software (IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp) was used for this analysis.

For the bivariate analysis of ALSD, Chi-square ($\chi^2$) statistics were used to compare categorical variables. Where continuous variables were not normally distributed, non-parametric methods (Mann-Whitney U Tests, and Kruskall Wallis Tests) were used, and the median values with their associated inter-quartile ranges were compared and the p values are reported.
All but one of the patients died whilst in the acute phase of trauma care. For these patients, it was possible to examine survival time according to length of acute stay days and association with covariates, and the main explanatory factors of interest, relative disadvantage and remoteness of residence. For the mortality bivariate analysis, Kaplan Meier estimates were plotted for each independent (factor) variable, to describe the cumulative proportion of deaths and the median time to death for the study sample. The graphical output was examined visually to determine whether any factor violated the proportional hazards assumption. The Log Rank statistic was used to identify statistically significant differences between the groups. Patients were censored if they did not die during the acute phase of hospital care.

To determine how aspects of a neighborhood independently affect trauma outcome, regression models were used to examine the relative contribution of neighborhood patient factors responsible for both outcomes. For the morbidity outcome, a negative binomial regression analysis was performed to predict the number of acute stay days based on the main explanatory factors, relative socioeconomic disadvantage and remoteness of residence, with confounding factors. Variables were included into the models if they were deemed to be clinically important confounders, or if p values were statistically significant in the bivariate analysis at p<0.10. IRSD and RA variables were included into the models regardless of the significance level. People who lived in rural areas were highly more likely to be injured in rural areas and therefore the decision to include place of residence or place of injury in the final multivariate models (for both outcomes) was made based on the statistical results from the ‘goodness of fit’ in the model.

The final model was built by entering the covariates were entered one at time to assess the relationship between confounders and ALSD. This enabled step-by-step
assessment of the goodness of fit of the model, the statistical significance of the
covariate in the model, and the presence of correlating variables. The fit of the models
was assessed using the Pearson Chi Squared Goodness of Fit and the likelihood ratio
Chi Squared statistic. Following specification of the confounder model the main
explanatory variables, IRSD and RA were entered into the model. The exponentiated
values, \( \exp (b_i) \) or rate ratios of the co-efficient estimates with their 95% confidence
intervals are reported as the main effect estimates, rate ratios. They are interpreted as:
RR=1: no effect, RR<1 reduction in risk: RR >1: increase in risk.

Multivariate modeling of mortality was approached in two ways. Firstly,
multilevel analysis was conducted to investigate the effects of spatial areas on
mortality, independently of patient factors. Variables identified as important from the
bivariate analyses were incorporated in a multi-level regression model. The individual
trauma patient data were defined as Level 1, nested within the spatial units of analyses
(Level 2) which was defined as SA4, or Statistical Local Areas 4. Random effect
terms were used to account for correlation of individuals nested within the same
spatial group.

Analysis of area did not show statistically significant, independent
neighborhood effects on mortality. As the precision of multi-level modeling is highly
dependent on the number of outcomes and ecological units for analysis, \(^{15}\) we then
performed Cox Proportional Hazards Regression multivariate analyses. For this
analysis each factor was added, one at a time, as described above, to examine its
contribution to the model and to determine the best final model for risk of death.
Contributing predictors to the model were determined by successive Chi Square
changes from previous steps between the -2 log-likelihood of the model, and the
statistical significance (p value) being as <0.05. Variables were excluded if the significance in the change was >0.10.

The results are reported in the same way as for the bivariate analysis. The hazard ratios (HR), defined in the models by the exponentiated values of the coefficient estimates $\exp(b)$ were produced for each covariate. HR are interpreted as the predicted change in the hazard for a unit increase in the predictor and are interpreted as for Rate Ratios above. Results are reported with their respective 95% intervals.

**Study 4**

The aim of this study was to quantify changes in caregiver resilience, quality of life and socio-ecological factors during the acute phase of caring for patients with severe traumatic musculoskeletal injuries, and to evaluate the independent role of a standard, valid resilience metric on caregiver burden and caregivers’ quality of life, as well as patient’s quality of life.

**Hypotheses**

That, in a prospective cohort study sample of informal caregivers of patients with severe multiple musculoskeletal traumatic injuries:

- Caregiver resilience (personal qualities and socio-ecological factors) is significantly decreased from baseline;
- Caregiver resilience is independently protective of caregiver burden;
- Caregiver resilience is independently and positively associated with physical and mental function; and
- Caregiver resilience is independently and positively associated with patient physical and mental health function.
**Research Design**

A prospective repeated measures cohort design was chosen to evaluate the temporal aspect of resilient adaptation. A prospective design is the preferred option to a retrospective design as exposure measures are collected before the outcomes of interest occur, thereby minimizing measurement/observer biases. This design also enables more choice and control over the type of information collected and can more effectively assess changes in exposures over time, and relationships of these changes to the outcomes of interest.

For this study, patients and their primary informal caregivers were recruited. Ecological systems theories emphasize the importance of understanding interactions and synergies between individuals or groups. For this study, such relationships are best-examined using patient and carer dyads. Methodological information on the longitudinal study of dyads is sparse, however a systematic review of the evidence for caregiver interventions recommended a study framework supporting the dyad approach. This information has guided decisions about the design of this study.

Baseline data was collected from patient and caregiver dyads at the time of hospital discharge. Follow up data was collected three months after hospital discharge.

**Study Setting**

The study was set in the GCUH. Participants were followed up in the community, 3 months after the patients were discharged from hospital. Recruitment was conducted over a 12-month period, commencing in January 2018 and follow up of participants ended in March 2019.
Study Participants

The participants were patient-caregiver dyads.

Informal Caregivers:

Caregivers were defined as the primary adult caregivers of eligible adult patients aged between 18 and 80 admitted to the GCUH between December 2017 and December 2018.

Eligible caregivers were:

- Self-identified, by both the patient (defined as eligible according to criteria below) and the caregiver to be the main person active in supporting and facilitating care of the patient’s rehabilitation;
- Over 18 and residents of Australia;
- Able to complete a paper survey form, or is willing to give consent for another to complete the form for them;
- Living with or near the patient in the study catchment area;
- Planning to reside in the same geographic area near the patient for at least 6 months;
- Competent in English; and
- Not cognitively impaired.

Eligibility patients were:

- Admitted for traumatic injuries to at least 2 any of the six body regions defined by the Abbreviated Injury Scale (AIS) (head and neck, face, thorax, abdomen, extremities, external and other) that did not include a clinically diagnosed moderate to severe brain injury or spinal cord injury
• Survived to be discharged home, from the GCUH or an associated rehabilitation facility from 2 January December 2018;
• Aged 18-80 years and Australian residents;
• Absent of Post-Traumatic Amnesia (assessed by Occupational Therapist using standard assessment protocols (for example the Westmead Post-Traumatic Amnesia Scale);
• Cognitively competent; and
• Able to complete a paper survey form, or willing to give consent for another to complete the form on their behalf.

Patients were excluded if they remained an inpatient for >24 hours for a condition that was not related to the acute treatment of injury, had delayed admission, greater than 7 days after injury. Injuries caused by hanging, poisoning or drug ingestion that was not related to physical injury were excluded, as were injuries secondary to medical procedures, isolated neck of femur fracture, pathology directly resulting in isolated injury. *(Informed by the Bi-National Trauma Minimum Dataset for Australia and New Zealand, Version 1.31, August 2013. Steering Committee Bi-National Trauma Minimum dataset for Australia and New Zealand).*

**Recruitment and Follow Up procedures**

Recruitment occurred during hospitalization, after the acute phase of care and shortly before discharge. Potentially eligible patients were identified using the hospital’s electronic data systems (EMR, TRIS) and the clinical notes. Advice from clinical, trauma registry and allied health staff was also sought for advice on eligibility. The approach to patients and caregivers was determined following consultation with the Trauma Social Worker and the Hospital’s Ethics Committee.
Once patient eligibility was confirmed in hospital, a process was initiated to identify the caregiver, and then recruit both the caregiver and patient to the study.

The proposed recruitment procedure is outlined as follows. Eligible patients were then approached to participate in the study after the acute phase of injury care, shortly before discharge from hospital. Consenting patients were, at this point, asked for contact details of their primary care giver. The meetings with the caregiver and the patient to discuss the study and obtain informed consent were conducted separately to avoid any potential unintended coercion. At these meetings the study’s aims and procedures were explained in detail. Separate Information Sheets were given to the caregiver and patient.

Face to face interviews were conducted shortly before the patient was discharged home or soon after discharge. In the event of caregiver distress, a referral plan for caregivers was developed with input from the Hospital’s Social Work Department.

Study participants were followed up approximately three months after discharge from hospital or rehabilitation. Participants were contacted by phone email, or by mail. Up to five attempts were be made to contact the participants, either by mail or phone before assigning them lost to follow up.

**Data Collection**

The questionnaires for both members of the dyad included items about the pre-injury/pre-caregiving period and demographic details (age, sex, marital status, occupation, household income, and educational level). Information about dispositional resilience and health related quality of life was collected, where the reference point was the ‘four-week period prior to the injury’.
Patients were additionally asked about intentions to return to work, and level of optimism about recovery. Patient data relating to the injury severity and mechanism, hospital length of stay and comorbidity, was collected from electronic medical records and the Hospital’s Trauma Registry.

The caregiver baseline interview schedule included additional questions about pre-injury health conditions, self-efficacy, coping, family resilience, community support, expectations of their caring role, health behaviors (physical activity, smoking, alcohol intake), health service use (GP, Hospital outpatients visits, hospital stay night, Emergency Department visits).

Follow-up questionnaires were posted (with a reply-paid envelope) to participants approximately three months after discharge. A small number of participants preferred email contact. This was followed up by phone-calls. At follow-up patients and caregivers were asked again, about resilience and quality of life. They were additionally asked about levels of satisfaction in several primary health services, use of health services and work status. Caregivers were additionally asked about caregiver burden, satisfaction with primary health care services whilst caregiving, and perceived work support. The reference point for all participants was ‘during the period you were cared for/were a caregiver’.

Materials

Socio-demographic and health related factors

Participants were asked standard socio-demographic questions about their age, sex, living situation, work status, household income, highest educational level and area of residence. They were also asked about past illnesses, health behaviors (physical activity, smoking and alcohol intake) and health service use and the extent to which primary health care services met their needs, at follow up. Question items
were sourced, where possible, from the Census of Population and Housing (Australia) and standard survey items.

Patient injuries were classified according to the Abbreviated Injury Scale\textsuperscript{13} that codes injuries according to their anatomic location (head or neck, face, chest, abdominal or pelvic contents, extremities or pelvic girdle and external) and assigns a severity score from 1-6, based on the probability of death or disability. Injuries >2 are classified as ‘severe’. Injury severity was examined using the Injury Severity Score (ISS), an ordinal scale ranging from 1 to 75, reflecting the sum of the highest AIS scores for the three most severely injured body regions. Pre-injury patient comorbidity was assessed by the American Society of Anesthesiologists classification (ASA) system.\textsuperscript{16}

\textbf{Resilience}

The Connor Davidson Psychometric Scale, (CD-RISC 10)\textsuperscript{17} was used to measure personal resilience. The CD-RISC 10 is a 10-item, validated abbreviated version of the full 25-item instrument, the CD-RISC 25.\textsuperscript{18} The CD-RISC 10 is reportedly one of only a few resilience scales deemed to be psychometrically robust for research purposes.\textsuperscript{19} The CD-RISC 10 is widely used, and has been validated in many community and clinical settings\textsuperscript{17,20} including trauma patients. It measures, on a five-point scale ranging from 0 to 4, five main factors relating to personal competence, tenacity, trust and tolerance and the strengthening effects of stress, positive acceptance of change, secure relationships, and emotional control. A typical question item asks: “I am able to adapt to change” and “I think of myself as a strong person”. The CD-RISC 10 is used in repeated measures research designs because of its capacity to capture changes in resilience over time.\textsuperscript{18,21}
For this study, internal reliability analysis yielded Cronbach’s Alpha scores for the CD-RISC 10 of 0.88. The Pearson correlation coefficient for test and re-test reliability was 0.65 (p<0.001) and concurrent validity with self-efficacy was demonstrated with a correlation coefficients of 0.70 (p<0.001) at baseline and 0.83 (p<0.001) at follow up.

**Self-efficacy**

Self-efficacy is correlated with health promoting behaviors, medication adherence, active forms of coping and physical activity and emotional and social functioning. The General Self Efficacy (GSE) Scale 22 was used to measure self-efficacy which characterises caregivers’ belief in their competence to tolerate, cope with and mobilise resources to meet a broad range of stressful or challenging demands. 23,24 The GSE is a 10-item scale with responses ranging from 1-4, where the range of total scores are from 10-40, where the higher the score the higher the level of self-efficacy. Population norms for the scale do not appear to exist in Australia but have been reported in US-American Adult Populations to be 29.5 (SD 5.13). A typical item in the scale is: “*If someone opposes me, I can usually find the means and ways to get what I want*” and “*I am confident I can deal efficiently with unexpected events*”.

The GSE scale has is psychometrically sound 25 and has been shown in meta-analyses to be correlated with a number of domains of human functioning, namely optimism 26,27 emotional and physical health, and health behaviors.28 For our study, the Cronbach’s alpha score for internal reliability of self-efficacy was 0.88.

**Family Resilience and Social Support**

Family resilience was measured suing the Family Hardiness Index (FHI).29 Family hardiness refers to the internal strengths and durability of the family unit and
characterizes a family’s sense of control over their lives, commitment to family, and confidence that the family will survive no matter what.\textsuperscript{30} The FHI conceptualizes family resilience as a form of stress resistance and adaptation resource in families, thereby incorporating the fundamental elements of resilience, adjustment and adaptation. A typical item asks: “\textit{We believe that things can work out if we can work together as a family}”. Caregivers were asked from a selection of questions, the degree to which each statement describes their current family situation (False, Mostly False, Mostly True, True).

Social support was measured using the Social Support Index,\textsuperscript{31} which describes the degree to which families find support in their communities. The instrument uses a five-point Likert Scale to measure ways in which the community can provide emotional, esteem and network support. A typical question asks: “\textit{People can depend on each other in this community}”. Internal reliability Cronbach’s alpha scores for family resilience and social support were, respectively 0.94 and 0.84.

**Caregiver strain**

The Modified Caregiver Strain Index (MCSI)\textsuperscript{32} was used to evaluate caregiver strain in family caregivers. The MCSI is a 13-item tool, containing subjective and objective elements measuring strain related to care provision. While it has been largely used for caregivers of older people, it was chosen for this study, because it was brief and easy for responders to complete. Items cover subjective and objective components in financial, physical, psychological, social and personal domains. Scoring is for a ‘Yes’ response (2 points), and a ‘Sometimes’ response (1 point) or 0 for ‘No’. Higher scores indicate higher levels of strain. Test-retest reliability date indicate high levels of reliability.\textsuperscript{32}

**Quality of life**
The Short-Form version 12 Survey tool was used to measure health related quality of life. The SF-12 is brief, comprehensive and psychometrically sound with demonstrated utility for measuring health status in a wide range of population groups, including trauma populations. Summary scores of physical function and mental health function were computed from eight domains measuring functional health and wellbeing. Scores range from 0 (lowest) to 100 (highest). Summary scores are based on a mean of 50 and a standard deviation of 10. There is a vast array of evidence reporting strong reliability and validity of the SF-12.

**Satisfaction with primary health care services**

At follow up, caregivers were asked if they visited any community health care (CHC) services: (General Practitioners, Specialist surgeon, physiotherapist, occupational therapist, psychologist, social workers, community nurse, dietician) and to rate, using a Visual Analogue scale from 1-10 their level of satisfaction with the service. Satisfaction was defined in terms of the extent to which the service responded to, and met their needs as a caregiver.

**Supportive work environment**

A six point Likert Scale measured the extent to which caregivers who were working, felt supported by their supervisors and work colleagues, whilst being a caregiver. Support was defined subjectively, according to ‘perceived support’ and by more objective measures including financial assistance, presence of supportive services (child care, counseling) and educational or training resources at the work site. Table 7 shows the data items that were collected and Table 8 shows the time points for collection.
Table 7. Main Data Items and measurement instruments for Patients and Caregivers

<table>
<thead>
<tr>
<th>Broad description of the Data Item</th>
<th>Data Details</th>
<th>Source of data</th>
<th>Reliability and Validity</th>
</tr>
</thead>
</table>
| Patient demographic factors at time of injury | Date of birth  
Gender  
Address, including postcode of residence and residential address  
Marital status  
Living circumstances  
Income  
Education | TRIS  
Supplemented by study participant where necessary with Questionnaire using standard survey items *(National Health Survey (NHS)) | Standard survey items |
| Injury and hospitalization details | Date of injury  
Place of injury  
Injury mechanism  
ISS Score  
NISS score  
GCS  
Polytrauma – number of body regions affected  
Comorbidity pre injury  
Length of Stay in Hospital  
ICU admission (days in ICU)  
Post–injury complications  
Date of discharge | Trauma Registry/Electronic Medical records | N/A |
<table>
<thead>
<tr>
<th>Quality of life (physical and mental function) - Pre-Injury</th>
<th>Comorbidity</th>
<th>Study participant (Questionnaire)</th>
<th>Strong Content and construct validity ( r=0.7 ) for the PCS and MCS compared to similar components in the Sickness Impact Profile Questionnaire. (Gosling et al 2011) for long term (6m) outcomes in orthopaedic traumatic injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment factors</td>
<td>Occupation at time of injury</td>
<td>Study participant (Questionnaire) Standard NHS items</td>
<td>The Revised work questions Cronbach’s alpha 0.69. (Jing Sun)</td>
</tr>
<tr>
<td>Intention to return to work (3 questions)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of work pre injury</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compensation status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work status at 12 months: delayed, sustained, non-sustained, sustained ‘off-work’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of first return to work after injury/type of work/Type of work (same/modified)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subsequent attempts to return?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Intention to RTW questions (LIKERT Scale):</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction with Rehabilitation support, primary health care</td>
<td>Type, duration, number of visits over 12 months</td>
<td>Study participant (Questionnaire) N/A</td>
<td>Visual Analog Scale: 1-10</td>
</tr>
<tr>
<td>Perceived quality – unmet needs</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Resilience | Connor Davidson Resilience Scale | CD-RISC-10 10 items – focused on hardiness and persistence items from the full CD RISC 25 item scale. Seen to reflect one latent factor of ‘resilience; Davidson JRT and Connor KM. Connor-Davidson Resilience Scale (CD-RISC) Manual. Unpublished. 06-01-2017 and partly accessible at www.cd-risc.com | Scale has performed well in many different populations
Chronbach’s alpha scores have been reported in clinical patients and in the general population as 0.88 and 0.89, respectively. The CD-RISC has been compared to numerous other measures that in one way or another are related to aspects of resilience, such as hardiness, social support, stress coping ability, self-esteem, life satisfaction, successful aging, positive and negative affect. Construct validity: moderating or mediating effects of resilience have been predicted and demonstrated with respect to associations between early adversity and outcomes like depression and suicide attempt, with the CD-RISC 10. An increase of 5 points on the CD-RISC 10 was associated with a decrease of 2.5 points on the Beck Depression Inventory (BDI2013), and Construct validity is supported by positive correlations with the Sense of Coherence scale and negatively correlations with the Hopkins Symptoms Checklist Scale |
<table>
<thead>
<tr>
<th>Information to be collected</th>
<th>Data Details</th>
<th>Data source</th>
<th>Reliability and Validity</th>
</tr>
</thead>
</table>
| **Socio-demographic details** | Name  
Date of birth  
Gender  
Education  
Relationship to patient  
Area of residence – changes in last 12 months  
Living circumstances – changes in last 12 months  
Income – changes in last 12 months  
Relationship status – changes in last 12 months | Study participant (Questionnaire) using  
Standard survey items (National Health Survey (NHS)) where possible. | N/A |
| **Physical health status/comorbidity** | Changes during period of caregiving:  
Existing and newly diagnosed conditions  
When? | Study participant (Questionnaire) using Standard survey items (National Health Survey (NHS)) where possible | N/A |
| **Occupation** | At start of caregiving: Type of work, Full time/ part time, Self-employed or not  
Changes in last 12 months – When?  
Supportive work environment? | Study participant (Questionnaire) using  
Standard survey items (National Health Survey (NHS)) where possible | N/A |
<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
<th>Methodology</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement with health services, during period of caregiving</td>
<td>Changes in visits: GP, hospital visits, allied health visits, complementary health practitioners</td>
<td>Study participant (Questionnaire) using Standard survey items (National Health Survey (NHS)) where possible</td>
<td>N/A</td>
</tr>
<tr>
<td>Health behaviors during period of caregiving</td>
<td>Changes in: Smoking, alcohol intake, physical activity</td>
<td>Study participant (Questionnaire) using Standard survey items (National Health Survey (NHS)) where possible</td>
<td>N/A</td>
</tr>
</tbody>
</table>
| Caregiving role                               | Expectations of role  
Reason for taking it on  
Type of assistance provided  
Average hours/week spent caring for patient  
Duration of caregiving (days/months) – when did it start/stop? | Study participant (Questionnaire) Standard ABS data items 4430.0 - Disability, Ageing and Caregivers, Australia: Summary of Findings, 2015 | N/A   |
| Caregiver burden                             | Modified Caregiver Strain Index | Study participant (Questionnaire)  
13 questions  
Thornton, M. and Travis, S. S. (2003). "Analysis of the reliability of the modified caregiver strain index." J Gerontol B Psychol Sci Soc Sci 58(2): S127-132 | Internal consistency reliability is high (alpha = 0.86) and construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation. |
| Quality of life                               | Study participant (Questionnaire) SF-12  
Mental and physical functioning and overall health-related-quality of life | As for patients (above) | As for patients (see above) |
<table>
<thead>
<tr>
<th>Resilience</th>
<th>Connor Davidson Resilience Scale CD-RISC-10</th>
<th>As for patients (above)</th>
<th>As for patients (above)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workplace support</td>
<td>Supportive work environment</td>
<td>Six Point Likert Scale.</td>
<td>N/A</td>
</tr>
<tr>
<td>Family Resilience</td>
<td>Family Hardiness Index –</td>
<td>20 items</td>
<td>Overall reliability is 0.82</td>
</tr>
<tr>
<td></td>
<td>Questions: (3,5,6,7,9,11,13,15,17,18)</td>
<td></td>
<td>Test-retest reliability is 0.86</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Concurrent Validity: Statistically significant associations demonstrated between FHI and measures of family flexibility, Family time and routines, and Quality of Family Life Internal consistency is satisfactory ($\alpha = .65–.82$) and temporal stability is strong ($r = .86$) (FHI Resources, unpublished, from Authours) Test internal reliability and construct validity of revised questionnaire</td>
</tr>
<tr>
<td>Self Efficacy</td>
<td>General Self Efficacy Scale GSE</td>
<td>Schwarzer, R., &amp; Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J.Weinman, S. Wright, &amp; M. Johnston, Measures in health psychology: A user’s portfolio. Causal and control beliefs (pp. 35-37). Windsor, UK: Cronbach’s alphas ranged from .76 to .90, with the majority in the high .80s. The scale is one-dimensional. Criterion-related validity is documented in numerous correlation studies where positive coefficients were found with favorable emotions, dispositional optimism, and work satisfaction.</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>Social Support Index (SSI)</td>
<td>McCubbin, H.I., Patterson, J., &amp; Overall reliability - Cronbach’s alpha is</td>
<td></td>
</tr>
<tr>
<td><strong>Questions</strong></td>
<td>Questions (1,4,5,6,8,11,15,16)</td>
<td><strong>Glynn, T. (1982). Social Support Index (SSI). In H.I. McCubbin, A.I. Thompson, &amp; M.A. McCubbin (Eds., 1996), Family assessment: Resiliency, coping and adaptation-Inventories for research and practice (pp. 357-389). Madison, WI: University of Wisconsin System</strong></td>
<td>0.82</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Satisfaction with Rehabilitation support, primary health care</strong></td>
<td>Type, duration, number of visits over 12 months, Perceived quality – unmet needs</td>
<td>Study participant (Questionnaire)</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>As for patients</td>
</tr>
</tbody>
</table>
Table 8. Questionnaire items for dyad participants, at baseline and at follow up

<table>
<thead>
<tr>
<th></th>
<th>Patient Baseline</th>
<th>Patient Follow up</th>
<th>Caregiver Baseline</th>
<th>Caregiver Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic factors</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Resilience</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Self Efficacy</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Family Resilience</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Community support</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Quality of life</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Optimistic about future</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Return to work</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Health behaviors (physical activity, smoking, alcohol intake)</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Health service use</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Satisfaction with Primary Health care</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

**Data Management**

A database was developed in SPSS for all phases of data collection for caregivers and patients. Data were coded numerically with coding descriptions entered into the database. A random sample of data was coded and entered to check
the validity of data entry. Exploratory analyses using the ‘Frequencies’ command were conducted to determine missing data, outliers and data distributions. Categorization of continuous variables was done to inform clinical interpretation of data and facilitate statistical analysis. This was also only done where categories were considered standard and valid. Decisions about the number of categories was guided by the number of patients in cells and the need to prevent patient identification.

The following table (Table 9) shows how the variables were defined.

**Table 9. Data item definitions for Study 4**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Type of Variable</th>
<th>Level of Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Confounding</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Occupation</td>
<td>Confounding</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Income</td>
<td>Confounder</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>Confounder</td>
<td>Ordinal</td>
</tr>
<tr>
<td>Physical activity</td>
<td>Confounder</td>
<td>Continuous</td>
</tr>
<tr>
<td>Alcohol intake (drinks/wk)</td>
<td>Confounder</td>
<td>Continuous</td>
</tr>
<tr>
<td>Patient injury severity</td>
<td>Confounder</td>
<td>Continuous</td>
</tr>
<tr>
<td>Patient Quality of life (SF-12) PCS and MCS</td>
<td>Confounder</td>
<td>Continuous</td>
</tr>
<tr>
<td>Resilience</td>
<td>Independent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Independent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Family resilience</td>
<td>Independent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Community support</td>
<td>Independent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Community health support</td>
<td>Independent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Health service use</td>
<td>Independent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Quality of life (SF-12) PCS and MCS</td>
<td>Dependent</td>
<td>Continuous</td>
</tr>
<tr>
<td>Caregiver Strain</td>
<td>Dependent</td>
<td>Continuous</td>
</tr>
</tbody>
</table>
**Statistical analysis**

SPSS statistical software (IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp) was used for this analysis. The estimated sample size for the study was 95 dyads. Sample size calculations were based on an estimated p value of 0.05, Power of 0.8, effect size for SF-12 PCS and MCS of 0.46, a 2-tailed hypothesis and an attrition rate of 12%.

Norm-based scores are reported for the summary physical and mental component scores of the SF-12. The caregiver sample at baseline was characterized using descriptive statistical analyses using means, standard deviations (SD) for normally distributed data, and medians and interquartile ranges (IQR) for non-parametric distributions, and percentages for categorical variables.

Regression analyses were used to determine bivariate associations between independent variables, (age, income, education, rurality, pre-injury conditions health behaviors, individual and family resilience, and social support) with outcome variables, CSI and the physical and mental health components of the SF-12. Paired sample T Tests was used to determine the mean differences from baseline to follow up in caregiver resilience, quality of life, self-efficacy, family resilience and social support, health service use and health behaviors.

Multiple regression analyses were performed to examine the independent effect of caregiver factors with the outcomes of interest. All tests were two-tailed and statistical significance was set at p<0.05.

**Procedure and Ethics**

The study received full Ethics approval from the Human Research Ethics Committees of the Tertiary Hospital Trauma Registry, the affiliated University and the Public Health Act, from the Queensland Government (HREC/QGC/256).
Summary

This chapter has outlined the methods used to address each hypothesis for this study of socio-ecological systems and severe trauma outcomes. A systematic review and meta-analysis was conducted to answer the question posed in Study 1, about the effectiveness of multi-dimensional resilience-based rehabilitation programs.

Studies 2 and 3, involved analysis of Trauma Registry Data to explore the relationship of neighborhood factors aligned with resilience in trauma patients, and their hospital outcomes. Geocoded residential information was used to create standard area-level neighborhood indices of relative disadvantage and remoteness of residence. These data were then linked to all individual patients represented in the Trauma Registry up to 2017. Study 2 used a cross sectional design to describe the association between aspects of ‘place’ related to relative neighborhood socio-economic disadvantage and rurality in severely injured hospitalized trauma survivors. A retrospective cohort study design was employed to investigate the relationship of contextual components of ‘place’ of residence on hospital mortality and acute length of stay days in these patients over a four-year period.

Finally, for Study 4, a prospective cohort study design was used to investigate the impact of resilience and socio-ecological factors on caregiver burden and quality of life in the informal caregivers of severe, acutely injured patients. The rationale for this study was that caregivers form an important component of the patient’s socio-ecological system, and resilience had not been studied extensively for caregivers of patients with severe musculoskeletal injuries. This study design enabled an examination of baseline ‘pre-caregiver’ factors and associations with resilience, temporal changes in resilience, socio-ecological support systems and caregiver health behaviors from baseline, and the predictive importance of resilience on caregiver
burden and quality of life. To be consistent with socio-ecological theories in relation to severe trauma recovery, patients and caregiver dyads were recruited, and families, communities and health systems support was studied in addition to resilience and the main outcome factors.
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31. McCubbin H, Patterson J, Glynn T. Social support index (SSI). HI McCubbin, AI
Thompson & MA McCubbin, Family assessment: Resiliency Coping and Adaptation-

32. Thornton M, Travis SS. Analysis of the reliability of the modified caregiver strain
index. The Journals of Gerontology Series B: Psychological Sciences and Social

33. Ware JE, Keller SD, Kosinski M. Sf-12: How to Score the Sf-12 Physical and Mental

34. Ware JE, Kosinski M, Turner-Bowker DM, Gandeck B. User's Manual for the SF-
12v2TM Health Survey:(with a Supplement Documenting SF-12 Health Survey).

35. Busija L, Pausenberger E, Haines TP, Haymes S, Buchbinder R, Osborne RH. Adult
measures of general health and health-related quality of life: Medical Outcomes Study
Short Form 36-Item (SF-36) and Short Form 12-Item (SF-12) Health Surveys,
Nottingham Health Profile (NHP), Sickness Impact Profile (SIP), Medical Outcomes
Study Short Form 6D (SF-6D), Health Utilities Index Mark 3 (HUI3), Quality of
Well-Being Scale (QWB), and Assessment of Quality of Life (AQOL). Arthritis Care
Chapter 4. Results for Study 1: The effectiveness of multi-dimensional resilience rehabilitation programs after traumatic physical injuries: a systematic review and meta-analysis.

Overview

The morbidity arising from non-fatal traumatic injuries is of public health importance, and evidence-based rehabilitation programs are required, that target injured individuals at risk for adverse rehabilitation outcomes. However the psychological and physical morbidity arising from TPI, along with the social and economic consequences, presents challenges for rehabilitation specialists. Because of its psychologically protective and positive features and amenability to modification, resilience, which is bolstered by supportive socio-ecological factors, could be promoted in rehabilitation programs to help patients adapt to their disabilities.

Despite the vast research data available on the importance of socio-ecological ecological factors for promoting health, there is a comparative lack of objective, empirical evidence as to whether, or which factors are effective in changing health behaviors or outcomes in injured patients.

This Chapter examines the effectiveness of community rehabilitation services targeting resilience after traumatic injury. A published manuscript of a systematic review and meta-analysis of rehabilitation programs targeting resilient recovery after traumatic injuries is presented. This paper attempts to addresses the methodological challenge of defining programs that target resilient recovery. As a construct, resilience has no standard form of measurement and this study attempted to adequately capture ‘resilience’ based programs in the search strategy. A very broad range of search terms was used, drawing from the published literature of known resilient qualities and contextual factors thought to promote resilience.
Outcomes were chosen based on the methodological literature for the study of resilience, which included describing resilient responses (self-efficacy, stress mitigation) and resilient outcomes, ‘better than expected’ from baseline, such as returning to work. The paper concludes with some suggestions for future research into resilience-based trauma rehabilitation programs.

**Statement of Contribution to co-authored published paper:**

This section includes a co-authored manuscript published in *Disability and Rehabilitation* as an original research paper.


The research candidate has made the following contributions to this study:

- Devised gaps in research for meta-analysis study.
- Undertook an extensive search of the literature and obtained relevant articles.
- Extracted and interpreted data for meta-analysis.
- Analysed the data and interpreted the findings.
- Prepared the manuscript and submitted to the Disability and Rehabilitation.

Signed: Jing Sun

(Supervisor and corresponding author) Jing Sun
Abstract

Objective: To synthesise evidence of the effectiveness of socio-ecological resilience rehabilitation programs on outcomes for people sustaining traumatic physical injuries. Outcomes included returning to work (RTW), self-efficacy and stress mitigation.

Methods: PubMed, Scopus, Proquest, Cinahl, Web of Science, Clinical Trials Database, and the Cochrane Central Register of Controlled Trials databases were searched. Methodological quality was assessed using the PEDro tool.

Study Selection: Randomised interventions aimed at promoting psychosocial resilience.

Data Extraction: 21 studies were retrieved and reviewed (11,904 participants). The results of 19 studies of moderate to high methodological quality were pooled using a random-effects meta-analysis. Mean differences for continuous outcomes and risk ratios for binary outcomes were calculated.

Data synthesis: Resilience rehabilitation programs significantly increased the likelihood of RTW (OR 2.09 95% CI 0.99-4.44 p=0.05), decreased the time taken to RTW (Mean difference -7.80, 95% CI -13.16 - -2.45 p=<0.001), and increased levels of self-efficacy (Mean difference 5.19, 95% CI 3.12 - 7.26 p<0.001). Favourable RTW outcomes resulted from programs involving workplace support (p<0.001) compared to programs without this support. Positive RTW outcomes were more common in people with musculoskeletal or orthopedic injuries compared with brain injuries (p=0.02).

Conclusion: Work based programs aimed at supporting resilient adaptation after injury appear to improve RTW outcomes and self-efficacy, compared to programs without these components.
**Background**

Injuries account for 300 million disability-adjusted life-years (DALYs), and represent 11% of the global burden of disease. Prospective cohort studies have documented persistent pain, impaired function depression and post-traumatic stress disorders (PTSD) reduced quality of life and work related productivity following hospital discharge for physical injuries. For people experiencing major trauma, described as an Injury Severity Score (ISS) >12, functional limitations and impaired quality of life persist for at least one year. Furthermore, there are unexplained variations in injury recovery outcomes for these people, including those with traumatic brain injuries (TBI).

Returning to work after injury is seen as important indicator of recovery and is therefore a significant goal of many injury rehabilitation programs. However, people sustaining acute traumatic injuries experience difficulties returning to work (RTW), particularly those suffering orthopaedic and musculoskeletal injuries where recovery is often prolonged. A systematic review identified numerous predictors of a longer duration of work disability compared to shorter duration after traumatic injury. These are multi-factorial and include low education levels, blue collar work, low levels of self-efficacy, and being on workers’ compensation. Inadequate supervisor and co-worker support have also been identified along with existing depression, comorbidity, number of injuries and injury type.

Underlying these patterns of injury morbidity data are unexplained variations in outcomes, where some people appear to adjust well to their physical impairments compared to others. Individual variations in resilience might be a contributing factor. Resilience is described as positive adaptation or adjustment in the face of...
adversity\textsuperscript{[19]} and is therefore perceived as a dynamic process, rather than a fixed trait.\textsuperscript{[18]} Resilience is reportedly associated with improvements in mental and physical health and well-being following spinal cord and mild TBI.\textsuperscript{[11, 19, 20]} Resilience is characterized by a number of positive individual qualities such as optimism, sense of control and coherence, self-efficacy and self-esteem.\textsuperscript{[21, 22]} Of these, self-efficacy has been empirically shown to be strongly related to resilience\textsuperscript{[23]} and could be a positive factor promoting functional recovery, work participation\textsuperscript{[24]} and quality of life.\textsuperscript{[25]} Resilience is also described according to certain skills which include ability to cope with stress, which is influenced by social support networks\textsuperscript{[26]} that are thought to moderate the effects of stress of health and adjustment to adversity.\textsuperscript{[27]} Other important resilient skills include the ability to successfully integrate with the workplace and with social and community resources.\textsuperscript{[22, 28-30]} Research evidence suggests that individual behaviour changes are unlikely to be sustained unless health programs target one or more factors in an individual’s ecological environment, consisting of biological social, economic, physical and cultural systems.\textsuperscript{[31, 32]} This model also applies to resilience promotion\textsuperscript{[33]} where supportive families and caregivers, peers and social networks, the workplace, community health services, and cultural and spiritual influences.\textsuperscript{[22, 29, 33]} are thought to enhance resilient behaviors, such as coping, social integration, stress mitigation and self-efficacy.\textsuperscript{[30, 34, 35]} For example, research shows that peer and workplace support can predict participation outcomes in people with TBI\textsuperscript{[36]} and integrating supportive relationships into the rehabilitation process can help promote resilience in patients with acquired brain injuries.\textsuperscript{[34]}

Programs aimed at fostering resilient adaptation in injured patients by targeting these social and ecological systems could promote recovery above what is normally
expected, enabling people to return to employment or to acceptable levels of productivity. These are important goals of injury rehabilitation, however resilience research in this domain is sparse.\textsuperscript{11, 37, 38} A Cochrane review of psychosocial interventions aimed at preventing physical, social and mental disabilities after injuries excluded people with TBI, and largely focused on psychological therapies and social interventions. The results of only five studies were reported, involving specific psychological therapies, self-help booklets or collaborative care models. There were inconsistent results of effectiveness and no apparent standard definition of the multi-dimensional resilience concept.\textsuperscript{39}

A systematic review and meta-analysis of resilience training programs for adults with diverse conditions, including chronic diseases, reported moderate but statistically significant improvements in depression and stress\textsuperscript{37} for the programs targeting ‘trauma-induced’ stress (SMD 0.37, 95% CI 0.18-0.57) $p=0.002$, $I^2=41\%$. A review of non-clinical adult studies found that resilience programs generally reported improvements in resilient responses.\textsuperscript{38} However most of the studies were not related to injured people, and there was substantial diversity among them with regards to the ways in which resilience was conceptualised.

There are currently no published systematic reviews and meta-analyses of the effects of these types of programs in terms of trauma rehabilitation. The aim of this study was to conduct a systematic review of the existing evidence of the effectiveness of multi-dimensional resilience promotion rehabilitation programs on resilient skills and functional outcomes (RTW) in adults following physical injuries.
**Methods**

The approach taken was based on the reporting guidelines for systematic reviews (PRISMA)\[^{40}\]. The study protocol was registered and updated at the Prospero International Prospective Register of Systematic Reviews (Registration ID CRD42016043332) website: [http://www.crd.york.ac.uk/PROSPERO](http://www.crd.york.ac.uk/PROSPERO).

**Inclusion criteria**

Eligible studies were randomised controlled trials, with a clearly defined intervention and comparison group, and prospective follow up. Interventions used one or more components of the socio-ecological resilience framework as part of the rehabilitation process following acute traumatic injury. Interventions were aimed at preventing the development of new disorders, or worsening disabilities following injuries.

Studies were excluded if they were pilot studies, quasi-experimental, case reports, case series, case control studies, cohort studies, or studies analysing non-numerical data. Studies were also excluded if patient selection was based on an existing psychological condition, if the intervention was not part of the post-discharge rehabilitation process or was treating an existing disorder other than the injury, diagnosed either before or in the immediate aftermath of the injury.

The search strategy was guided by the PICO framework\[^{41}\] described as follows:

The population was defined as adult patients aged 18-70 years, who had sustained a physical injury, presented to a hospital or clinic for acute management of the injury, and recruited to the study during the rehabilitation phase for that injury. Studies of elite athletes, or active military personnel exposed to psychological and physical trauma were excluded.

Because of the many different qualities that encompass resilience and the current lack
of a standard definition of ‘resilience training’ programs, a number of measures were taken at the design stage of the review, to minimise ambiguity. For example, the inclusion criteria for eligible interventions were informed a priori, by theoretical models described in the literature.[22, 37, 39, 42] These included interventions aimed at enhancing resilient qualities and skills in the patient, as described above, or their external support sources.[35] Interventions were required to target at least one component of the socio-ecological framework in the study design, such as the individual, their family members, primary caregivers, workplace or social support networks and community resources. Control participants were those receiving standard rehabilitation care, or who did not use any of the components in the resilience model described above.

In addition, measures were taken to minimise subjective or self-reported outcomes, which, in un-blinded trials, can lead to biased results. The primary outcome therefore consisted of two objective and recommended measures of occupational re-integration (Hou et al 2013), firstly the proportion of people who were working at the designated study follow up time point, following the injury event, and secondly as the average time in days taken to return to work following the injury event. Secondary outcomes were self-reported changes in resilient behaviors such as: changes in the mean differences of self-efficacy and stress levels.

Finally, the follow up time was restricted to 2 years after the acute injury event, thereby minimising the potential for cross-overs between groups and other long term, and unmeasured factors to contaminate the association under investigation. Where the intervention was delivered to the target patients and one or more other groups (eg family or caregiver), the outcome measures were to include at least one concurrent outcome measure of the patient.
Search methods for identification of the studies

A research librarian advised on the database searches and worked with two authors to conduct the searches. Databases were searched for relevant studies published during the past 30 years (1986-2017): PubMed, Scopus, Proquest, Cinahl, Web of Science, Clinical Trials Database, and the Cochrane Central Register of Controlled Trials (CENTRAL). No limits were placed on language. The reference lists of the identified papers were also searched.

The search strategy was broadly defined to capture the different qualities associated with resilient adaptation following injury. The key words used to search literature included: “Wounds and Injuries” AND "Resilience, Psychological” OR "Adaptation, Psychological” and “Randomised Controlled Trial”. These key words were searched in the Title and Abstract and MeSH terms were used were possible. An example of one of the search strategies, using MeSH terms is described as follows:

**Data collection and analysis**

**Selection of studies**

Potentially eligible articles were imported into an EndNote bibliographic reference management software program (EndNote X7 (Bld 11961), Copyright 1988-2016 Thomson Reuters). Duplicates were removed and the remaining abstracts were screened using pre-specified inclusion and exclusion criteria. The research team (KH, JS) met to assess and classify the abstracted papers. Articles labeled as potentially relevant were retrieved and the full text examined. Disagreement was resolved by discussing with a third reviewer (MW) wherever necessary. A pre-tested EXCEL spreadsheet form was used to extract data from the identified studies.

Data were retrieved from eligible articles as follows:

1. **Study characteristics**: year of study, study setting, demographics, nature and severity of the injury, study design and methodology, type and duration of resilience program, resilience measurement instrumentation, control or comparison group;

2. **Outcomes**: the proportion RTW, average days to return to RTW, self-efficacy, and stress.

3. **Subgroup variables**: Injury type (Spinal Cord injury (SCI), TBI and musculoskeletal or orthopedic), follow up time point (<6months, ≥6 months), socio-ecological components (social support, workplace support, community support) and resilient skills (self-efficacy and coping strategies) that were targeted in the intervention.
**Assessment of methodological quality**

The PEDro tool[43, 44] was used to classify the quality of the evidence (Supplemental Table 1).

The authors of all the original studies were contacted for missing data from the published reports. Data were received from one of these authors.

**Data analysis method**

Data from RCTs were pooled using Comprehensive Meta-analysis software (*Comprehensive Meta-analysis*. Version 2. Englewood, NJ.: Biostat, n.d. Computer software.) For continuous outcomes, mean differences and standard deviations were extracted. For dichotomous outcomes, ‘return to work’ event rates were calculated and expressed as the proportion of patients working or employed at follow up.

The results were pooled using a random-effects meta-analysis, and mean differences for continuous outcomes including average taken to return to work, self-efficacy and stress, and risk ratios for binary outcomes including return to work, along with their 95% Confidence Intervals were calculated. We calculated 95% confidence intervals and two-sided $p$ values for each outcome.

Heterogeneity for all studies was estimated based on the $I^2$ index. Low heterogeneity was defined as $I^2$ was less than 30%, moderate heterogeneity was $I^2$ was 30-49% and a high level of heterogeneity, was $I^2$ was 50% or more.

Subgroup analyses were performed to investigate heterogeneity across the different program components for the ‘RTW’ outcome. These subgroup factors focused on types of program components fostering resilience, follow up time points, and injury types. Sensitivity analyses were conducted to assess whether statistically significant
results were due to a particular study, or studies. Publication bias was assessed using Egger Regression Analytical techniques.[45]

**Results**

Figure 1 shows the PRISMA flowchart of the numbers of studies identified and screened.

The initial database searches yielded 4877 articles. An additional 18 articles were retrieved after ongoing searches and after checking the reference lists of all selected reviews. Endnote identified 439 duplicates, leaving 4,356 articles that were then screened by examining the title and abstracts. Of these, 4374 articles were excluded as they clearly did not meet the eligibility criteria in terms of study design, participants or injury specifications. The full text of the remaining 82 articles was retrieved and evaluated for eligibility using our checklist of eligible criteria.

Of these 82 studies, 61 were excluded for reasons outlined in Figure 6. This left 21 articles available for review.
Figure 6. PRISMA Flow Diagram
**Characteristics of the studies**

Table 7 describes the characteristics of the 21 included studies.

### Table 7. Summary of the included studies

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Country</th>
<th>Study Type</th>
<th>Injury type1,2</th>
<th>Setting</th>
<th>Study participants at baseline</th>
<th>Characteristics of the Groups, including the theoretical framework for the resilience component in the intervention</th>
<th>Outcomes</th>
<th>Summary of findings:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andersson et al 2007367 (Sweden)</td>
<td>Sweden</td>
<td>Randomized controlled intervention</td>
<td>Uncomplicated MTBI</td>
<td>Hospital/Community</td>
<td>1) 16-60 395: 264/131 I: 157M, 107F C:88M, 43F</td>
<td>Early personalized rehabilitation, focusing on coping skills, encouragement, counselling, referrals as required, assessment and management of post-concussion symptoms,</td>
<td>Number of post-concussion symptoms  Life satisfaction  Community integration  Quality of life</td>
<td>Follow up details Results for the primary and secondary outcomes specified in the Review</td>
</tr>
</tbody>
</table>

1 Injuries abbreviated as follows: MTBI = Mild traumatic brain injury; TBI=Traumatic Brain Injury; SCI= Spinal cord injuries
2 Injury type and participant recruitment is consistent with eligibility details outlined in the protocol
3 I=Intervention, C=Control
4 Not all data are available for the gender criteria according to treatment group
<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention Details</th>
<th>Comparison Group</th>
<th>Outcome Measures</th>
<th>Follow-up Time</th>
</tr>
</thead>
</table>
| Bultmann et al 2009 [62](Denmark) Randomized controlled intervention | Coordinated and Tailored Work Rehabilitation (CTWR) over a 3-month period, consisting of a work disability screening by an interdisciplinary team followed by the collaborative development of a RTW plan. Theoretical framework based on biopsychosocial model, readiness for return to work and self-efficacy. | Conventional Case Management (CCM) | Cumulative sickness absence hours, Work status, Pain intensity, Functional disability | At 1 year follow up N = 80

For the time intervals 0–6 months, 6–12 months, and the entire follow-up period, (0–12 months), the number of sickness absence hours was statistically significantly lower in the CTWR group compared to the CCM controls. |

| Cheng et al 2009 [59](Hong Kong) Randomized controlled intervention | A 4-week workplace based work hardening (WWH) training. Each participant was assigned a job coach who worked with the supervisor at work to arrange work tasks and deliver the training program. Program focused on educational and physical strengthening exercises, tailored to the specific job. | Clinic work based hardening (SWH) program consisting of conventional clinic based work hardening training with no workplace intervention | Perceived pain, Functional capacity, Return to work | At 4 weeks follow up Total N = 94

A statistically significant decrease in perceived shoulder problems (pain and function) within workers of WWH group. 71.7% of the workers in WWH group could return to normal or modified duties (21 to normal duties, 12 to modified duties) in contrast to 37.5% of the workers in CWH group. This was statistically significant. |
<table>
<thead>
<tr>
<th>Dorstyn et al 2012[^53] (Australia)</th>
<th>Recently acquired SCI (&lt;=1y)</th>
<th>Aged ≥18 years</th>
<th>Telephone counselling program delivered by psychologist over 3 months. Focusing on: motivational interviewing, developing positive coping skills, addressing psychosocial impacts, transitioning to community, developing social support networks, self-health care.</th>
<th>Standard care consisting of routine individual medical follow-up and physical therapies, in addition to a face-to-face consultation with a psychologist, at 3 months post discharge.</th>
<th>Depression Anxiety Stress Coping (SCL CSQ) Adequacy of social networks. Perceived social support from family and friends</th>
<th>At 3 months follow up: N=39. No statistically significant results for any of the outcome measures. Possibly small clinical improvements in depression and anxiety and degree of disability acceptance for the Intervention compared with the control group.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients referred to inpatient psychology service to assist with adjusting to disability, and recently discharged home</td>
<td>40:20/20 I: 16M,7F C: 14M,5F</td>
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<tr>
<td>Elbers et al 2013[^50] (Netherlands)</td>
<td>Musculoskeletal and orthopaedic injuries</td>
<td>Adults aged &gt;18</td>
<td>A internet website containing three modules that provided information about the compensation process and problem solving therapies (mainly addressing coping skills) and</td>
<td>A control website containing links to existing information and support websites.</td>
<td>Empowerment/Mastery Self-efficacy Health status Organisational justice Ability to work Claim knowledge</td>
<td>At 12 months of follow up N=141 No statistically significant differences between the groups for any of the outcomes, apart from increased perceived fairness of the compensation amount for those enrolled in the intervention group.</td>
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<td></td>
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<td>176: 88/88 I: 44M,44F C: 49M, 39F</td>
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<tr>
<td>Study</td>
<td>Intervention Type</td>
<td>Setting</td>
<td>Aged:</td>
<td>Description</td>
<td>Outcome Measure</td>
<td>Outcome</td>
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<tr>
<td>Gassaway et al 2017 (US)</td>
<td>Randomized controlled intervention</td>
<td>Spinal cord injury/disease</td>
<td>Adults (not specified)</td>
<td>A peer mentor program where a mentor was assigned to a patient and met them weekly throughout the inpatient stay and after discharge into the community. Provided information about community resources and encouraged and facilitated community integration. Also participated in the Facebook (FB) page for SCI Peers.</td>
<td>Self Efficacy</td>
<td>Unplanned hospital readmissions</td>
</tr>
<tr>
<td>Hasset et al 2009 (Australia)</td>
<td>Randomized controlled intervention (multi-centre)</td>
<td>TBI pts Community</td>
<td>Aged 15-65</td>
<td>12-week fitness based program undertaken independently at home Patients given the same training parameters as the Intervention group – only the setting was different.</td>
<td>CV fitness</td>
<td>BMI, WHR Depression Anxiety/tension Moods Stress Community rehabilitation Social Reintegration</td>
</tr>
<tr>
<td>Kim et al 2017 (North Korea)</td>
<td>Spinal Cord Injury Multi-site</td>
<td>Hospital/Rehabilit</td>
<td>Age &gt;=20</td>
<td>An 8-week self-efficacy enhancement small group program consisting of education and skills Small group education (Booklet only)</td>
<td>Self-care</td>
<td>Self-efficacy Pressure ulcer occurrence and skin condition</td>
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</tbody>
</table>

Statistically significantly increased rate of growth of self-efficacy in the first 6 months post-discharge
<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention Type</th>
<th>Diagnosis</th>
<th>Age</th>
<th>Gender</th>
<th>Population Details</th>
<th>Intervention Details</th>
<th>Outcomes</th>
<th>Results</th>
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</thead>
<tbody>
<tr>
<td><strong>Lee et al 2013</strong>&lt;sup&gt;[61]&lt;/sup&gt; (China)</td>
<td>Randomized controlled intervention</td>
<td>Musculoskeletal injuries</td>
<td>18-55 years</td>
<td>47: 24/23</td>
<td>I: 11M, 13F C:13M, 10F</td>
<td>An integrated work rehabilitation program based on CBT principles with main focus functional improvement. Program involved graded activity, pacing techniques, work reconditioning, job analysis ergonomic advice. Focused on aspects of self-management, self-efficacy, pain coping and return to work goal setting.</td>
<td>Individual patient and peer</td>
<td>Conventional physiotherapy treatment</td>
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<tr>
<td><strong>Li et al 2006</strong>&lt;sup&gt;[50]&lt;/sup&gt; (Hong Kong)</td>
<td>Randomized controlled intervention</td>
<td>Musculoskeletal injuries</td>
<td>Aged 20-59 years</td>
<td>63: 32/31</td>
<td>I: 20M, 12F C: 19M, 12F</td>
<td>A three-week job placement and support program involving vocational counselling, job preparation and job seeking, with support of case managers who coordinated the return to work process. Self-placement program – participants referred to a Workers Health Centre for services to help them search for jobs.</td>
<td>Individual patient, peer</td>
<td>Readiness to return to work, return to work, Anxiety, Quality of life</td>
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<tr>
<td>Study Authors and Year</td>
<td>Type of Interventions</td>
<td>Characteristics</td>
<td>Duration</td>
<td>Details</td>
<td>Outcomes</td>
<td>Findings</td>
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<td>Mouthaan et al 2013[51]</td>
<td>Randomized controlled intervention</td>
<td>Patients with severe injuries requiring specialised medical care</td>
<td>18 years and older</td>
<td>300: 151/149; I: 89M, 62F; C: 91M, 58F</td>
<td>Trauma TIPS (4 sessions; 30-minute internet-based intervention based on CBT principles to improve coping and prevent onset of PTSD symptoms)</td>
<td>Care as usual– incidental non-structured talks with trauma center staff or with a patient’s GP directly following injury or during the course of the trial</td>
<td>No statistically significant findings between groups for all major outcomes over time. No clinically significant findings according to their a priori definition.</td>
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<tr>
<td>Ponzer et al 2000[58]</td>
<td>Randomized controlled intervention</td>
<td>Hospitalised for orthopaedic injuries</td>
<td>15-65 years</td>
<td>151: 68/65; I: 37M, 41F; C: 38M, 27F</td>
<td>A psychosocial CBT based intervention program where a multi-disciplinary expert group (including a representative from the public insurance office) focused on the early phase of rehabilitation and involved liaising with the employer with an aim to encouraging patient to return to work</td>
<td>Quality of life, Depression, Pain</td>
<td>Patients in the control group had an increased risk of having psychiatric complaints compared with patients in the I group. These patients also had significantly higher risk of having a poorer outcome regarding their general health and vitality</td>
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<td>Sheenen et al 2017[52]</td>
<td>Patients hospitalised for MTBI and at risk for post-traumatic complaints.</td>
<td>18-65 years</td>
<td>91:44/47; I: 19M, 20F; C: 19M, 26F</td>
<td>A CBTi intervention using cognitive restructuring methods and aimed at enhancing active and assertive approaches</td>
<td>A Telephonic counselling intervention consisting of five sessions/conversations over the phone. Aimed at</td>
<td>Return to work (%)</td>
<td>No statistically significant differences between the groups with respect to the % RTW.</td>
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<td>Study</td>
<td>Setting</td>
<td>Participants</td>
<td>Description</td>
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<td>Scholz et al 2016&lt;sup&gt;[65]&lt;/sup&gt; (Switzerland)</td>
<td>Three Level 1 Trauma Centres</td>
<td>Victims of severe accidents with musculoskeletal injuries</td>
<td>A 1-2-year Intensive case management program, provided by individual case managers and aimed at coaching patients through the whole rehabilitation process and facilitating their return to work or to a modified job.</td>
<td>Providing information and reassurance</td>
<td>Average work incapacity (the % of pre accident work capacity lost over the follow up period)</td>
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<td>Treatment costs</td>
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<td>Length of stay in hospital</td>
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<td>Number of care providers</td>
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<td>Schultze et al 2009&lt;sup&gt;[47]&lt;/sup&gt; (US)</td>
<td>SCI patients and caregivers – Community</td>
<td>SCI patients and caregivers – Community: Recruited at least 1 year after injury</td>
<td>Aged 16-55 years</td>
<td>Multi-site intervention using computer telephone technology and delivered over 6 months. Main resilience components related to skills training for obtaining social support and integrating with community, engaging with family, friends, improving coping, mood, stress management.</td>
<td>Information only control group – caregiver</td>
<td>Depression</td>
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<td>Caregiver burden</td>
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<td>Social support and social integration</td>
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<td>Self-care</td>
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<td>At 12 months follow up</td>
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<td>Dual target: 99</td>
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<td>Caregiver only: 99</td>
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<td>Control gp:111</td>
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<td>No statistically significant intervention effects found for the care recipients. Significat improvements for caregiver outcomes when comparing dual group with the control group and with the caregiver group: Dual group vs control groups: Improvements for caregiver outcomes for health symptoms and social integration Dual group vs caregiver only: Improvements for depression, and health symptoms</td>
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<tr>
<td>Study</td>
<td>Patient Group</td>
<td>Care recipient</td>
<td>Intervention Details</td>
<td>Return to work status/time taken to RTW</td>
<td>Vocational independence scale</td>
<td>Time to return to work</td>
<td>Psychological distress</td>
<td>Analysis</td>
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<tr>
<td>Tan et al 2016(^{[63]}) (Singapore)</td>
<td>Work related injuries (falls, blunt injuries, cuts)</td>
<td>(N=57/56/60)</td>
<td>1:79M, 34F C:33M, 27F</td>
<td>Standard hospital care, plus a return to work coordinated program, incorporating biopsychosocial assessment, work accommodation, offers, contact with healthcare provider, and workplace, ergonomic worksite visits and a RTW coordinator. Decisions about RTW made by the doctor based on the biomedical recovery process. Employers not involved in care of the RTW decisions.</td>
<td>Standard care in hospital – routine medical rehabilitation treatment.</td>
<td>At 9 months of follow up N=153</td>
<td>No statistically significant differences in RTW status between groups, but a higher proportion of people in the Intervention group returned to modified job duties, and were prescribed light duties compared to the control group. Statistically significant reduction in the number of days to RTW in the Intervention group (average 10 days earlier) compared to the control. Significantly higher rate of work injury notifications in the intervention group. No statistically significant differences in QoL over time between the groups.</td>
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<tr>
<td>Tresler et al 2016(^{[68]}) (US)</td>
<td>ABI (included mostly TBI cases)</td>
<td>Aged 18-60 years</td>
<td>44: 22/22 M: 27 /F: 17</td>
<td>A 15-month Resource facilitation intervention (RFI). Conceptual underpinnings of the intervention relate to multidisciplinary care, social integration, vocational functioning, community re-entry, behaviour support. Intervention also provided control participants had access to acute and outpatient rehabilitation therapies and were contacted at 6 months post enrolment for follow up measures. No other contact was made</td>
<td>No statistically significant findings between groups for the other measures.</td>
<td>At 15 months of follow up N=44.</td>
<td>There were statistically significant improvements for the rate and rate and timing of return to work (mostly those in professional positions) and in productive community based activity for Intervention group. No statistically significant findings between groups for the other measures.</td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Population</td>
<td>Treatment</td>
<td>Follow up</td>
<td>Outcome Measures</td>
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<tr>
<td>Vikane et al 2017 [66] (Norway)</td>
<td>Randomized controlled intervention</td>
<td>mTBI Outpatient rehabilitation clinic</td>
<td>Aged 16-56 years, 151:81/70 I=49M, 32F C=43M,27</td>
<td>A multi-disciplinary outpatient follow up program initially consisting of individual contacts and psycho-educational intervention, 1/week, for 4 weeks. Focussed on developing schedules for RTW while patient was sick-listed. Ongoing group sessions commencing at 9-16 weeks post-injury addressed strategies for facilitating RtW and coping with difficulties following mTBI.</td>
<td>Days to sustainable RTW up to 12 months post-injury</td>
<td>Anxiety and depression</td>
<td></td>
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<tr>
<td>Wade et al 1997 [55] (UK)</td>
<td>Randomized controlled intervention</td>
<td>Clinically diagnosed Head injury, Community</td>
<td>Aged 16-65 years, 1156:579/577 I=381M, 198F C=379M, 198F</td>
<td>Basis of the intervention related to early follow up (at seven to 10 days after injury). Multidisciplinary face to face rehabilitation sessions Main area of resilience enhancement involved helping patients cope with processing information about the likely prognosis and Controls had access to existing hospital services such as the outpatient fracture clinic, with no routine follow up. Not contacted until six months after injury</td>
<td>Post-concussion symptoms (PCS)</td>
<td>Anxiety and depression</td>
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</table>

At 12 months of follow up N=126
No statistically significant findings between groups for the number of days to sustainable RTW 12 months after injury

At 6 months follow up: N= 479
No significant results, between groups for PCS
No significant changes for any items on the RHFUQ.
<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention Type</th>
<th>Patient Characteristics</th>
<th>Description</th>
<th>Outcome</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Wade et al 1998&lt;sup&gt;[56]&lt;/sup&gt; (UK)</td>
<td>Randomized controlled intervention</td>
<td>As for Wade et al 1997, however this study sample included only those admitted to hospital, with or without other injuries. Aged 16-65 years 314: 184/130 I=130M, 54F C=102M, 28F</td>
<td>Described above for Wade et al 1997</td>
<td>At 6 months of follow up: N=218</td>
<td>The trial group experienced fewer or less severe post-concussion symptoms compared with the control group. This group also experienced significantly less disruption of overall social activities compared with the control group (total RHFUQ scores).</td>
</tr>
<tr>
<td>Zemper et al 2003&lt;sup&gt;[49]&lt;/sup&gt; (US)</td>
<td>Randomized controlled intervention</td>
<td>SCI At least 1 year post injury Hospital/Community 18-80 67: 36/31</td>
<td>6, half day wellness workshops conducted over 3 months. Theoretical framework for the model and resilience component is well described: interventions to enhance social support and increase self-efficacy for health behaviors would result in improved health promoting behaviors and quality of life</td>
<td>At 7 months f/up: N=43</td>
<td>No statistically significant results for between group tests for all measures</td>
</tr>
</tbody>
</table>
A total of 11,904 participants were represented in the 21 studies. Four studies were conducted in the United States.[46-49] Three studies were conducted in the Netherlands[50-52] and two studies were conducted in each of the following countries: Australia[53, 54] United Kingdom[55, 56] and Sweden[57, 58] and Hong Kong.[59, 60] One study came from each of the following countries: China,[61] Denmark,[62] Singapore,[63] North Korea,[64] Switzerland,[65] Norway.[66]

Five studies were of patients with TBI,[48, 54-56, 66] seven studies were of patients with SCI[46, 47, 49, 52, 53, 64, 67] and the remaining studies were of patients with orthopaedic or musculoskeletal injuries.[50, 51, 58-63, 65]

**Types of interventions**

Most interventions were conducted face to face. In two studies the interventions were administered by telephone[47, 53] and two studies conducted the intervention via the internet.[50, 51] The interventions were aimed at either directly addressing personal resilience and/or contextual factors promoting individual resilience. Five studies were of intervention programs aiming to develop self-efficacy,[46, 49, 50, 62, 64] seven studies addressed coping skills[51-53, 55, 56, 66, 67] and four studies targeted goal setting skills.[46, 52, 60, 64] Contextual factors were targeted in 16 studies. Of these, three studies[47, 67, 68] included the family and caregiver, four studies had a component aimed at increasing social support,[47, 53, 57, 60] and five included components aimed at increasing community integration.[46, 47, 54, 60, 67, 68] Nine studies included components involving workplace rehabilitation.[58-63, 65, 66, 68] Twelve studies addressed only one resilient component in their program.[46, 49, 51, 52, 54-56, 58, 59, 61, 63, 65]
The follow up time points periods varied across the studies. Nine studies followed patients up to 6 months after the injury,[47, 49, 53, 54, 59-61, 63, 64] with the remaining studies following up patients between 6 and 12 months, apart from one study that followed up patients beyond 12 months.[68]

**Quality assessment**

Agreement about study quality was reached between two reviewers (JS and KH) for all of the included studies. Of the 21 RCTs, (Supplementary Figure 2) nine studies [50, 54, 56, 60-63, 66, 67] were found to be of high quality (8 points or more), ten studies were of moderate quality (5-7 points),[46-49, 51, 53, 58, 59, 64, 65] with two studies[52, 55] of low quality. Six studies provided information about allocation concealment.[46, 48, 54, 62, 63, 66] Participants were blinded to their program allocation in two of the studies.[50, 61] Of these, therapists were also blinded to outcome in one study.[46, 50, 53, 56, 60-62, 66, 67] Assessors were blinded in nine studies. [46, 50, 53, 56, 60-62, 66] Two studies provided insufficient information about drop outs[57, 58] and all studies clearly reported on pre-stated outcomes. All but five studies[47, 49, 52, 55, 64] conducted an intention to treat analysis.

Attrition rates varied in all the studies. Most (N=15) studies had attrition rates of \(<=20\%\).[46-48, 50, 52-54, 58-61, 63, 65-67] and only two studies had attrition rates of over 60\%.[51, 55] Two studies reported power calculations with estimates of the minimum clinically important effect size for the primary outcome of interest.[51, 67] The definition of ‘usual care’ for the control group varied between studies, and included ‘non-structured talks with trauma staff’, ‘access to rehabilitation services as needed’, ‘psychosocial support if needed’, a ‘one-off phone contact’ or ‘non-individualised
care’. No studies collected data about any non-scheduled form of rehabilitation treatment undertaken in either group during the study period.

Effects of the interventions on outcomes

The two studies that were of low quality (PEDro score 4) were excluded from the meta-analysis. Table 8 shows the pooled mean differences for the remaining 19 studies of moderate to high quality, for the outcomes of interest: returning to work, average days to return to work, self-efficacy and stress.
Table 8: Overall main effects for resilience promotion rehabilitation programs on outcomes

<table>
<thead>
<tr>
<th>Variable</th>
<th>Effect Estimate (Mean Difference) (95% CI)</th>
<th>I²</th>
<th>P Value (I²)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return to work‡†</td>
<td>2.09 (0.99-4.44) *</td>
<td>76.30%</td>
<td>P&lt;0.001</td>
</tr>
<tr>
<td>Average days taken to return to work‡</td>
<td>-7.80 (-13.16 – 2.45) ***</td>
<td>45.70%</td>
<td>P=0.12</td>
</tr>
<tr>
<td>Self-Efficacy††</td>
<td>5.19 (3.12.-7.26) ***</td>
<td>0%</td>
<td>P=0.62</td>
</tr>
<tr>
<td>Stress††</td>
<td>-0.85 (-2.42-0.72) NS</td>
<td>0 %</td>
<td>P=0.46</td>
</tr>
</tbody>
</table>

‡ Primary Outcomes: Return to Work, Average days taken to return to work

†† Secondary Outcomes: Self-Efficacy, Stress

† Effect estimate expressed as an Odds Ratio

*Effect size significant at p<=0.05; **Effect size significant at p<0.01; *** Effect size significant at p<0.001, NS: Not statistically significant
Return to work status at follow up

Eight studies (701 participants) were available for analysis of return to work status (‘Yes’ or ‘No’) at follow up (Figure 2a). Seventy-four percent of people in the intervention groups returned to work compared to 59% in the control groups. The overall effect size, reported as a Risk Ratio, was 2.09 (95% CI 0.99-4.45 $p=0.06$), with significant heterogeneity ($I^2=76.3\%$, $p<0.001$). These results favour the intervention group, showing just over a twofold increased risk for returning to work compared with control patients.

Average days taken to return to work

Five studies (8,600 participants) reported on the average number of days to return to work following injury. The mean time to RTW in the intervention group was 270 days compared to 338 days in the control groups. The pooled mean difference for the average number of days taken to return to work was in favor of the intervention, suggesting that participants returned to work, on average 7-8 days earlier compared to the control groups; mean difference -7.8 (95% CI -13.16 - -2.45 $p<0.001$). Heterogeneity was not statistically significant ($I^2=45.7\%$, $p=0.12$).

Self-Efficacy

Three studies were available for analysis of self-efficacy as a primary outcome (137 participants). The mean increase in self-efficacy in the intervention groups was 9.45 compared to 4.59 in the control groups. The pooled mean difference for self-efficacy was 5.19 (95% CI 3.12-7.26 $p<0.001$), suggesting a statistically significant improvement in this outcome for the interventions, compared to the control programs. Heterogeneity was not statistically significant ($I^2=0\%$, $p=0.62$).
**Stress mitigation**

Four studies reported on global measures of stress (N=444 participants) as an outcome measure.\(^{49, 51, 53, 54}\) The total mean difference in reduction in scores for the intervention group was 2 points, compared to 0.4 for the control groups. The pooled mean difference for stress was \(-0.85\) (95% CI \(-2.42-0.71\) \(p=0.29\)). Heterogeneity was not statistically significant \(I^2=0\%, p=0.46\). Figure 7 shows the Forest Plots for each of the main outcomes.

**Figure 7: Forest Plots of the Main Outcomes**
Subgroup analyses: Return to work status

The subgroup analysis results for RTW are shown in Table 9.

Program components: Interventions that included a work-related training component compared to those that didn’t, were significantly associated with an increased likelihood of returning to work ($p<0.01$) yet these findings showed statistical heterogeneity ($I^2=74.35\%$).

Community integration: There were no statistically significant differences between programs according to the presence of a community integration component.

Follow up time point: Programs with a longer period of follow up (6 months or more) were significantly associated with an increased likelihood of returning to work ($p<0.001$) compared to those with a shorter (less than six months) follow up time period ($p=0.08$), with minimal heterogeneity in these findings ($I^2=5.72\%$)

Injury types: People with orthopaedic or musculoskeletal injuries were more likely to RTW ($p=0.02$) compared to those with brain ($p=0.61$) however these results showed high levels of heterogeneity.
Table 9. Subgroup analyses of the effects of resilience program components on rates of returning to work after injury

<table>
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<tr>
<th>Program Component</th>
<th>No. of studies (Participants)</th>
<th>Mean Difference (95% CI)*</th>
<th>I²</th>
<th>P value (I²)</th>
<th>Q-test</th>
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<tbody>
<tr>
<td><strong>Community Integration</strong></td>
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<tr>
<td>Community integration</td>
<td>3 (169)</td>
<td>2.19 (0.52-9.25) NS</td>
<td>76.2%</td>
<td>P=0.01</td>
<td>8.40</td>
</tr>
<tr>
<td>No Community integration</td>
<td>5 (532)</td>
<td>2.07 (0.77-5.57) NS</td>
<td>80.48%</td>
<td>P&lt;0.001</td>
<td>21.13</td>
</tr>
<tr>
<td><strong>Work related rehabilitation</strong></td>
<td></td>
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</tr>
<tr>
<td>Work related training</td>
<td>6 (594)</td>
<td>3.18 (1.41-7.15)**</td>
<td>74.35%</td>
<td>p =0.00</td>
<td>19.49</td>
</tr>
<tr>
<td>No work-related training</td>
<td>2 (101)</td>
<td>0.55 (0.24-1.23) NS</td>
<td>0%</td>
<td>p =0.76</td>
<td>0.10</td>
</tr>
<tr>
<td><strong>Follow up time point</strong></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>5 (411)</td>
<td>1.83 (0.55-6.17) NS</td>
<td>84.57%</td>
<td>p &lt;=0.001</td>
<td>25.93</td>
</tr>
<tr>
<td>6 months or more</td>
<td>3 (290)</td>
<td>2.35 (1.31-4.23) ***</td>
<td>5.72%</td>
<td>p =0.35</td>
<td>25.93</td>
</tr>
<tr>
<td><strong>Injury type</strong></td>
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<tr>
<td>Traumatic brain injuries</td>
<td>2 (106)</td>
<td>1.83 (0.18-18.35) NS</td>
<td>84.98%</td>
<td>p =0.01</td>
<td>6.66</td>
</tr>
<tr>
<td>Others (orthopaedic, musculoskeletal)</td>
<td>5 (595)</td>
<td>2.87 (1.19-6.96) *</td>
<td>77.26%</td>
<td>P&lt;0.001</td>
<td>17.59</td>
</tr>
</tbody>
</table>

**Sensitivity and publication bias**

Sensitivity analyses were conducted, where one study at a time was removed to assess that the statistically significant results were not due to a particular study or studies. Publication bias using Egger Regression Analytical techniques (Table 10) demonstrated that the results are not statistically significant, suggesting there was minimal publication bias. [45]
Table 10. Egger analysis on publication bias

<table>
<thead>
<tr>
<th>Variables</th>
<th>t value</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return to work</td>
<td>2.83</td>
<td>0.11</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>(-0.92, 6.59)</td>
<td></td>
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<tr>
<td>Days to return to work</td>
<td>0.10</td>
<td>0.90</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>(-2.45, 2.66)</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>-2.50</td>
<td>0.06</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>(-5.10, 0.19)</td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>0.44</td>
<td>0.74</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>(-13.44, 12.57)</td>
<td></td>
</tr>
</tbody>
</table>
Discussion

Summary of the main results

Our review aimed to evaluate the role of resilience-based interventions in traumatic injury recovery, primarily defined according to two different measures of occupational engagement. Meta-analyses of 19 RCT studies of the effectiveness of multi-dimensional resilience rehabilitation programs showed statistically significant improvements in the proportion of people RTW and reductions in the average days to RTW compared to control programs. Intervention programs were also statistically significantly more likely to result in improvements in self-efficacy.

The evidence regarding social, physical and general health benefits of re-employment after a period of disability is well documented. Resilience intervention programs that return people to work sooner, rather than later are valued for a number or reasons. There is a negative association between the number of days off work after injury and the likelihood of ever returning to work suggesting shortened periods of work disability are related to increased self-efficacy. The earlier return to work may also reduce the direct costs of unemployment from injury, which includes the direct costs of workers’ compensation, rehabilitation and health care. Indirect costs are not easily quantified, but thought to be substantial, and include lost productivity, lost current and future earnings for the patient, some of which also affect the informal caregivers of injured patients. Our results are consistent with a recent synthesis of systematic reviews of factors affecting RTW after TBI reported that a wide range of personal and contextual factors favour RTW outcomes. Elsewhere, studies have shown that supportive families and friends are important and that multidisciplinary, coordinated approaches to vocational rehabilitation lead to favourable
work outcomes.\textsuperscript{[69, 70]} All these factors are consistent with the socio-ecological resilience based model of rehabilitation and support the results of this review.

Higher levels of self-efficacy appeared to occur in patients undertaking multidimensional rehabilitation programs aimed at promoting resilient capacity, in comparison with patients in the control group. Self-efficacy is an important positive and protective quality related to resilience and is also associated with positive coping behaviors, personal mastery and behavioural change.\textsuperscript{[71]} Studies have shown that self-efficacy is strongly associated with\textsuperscript{,}[72] and predictive of validated measures of resilience\textsuperscript{[73]} in patients who have sustained SCI. Meta-analyses have shown that personal self-efficacy is one of the most important components of resilience\textsuperscript{[23]} over and above factors such as coping and optimism. Self-efficacy has also been shown to positively predict return to work in people with musculoskeletal disorders.\textsuperscript{[24, 74]}

This study did not find statistical evidence for an interventional effect of resilience enhancement on stress reduction although visual inspection of the forest plot (Figure 2C) suggests a trend towards negative stress responses as a result of the programs. The relationship between resilience and stress reduction has not been extensively studied in populations, yet it is thought that social support networks which are known to foster resilience by acting as a buffer for stress. Social support networks could mediate the stress-resilience relationship, by influencing neurochemical stress responses\textsuperscript{[26]} such as the role of the central oxytocin system in regulating ‘pro-social’ interactions.\textsuperscript{[75]}

Subgroup analyses further identified factors that may have contributed to the significant improvements in RTW rates in the intervention groups. Not surprisingly, programs that had a longer period of follow up, beyond 6 months, were statistically significantly more likely to result in favourable RTW outcomes. The critical time points for evaluating RTW outcomes
after trauma are currently unclear, yet research evidence suggests that RTW rates increase over time, particularly from 6 months post-injury.[76] Vocational rehabilitation programs operating with a resilience framework are often conducted over several months as was the case for the studies in this review.[48, 58, 62]

Subgroup analysis further found vocational based rehabilitation programs are associated with positive RTW outcomes. It is possible worksites that promote workplace social cohesion, and have trustworthy and supportive supervisors are important.[77, 78] Other positive factors in vocational based rehabilitation programs could be worksites with flexible work arrangements, physical activity programs and a culture that promotes employee participation, involving coaching and mentoring, enabling help seeking and supporting workers’ stressful life experiences.[79] It is also possible the social support networks in the workplace may promote resilient growth following trauma.[23, 80] Research evidence suggests that specific types of social support systems in the workplace could be important for promoting resilience[77, 81] thereby optimizing sustained RTW outcomes. For the studies included in this review, successful RTW was associated with some of these features including multi-disciplinary case management,[60, 62] programs tailored to the individual’s needs,[60] inclusion of occupational specialists[68] and involvement of others important to vocational rehabilitation, such as the workplace, the employer and public insurance officers[58]. Other major stakeholders, such as primary and secondary health care sectors and the community sector were common components to these programs.[58, 60, 62, 68] In addition, most of the interventions had ‘dynamic loops’ of feedback, where evaluations and interventions were re-adjusted as needed[62, 68] and feedback was continuously provided between the disciplines about the patients’ work readiness. Teams educated the patients about RTW processes (including compensation),
worked with the workplace to accommodate patients’ needs, and addressed various environmental barriers and social and community support structures.

Sub-group analyses also showed that resilience-based programs might result in positive work-related outcomes for patients who have experienced orthopaedic and musculoskeletal injuries, compared to those with TBI. Previous systematic reviews failed to find strong evidence of modifiable factors predicting successful employment after TBI. While the results from this review should be interpreted cautiously given the statistical heterogeneity, musculoskeletal or orthopaedic trauma (injury to the soft tissue, muscle and/or bone) is the cause of the majority of hospitalizations for injury. Those affected include younger adults, particularly those under 45 years who are likely to be in the workforce. Orthopaedic trauma is associated with ongoing pain and disability and slower functional recovery compared to other injuries, and therefore incurs a large proportion of claims for compensation under traffic compensation system and workers compensation claims. Compensation status has been reported as a negative predictor of returning to work following injury, and these results suggest this subgroup of patients should be particularly targeted for resilience based rehabilitation programs.

Programs including community integration components were not shown to be important in terms of RTW outcomes. Reintegration into the community following injury is a desirable rehabilitation goal, and an indicator of resilient adaptation, particularly for people with traumatic brain injuries. The relationship between community integration, vocational integration and RTW is not clear and it is possible that vocational programs aimed towards integration into the workplace, are tangibly more important for enabling return to work for people who don’t have brain injuries. Our results show that multi-disciplinary rehabilitation programs that emphasized the importance of workplace support to people with injuries were
significantly more likely to be associated with positive RTW outcomes compared to those that did not have this component.

**Quality of the evidence**

The studies in this review were of moderate to high quality and details of the resilience interventions were well documented. Although participants and assessors in most studies were not blinded, the occupational outcomes provide objective assessments of functional recovery compared to self-reported outcomes. The self-reported outcomes related to resilient skills, were all measured using validated scales and the findings for resilient responses, such as self-efficacy are consistent with the socio-ecological model of prevention that emphasizes the importance of evaluating behaviour changes as interim indicators of longer health outcomes, such as RTW.

**Limitations**

Resilience research in trauma is still in its infancy. There is currently no instrument that comprehensively measures a multi-dimensional construct of resilience. For this review, a carefully constructed definition of a ‘resilience enhancing’ program was developed, informed by the published literature. This was done prior to conducting the literature search.

In addition, there is currently insufficient information about the clinical effectiveness of resilience programs, including the harms as well as the benefits. The design of future interventions will benefit from research that can develop and validate resilience instruments, particularly those that incorporate multiple dimensions of resilient adaptation. Finally, there is a need for agreed, and standardized measures of rehabilitation outcomes that can be attributed to resilient adaptation during the rehabilitation phase.
A cautious interpretation is needed of the RTW outcome as a surrogate measure of successful functional recovery. The measures of RTW in this review do not fully capture the complicated pathways of returning to work after injury, and the various work role scenarios that might eventuate once employment has recommenced.[85] Further research should explore various work role scenarios and other measures of daily function and patient quality of life and wellbeing, which might in turn, positively influence the likelihood of occupational re-integration.

**Implications for clinical practice and future research**

Interventions aimed at high risk population sub-groups are cost effective and a worthy public health investment.[86] The ‘social ecology’ of resilience which embeds the individual within larger social and structural systems, is an important principle guiding rehabilitation practices. Synthesised empirical data, as presented here, can inform practitioners about the evidence base in this field and the relative contribution of these socioecological systems on enhancing resilient skills such as self-efficacy, and promoting trauma recovery, defined as returning to work.

This review has identified specific strategies that could be incorporated into rehabilitation programs aiming to foster earlier occupational re-engagement following injury. These include multi-disciplinary teams that case-manage patients, include employers and occupational rehabilitation specialists, and are activated early in the rehabilitation phase. The review’s findings suggest that the most effective interventions to enable earlier RTW are individualised, dynamic and adaptive, and consider psychosocial factors in addition to medical and occupational factors in the RTW assessment. The 7-8 days earlier return to work is likely to result in reduced direct and indirect costs of unemployment following injury. Our study results highlight the importance of considering the workplace setting when designing
rehabilitation programs aimed at promoting resilient recovery following traumatic injury.

Conclusions

Multi-dimensional rehabilitation programs aimed at fostering resilience following physical trauma can assist with RTW and improve self-efficacy. The results of this review suggest that resilient adaptation following injury could be increased by targeting systems in the patients’ socio-ecological environment. These results also highlight the importance of considering the workplace setting when designing rehabilitation programs aimed at promoting resilient recovery following traumatic injury.

Acknowledgements

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References


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Supplemental Table 1. Quality assessment results of included randomized controlled trials, using the PeDRO tool (1=yes, 2=no)

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Chapter 5: Results for Study 2: Association between socioeconomic and geographical factors in severely injured

trauma patients using trauma registry data.

Overview

Trauma Registries typically collect data based on the acute hospital phase of care yet do not collect information on long term outcomes. However, as the focus on trauma outcomes turns increasingly towards communities, it will be important for Registries to collect standard and robust data that can, to some extent, describe the communities where people were injured and return home, to rehabilitate.

This Study describes methods for characterizing resilient qualities of neighborhoods. These include qualities such as economical prosperity, healthy and connected residents with strong and effective communication networks. Resilient communities also have access to quality health care and to a high level of other community resources. Safe neighborhoods and healthy living infrastructure are also important.

For the next two studies (2 and 3), the neighborhood factors are depicted as a multi-faceted index of socio-economic disadvantage and an index of geographic remoteness from services. These ecological indices were linked with individual patients represented on the Trauma Registry of the GCUH. This study describes the association between these ecological ‘exposures’ of relative disadvantage and remoteness with individual, severely injured hospitalized trauma patients.
Statement of Contribution to co-authored published paper:

This section includes a co-authored manuscript was published as a peer reviewed manuscript, in conference proceedings at the Biennial ACSPRI Social Science Methodology Conference, held in Sydney, December 2018.


The research candidate has made the following contributions to this study:

- Identified research gaps and designed the study.
- Completed all the required documentation for human research ethics approval from Griffith University Human Research Ethics Committee (Protocol Number: (GU Ref No: 2017/879) and the Gold Coast Health Ethics Committees (HREC/17/QGC/256 ) and the Queensland Health Public Health Act approval (Reference number RD007132)
- Analysed the data and interpreted the findings.
- Prepared the manuscript and submitted it for peer review and publication (described above).

Signed: 

[Signature]
Signed

(Supervisor and corresponding author: Jing Sun)
Abstract

**Background:** Injuries remain a significant cause of premature death, morbidity and disability in Australia, and include a disproportionate number of people who are socioeconomically disadvantaged. A mix of economic, social, physical, and environmental factors defines a person’s socioeconomic status and can influence an individual’s injury risk behaviors, employment, education and ability to access to services. The positive gradient between rurality and socioeconomic disadvantage in Australia is well recognized yet has not been well described for trauma populations. As time to definitive trauma care is associated with major trauma outcomes, geographical factors could confound studies of social disadvantage and trauma occurrence. This study aimed to describe the relationship between neighborhood socioeconomic disadvantage and geographic remoteness on injury patterns, including injury severity and pre-tertiary management of patients admitted to a Level 1 Metropolitan Trauma Centre in Queensland, Australia, between 2014 and 2017.

**Methods:** A cross-sectional study was conducted of adults hospitalized in a Level 1 Trauma Centre who met criteria for major trauma. Area-level explanatory variables included the Index of Relative Socioeconomic Disadvantage, and the Australian Standard Geographical System (ASGS) remoteness structure. These were linked to patient variables, which included age, injury severity, number of comorbidities, injury mechanism, postcode of injury occurrence, and the first provider of care.

**Results:** 1025 patients were available for analysis, of which 77% were male. The mean age was 45 (SD 19.46) and median ISS was 17 (IQR=12). Increasing relative socioeconomic disadvantage was statistically significantly, and positively associated with remoteness of residence ($\chi^2=41.61, p<0.001$) remoteness of injury location ($\chi^2=19.73, p<0.001$), and number...
of comorbidities (KW H Statistic=11.26, p=0.01). Of those who received initial care from a regional hospital, there is a significant and positive trend according to increased likelihood of being disadvantaged category compared with those treated at the major trauma center. ($\chi^2=14.14, p=0.003$). After adjusting for age, sex, injury severity and remoteness of injury location, a positive gradient of increasing disadvantage according to geographical remoteness of residence was evident, with a six fold increase in the odds of being in the most disadvantaged category, compared to the least disadvantaged (OR 6.21, 95% CI 3.07-12.57, p<0.001).

**Conclusions:** Robust socio-ecological measures linked to a Trauma Registry can enable examination of contextual factors associated with injury patterns and early management. Geographical factors related to rurality of residence and regional trauma care are positively associated with neighborhood socioeconomic disadvantage and should be considered when designing epidemiological studies of disparities in injury risk or injury outcomes.

**Introduction**

The development of modern trauma care and the establishment of coordinated trauma systems has led to improvements in major injury outcomes, worldwide. (1) Despite these gains, traumatic physical injuries in Australia remain a major cause of death and disability and represent one of the five disease groups causing the most burden of ill health in society.(2)

Inequalities exist in trauma populations where, in Australia, there is an over-representation of people from socioeconomically disadvantaged backgrounds. Low levels of income, education, blue-collar work and unemployment are strong indicators of an individual disadvantage and associated with increased injury mortality,(3-5) however these indicators
appear to have varying impacts on injury patterns. American data show that being unemployed is independently related to increased risk of death from suicide, where race and ethnicity, income or education is not. Being in a blue-collar occupation is a significant risk factor for non-fatal injury and injury severity, over and above factors such as educational attainment or income.(5)

Disadvantage is also associated with higher rates of risky behaviours, speeding, and alcohol and drug intake. (6) Greater levels of comorbidity are reportedly associated with disadvantage(3, 7), as is severity of the crash(8) the degree of injury severity(3, 8) and the crash mechanism, where traffic related accidents prevail over others.(9) As such this information is collected by Trauma Registries to monitor trauma care, assist with injury prevention and control and identify areas for clinical and epidemiological research.

However, an individual’s SES is influenced by a myriad of social and environmental factors, all interacting with their individual level factors to shape behaviors.(10-13) These social determinants of health have been described by Marmot and are fundamentally important to the theory and practice of public health,(11-14) recognising that an individual’s social and physical environment provides opportunities or the capacity for positively influencing health behaviors. At the center of this framework is the individual, including their personal and biological characteristics, behaviors, attitudes and preferences. The social context includes individuals or groups who have close relationships with the individual, such as family, friends, peers, schools, sporting, religious or community groups, health service personnel or work colleagues. The physical environment defines the natural environment and places where people live and work and include roads, transport, parks, and housing, community or health facilities. Access to services is an important part of this layer. Finally, policies from any level
of Government are important in terms of creating environmental change and providing work force and urban planning, funding and taxes.

From the injury perspective, these linkages between an individual and their community are key to addressing disparities in injury risk and outcomes. The neighborhood factors important to injury but not routinely collected by Trauma Registries includes its material wealth, which influences the quality of housing and the built environment.(15) Family and social networks, occupational exposures, and availability of services or resources that provide education or promote safety are also important.(15, 16) Neighborhood factors have been shown to be more powerful predictors of injury mortality and morbidity beyond individual factors.(16) Notably, many of these factors are strongly linked to various dimensions of ‘place’ and this represents a plausible link with injury causation, given that injury has ‘external (or environmental) causes’ entwined in its definition.

Rurality, or remoteness of residence is a contextual factor strongly associated with the socioeconomic dimensions of ‘place’ but is not included in traditional measures of SES. Compared to urban dwellers, rural residents have relatively poorer access to health services, higher levels of risk behaviors including occupational and physical risk, and higher rates of disease and injury.(17) Patterns of injury are different for rural residents compared to urban residents. Compared to urban dwellers, rural residents are more likely to be involved in serious incidents involving firearms, farming, mining, natural environmental factors and road injuries and are at least twice as likely to be admitted to hospital for injury compared to urban residents(18). Rates of traffic related injuries are more common in rural areas, compared to urban areas.(19, 20)
Measures of residential rurality or remoteness from services have not been routinely factored into studies of social and economic variations in injury patterns. This is surprising, given that the time taken to receive definitive care following severe trauma is a critical factor influencing survival. Caring for people who are injured in rural areas pose specific challenges in this respect, yet the location of injury does not always reflect the location of where the person lives. This distinction has also not been adequately addressed in studies of SES or remoteness, in the injury context.

Because of the strong relationship between injury and disadvantage, many studies adjust for social disadvantage in analyses, however there is little understanding of how SES might operate as a primary explanatory factor for injury. Increasingly, people are now surviving serious injury and are discharged home to their communities. Therefore, understanding the nature of disadvantage from the communities that people come from, and return to, could ultimately assist in understanding patterns of primary risk, and the appropriate types of rehabilitation programs for injury survivors.

The existing evidence base of the role of socio-ecological factors on health is vast,(21-23) yet is littered with subjective assessments from individuals and prone to information biases. There is a comparative lack of objective, empirical evidence as to whether, or which factors are effective in changing health behaviors or outcomes in injured patients.(24)

The aim of this study was to report the association between objective neighborhood measures of socioeconomic disadvantage and geographical remoteness with patterns of injury, for severely injured trauma patients admitted to a Level 1 Tertiary Trauma Centre between 2014 and 2017.
Methods

Study setting

The study population was severely injured patients admitted to a Level 1 Tertiary referral center in Queensland (Qld). This hospital provides care for severely injured patients across two State borders, including the wider population injured in the designated catchment area of the region (68%) where the Trauma Centre is located, and patients injured in mostly regional areas of northern New South Wales (NSW). The remainder come largely from inner regional areas of the catchment area in both States, dominated by patients referred from hospitals in northern NSW (71%). (25) Both States have advanced trauma services, with well-developed rural and regional referral networks.

Study design and data sources

The study design is a retrospective analysis of adult injury cases hospitalized for >24 hours, in a Level 1 Trauma Centre in Australia, where the date of injury occurred any time after January 01 2014 to December 31, 2017. Eligible patients were aged over 18 years, admitted to the hospital for severe (ISS > 12) traumatic physical injury resulting from external causes.

Patient data were sourced from the Hospital’s Trauma Registry which represents all patients presenting to hospital satisfying the standard criteria for a major trauma event, defined by the injury mechanism, the pattern of injury and various clinical features. The Registry focuses on collecting information that enables analysis of the quality of patient care, improvements in patient care, and reduction in mortality and morbidity from traumatic injury. The Trauma Registry has well-defined data integrity processes that ensure data reliability and validity.(25)
**Area level variables**

Information about the patients’ residential address at the time of injury obtained from the 2011 Census of Population and Housing was used to generate area-level measures described below.

**Socioeconomic status**

Many individual characteristics associated with disadvantage and trauma outcomes, such as gender, injury severity, comorbidity, substance abuse, and occupation. Trauma Registry staff typically collect this information for the purposes of injury surveillance and control. However, information on SES contextual factors is not routinely collected. Linkage of Census Tract data to Trauma Registries can enable the study of the multi-dimensional construct of socioeconomic disadvantage at the ‘neighborhood’ level. In Australia, socio-demographic information is summarised into an Index or Relative Social Disadvantage (IRSD) (26, 27) as shown in Table 11. The IRSD is often analysed as an area-level explanatory factor or exposure for individual level outcomes and has explained health differentials and influenced health policies (28) This index summarises 17 different pieces of information about the economic and social conditions of people and households in an area, such as low income, low education, high unemployment and unskilled occupations. A low score indicates relatively greater rates of disadvantage in that area compared to other areas, and is characterized by many low-income families, people with little training and working in unskilled occupations A high score indicates a relative lack of disadvantage according to these characteristics.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Annual household income</td>
<td>Less than $20,799</td>
</tr>
<tr>
<td>Employment</td>
<td>% Families with children under 15 years of age who live with jobless parents</td>
</tr>
<tr>
<td></td>
<td>% Employed people classified as ‘labourers’</td>
</tr>
<tr>
<td></td>
<td>% people in the labour workforce unemployed</td>
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<tr>
<td></td>
<td>% Employed people classed as machinery operators or drivers</td>
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<tr>
<td></td>
<td>% People classified as Low Skill Community and Personal Service workers</td>
</tr>
<tr>
<td>Internet connection</td>
<td>% Occupied private dwellings with no internet connection</td>
</tr>
<tr>
<td>Education</td>
<td>% people aged 15 years or over whose highest level of education is Year 11 or lower</td>
</tr>
<tr>
<td></td>
<td>% people aged 15 years and over who have no educational attainment</td>
</tr>
<tr>
<td>Household factors</td>
<td>% Occupied private dwellings paying rent less than $166/week.</td>
</tr>
<tr>
<td></td>
<td>% Occupied private dwellings with no car</td>
</tr>
<tr>
<td></td>
<td>% Occupied private dwellings requiring one or more extra bedrooms</td>
</tr>
<tr>
<td>Family structure</td>
<td>% one-parent families with dependent offspring</td>
</tr>
<tr>
<td></td>
<td>% People aged 15 or over who are separated or divorced</td>
</tr>
<tr>
<td></td>
<td>% People who do not speak English very well.</td>
</tr>
<tr>
<td>Health</td>
<td>% people aged &lt;70 who have a longer-term health condition or disability and need assistance</td>
</tr>
</tbody>
</table>

*Source: Socio-Economic Indexes for Areas (SEIFA) 2011. Canberra. ABS Catalogue no. 2033.0.55.001.*

**Geographical remoteness**

Geographic remoteness is a measure of the physical distance of a location from the nearest urban center, which serves as a proxy measure of the level of access to goods and services.
For this analysis, the enhanced Accessibility/Remoteness Index of Australia classification (ARIA+) was used to describe areas in terms of relative remoteness. (29) These scores are used by many Government organizations in Australia, including the Australian Bureau of Statistics to publish statistics that are comparable and spatially integrated. The ARIA scores are categorized into five classes of remoteness: a value of ‘1’ defines Major cities of Australia, ‘2’ defines Inner Regional Australia, ‘3’ is Outer regional Australia, ‘4’ is Remote Australia and ‘5’ defines ‘Very Remote Australia. The hospital catchment area for this study sample lies mostly in Categories 1 and 2, hence there are small numbers of cases in categories 3,4 and 5 (N=26), these were combined within category 2. For this analysis, two remoteness variables were developed and assigned to each patient describing their area of residence, and where the injury was sustained.

**Individual patient factors**

Data from the Trauma Registry considered to be important covariates for the study’s hypothesis were analyzed. Age and sex are risk factors for injury, as is injury severity. Injuries were classified according to the Abbreviated Injury Scale (AIS) (30) that codes injuries according to their anatomic location (head or neck, face, chest, abdominal or pelvic contents, extremities or pelvic girdle and external) and assigns a severity score from 1-6, based on the probability of death or disability. Injuries >2 are classified as ‘severe’.

For this analysis, injury severity was examined using the Injury Severity Score (ISS), an ordinal scale ranging from 1 to 75, reflecting the sum of the highest AIS scores for the three most severely injured body regions. While ISS was the primary measure for this analysis, the New Injury Severity Score (NISS) was also assessed. This is the sum of the squares of the three highest Abbreviated Injury Scale scores for each patient, regardless of body region.
Both have similar predictive capacity for mortality, however some studies suggest that the NISS is thought to be a better measure of severity for blunt trauma patients, (31) which constitute most (95%) of injury cases in Australia.

The mechanism of injury, injury location and the number of comorbidities were also included in the analysis. Details of the first hospital provider after the injury were also incorporated into the analysis, as some patients were initially treated at another hospital before being transferred to definitive care.

**Statistical analysis**

The patients were categorized by their IRSD score into four groups (quartiles of relative socioeconomic disadvantage) such that each quartile contained about 25% of the total patient population. Exploratory analysis firstly determined the patients’ age, sex, and injury characteristics and area-level socio-demographic (IRSD) and geographical variables. Categorical variables were summarized using counts and percentages; continuous variables were described according to means and standard deviations (SD). For the bivariate analyses, independent t-tests were used where the variables were normally distributed. Chi-square ($\chi^2$) statistics were used to compare categorical variables. Where the variables were not normally distributed, non-parametric methods were used (Kruskall Wallis H Test, Mann Whitney U Test) and median values reported.

Binary logistic regression was performed to determine the relative odds (adjusted for age and sex) of sustaining injury based on remoteness of residence, injury, referring hospital and State of injury, where, for each factor, IRSD was the main explanatory variable. Similarly, multiple regression was performed to evaluate the relationship between IRSD and the following dependent variables: the number of comorbidities and ISS, NISS. For each analysis, IRSD
was forced into the model to help determine the relationship between IRSD, remoteness and patient and injury factors.

SPSS statistical software (IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp) was used for this analysis. The study received full Ethics approval from the GCH Human Research Ethics Committee, the GCUH Trauma Registry, Griffith University, and approval under the Public Health Act, from the Queensland Government.

**Results**

A total of 1025 patients were identified from the hospital’s Trauma Registry data base for the four-year period 2014 to 2017 (Table 12). Of these 790 (77%) were male and 235 (23%) were female. The median ISS was 17 (IQR 14-26), with 30% of patients in the high ISS category. The median NISS was 24 (IQR 17-34), with 30% of patients in the high ISS category. Compared to those living in ‘Major Cities’, 22% of patients lived in areas defined as ‘regional’ or ‘remote’ and 24% sustained their injuries in these locations (Figure 8). There were 34% of patients with no comorbidities, where 28% had more than two co-morbidities. The median number of comorbidities was 1 (IQR=0-3).

In relation to people sustaining severe injuries (AIS >2), 16% of these were abdominal injuries, 1% external injuries, 25%, injuries to the extremities, 56%, injuries to the chest and 36% sustained severe head injuries. Of those sustaining abdominal injuries (N=371), 43% were severe (AIS>2), for external injuries (N=863), 2% were severe, for extremity injuries (N=629), 41% of injuries were severe, for face injuries (N=229), 19% were severe, for chest injuries (N=709), 81% were severe, and for head injuries (N=536), 69% were severe.
Figure 8. Residential Origin of the study sample (location by central point of the Postal Code – one point may indicate many patients)
Table 12. Socio-demographic and injury data according to sex

<table>
<thead>
<tr>
<th></th>
<th>Male (n=790)</th>
<th>Female (N=235)</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
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</tr>
<tr>
<td>Mean (SD)</td>
<td>49.6 (21.41)</td>
<td>44.4 (18.7)</td>
</tr>
<tr>
<td><strong>Year of admission</strong></td>
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</tr>
<tr>
<td>2014</td>
<td>168 (21.3)</td>
<td>46 (19)</td>
</tr>
<tr>
<td>2015</td>
<td>194 (24.2)</td>
<td>62 (26.4)</td>
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<tr>
<td>2016</td>
<td>230 (29.1)</td>
<td>63 (26.8)</td>
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<tr>
<td>2017</td>
<td>230 (29.1)</td>
<td>64 (27.2)</td>
</tr>
<tr>
<td><strong>Remoteness of residence category</strong></td>
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</tr>
<tr>
<td>Major Cities (766)</td>
<td>590 (76.7)</td>
<td>176 (79.6)</td>
</tr>
<tr>
<td>Regional/Remote (224)</td>
<td>179 (23.3)</td>
<td>45 (20.4)</td>
</tr>
<tr>
<td><strong>State of Injury</strong></td>
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<tr>
<td>A (NSW) (239)</td>
<td>186 (24.8)</td>
<td>53 (23.1)</td>
</tr>
<tr>
<td>B (QLD) (741)</td>
<td>565 (75.2)</td>
<td>176 (76.9)</td>
</tr>
<tr>
<td><strong>Relative Socioeconomic Disadvantage</strong></td>
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<td></td>
</tr>
<tr>
<td>Q1. Most disadvantaged (243)</td>
<td>193 (25.4)</td>
<td>50 (20.6)</td>
</tr>
<tr>
<td>Q2. (245)</td>
<td>192 (25.3)</td>
<td>53 (21.6)</td>
</tr>
<tr>
<td>Q3. (248)</td>
<td>188 (24.7)</td>
<td>60 (24.2)</td>
</tr>
<tr>
<td>Q4. Least disadvantaged (247)</td>
<td>187 (24.6)</td>
<td>60 (24.3)</td>
</tr>
<tr>
<td><strong>Severity- Injury Site (AIS&gt;2)</strong></td>
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<td></td>
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<tr>
<td>Abdominal injuries N, (%)</td>
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</tr>
<tr>
<td>Nil</td>
<td>509 (64.4)</td>
<td>145 (61.7)</td>
</tr>
<tr>
<td>Minor-Moderate</td>
<td>160 (20.3)</td>
<td>51 (21.7)</td>
</tr>
<tr>
<td>Severe</td>
<td>121 (15.3)</td>
<td>39 (16.6)</td>
</tr>
<tr>
<td></td>
<td>Male (n=790)</td>
<td>Female (N=235)</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td><strong>External injuries</strong></td>
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<td></td>
</tr>
<tr>
<td>N, (%)</td>
<td></td>
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</tr>
<tr>
<td>Nil</td>
<td>124 (15.6)</td>
<td>38 (16.2)</td>
</tr>
<tr>
<td>Minor-Moderate</td>
<td>654 (82.8)</td>
<td>195 (83)</td>
</tr>
<tr>
<td>Severe</td>
<td>12 (1.5)</td>
<td>2 (0.9)</td>
</tr>
<tr>
<td><strong>Extremity injuries</strong></td>
<td></td>
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</tr>
<tr>
<td>N, (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td>315 (79.5)</td>
<td>81 (34.5)</td>
</tr>
<tr>
<td>Minor-Moderate</td>
<td>277 (35.1)</td>
<td>95 (40.4)</td>
</tr>
<tr>
<td>Severe</td>
<td>198 (25.1)</td>
<td>59 (25.2)</td>
</tr>
<tr>
<td><strong>Face injuries</strong></td>
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<td></td>
</tr>
<tr>
<td>N, (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td>612 (77.5)</td>
<td>184 (78.3)</td>
</tr>
<tr>
<td>Minor-Moderate</td>
<td>142 (18)</td>
<td>43 (18.3)</td>
</tr>
<tr>
<td>Severe</td>
<td>44 (4.3)</td>
<td>8 (3.4)</td>
</tr>
<tr>
<td><strong>Head Injuries</strong></td>
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<td></td>
</tr>
<tr>
<td>N, (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td>378 (47.8)</td>
<td>111 (47.2)</td>
</tr>
<tr>
<td>Minor-Moderate</td>
<td>132 (16.7)</td>
<td>33 (14.0)</td>
</tr>
<tr>
<td>Severe</td>
<td>280 (35.4)</td>
<td>91 (38.7)</td>
</tr>
<tr>
<td><strong>Chest injuries</strong></td>
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<tr>
<td>N, (%)</td>
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<tr>
<td>Nil</td>
<td>246 (31.1)</td>
<td>70 (29.8)</td>
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<tr>
<td>Minor-Moderate</td>
<td>102 (12.9)</td>
<td>32 (13.6)</td>
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<tr>
<td>Severe</td>
<td>442 (55.9)</td>
<td>133 (56.6)</td>
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<td><strong>ISS</strong></td>
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<tr>
<td>Median (IQR)</td>
<td>17 (14-26)</td>
<td>18 (14-26)</td>
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<tr>
<td>Median (IQR)</td>
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<tr>
<td><strong>Number comorbidities</strong></td>
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<tr>
<td>0</td>
<td>272 (34.4)</td>
<td>74 (31.5)</td>
</tr>
<tr>
<td>1</td>
<td>164 (20.8)</td>
<td>55 (23.4)</td>
</tr>
<tr>
<td>&gt;=2</td>
<td>354 (77.0)</td>
<td>106 (45.1)</td>
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*Missing data =42 (patients’ residences not listed in Australia), ** Missing data=45 ,
**Bivariate association of IRSD with patterns of severe injury for hospitalised patients**

Table 13 shows the association of key injury and geographic variables, with relative socioeconomic disadvantage (IRSD). A total of 983 cases were available for analysis, and additional data were missing for remoteness of residence (0.5%), remoteness of injury location (8%), and State of Injury (4%).

There were no statistically significant differences between IRSD category and age group, year of admission and sex. Similarly, quartiles of IRSD did not significantly vary according to both measures of injury severity, however a positive trend for injury severity and disadvantage is apparent. There is also an apparent trend in injury mechanism where injuries that are not transport related, or caused by falls are twice as likely to occur for people in the most disadvantaged group compared to those in the least disadvantaged group.

Of those who lived in regional or remote areas, 33% were in the ‘most disadvantaged’ category compared to 9% in the ‘least disadvantaged category’. For those people living in major cities the difference is 21% and 29% respectively (p<0.001). Similar patterns were evident for the geographical location of the injury (p<0.001), and for State of Injury (p<0.001).

There were more comorbidities in people in the ‘most disadvantaged’ category (Median=2, IQR 0-3) compared to those in other groups with median values of 1 (p=0.01).

There is a significant association trending towards increased disadvantage according to those patients whose first provider was a hospital other than the main Trauma Centre. For those whose first point of treatment was at a regional hospital (N=197), 27% were in the most disadvantaged category compared to 15% in the least disadvantaged category (p=0.003). This
was related to the State of injury, where, of the 239 cases that were injured across the border from the Trauma Centre, (NSW) 133 cases (56%) were managed at one or more referring hospitals prior to arrival at the tertiary trauma center. This contrasts to those who were injured in Qld where most of the 740 patients (91.4%) were directly managed at the tertiary trauma center in Qld (p<0.001).
Table 13. Association of relative socioeconomic disadvantage with injury patterns

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>IRSD 1</th>
<th>IRSD 2</th>
<th>IRSD 3</th>
<th>IRSD 4</th>
<th>χ²</th>
<th>P</th>
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<tr>
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<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
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<tr>
<td>16-44 (480)</td>
<td>119 (49.0)</td>
<td>128 (52.2)</td>
<td>131 (52.8)</td>
<td>102 (41.3)</td>
<td>10.74</td>
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<td>45-64 (311)</td>
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<td>74 (30.2)</td>
<td>73 (29.4)</td>
<td>86 (34.8)</td>
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<td>65-74 (100)</td>
<td>26 (10.7)</td>
<td>23 (9.4)</td>
<td>19 (7.7)</td>
<td>32 (13.00)</td>
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<tr>
<td>75+ (92)</td>
<td>20 (8.2)</td>
<td>20 (8.2)</td>
<td>25 (10.1)</td>
<td>27 (10.9)</td>
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<tr>
<td><strong>SEX</strong> N (%)</td>
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<tr>
<td>Male (760)</td>
<td>193 (79.4)</td>
<td>192 (78.4)</td>
<td>188 (75.8)</td>
<td>187 (75.7)</td>
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<td>2014 (208)</td>
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<td>58 (23.4)</td>
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<td>5.54</td>
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<td>2017 (249)</td>
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### QUARTILES OF SOCIOECONOMIC DISADVANTAGE

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<th>VARIABLES</th>
<th>IRSD 1 MOST D/A</th>
<th>IRSD 2</th>
<th>IRSD 3</th>
<th>IRSD 4 LEAST D/A</th>
<th>( \chi^2 )</th>
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<td>REMOTENESS (RESIDENCE)</td>
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<td>Major Cities (763)</td>
<td>162 (66.9)</td>
<td>184 (75.1)</td>
<td>193 (78.8)</td>
<td>224 (90.7)</td>
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<td>Regional/Remote (216)</td>
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<td>29.4 (9.3)</td>
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<td>STATE OF INJURY EVENT</td>
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<td>Tertiary Trauma Care (720)</td>
<td>157 (62.6)</td>
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<td>Major Cities (675)</td>
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<td>177 (77.6)</td>
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<td>22 (17, 34)</td>
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## QUARTILES OF SOCIOECONOMIC DISADVANTAGE

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<th>VARIABLES</th>
<th>IRSD 1 MOST D/A</th>
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<th>IRSD 3</th>
<th>IRSD 4 LEAST D/A</th>
<th>( \chi^2 )</th>
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<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
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</tr>
<tr>
<td>FACE</td>
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</table>
## QUARTILES OF SOCIOECONOMIC DISADVANTAGE

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<th>VARIABLES</th>
<th>IRSD 1 MOST D/A N (%)</th>
<th>IRSD 2 N (%)</th>
<th>IRSD 3 N (%)</th>
<th>IRSD 4 LEAST D/A N (%)</th>
<th>χ²</th>
<th>P</th>
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<td>Transport-Pedestrian (46)</td>
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<td>Transport-Cyclist (77)</td>
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<td>Transport-Motorbike (198)</td>
<td>43 (17.9)</td>
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<td>Transport-Vehicle occupant (255)</td>
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<td>71 (29.1)</td>
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<td>Falls (260)</td>
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<td>243</td>
<td>245</td>
<td>248</td>
<td>247</td>
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<tr>
<td>GCUH (795)</td>
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<td>198</td>
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### QUARTILES OF SOCIOECONOMIC DISADVANTAGE

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<tr>
<th>VARIABLES</th>
<th>IRSD 1 MOST D/A N (%)</th>
<th>IRSD 2 N (%)</th>
<th>IRSD 3 N (%)</th>
<th>IRSD 4 LEAST D/A N (%)</th>
<th>$\chi^2$</th>
<th>P</th>
</tr>
</thead>
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<tr>
<td>hospital (187)</td>
<td>47 (19.2)</td>
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</table>

* Kruskall Wallis H Test Statistic

* Includes self-harm, assault, legal intervention, undetermined mechanism

** Excludes school/sports injuries (due to small numbers in cells)
Multivariate association of IRSD with key explanatory injury for hospitalised patients

Table 14 shows the association of IRSD with key geographical parameters, after adjusting for age and sex. The ‘least disadvantaged’ category is the reference category. For each geographical characteristic, there is a statistically significant and positive trend towards increasing disadvantage according to remoteness of residence (p<0.001). People living in regional and remote areas were nearly five times more likely to be in the ‘most disadvantaged’ category compared to those in the ‘least disadvantaged’ category. Similarly, the odds of being injured in a regional and remote area were nearly threefold higher in the ‘most disadvantaged’ category compared to those in the ‘least disadvantaged’ category. Positive, increasing gradients of disadvantage were also evident for injuries occurring in NSW compared to QLD, and where the first provider was a hospital other than the GCUH Trauma Service.
<table>
<thead>
<tr>
<th>Variables</th>
<th>Quartiles of socioeconomic disadvantage</th>
<th>OR (95% CI)</th>
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<td></td>
<td>IRSD 1</td>
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</tr>
<tr>
<td></td>
<td>Most disadvantaged</td>
<td></td>
</tr>
<tr>
<td>Area of residence</td>
<td>Major cities</td>
<td>4.90 (2.95 - 8.15)***)</td>
</tr>
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<td></td>
<td>Regional/Remote</td>
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<tr>
<td>Area of injury incident</td>
<td>Major cities</td>
<td>2.51 (1.63 - 3.89)***)</td>
</tr>
<tr>
<td></td>
<td>Regional/Remote</td>
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<tr>
<td>State of injury incident</td>
<td>Queensland</td>
<td>3.57 (2.28 - 5.58)**)</td>
</tr>
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<td></td>
<td>NSW</td>
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<td>Trauma Centre</td>
<td>2.16 (1.37 - 3.40)**)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
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</table>

*Adjusted for age group and sex, *** p<=0.001, ** p<=0.01, * p<=0.05

In terms of patient factors, there was a statistically significant inverse correlation between the number of comorbidities and disadvantage (p<0.001), however neither measure of injury severity was significantly associated with relative socioeconomic disadvantage (Table 15). Further analysis showed that both ISS (B=2.18, 95% CI 0.80-3.67, p<0.01) and NISS (B=3.25, 95% CI 1.35-4.94, p<0.001) were positively and significantly associated with remoteness of residence independently of age, sex and remoteness of injury site (data not shown). However the number of comorbidities was not statistically significantly associated with remoteness of residence (OR 0.99 95% CI 0.92-1.05, p=0.68) (data not shown).
Table 15: Association of IRSD with patient factors: number of comorbidities and injury severity *

<table>
<thead>
<tr>
<th>Variables</th>
<th>B</th>
<th>(95% CI)</th>
</tr>
</thead>
</table>
| Number of comorbidities | -0.26 (-0.39 - -0.13)***
| ISS                 | -0.77 (-0.60-0.44) |
| NISS                | -0.41 (-1.08-0.27)  |

* Adjusted for age group and sex

*** p<=0.001, ** p<=0.01, *p<=0.05

Further, as Table 16 shows, the relationship between relative socio-economic disadvantage and remoteness of residence persists and in fact strengthens, after adjusting for age, sex, injury severity and remoteness of injury location. In this model ISS was not statistically significant (OR 1.01 95% CI 0.99-1.03, p=0.37) and there was an inverse relationship between disadvantage and remoteness of injury location (OR 0.03, 95% CI 0.02-0.05). The findings for age and sex were not statistically significant in this model.
Table 16. Association of IRSD with residential remoteness, accounting for remoteness of injury location and injury severity#

<table>
<thead>
<tr>
<th>Variables</th>
<th>Quartiles of socioeconomic disadvantage \ OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>IRSD 1 Most disadvantaged</td>
</tr>
<tr>
<td>Regional/remote area of residence</td>
<td>6.21 (3.07-12.57)***</td>
</tr>
</tbody>
</table>

# Adjusted for age group and sex, ISS, remoteness of injury location

*** p<=0.001, ** p<=0.01, *p<=0.05

Discussion

The places in which people live and work are inextricably linked to their health behaviors and health outcomes, however the causal mechanisms through which these factors influence injury risk are unclear. For this study, we applied Marmot’s model of the social determinants of health to better understand the relationship of social disadvantage and residential remoteness in hospitalized patients with severe traumatic injuries.

We found that neighborhood socioeconomic disadvantage is positively linked to residential remoteness, defined by limited accessibility to services, which is most likely occurring in NSW regional areas, compared to QLD. Furthermore, there is a positive and statistically significant gradient of increased risk of disadvantage if living in a regional or remote area. These trends persisted after controlling for age, sex, injury severity and remoteness of injury.
location, where the odds of living in a regional or remote area are nearly six-fold higher for people in the most disadvantaged group, compared to those in the least disadvantaged group.

Additional analysis showed similar significant trends, but of a lesser magnitude, for those who received initial trauma cares from a hospital other than the main trauma center. Unsurprisingly, the numbers of comorbidities in patients were significantly and positively associated with increased disadvantage, but not remoteness. There was no statistical evidence of variations in disadvantage according to the severity of the injuries, injury mechanism and location and the body region of injury, however injury severity was significantly associated with remoteness of residence.

Studies of socioeconomic disadvantage and injury patterns in people who have survived serious trauma long enough to be transported to definitive trauma care are sparse. Furthermore, there is limited evidence of the association of remoteness of residence with disadvantage, independently of where the injury occurred.

Our primary findings are somewhat consistent with those from a large comprehensive Australian study of newly licensed drivers hospitalized for crash injuries. The study reported higher risks for people low SES areas, which persisted after adjusting for rurality and a range of driver behavioral factors.(4) The study sample was considerably younger than our sample. Income was excluded from the SES index and proxy measures of injury severity were analyzed as confounding factors. Elsewhere, a population case-control study of 7,382 trauma patients and residential controls found that cases with low levels of income and education were, for each, independently associated with increased odds of being in the lowest categories of SES.(7) The study also showed associations with comorbidity and disadvantage, similar to our results.
We did not find any associations with injury mechanism and socioeconomic disadvantage and this has been reported elsewhere. (7) However, a large study of neighborhood SES category in adult patients (N=17,658) admitted to a level one trauma center found significant trends for increased admission rates for injuries and disadvantage according to all categories of blunt mechanisms of injury, penetrating mechanism, and injury severity. (32) Other research of hospitalised children has confirmed the relationship between relative socioeconomic disadvantage and transport related injuries. (33).

Contrary to our results, an analysis of hospitalised trauma patients in NSW showed that injury severity did not vary according to rural/urban status, yet the mechanism of injury and the site of severe injury did. Also, road trauma and head injuries were respectively more common in rural areas compared to urban areas. (19)

About 80% of all trauma deaths occur either at the scene, or within a few hours of injury (34) and presumably, in Australia, most of these deaths occur in rural or remote areas. These patients would not be represented on most Trauma Registries. Our sample of hospitalised trauma survivors might explain the non-significant association with injury severity and SES/remoteness, a pattern that has also been reported elsewhere in Australia. (19) Regional hospitals are often the first point of contact for severely injured people in rural areas and evidence is mixed as to whether trauma care regionalization decreases the risk of adverse outcomes compared with patients who are directly transferred to major trauma centers. (35-37) It is possible that many small, regional hospitals are ill-equipped to manage major trauma. If, as our results suggest, these patients more likely to be more disadvantaged, further empirical research about patterns of care in rationalized trauma systems is required to support this view.
Studies of remoteness and injury patterns in Australia further highlight the importance of interpreting the results in the context of the ‘study setting’. In Western Australian (WA) a significant and positive gradient for trauma deaths according to remoteness has been reported, independent of injury severity, age and time to definitive care, with the findings more pronounced in remote to very remote areas.\(^{38, 39}\) WA differs from most of the other States as it has vast areas of remoteness and only one tertiary trauma center in Perth. Transferal of severe trauma cases often involves travel distances of thousands of kilometers.\(^{38}\) Hence, the geographical characteristics of WA are quite different to our study setting, which straddles the NSW and Qld border and where most of the population lived in major cities or ‘inner regional’ areas. Distance to definitive care is vastly less here, compared to those injured in WA. However, the WA study supports the concept that remoteness is more than just a ‘distance’ measure to services, but most likely reflects the social, environmental and economic fabric of neighborhoods that differentially expose people to injury risk.

**Limitations**

Multiple, interacting ecological factors underlie the expression of individual behaviors and provide a framework for understanding the socioeconomically disadvantaged communities in which people live. The ecological fallacy is also an important consideration where area-level SES exposure was used as a proxy for individual SES status, limiting our ability to account for factors that confound the relationship between an individual’s SES and injury patterns. However, the IRSD is a widely used and robust index of SES in Australia. As a multi-faceted measure, it appropriately captures the community context, particularly its wealth, which in turn influences the quality of municipal services, road conditions, crime rates and access to material resources that could mitigate injury risk.
Trauma patients who survive serious injuries to receive definitive trauma care at a Level 1 Trauma Centre represent a unique, highly select group of severe trauma survivors and care should be taken in terms of extrapolating these findings to all cases of traumatic injuries in other settings. Arguably, the many different dimensions of SES are specific to time and place. In terms of acute serious trauma, there are numerous, unmeasured confounding factors in place, particularly in relation to known variations in patterns of pre-tertiary care, care given by the ‘first provider’ along with different types of transportation modalities to the Trauma Centre. Trauma systems are State-based and the extent of cross-border variations in trauma referrals and management are not known. The characteristics of our hospital sample might not be comparable with the findings of other studies.

Compared to other studies our sample size was relatively small and it is possible that our study lacked sufficient study power to detect real differences if any existed. Additionally, we could not examine SES in relation to people living in remote or very remote areas, or the impact of race on these associations. Aboriginal people are more likely to live in regional areas and have higher rates of disadvantage.

**Conclusions**

Severely injured trauma patients who are from social and economically disadvantaged communities are more likely to reside in areas that have comparatively less access to service centres. They tend to have more comorbidities and have received initial trauma care from a regional hospital, mostly located in NSW rather than the Trauma Centre located in QLD. These factors are all potentially important in terms of understanding variations in trauma outcomes in this study region. Studies of social and economic disadvantage in relation to
injury risk and outcomes should include measures of co-morbidity, the first provider of care and remoteness of residence, in addition to injury location.
References


27. ABS. *Socio-economic indexes for areas: robustness, diversity within larger areas and the new geography standard*. Australian Bureau of Statistics; 2012.


34. Trunkey D. Accidental and intentional injuries account for more years of life lost in the US than cancer and heart disease. Among the prescribed remedies are improved preventive efforts, speedier surgery and further research. *Sci Am.* 1983;249:28-35.


Chapter 6: Results for Study 3. The importance of place of residence on hospitalized outcomes for severely injured trauma patients: A Trauma Registry Analysis.

Overview

Physiological and other clinical factors have dominated prognostic research work in early severe trauma, yet there is increasing recognition that Registries should adapt data collection methods to accommodate long term surveillance of trauma patient outcomes. Australian data reports show that there is an over-representation of injured patients who are socioeconomically disadvantaged. While the definition of a ‘resilient’ community is complex and not yet clearly defined, evidence is emerging that key factors are a high population density, economic prosperity and strong communication and support systems. Early identification of patients at risk for poor outcomes in terms of their social, economic and physical environment after discharge could influence decisions about management and rehabilitation.

This purpose of this study was to build on the data analysis of Study 3, to examine characteristics of patients’ neighborhood, specifically socioeconomic disadvantage and residential on trauma outcomes. In the absence of routinely collected post-discharge outcomes for Trauma Registry patients, this study analysed acute inpatient outcomes in relation to these two ecological variables: acute length of stay days (ALSD) and inpatient mortality.
Statement of Contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication in *Journal Rural Health* as an original research paper. Evidence for submission is below.


The research candidate has made the following contributions to this study:

- Identified research gaps and designed the study.
- Completed all the required documentation for human research ethics approval from Griffith University Human Research Ethics Committee (Protocol Number: (GU Ref No: 2017/879) and the Gold Coast Health Ethics Committees (HREC/17/QGC/256 ) and the Queensland Health Public Health Act approval (Reference number RD007132)
- Analysed the data and interpreted the findings.
- Prepared the manuscript and submitted it for peer review and publication: April 2019.
- Revised the manuscript, addressing Reviewers’ comments, and re-submitted it on 17 July 2019. *(This Chapter is the revised version, currently under review)*

Signed:

(Supervisor and corresponding author: Jing Sun)

258
Evidence of re-submission to ‘Journal of Rural Health’ (revised document)

17 July 2019

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**Submission Confirmation**

Thank you for your revision

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</tr>
<tr>
<td>Authors</td>
<td>Heathcote, Katherine; Wulfschlegler, Martin; Gardiner, Ben; Morgan, Geoffrey; Bittaggin, Holly; Sun, Jieq</td>
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<td>Date Submitted</td>
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The importance of place of residence on hospitalised outcomes for severely injured trauma patients: A Trauma Registry analysis

Abstract

Purpose

Socio-ecological factors are relatively understudied in trauma patients’ hospital outcomes. This study investigated the association of neighbourhood socioeconomic disadvantage (SED) and remoteness of residence on acute hospital stay days (ALSD) and inpatient mortality.

Methods

A retrospective cohort study was conducted on adults hospitalised for major trauma in a level 1 Trauma Centre, in South East Queensland from 2014 to 2017. Neighborhood SED and remoteness of residence and of injury site were linked to patient variables. Step-wise multivariable negative binomial regression and proportional hazards regression analyses were undertaken, adjusting for age, injury factors, mechanism and comorbidity. Outcome variables were acute length of stay days (ALSD) and inpatient mortality.

Findings

1025 patients were analysed. Increased hazard of inpatient mortality was found for age (75+), (HR 3.53, 95% CI 1.77-7.11 p=0.003), higher ISS (HR 5.27, 95% CI 2.78-10.02, p<0.001), and injury mechanisms related to intentional self-harm or assault (HR 2.72, 95% CI 1.48-5.03, p=0.001). Increased risk for longer ALSD was evident for: older age (65-74) (RR 1.37, 95% CI 1.10-1.83), head injury (HR 1.36 95% CI 1.15-1.62, p<0.001), extremity injuries (RR 1.62 95% CI 1.36-1.94 p<0.001), higher ISS (RR 2.05, 95% CI 1.76-2.39, p<0.001), discharge to rehabilitation facility (RR 1.75 95% CI 1.43-2.14, p<0.001).
Conclusions

Rural patients sustaining severe traumatic injuries are more likely to be socioeconomically disadvantaged and have injuries predisposing them to worse hospital outcomes. Further research is needed to understand more about care pathways and the severity, mechanism and clinical consequences of severe traumatic injury in rural areas.

Introduction

There have been substantial reductions in the number of fatalities that result from injuries in countries like Australia, where modern integrated trauma systems exist(1-4). However, as more people survive and receive definitive trauma care, increased rates of hospitalisation(5) and morbidity(6, 7) have ensued. Almost half a million people are hospitalised each year in Australia because of injuries(8), and injury hospitalisations have been estimated to cost upwards, annually of around five billion dollars(9).

The healthcare system has only a small influence on health outcomes when compared to the social, structural, environmental and economic factors that characterise a person’s ‘place of residence’ or their neighbourhood(10). Socio-ecological factors are thought to act as distal exposures, influencing individuals’ health behaviours, which in turn interact with biological and physiological processes that are more proximal to disease causation(11). They provide a contextual framework for understanding and addressing health inequalities, and can be used to potentially promote positive functional outcomes after trauma(12). Neighbourhoods suffering socioeconomic disadvantage (SED), best conceptualised as a multifaceted indicator of average income and education, housing values, labour force participation, and employment, are associated with a higher risk of serious injury and death(13-18), even after
controlling for individual factors such as personal income and education\(^\text{(15, 17)}\). The potential for a ‘place’, therefore, to be a risk factor to all its inhabitants, as opposed to just some of them, has prompted concerns that unless contextual factors are addressed, individual risk and inequalities will fester \(^\text{(19-21)}\).

There has been little research on how ‘place’ in all its forms affects outcomes after traumatic injuries. This is an emerging area of public health concern, given that more patients are surviving serious trauma, resulting in hospital admission followed by discharge back to their place of residence. Most studies of socio-ecological factors and trauma outcomes draw on population data sources, yet there is comparatively little information available on the influence of the various dimensions of ‘place’, where a complex range of factors relating to access and disadvantage may have an influence on specialised healthcare. Patients who have survived serious trauma to be admitted to a Level 1 Trauma Centre (one that provides the highest level of trauma care) therefore represent a highly select cohort of survivors.

Various components of SED, usually expressed as median income, have been used to predict inpatient trauma deaths in countries without universal health coverage\(^\text{(22, 23)}\); however, not all these studies have accounted adequately for injury severity, which is also associated with SED. The period of hospitalisation, which reflects patient morbidity, and to some extent injury severity, tends to be longer for trauma patients suffering the most social and material deprivation\(^\text{(24, 25)}\).

Because access to definitive trauma care is critical for survival, rural location, another component of ‘place’, has been widely studied in relation to trauma outcomes. Rural and remote areas in Australia are characterised by long distances between centers, lower population density, poorer health infrastructure and fewer resources for dealing with severe
trauma(26). When compared to urban Australians, rural residents, particularly those living in the most remote parts of the country, are at greater risk of injury and death(27) despite advances in integrated trauma systems(28).

Research into the impact of remoteness of residence on hospital trauma outcomes in Australia has produced conflicting results. This is possibly because of variations in the ways in which ‘place’ has been studied (either as remoteness of residence or as remoteness of injury location), selective survivorship, or unmeasured variations in care and triage decisions in regional trauma services, which are often the first point of care for patients requiring stabilisation before transferal to definitive trauma care(26).

For the most part, and in the absence of other, more precise measures, remoteness is measured in Australia using an unambiguous index of geographical distance to service centers. Conceptually, ‘access’ is at the forefront of this measure, yet notably, it does not specifically measure access to definitive trauma care. Based on this measure, it seems that in-patient mortality for those injured in rural locations has improved over time(29), suggesting that factors such as the regionalisation of trauma centers and improved transport to tertiary care are important(30). In Western Australia, where there are vast areas that are very distant from there is compelling evidence that mortality increases according to the remoteness of the site where the injury occurred(27). Other studies have shown an increased risk of death in hospital for patients residing in rural areas compared to urban patients after accounting for traditional prognostic factors(31, 32). For brain-injured patients in NSW, length of hospital of stay does not appear to vary according to rural/urban residence(33).

In Australia, socioeconomic disadvantage and a rural place of residence are closely related, and this has recently been shown for severely injured hospitalised patients(34). The various
dimensions of ‘place’ are rarely studied together in relation to trauma patients and trauma outcomes, so it is unclear whether poorer outcomes are the result of preventable factors embedded within disadvantaged rural neighbourhoods, or whether the issue is with geographical access to essential trauma care. The prevailing theory is that in terms of rural/urban health disparities, entrenched SED is the most important factor, but that this is compounded by remoteness (35).

Identification of patients at risk of poor trauma outcomes because of their social, economic and physical environment could influence decisions about early management and prognosis after discharge. The aim of this study is to model the prognostic importance of the various dimensions of ‘place’ on the outcomes of patients hospitalised in a tertiary trauma center in South East Queensland (SE QLD), Australia. These include a multi-faceted index of neighbourhood SED, unambiguous measures of geographical remoteness of residence and of injury location, and the location of the first care provider. The catchment area for this trauma center incorporates just one major city and includes regional areas that cross two state borders. The hospital does not typically receive patients from very remote areas; this study therefore offers a unique perspective on the effect of regional trauma patterns on patient outcomes, which may differ from studies of trauma outcomes in remote areas of Australia.

**Methods**

*Study design and study setting*

Detailed information about the study population and setting is published elsewhere (34). Briefly, the study was a retrospective cohort study of adult injury cases hospitalised for >24 hours, in a Level 1 Trauma Centre in SE QLD, Australia. Eligible patients were sourced from
the Hospital’s Trauma Registry and satisfied the standard criteria for a major trauma event, aged over 18 years, and admitted to the hospital for at least 24 hours, from January 2014 to December 2017. The study received full Ethics approval from the Human Research Ethics Committees of the tertiary hospital and the affiliated University (HREC/QGC/256) and from the Queensland Government who granted approval to access patient data via the Public Health Act (RD007485).

The hospital provides trauma care for severely injured patients across two State borders, including the wider population in the designated catchment area of SE QLD and patients injured in mostly regional areas of northern New South Wales (NSW). The catchment area for injury admissions includes people mostly living in major cities in SE QLD (68%), with the remainder coming mostly from inner regional areas of the catchment area in both States, which is dominated by patients transferred from northern NSW (71%). Both States have advanced trauma services, with well-developed rural and regional referral networks.

‘Place’-related Variables

Area level measures of relative disadvantage and remoteness were developed using the Australian Statistical Geography Standard (ASGS) framework, and geocoded information about the patients’ residential address at the time of injury and Census Tract data.(36)

Neighbourhood Socioeconomic Disadvantage

The Index of Relative Socioeconomic Disadvantage (IRSD) was used as an area-level proxy measure to describe individual socio-economic status.(36-38) This index does not incorporate any measure of remoteness, and is multi-faceted, defined by 17 different pieces of information depicting the relative wealth of a community, and its capacity to use its material and social resources and participate in society (STable 1, Supplemental Tables). Each patient
was assigned an IRSD score. A low score indicated relatively greater rates of disadvantage in that area compared to other areas, and is characterised by many low-income families, people with little training and working in unskilled occupations A high score indicates a relative lack of disadvantage according to these characteristics.

**Geographical remoteness of residence**

Remoteness of residence for the study sample was represented by an index describing the physical distance of a location from the nearest urban center, otherwise, a proxy measure of the level of access to goods and services (36) Study participants were divided into 5 classes of remoteness based on their relative access to services, otherwise known as Remoteness Areas (RAs). A value of ‘1’ defines Major cities of Australia, ‘2’ defines Inner Regional Australia, ‘3’ is Outer regional Australia, ‘4’ is Remote Australia and ‘5’ defines ‘Very Remote Australia. Because of small numbers of cases in categories 3,4 and 5 (N=26), all were combined with category 2. For this study, the ‘major city’ was most likely to be the city where the Trauma Centre is located.

**Geographical location of injury site**

Postcode of injury location was used to create two variables, one describing the State in which the injury occurred (NSW or QLD) and the other describing the ASGS remoteness categories, (RA) as described above.

**First provider**

Details of the first hospital provider after the injury were recorded, as some patients were initially treated at a regional hospital before being transferred to definitive tertiary Trauma care.
**Individual patient factors**

Patient covariates for the study included age, sex, injury severity, Glasgow Coma Score (GCS), injury mechanism, number of comorbidities, discharge disposition for trauma survivors (home, or rehabilitation) and anatomical region of injury defined by the Abbreviated Injury Scale (AIS). (39) Polytrauma was defined as AIS >2 in 2 or more AIS regions. Injury severity was defined using the Injury Severity Score (ISS), an ordinal scale ranging from 1 to 75, reflecting the sum of the highest AIS scores for the three most severely injured body regions. The mechanism of injury and number of comorbidities were derived from standard ICD-10 codes. Injury mechanism was divided into 4 groups detailing injuries caused by transport, falls, ‘other external causes’ and intentional causes.

**Outcome variables**

The two outcomes for this study were death in hospital and a measure of morbidity described as the number of days spent receiving acute care for patients who survived to hospital discharge. This latter measure was the preferred measure of morbidity compared to hospital length of stay, as it excludes time spent in hospital receiving other forms of care such as rehabilitation, palliative care or mental health care, which could produce spuriously inflated estimates of time spent receiving trauma care. The acute length of stay days (ALSD) was coded according to standard criteria (https://meteor.aihw.gov.au/content/index.phtml/itemId/181162).

**Statistical analysis**

The IRSD scores were categorised into quartiles to create an ordinal variable. A dichotomised measure of ISS was produced by plotting a receiver operator curve (ROC) of ISS scores against in-hospital mortality. The cut-off was defined as the point that maximized
the true positive rate of the statistical model whilst minimising the false positive rate. The Area under the Curve (AUC) for ISS was 78.6%, (95% CI 0.72-0.84, (p<0.001)).

Chi-square ($\chi^2$) statistics were used in bivariate analysis to compare categorical variables. Where continuous variables were not normally distributed, non-parametric were used. For the mortality outcome, Kaplan Meier estimates were plotted for each independent (factor) variable, to describe the cumulative proportion of deaths in acute care and the median time to death for the study sample. The Log Rank statistic was used to identify statistically significant differences between the groups. Patients were censored if they did not die during the acute phase of hospital care.

Regression modeling was done to examine the independent contribution of neighbourhood patient factors responsible for both outcomes (40). As the various definitions of ‘place’ defining rurality and disadvantage were highly correlated, decisions to include any of these variables in the final multivariate models (for both outcomes) were made based on the statistical results from the ‘goodness of fit’ in the model. The final models were built by entering the covariates were entered one at time to enable a step-by-step assessment of the goodness of fit of the model, the statistical significance of the covariate in the model, and the presence of correlating variables.

For the morbidity outcome, a negative binomial regression analysis was performed to predict the number of acute stay days based on the main explanatory factors with confounding factors. Variables were included into the models if they were deemed to be clinically important confounders, or if p values were statistically significant in the bivariate analysis at p<0.10. Goodness of fit was assessed using the Pearson Chi Squared Goodness of Fit and the
Likelihood Ratio Chi Squared statistic. The exponentiated values, \( \exp(b_i) \) or risk ratios of the co-efficient estimates are reported as the main effect estimates, risk ratios.

For mortality, variables identified as important from the Kaplan Meier analyses were incorporated in a multi-level regression model. The individual trauma patient data were defined as Level 1, nested within the spatial units of analyses (Level 2), defined as SA4, or Statistical Local Areas 4. Random effect terms were used to account for correlation of individuals nested within the same spatial group. This analysis of areas did not show statistically significant, independent neighbourhood effects on mortality.

As the precision of multi-level modeling is highly dependent on the number of outcomes and ecological units for analysis, we subsequently performed Cox Proportional Hazards Regression multivariate analyses. Contributing predictors to the model were determined by successive Chi Square changes from previous steps between the -2 log-likelihood of the model, and the statistical significance (p value) being as \(<0.05\). The hazard ratios (HR), defined by the exponentiated values of the co-efficient estimates \( \exp(b_i) \) were produced for each covariate and interpreted as the predicted change in the hazard for a unit increase in the predictor. Results for all models are reported with their respective 95% intervals.

SPSS statistical software (IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp) was used for this analysis.

**Results**

A detailed description of the study sample is published elsewhere and shown in the Appendix (STable 2). Briefly, 1025 patients were available for analysis with the mean age of 45 years and 790 (77%) were male. A total of 67 people died in hospital, and the crude
cumulative mortality rate for the study period was 6.1%. The median length of acute stay days was 8 (IQR 14). Table 3 (Supplemental Tables) describes the bivariate associations of patient and injury factors in relation to the main area-level variables of interest. Most people who resided in rural locations were injured in rural locations. Rurality overall, was statistically significantly associated with SED, ISS, NSW State of residence, first provider (regional), injury mechanism, GCS, polytrauma, external injuries and head injuries. Rural residents were also significantly more likely to be discharged to a rehabilitation facility compared to their urban counterparts. Lower SED was significantly associated with some, but not all factors also related to rurality, including remoteness of injury site and residence, NSW State of residence and GCS.

**Inpatient mortality**

The bivariate associations of individual and area-level factors with crude hospital mortality are shown in Table 17. There is a significant and positive gradient of increasing hazard of death according to SED. Similar patterns were seen for age group. Inpatient deaths were also significantly associated with injury mechanisms other than transport causes, along with injuries to the head where patient were around 6 times more likely to die compared to those without head injuries. People with severe GCS and higher ISS were 9 and 7 times at higher risk of death compared to those with mild to moderate GCS and lower ISS. There was an inverse association between mortality and injuries to the extremities, however, because of small number of deaths for this injury site, this estimation is relatively unstable. People living in regional areas were more than twice as likely to die in hospital compared to people in major cities with similar, significant trends apparent for those who were injured in regional or
remote areas, and in NSW compared to QLD. There was no significant association between first provider of care and mortality.

Table 17: Bivariate analysis: Association of injury patterns, remoteness and socioeconomic factors with inpatient deaths

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<tr>
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<td>24 (6.9)</td>
<td>1.00</td>
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<td>1 or more</td>
<td>636 (93.7)</td>
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<td>706 (98.1)</td>
<td>14 (1.9)</td>
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<tr>
<td>&gt;=24***</td>
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<td>Mild/Mod</td>
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<td>Severe</td>
<td>116 (74.4)</td>
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<td>AIS &gt;2 in 2 or more AIS regions/</td>
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<td>0.60-1.65</td>
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<td></td>
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<td>Abdomen</td>
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<td></td>
<td></td>
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<td>* (3.8)</td>
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<td>Chest</td>
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<td>* (7.1)</td>
<td>1.44</td>
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<td>Extremity</td>
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<td>No</td>
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<td>0.09–0.52***</td>
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<td>Yes</td>
<td>250 (97.3)</td>
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### Face

<table>
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<th>Yes</th>
<th>p-Value</th>
<th>95% CI</th>
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<td></td>
<td>917 (93.5)</td>
<td>41 (93.2)</td>
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<td>0.18 – 2.94</td>
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### Head<sup>c</sup>

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<tr>
<td></td>
<td>638 (97.6)</td>
<td>320 (86.3)</td>
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<td>2.94 – 9.01***</td>
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### IRSD: Socioeconomic disadvantage<sup>a,c</sup>

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<th>No</th>
<th>Yes</th>
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</thead>
<tbody>
<tr>
<td>Least disadvantaged</td>
<td>238 (96.4)</td>
<td>234 (94.4)</td>
<td>1.00</td>
<td>0.718-3.82</td>
</tr>
<tr>
<td>Disadvantaged</td>
<td>26 (6.5)</td>
<td>9 (2.4)</td>
<td>1.00</td>
<td>0.97-4.73</td>
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<tr>
<td>Q2</td>
<td>226 (92.2)</td>
<td>19 (7.8)</td>
<td>1.00</td>
<td>0.97-4.73</td>
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<tr>
<td>Q3</td>
<td>223 (92.1)</td>
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<td>1.00</td>
<td>0.97-4.73</td>
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<tr>
<td>Most disadvantaged</td>
<td>64 (6.5)</td>
<td>16 (2.4)</td>
<td>1.00</td>
<td>0.718-3.82</td>
</tr>
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</table>

### Remoteness of residence<sup>c</sup>

<table>
<thead>
<tr>
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<th>Yes</th>
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<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major cities: GC</td>
<td>727 (94.9)</td>
<td>39 (5.1)</td>
<td>1.00</td>
<td>1.12-3.09**</td>
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<td>Regional/remote</td>
<td>199 (89.2)</td>
<td>24 (10.8)</td>
<td>1.86</td>
<td>3.09-5.01**</td>
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### Remoteness of injury location<sup>c</sup>

<table>
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<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major cities: GC</td>
<td>663 (94.7)</td>
<td>37 (5.3)</td>
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<td>1.29-3.42**</td>
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<td>Regional/remote</td>
<td>216 (88.2)</td>
<td>29 (11.8)</td>
<td>2.10</td>
<td>1.29-3.42**</td>
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### State of Injury<sup>c</sup>

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<th>Yes</th>
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<th>95% CI</th>
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<td>QLD</td>
<td>701 (94.6)</td>
<td>40 (5.4)</td>
<td>1.00</td>
<td>1.11-2.98*</td>
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<tr>
<td>NSW</td>
<td>212 (89.1)</td>
<td>26 (10.9)</td>
<td>1.82</td>
<td>1.11-2.98*</td>
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### First Provider

<table>
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<th>p-Value</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tertiary Level 1 Centre</td>
<td>771 (93.3)</td>
<td>55 (6.7)</td>
<td>1.00</td>
<td>0.42-1.52</td>
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<tr>
<td>Regional /Other</td>
<td>186 (94.4)</td>
<td>11 (5.6)</td>
<td>0.79</td>
<td>0.42-1.52</td>
</tr>
</tbody>
</table>

---

***p<=0.001, **p<=0.01, *p<=0.05

<sup>a</sup> Excludes 10 cases of undetermined mechanism

<sup>a</sup>Data not shown (N<10) to preserve patient confidentiality

<sup>b</sup> Excludes 1 patient who died after the acute phase of care.

<sup>c</sup> Log Rank (Mantel-Cox) Statistic <0.05

<sup>d</sup> Log Rank (Mantel-Cox) Statistic <0.10, >= 0.05

---

**Multi-variate analyses**

Statistically significant covariates entered in the baseline model included patient age, injury severity and AIS head injury. Glasgow coma score was significantly correlated with ISS (p<0.001). Because of the high probability that low GCS scores in the Registry reflected intubated patients and given that ISS is a stronger and more widely accepted predictor of mortality the decision was made to retain ISS in the model. Other AIS regions that were
statistically significant in the bivariate analysis were not examined because of extremely small cell counts (N<5) in the mortality category.

The positive trend for IRSD and mortality remained but was not significant. As remoteness of injury location was a better statistical fit compared to remoteness of residence it was therefore included in the final model (See Table 18). This showed that people who were injured in a relatively remote location were nearly twice as likely to die (HR 1.75 95% CI 1.86-2.89) compared to those injured in major cities (p=0.028). Other important covariates in the final model included increased age (p=0.003), where, for patients over 75 years, the hazard for death is 3.53 times higher, compared to younger patients aged 16-44 years. For patients with ISS scores over 23 the hazard of dying is five times higher compared to those with less severe injuries (p<0.001). Compared to people who had transport related injuries, people with injuries that were self-inflicted, caused by assault or involved external legal interventions were nearly 3 times more likely to die compared to those who sustained transport related injuries. Patients sustaining head injuries were 2.53 times more likely to die compared to those without head injuries (HR 2.53 95% CI 2.78-10.02, p=0.028)
Table 18: Multivariate analysis: Predictors of in-hospital deaths##

<table>
<thead>
<tr>
<th>Variables</th>
<th>HR</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-44</td>
<td>1.00</td>
<td>0.61-2.06</td>
<td>0.003</td>
</tr>
<tr>
<td>45-64</td>
<td>1.19</td>
<td>0.66-1.18</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>1.06</td>
<td>0.43-2.62</td>
<td></td>
</tr>
<tr>
<td>75+</td>
<td>3.53</td>
<td>1.77-7.11</td>
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</tr>
<tr>
<td><strong>Injury Severity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>1.00</td>
<td>2.78-10.02</td>
<td>&lt;0.001</td>
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<tr>
<td>High</td>
<td>5.27</td>
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<td><strong>Head Injury</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td>1.38-4.62</td>
<td>0.003</td>
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<tr>
<td>Yes</td>
<td>2.53</td>
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</tr>
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<td><strong>Injury Mechanism</strong></td>
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<td></td>
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</tr>
<tr>
<td>Transport</td>
<td>1.00</td>
<td>0.66-2.29</td>
<td>0.001</td>
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<tr>
<td>Falls</td>
<td>1.23</td>
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<tr>
<td>External – other causes</td>
<td>2.72</td>
<td>1.48-5.03</td>
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<tr>
<td>Intentional/Self</td>
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<tr>
<td>Harm/Assault/Legal interventions</td>
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<tr>
<td><strong>Remoteness of injury location</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Major cities</td>
<td>1.00</td>
<td>1.06-2.89</td>
<td>0.028</td>
</tr>
<tr>
<td>Regional/Remote</td>
<td>1.75</td>
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</table>

# Excludes 10 cases of undetermined mechanism

## Excludes 1 death that did not occur during acute care phase

**Acute length of stay days (ALSD)**

The ALSD analysis was conducted on all trauma patients who survived hospitalisation to discharge. Bivariate analyses of median values for individual and area-level factors with ALSD are shown in Table 19. The median length of acute stay days was higher, by 3 days for older people (over 65 years) and people living in regional and remote areas, where the median ALSD was 12 days compared to 8 days for urban dwellers (p<0.001). For those injured in NSW median ALSD was on average, 3 days more than those injured in Qld (p<0.001). Risk for longer ALSD was more than doubled for people with higher ISS compared to those with lower ISS (p<0.001). Similar patterns were evident for patients with polytrauma. The median ALSD for those with 1 or more comorbidities was 9 days compared
to 7 days for patients with no comorbidity (p=0.004). Patients with injuries to the chest, abdomen, extremities and head had a significantly higher median length of acute stay days (p<0.001). For those patients who were ultimately discharged to other facilities, the median ALSD was nearly three times that of patients who were discharged home (p<0.001). Patients with severe GCS scores had a median ALSD three times that of those with mild to moderate GCS scores. (p<0.001).

**Table 19: Bivariate analysis: Association of injury, regional and socioeconomic factors with acute length of stay days (ALSD) for trauma survivors**.

<table>
<thead>
<tr>
<th>Level of Variable (N)</th>
<th>Length of acute stay</th>
<th>Test Statistic #</th>
<th>P</th>
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<tr>
<td><strong>Median (IQR)</strong></td>
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<td><strong>Age group</strong></td>
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</tr>
<tr>
<td>16-44 (506)</td>
<td>7.00 (4,16)</td>
<td>10.17</td>
<td>0.038</td>
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<tr>
<td>45-64 (324)</td>
<td>9.00 (4,19.75)</td>
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<tr>
<td>65-74 (102)</td>
<td>10.00 (5,22)</td>
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<tr>
<td>75+ (93)</td>
<td>10.00 (5,18)</td>
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<tr>
<td><strong>Sex</strong></td>
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<td></td>
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<tr>
<td>Male (790)</td>
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<td>89132</td>
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<tr>
<td>Female (235)</td>
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<td><strong>Comorbidity group</strong></td>
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<td>0 (346)</td>
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<td>N (%)</td>
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<td>3. (248)</td>
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<td>4. Least disadvantaged. (247)</td>
<td>9.00 (4,23)</td>
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<td><strong>Remoteness of residence</strong></td>
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<td>Major cities (766)</td>
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<td>Major cities (700)</td>
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<td>9.00 (4.75, 20.25)</td>
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<tr>
<td>Abdomen</td>
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<tr>
<td>Chest</td>
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<td>103615&lt;sup&gt;#&lt;/sup&gt; &lt;0.001</td>
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<td>Yes (542)</td>
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<tr>
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<td>Extremity</td>
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<tr>
<td>Face</td>
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<td>9.0 (4,19)</td>
<td>17540 0.47</td>
</tr>
<tr>
<td></td>
<td>Yes (41)</td>
<td>6.0 (3,25)</td>
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</tr>
<tr>
<td>Head</td>
<td>No (638)</td>
<td>8.0 (4,15)</td>
<td>83487&lt;sup&gt;#&lt;/sup&gt; &lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Yes (320)</td>
<td>11.0 (5.27)</td>
<td></td>
</tr>
<tr>
<td><strong>First Provider</strong></td>
<td>GCUH (827)</td>
<td>8.00 (4,18)</td>
<td>75438&lt;sup&gt;#&lt;/sup&gt; 0.106</td>
</tr>
<tr>
<td></td>
<td>Regional /Other hospital (197)</td>
<td>9.00 (5,18)</td>
<td></td>
</tr>
<tr>
<td><strong>Discharge Disposition</strong></td>
<td>Home (698)</td>
<td>7.00 (4-12)</td>
<td>18273.5&lt;sup&gt;#&lt;/sup&gt; &lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation (141)</td>
<td>26.00 (14.5-30)</td>
<td></td>
</tr>
</tbody>
</table>

*Excludes 10 cases of undetermined mechanism

** Excludes in-hospital deaths

<sup>#</sup> Test statistic is Mann -Whitney U Test. All other statistical Tests are Kruskal-Wallis Tests
Statistically significant covariates in the baseline confounder model included patient age, injury severity, head, and extremity injuries and discharge disposition. When residential remoteness was entered into the final model, all baseline covariates retained statistical significance in the model, apart from remoteness of residence (RR 1.05 95% CI 0.87-1.27). As Table 20 shows, there was notably a sustained increased risk according to age, most pronounced in the second oldest age category where risk of mean ALSD was 1.37 times higher than that compared to younger patients. For patients with ISS scores over 23, the risk of a higher median ALSD was 1.5 times that of patient with lower ISS (p<0.001). The estimates of the other injury-related covariates were of a similar magnitude and all statistically significant (p<0.001); extremity injuries (RR 1.62) and head injuries (1.36).

Table 20: Multivariate association of relative socioeconomic disadvantage, rurality of residence and patient factors with acute length of stay days (ALSD) for trauma survivors.

<table>
<thead>
<tr>
<th>Variables</th>
<th>RR</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-44</td>
<td>1.00</td>
<td>0.99-1.36</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>45-64</td>
<td>1.16</td>
<td>1.10-1.83</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>1.37</td>
<td>0.97-1.37</td>
<td></td>
</tr>
<tr>
<td>75+</td>
<td>1.26</td>
<td>0.97-1.37</td>
<td></td>
</tr>
<tr>
<td>AIS Extremity Injury</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.62</td>
<td>1.36-1.94</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>AIS Head Injury</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.36</td>
<td>1.15-1.62</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Injury Severity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>1.49</td>
<td>1.25-1.79</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Discharge disposition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation facility</td>
<td>1.75</td>
<td>1.43-2.14</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Remoteness of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major cities</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regional/Remote</td>
<td>1.05</td>
<td>0.87-1.27</td>
<td>0.59</td>
</tr>
</tbody>
</table>

As Table 20 shows, there was notably a sustained increased risk according to age, most pronounced in the second oldest age category where risk of mean ALSD was 1.37 times higher than that compared to younger patients. For patients with ISS scores over 23, the risk of a higher median ALSD was 1.5 times that of patient with lower ISS (p<0.001). The estimates of the other injury-related covariates were of a similar magnitude and all statistically significant (p<0.001); extremity injuries (RR 1.62) and head injuries (1.36).
Notably, the risk of length of longer median acute stay was nearly twice that for patients who were discharged to a rehabilitation facility compare to home (RR 1.75).

**Discussion**

This study linked area-level dimensions of ‘place’ to individual trauma patients to examine contextual factors on hospital outcomes. Rurality of residence had little impact on the length of acute stay days. These findings are somewhat aligned with other work.(9) Australian studies of brain-injured patients(33) and a large cohort study of all NSW trauma patients have also reported little differences in rural/urban variations in length of stay.(9) However the length of acute stay days was not measured in these other studies and not all studies were of patients from Level 1 Trauma Centers.

Trauma patients from rural areas in our study were significantly more likely to have a higher injury severity (35%) compared to those living in urban areas (28%), thereby requiring longer stays in acute care. This factor, in conjunction with relatively limited access to rehabilitation services in rural areas is the most plausible explanation for our findings. Injuries to the head and extremities were also significantly associated with longer length of acute care stay, independently of other factors. The findings in relation to head injuries are not unexpected assuming that TBI is most likely involved. Evolving damage to the brain and secondary injuries are serious consequences of TBI, increasing the likelihood of inpatient death and prolonging acute hospital care. Injuries to the extremities involve the upper, and lower limbs and the pelvis. If these injuries involved vascular trauma, limb loss, amputations or poly-trauma, then the risk of death is higher and longer stays in acute care are expected. However, musculoskeletal injuries to the extremities, in general, are costly and typically associated with
ongoing pain, disability and poor function. Evaluation of acute care management on rehabilitation outcomes could help to justify the expense associated with longer stays in acute care for extremity injuries.

Our study found that longer length of ALSD was significantly related to discharge disposition, specifically discharge to a rehabilitation facility compared to discharge home or to self-care. Notably in our cohort, rurality of residence was strongly and significantly associated with discharge to a rehabilitation facility. As rural patients in this study mostly lived and were injured in NSW, cross-border factors could also play a part in these results. In Australia, State and Territory Governments manage public hospitals. It is possible that rurality of residence explains these findings, where longer stays in tertiary trauma care facilities are the result of delays in repatriation to NSW, either in the form of cross-border hospital transfers or discharges home.

If so, these findings have implications for inter-State health service planning, evaluation of outcomes and allocation of public resources. Inappropriate use of acute beds is reported to be greater than 20% across many settings (42) and prolonged duration in hospital can adversely affect inpatient morbidity and mortality.(43) Compared to other health conditions, trauma care is extremely resource intensive, and incurs significant direct, and indirect health care costs. (44) Higher costs are reportedly associated with rural and remote road trauma(45) and extended durations of stay increases these costs.

Many patient-related factors influence early deaths from acute trauma, potentially over-riding the impact of contextual factors. Our results, showing no statistical association between SED and hospital mortality are consistent with at least one other study.(46) However, the trend towards increased SED and risk of death remained. SED and rurality are closely correlated in
our study sample hence our step-wise model building approach enabled a fine-grained examination of each, with risk of early trauma death.

Rural place of injury was correlated with place of residence and was a significant prognostic factor for inpatient death, independent of injury severity and head injuries. These results do not align with a study reporting mortality improvements in patients injured in rural locations. (29) Also, a Western Australian study showed that, for rural/remote patients who reached the definitive care hospital, the risk of death did not significantly differ to urban patients, after accounting for time factors and other covariates.

Western Australia is characterised by vast areas of remoteness, where our study in contrast, does not encompass remote areas. In rural or remote areas, several challenges arise in managing the traumatic injury event, thereby introducing variations in care, that range from the time to discovery and rescue, coordination of retrieval and transfer, the nature of emergency on-site care, availability of specialists, and triage practices at regional hospitals. These factors are further compounded by the cross-border context of the catchment area in our Study, where two States independently manage retrieval services.

Nonetheless, our findings underpin the importance of timely access to definitive trauma care, and of effective regional trauma centers. (30) In our study, rurally injured patients were 4 times more likely to be initially managed at a regional hospital compared to the Trauma Centre, however there were no statistically significant differences in mortality at the Level 1 Trauma Centre, between the different levels of first provider. Our findings are consistent with other research (30) and suggest that regional trauma care in this catchment area is working well. Further research could identify the elements of regionalisation that are associated with optimal trauma outcomes.
Our findings suggest that severely injured rural patients, who survive to definitive trauma care, are quite different to their surviving urban counterparts. Of interest, is whether these differences systematically predispose rural patients to greater risk of death. People with injuries involving more serious mechanisms (self-inflicted or the result of assault or a legal intervention) were rural based and were at higher risk of dying compared to those with transport injuries. Rural residents are more likely to have serious injury mechanisms involving machinery, fire, electrocution and firearms.(29, 32, 47) Although we cannot report specific mechanisms it is likely that these relate to ‘place’, and confer additional prognostic risk of death, that is not captured by other prognostic measures.

Unsurprisingly, higher ISS scores independently predicted higher risk for morbidity and mortality outcomes. The ISS, while the most commonly used prognostic factor for hospital based trauma mortality (48) has known limitations(49, 50) and the extent to which it is a proxy measure for other significant prognostic factors related to ‘place’ is unknown. In this study, the ISS was significantly worse for rural areas, but not for disadvantaged areas. ISS may not adequately capture other elements of trauma severity associated with rural injuries and rural injury mechanisms that predispose people to early death.

Increased age was an independent predictor of both outcomes and this has been reported elsewhere.(51) Excess mortality risk was more so confined to the very elderly patients, over 75 years. This pattern supports the findings of a systematic review of predictors of geriatric trauma mortality(52) suggesting that different prognostic factors other than established ones are important in terms of outcomes for this age group.
Limitations

There are limitations to this study, which should be considered when interpreting the results. Because of lack of data availability, we could not account for some trauma-induced physiological factors predictive of death, or in-hospital complications, which are associated with adverse outcomes.(53, 54) including mode of transport to the hospital, and the time of arrival to definitive care. We could not account for the various types of comorbidities, however the number of comorbidities was not significant in the final models. The study would benefit from analysis of longer term, out-of-hospital outcomes; however, in the absence of data linkage systems, this analysis was not possible.

Because of small sample sizes, we were unable to study people living in remote or very remote areas, or the impact of Aboriginality on these outcomes. For this reason, we also cannot rule out that Type 2 errors exist with the reported data. And finally, we could not include deaths occurring prior to arrival to hospital. This is of concern if the early deaths vary systematically according to rurality and disadvantage. However, if there is a positive association between these factors and the deaths not included in our sample, then our findings are likely to be under-estimates of the true associations.

Implications

The social and structural components of neighbourhoods can shape peoples’ lives and influence opportunities for health gain. However, the ways in which components of ‘place’ affect prognosis after trauma is not well understood. Existing geographic measures of distance to services and the SED may not adequately capture the social, environmental and cultural complexity that varies among communities and induces higher individual trauma risk, injury severity and worse injury mechanisms.
Deciphering the important components in rural areas that predispose people to behavioural risk and trauma adversity might therefore be the next step in socio-ecological trauma research. Some pose the view that aspects of rural life pose unique and subtle risks that are not directly related to SED or remoteness, but to social norms influencing health risk and health seeking behaviours, or occupational risk associated with rural industries, environmental hazards(35, 55). For example, the effects of climate change are experienced more profoundly in rural areas with weak infrastructure (56) and may adversely affect mental health,(57, 58) and subsequent, intentional injury patterns in rural areas.

Social capital is an area worthy of further empirical study and could potentially contribute to the evidence base of socio-ecological factors and trauma outcomes.(59) Social capital defines an individual’s ability to access social infrastructure, which is characterised by trust, shared norms and reciprocity, thereby enabling people to access much-needed resources.(60) Social capital is mostly defined as a community level resource and can influence a community’s economic prosperity(61) and resilience(62). Research has found that people living in communities with strong social capital experience better health.(63) However Australian data suggests there are rural and urban disparities in social capital, adversely influencing physical health in rural areas.(64) Ongoing efforts to unravel these phenomena and develop linkages to individual trauma data, as has been done here, can hopefully yield more conclusive information.

**Conclusion**

This study hypothesised that socio-ecological explanatory factors of neighbourhoods could predict early, adverse trauma outcomes. Social economic and geographical factors related to
place of residence and place of injury are associated with certain patterns of injury and adverse inpatient outcomes following traumatic injury. Factors specific to rural culture and life could also be important. Identifying these factors early, in the acute phase of trauma care could be important for reducing the risk of lengthy acute hospital stay, mortality and ongoing morbidity.
References


34. Heathcote K, Gardiner B, Barbagallo H, Sun J, M W, editors. Association between socioeconomic and geographical factors in severely injured trauma patients using trauma registry data. ACSPRI Social Science Methodology Conference, 2018; Sydney Australia: ACSPRI.


37. ABS. *Socio-economic indexes for areas: getting a handle on individual diversity with areas.* Australian Bureau of Statistics; Canberra. 2011.

38. ABS. *Socio-economic indexes for areas: robustness, diversity within larger areas and the new geography standard.* Australian Bureau of Statistics; Canberra. 2012.


**Supplemental Tables**

**STable 1: Properties of the IRSD index**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Annual household income</strong></td>
<td>Less than $20,799</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td>% Families with children under 15 years of age who live with jobless parents</td>
</tr>
<tr>
<td></td>
<td>% Employed people classified as ‘labourers’</td>
</tr>
<tr>
<td></td>
<td>% people in the labour workforce unemployed</td>
</tr>
<tr>
<td></td>
<td>% Employed people classed as machinery operators or drivers</td>
</tr>
<tr>
<td></td>
<td>% People classified as Low Skill Community and Personal Service workers</td>
</tr>
<tr>
<td><strong>Internet connection</strong></td>
<td>% Occupied private dwellings with no internet connection</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>% people aged 15 years or over whose highest level of education is Year 11 or lower</td>
</tr>
<tr>
<td></td>
<td>% people aged 15 years and over who have no educational attainment</td>
</tr>
<tr>
<td><strong>Household factors</strong></td>
<td>% Occupied private dwellings paying rent less than $166/week.</td>
</tr>
<tr>
<td></td>
<td>% Occupied private dwellings with no car</td>
</tr>
<tr>
<td></td>
<td>% Occupied private dwellings requiring one or more extra bedrooms</td>
</tr>
<tr>
<td><strong>Family structure</strong></td>
<td>% one-parent families with dependent offspring</td>
</tr>
<tr>
<td></td>
<td>% People aged 15 or over who are separated or divorced</td>
</tr>
<tr>
<td></td>
<td>% People who do not speak English very well</td>
</tr>
<tr>
<td><strong>Health</strong></td>
<td>% people aged &lt;70 who have a longer-term health condition or disability and need assistance</td>
</tr>
</tbody>
</table>

*Source: Socio-Economic Indexes for Areas (SEIFA) 2011. Canberra. ABS Catalogue no. 2033.0.55.001.*
Table 2: Description of the Study Sample

<table>
<thead>
<tr>
<th></th>
<th>Male (n=790)</th>
<th>Female (N=235)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>49.6 (21.41)</td>
<td>44.4 (18.7)</td>
</tr>
<tr>
<td><strong>Year of admission</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2014: 214</td>
<td>168 (21.3)</td>
<td>46 (19)</td>
</tr>
<tr>
<td>2015: 256</td>
<td>194 (24.2)</td>
<td>62 (26.4)</td>
</tr>
<tr>
<td>2016: 293</td>
<td>230 (29.1)</td>
<td>63 (26.8)</td>
</tr>
<tr>
<td>2017: 294</td>
<td>230 (29.1)</td>
<td>64 (27.2)</td>
</tr>
<tr>
<td><strong>Remoteness of residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>category*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major Cities (766)</td>
<td>590 (76.7)</td>
<td>176 (79.6)</td>
</tr>
<tr>
<td>Regional/Remote (224)</td>
<td>179 (23.3)</td>
<td>45 (20.4)</td>
</tr>
<tr>
<td><strong>State of Injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>State of Injury</strong></td>
<td>A (NSW) (239)</td>
<td>B (QLD) (741)</td>
</tr>
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<td>186 (24.8)</td>
<td>565 (75.2)</td>
</tr>
<tr>
<td>2015: 256</td>
<td>192 (25.3)</td>
<td>176 (76.9)</td>
</tr>
<tr>
<td>2016: 293</td>
<td>188 (24.7)</td>
<td>60 (24.2)</td>
</tr>
<tr>
<td>2017: 294</td>
<td>187 (24.6)</td>
<td>60 (24.3)</td>
</tr>
<tr>
<td><strong>Relative Socioeconomic</strong></td>
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</tr>
<tr>
<td>Disadvantage</td>
<td>Q1. Most disadvantaged (243)</td>
<td>193 (25.4)</td>
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<tr>
<td>Q2. (245)</td>
<td>192 (25.3)</td>
<td>53 (21.6)</td>
</tr>
<tr>
<td>Q3. (248)</td>
<td>188 (24.7)</td>
<td>60 (24.2)</td>
</tr>
<tr>
<td>Q4. Least disadvantaged (247)</td>
<td>187 (24.6)</td>
<td>60 (24.3)</td>
</tr>
</tbody>
</table>

Severity- Injury Site
<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=790)</td>
<td>(N=235)</td>
</tr>
<tr>
<td>(AIS&gt;2)</td>
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<tr>
<td>Abdominal injuries</td>
<td>Nil</td>
<td>509 (64.4)</td>
</tr>
<tr>
<td></td>
<td>Minor-Moderate</td>
<td>160 (20.3)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>121 (15.3)</td>
</tr>
<tr>
<td>External injuries</td>
<td>Nil</td>
<td>124 (15.6)</td>
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<tr>
<td></td>
<td>Minor-Moderate</td>
<td>654 (82.8)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>12 (1.5)</td>
</tr>
<tr>
<td>Extremity injuries</td>
<td>Nil</td>
<td>315 (79.5)</td>
</tr>
<tr>
<td></td>
<td>Minor-Moderate</td>
<td>277 (35.1)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>198 (25.1)</td>
</tr>
<tr>
<td>Face injuries</td>
<td>Nil</td>
<td>612 (77.5)</td>
</tr>
<tr>
<td></td>
<td>Minor-Moderate</td>
<td>142 (18)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>44 (4.3)</td>
</tr>
<tr>
<td>Head Injuries</td>
<td>Nil</td>
<td>378 (47.8)</td>
</tr>
<tr>
<td></td>
<td>Minor-Moderate</td>
<td>132 (16.7)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>280 (35.4)</td>
</tr>
<tr>
<td>Chest injuries</td>
<td>Nil</td>
<td>246 (31.1)</td>
</tr>
<tr>
<td></td>
<td>Minor-Moderate</td>
<td>102 (12.9)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>442 (55.9)</td>
</tr>
<tr>
<td>ISS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>17 (14-26)</td>
<td>18 (14-26)</td>
</tr>
<tr>
<td>NISS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>24 (17-34)</td>
<td>22 (17-33)</td>
</tr>
<tr>
<td>Number comorbidities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>272 (34.4)</td>
<td>74 (31.5)</td>
</tr>
<tr>
<td>1</td>
<td>164 (20.8)</td>
<td>55 (23.4)</td>
</tr>
<tr>
<td>&gt;=2</td>
<td>354 (77.0)</td>
<td>106 (45.1)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td>-------------</td>
</tr>
<tr>
<td>(n=790)</td>
<td></td>
<td>(N=235)</td>
</tr>
</tbody>
</table>

*Missing data =42 (patients’ residences not listed in Australia), ** Missing data=45 ,
Table 3: association of IRSD, Geographic remoteness from services (residential and injury location) with patient factors and injury patterns

<table>
<thead>
<tr>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
<th>Remoteness of Residence</th>
<th>Remoteness of Injury location</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRSD 1 Most disadvantaged N (%)</td>
<td>IRSD 2 N (%)</td>
<td>IRSD 3 N (%)</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-44 (480)</td>
<td>119 (49.0)</td>
<td>128 (52.2)</td>
</tr>
<tr>
<td>45-64 (311)</td>
<td>78 (32.1)</td>
<td>74 (30.2)</td>
</tr>
<tr>
<td>65-74 (100)</td>
<td>26 (10.7)</td>
<td>23 (9.4)</td>
</tr>
<tr>
<td>75+ (92)</td>
<td>20 (8.2)</td>
<td>20 (8.2)</td>
</tr>
<tr>
<td>χ² = 10.74, p=0.29</td>
<td>χ² = 10.74, p=0.29</td>
<td>χ² = 10.74, p=0.29</td>
</tr>
<tr>
<td>Sex N (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (760)</td>
<td>193 (79.4)</td>
<td>192 (78.4)</td>
</tr>
<tr>
<td>Female (223)</td>
<td>50 (20.6)</td>
<td>53 (21.6)</td>
</tr>
<tr>
<td>χ² = 1.46, p=0.69</td>
<td>χ² = 1.46, p=0.69</td>
<td>χ² = 1.46, p=0.69</td>
</tr>
<tr>
<td>162 (66.9)</td>
<td>184 (75.1)</td>
<td>193 (78.8)</td>
</tr>
<tr>
<td>80 (33.1)</td>
<td>61 (24.9)</td>
<td>52 (21.2)</td>
</tr>
<tr>
<td>χ² = 1.29, p=0.29</td>
<td>χ² = 1.29, p=0.29</td>
<td>χ² = 1.29, p=0.29</td>
</tr>
<tr>
<td>χ² = 41.61, p&lt;0.001</td>
<td>χ² = 41.61, p&lt;0.001</td>
<td>χ² = 41.61, p&lt;0.001</td>
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</tbody>
</table>
## Table 3: Association of IRSD, Geographic remoteness from services (residential and injury location) with patient factors and injury patterns

<table>
<thead>
<tr>
<th>State of Injury Event</th>
<th>IRSD: Quartiles of Socioeconomic Disadvantage</th>
<th>Remote Residence</th>
<th>Remote Injury Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>QLD (720)</td>
<td>157 (62.6) 88 (37.4) 170 (73.0) 34 (14.5) 201 (85.5) 35 (14.8)</td>
<td>654 (89.0) 81 (11.0)</td>
<td>67 (31.6) 145 (68.4) 660 (94.3) 40 (5.7)</td>
</tr>
<tr>
<td>Northern NSW (220)</td>
<td>157 (62.6) 88 (37.4) 170 (73.0) 34 (14.5) 201 (85.5) 35 (14.8)</td>
<td>654 (89.0) 81 (11.0)</td>
<td>67 (31.6) 145 (68.4) 660 (94.3) 40 (5.7)</td>
</tr>
</tbody>
</table>

χ² 47.89, p<0.001

<table>
<thead>
<tr>
<th>Remote Residence</th>
<th>Remote Injury Location</th>
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<tbody>
<tr>
<td>67 (31.6) 145 (68.4) 660 (94.3) 40 (5.7)</td>
<td>67 (31.6) 145 (68.4) 660 (94.3) 40 (5.7)</td>
</tr>
</tbody>
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χ² 298.12, p<0.001

<table>
<thead>
<tr>
<th>Remoteness (Injury Location)</th>
<th>First Provider</th>
<th>ISS Low (12-23)</th>
<th>ISS High (24 and higher)</th>
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</thead>
<tbody>
<tr>
<td>Major Cities (675)</td>
<td>GCUH (795)</td>
<td>178 (73.3) 65 (26.7)</td>
<td>162 (66.7) 81 (33.3)</td>
</tr>
<tr>
<td>Regional/Remote (232)</td>
<td>Regional /Other hospital (187)</td>
<td>198 (80.8) 47 (19.2)</td>
<td>181 (73.9) 64 (26.1)</td>
</tr>
<tr>
<td>177 (77.6) 51 (22.4)</td>
<td>174 (70.2) 74 (29.8)</td>
<td>181 (73.3) 66 (26.7)</td>
<td>555 (72.5) 211 (27.5)</td>
</tr>
<tr>
<td>183 (81.7) 41 (18.3)</td>
<td>209 (85.0) 37 (15.0)</td>
<td>181 (73.3) 66 (26.7)</td>
<td>146 (65.2) 78 (34.8)</td>
</tr>
<tr>
<td>637 (89.2) 77 (10.8)</td>
<td>677 (88.5) 88 (11.5)</td>
<td>555 (72.5) 211 (27.5)</td>
<td>500 (71.4) 200 (28.6)</td>
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<tr>
<td>40 (20) 160 (80)</td>
<td>124 (55.4) 100 (44.6)</td>
<td>146 (65.2) 78 (34.8)</td>
<td>158 (64.2) 88 (35.8)</td>
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χ² 19.73, p<0.001

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<tr>
<th>ISS Low (12-23)</th>
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<tr>
<td>162 (66.7) 81 (33.3)</td>
<td>181 (73.9) 64 (26.1)</td>
</tr>
<tr>
<td>174 (70.2) 74 (29.8)</td>
<td>181 (73.3) 66 (26.7)</td>
</tr>
<tr>
<td>555 (72.5) 211 (27.5)</td>
<td>146 (65.2) 78 (34.8)</td>
</tr>
<tr>
<td>500 (71.4) 200 (28.6)</td>
<td>158 (64.2) 88 (35.8)</td>
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</tbody>
</table>

χ² 14.14, p=0.003

χ² 125.60, p<0.001

χ²=150.73 p<0.001
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<tr>
<th>Injury mechanism</th>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
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<th>Remoteness of Injury location</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>$\chi^2 = 3.9$, $p = 0.27$</td>
<td>$\chi^2 = 4.40$, $p = 0.04$</td>
<td>$\chi^2 = 4.46$, $p = 0.037$</td>
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<tr>
<td>Transport-Falls (260)</td>
<td>132 (54.5) 58 (24) 11 (4.5) 38 (15.7)</td>
<td>142 (58.7) 70 (28.9) * 19 (7.9)</td>
<td>445 (58.9) 214 (28.3) 26 (3.4) 60 (7.9)</td>
</tr>
<tr>
<td>External Other* (139)</td>
<td>147 (60) 68 (27.8) 11 (4.5) 18 (7.3)</td>
<td>153 (62.7) 64 (26.2) 10 (4.1) 13 (5.3)</td>
<td>133 (59.4) 47 (21) 16 (7.1) 28 (12.5)</td>
</tr>
<tr>
<td>Intentional/Self harm/Legal (78)</td>
<td>* * * *</td>
<td>* * * *</td>
<td>* * * *</td>
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<tr>
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<td>11 (1.5)</td>
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<td>11 (1.6)</td>
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<tr>
<td></td>
<td>$\chi^2 = 18.10$, $p = 0.26$</td>
<td>$\chi^2 = 16.29$, $p = 0.003$</td>
<td>$\chi^2 = 14.45$, $p = 0.006$</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Injury mechanism</th>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
<th>Remoteness of Residence</th>
<th>Remoteness of Injury location</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$\chi^2 = 18.10$, $p = 0.26$</td>
<td>$\chi^2 = 16.29$, $p = 0.003$</td>
<td>$\chi^2 = 14.45$, $p = 0.006$</td>
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<tr>
<td>Transport-Falls (260)</td>
<td>132 (54.5) 58 (24) 11 (4.5) 38 (15.7)</td>
<td>142 (58.7) 70 (28.9) * 19 (7.9)</td>
<td>445 (58.9) 214 (28.3) 26 (3.4) 60 (7.9)</td>
</tr>
<tr>
<td>External Other* (139)</td>
<td>147 (60) 68 (27.8) 11 (4.5) 18 (7.3)</td>
<td>153 (62.7) 64 (26.2) 10 (4.1) 13 (5.3)</td>
<td>133 (59.4) 47 (21) 16 (7.1) 28 (12.5)</td>
</tr>
<tr>
<td>Intentional/Self harm/Legal (78)</td>
<td>* * * *</td>
<td>* * * *</td>
<td>* * * *</td>
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<tr>
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<td>11 (1.6)</td>
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# Table 3: association of IRSD, Geographic remoteness from services (residential and injury location) with patient factors and injury patterns
<table>
<thead>
<tr>
<th>Injury location#</th>
<th>Residence (224)</th>
<th>Street/Highway (460)</th>
<th>Sports/School (34)</th>
<th>Commercial (58)</th>
<th>Other/Unspecified (167)</th>
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<tr>
<td>Quartiles of socioeconomic disadvantage</td>
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<td></td>
<td></td>
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<td>63 (27.7)</td>
<td>115 (48.7)</td>
<td>17 (7.2)</td>
<td>37 (15.7)</td>
<td></td>
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<tr>
<td>Remoteness of Residence</td>
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<td></td>
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<td></td>
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</tr>
<tr>
<td>Remoteness of Residence</td>
<td>63 (27.7)</td>
<td>115 (48.7)</td>
<td>17 (7.2)</td>
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<tr>
<td>Remoteness of Injury location</td>
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<tr>
<td>Remoteness of Injury location</td>
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</tbody>
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χ² = 12.15, p=0.43

χ² = 4.0, p=0.41

χ² = 1.93, p=0.75

χ² = 10.19, p=0.12

χ² = 0.75, p=0.69

χ² = 0.31, p=0.86

χ² = 7.117, p=0.04

χ² = 43.44, p<0.001

χ² = 25.85, p<0.001
Table 3: association of IRSD, Geographic remoteness from services (residential and injury location) with patient factors and injury patterns

<table>
<thead>
<tr>
<th>Polytrauma</th>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
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<th>Remoteness of Injury location</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>81 (33.3)</td>
<td>62 (25.3)</td>
<td>72 (29)</td>
</tr>
<tr>
<td>Yes</td>
<td>81 (32.8)</td>
<td>210 (27.4)</td>
<td>88 (39.3)</td>
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<tr>
<td>Yes</td>
<td>202 (28.9)</td>
<td>95 (38.6)</td>
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</table>

\[ \chi^2 = 4.868 \quad p = 0.865 \]
\[ \chi^2 = 11.607 \quad p = 0.001 \]
\[ \chi^2 = 8.05 \quad p = 0.005 \]

<table>
<thead>
<tr>
<th>AIS Region</th>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
<th>Remoteness of Residence</th>
<th>Remoteness of Injury location</th>
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</thead>
<tbody>
<tr>
<td>Abdomen</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Abdomen</td>
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<td>32 (13.1)</td>
<td>46 (18.5)</td>
</tr>
<tr>
<td>Abdomen</td>
<td>44 (17.8)</td>
<td>116 (15.1)</td>
<td>39 (17.4)</td>
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<tr>
<td>Abdomen</td>
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<td>38 (15.4)</td>
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\[ \chi^2 = 5.26 \quad p = 0.046 \]
\[ \chi^2 = 0.675 \quad p = 0.410 \]
\[ \chi^2 = 0.05 \quad p = 0.82 \]

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<th>Remoteness of Injury location</th>
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<tbody>
<tr>
<td>Chest</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Chest</td>
<td>135 (55.6)</td>
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<td>140 (56.5)</td>
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<tr>
<td>Chest</td>
<td>150 (60.7)</td>
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<td>121 (54.0)</td>
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<td>Chest</td>
<td>391 (55.9)</td>
<td>143 (58.1)</td>
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\[ \chi^2 = 2.89 \quad p = 0.19 \]
\[ \chi^2 = 0.705 \quad p = 0.223 \]
\[ \chi^2 = 0.38 \quad p = 0.54 \]
Table 3: association of IRSD, Geographic remoteness from services (residential and injury location) with patient factors and injury patterns

<table>
<thead>
<tr>
<th>AIS Region</th>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
<th>Remoteness of Residence</th>
<th>Remoteness of Injury location</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>* (2.5)</td>
<td>* (1.6)</td>
<td>* (0.4)</td>
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χ² = 3.88  p = 0.14  \hspace{1cm} χ² = 6.078  p = 0.014  \hspace{1cm} χ² = 4.35  p = 0.045

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<tr>
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<td>External</td>
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<tr>
<td></td>
<td>* (2.5)</td>
<td>* (1.6)</td>
<td>* (0.4)</td>
<td>* (1.2)</td>
<td>* (1)</td>
<td>*(3.1)</td>
<td>* (1)</td>
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</table>

χ² = 1.30  p = 0.634  \hspace{1cm} χ² = 3.78  p = 0.05  \hspace{1cm} χ² = 0.272  p = 0.60

<table>
<thead>
<tr>
<th>AIS Region</th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>Extremity</td>
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<tr>
<td></td>
<td>61 (25.1)</td>
<td>54 (22)</td>
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<td>177 (23.1)</td>
<td>66 (29.5)</td>
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χ² = 1.30  p = 0.634  \hspace{1cm} χ² = 3.78  p = 0.05  \hspace{1cm} χ² = 0.272  p = 0.60

<table>
<thead>
<tr>
<th>AIS Region</th>
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<tbody>
<tr>
<td></td>
<td>Face</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>11 (4.5)</td>
<td>* (3.3)</td>
<td>* (3.2)</td>
<td>* (4.9)</td>
<td>31 (4)</td>
<td>* (3.6)</td>
<td>34 (4.9)</td>
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χ² = 1.39  p = 0.860  \hspace{1cm} χ² = 0.10  p = 0.748  \hspace{1cm} χ² = 2.62  p = 0.07

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<tbody>
<tr>
<td></td>
<td>Head</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>97 (39.9)</td>
<td>94 (38.4)</td>
<td>81 (32.7)</td>
<td>78 (31.6)</td>
<td>253 (33)</td>
<td>98 (43.8)</td>
<td>237 (33.9)</td>
</tr>
</tbody>
</table>
Table 3: association of IRSD, Geographic remoteness from services (residential and injury location) with patient factors and injury patterns

<table>
<thead>
<tr>
<th>Discharge Disposition (excluding inpatient deaths)</th>
<th>IRSD: Quartiles of socioeconomic disadvantage</th>
<th>Remoteness of Residence</th>
<th>Remoteness of Injury location</th>
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<tbody>
<tr>
<td>Home Rehabilitation</td>
<td>( \chi^2 = 5.47 ) p = 0.025</td>
<td>( \chi^2 = 8.71 ) p = 0.003</td>
<td>( \chi^2 = 9.93 ) p = 0.001</td>
</tr>
<tr>
<td>142 (63.7) 31 (13.9)</td>
<td>166 (73.5) 29 (12.8)</td>
<td>185 (79.1) 32 (13.7)</td>
<td>178 (74.8) 45 (18.9)</td>
</tr>
<tr>
<td>178 (74.8) 45 (18.9)</td>
<td>564 (77.7) 94 (12.9)</td>
<td>109 (54.8) 45 (22.6)</td>
<td>503 (75.9) 91 (13.7)</td>
</tr>
<tr>
<td>503 (75.9) 91 (13.7)</td>
<td>109 (54.8) 45 (22.6)</td>
<td>137 (63.4) 39 (18.1)</td>
<td></td>
</tr>
</tbody>
</table>

\( \chi^2 = 3.11 \) p < 0.50
\( \chi^2 = 19.61 \) p < 0.001
\( \chi^2 = 4.52 \) p = 0.02

* N <= 10
Chapter 7: Results for Study 4. Caregiver resilience and patients with severe musculoskeletal traumatic injuries

Introduction

There is a paucity of empirical evidence about the contribution of multiple and potentially modifiable dimensions of caregiver resilience and resilience ‘resources’. This Chapter describes a prospective cohort study undertaken of caregiver resilience for carers of severely injured musculoskeletal trauma patients.

Informal caregivers are an integral part of the patients’ socio-ecological environment. They have the closest relationship with the injured patient, and play a vital role in facilitating their physical, psychological, recovery and improving their health-related quality of life. However, informal caregivers come to their caregiver role unprepared and often overwhelmed. The costs borne by the caregiver of traumatic injury survivors are likely to be substantial representing a significant proportion of injury burden. Identifying the skills and qualities of caregiver who can adapt to significant adversity more successfully than others could enable the design of early interventions for caregivers.

One area that has received little specialized attention in caregivers of patients with traumatic injuries is that of resilience. While there is no consensus as to how resilience should be measured, few studies have examined the utility of a psychometric measurement of resilience on caregivers’ physical and mental health, and the mediating role of socio-ecological factors such as family, community, and health services.

Statement of Contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication in Journal Rural Health as an original research paper. Evidence for submission is below.

The research candidate has made the following contributions to this study:

- Identified research gaps and designed the study.
- Completed all the required documentation for human research ethics approval from Griffith University Human Research Ethics Committee (Protocol Number: (GU Ref No: 2017/879) and the Gold Coast Health Ethics Committees (HREC/17/QGC/256 ) and the Queensland Health Public Health Act approval (Reference number RD007132)
- Designed all the study forms
- Collected the data and supervised data entry and data management.
- Analysed the data and interpreted the findings.
- Prepared the manuscript and submitted it for peer review and publication (described above).

Signed: [signature]

(Supervisor and corresponding author: Jing Sun)
**Evidence of submission to ‘Disability and Rehabilitation’**

**Submission Confirmation**

Thank you for your submission

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<tr>
<td>Title</td>
<td>Caregiver resilience and patients with severe musculoskeletal traumatic injuries</td>
</tr>
<tr>
<td>Authors</td>
<td>Heathcoat, Katherine</td>
</tr>
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<td>Sun, Jiqg</td>
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Abstract

Background/Objectives: The importance of resilience has not been extensively studied for informal caregivers of musculoskeletal trauma patients. This study aimed to quantify the association of caregiver resilience on caregiver burden, and quality of life in informal caregivers of patients with severe traumatic musculoskeletal injuries.

Methods: A prospective cohort study of eligible caregivers of acutely injured patients was conducted during 2018, at a Tertiary Referral Trauma Centre in South East Queensland, with follow-up 3 months after discharge. Resilience was examined using the CD-RISC 10. Primary outcomes were caregiver burden and quality of life measured respectively, using the Caregiver Strain Index and the Short Form Version 12 (SF-12) Health Survey.

Results: Fifty-three (77%) patient/carer dyads participated, with an attrition rate of 28%. At baseline, caregiver resilience was statistically significantly (p<0.05) associated with their physical health, community support and family resilience. Significant reductions from baseline were found at follow up, for levels of resilience, mental health, physical exercise and community support. In multiple regression models, caregiver resilience independently predicted lower caregiver burden (β= -0.74, p=0.008) and higher levels of patient physical health and function (β= -0.69, p=0.003).

Conclusions: Three months after commencing informal care caregivers experience declines in resilience, mental health, healthy behaviors and social support networks. However, caregivers with higher levels of resilience appear to be protected against caregiver burden, and this could translate to better physical function in patients. Early evaluation of caregivers’ resilience, their physical and mental health and socio-ecological networks could improve carer and patient health outcomes.
**Introduction**

Injury mortality rates have declined in many countries (1), however the morbidity following severe traumatic physical injury is an important public health matter. Disabilities can persist for up to 2 years after severe trauma for wide range of injury types (2). Almost half of major trauma patients are left with permanent residual problems (3) and health related quality of life is below population norms up to five years after injury (4). The increased use of health care services (5), rehabilitation costs (6), lost productivity in wages (7) and the social costs are substantial, representing a significant proportion of injury burden (1). Studies show that prognostic factors for poor outcomes include comorbidity, injury severity and injury type (8). However other factors embedded within the patients’ broader socio-ecological environment also independently predict poorer longer-term functional outcomes (9-11) such as lower education, blue-collar work, poor social support (10, 12, 13).

Inequalities in trauma outcomes can be addressed using the socio-ecological model of health. This framework is important to the theory and practice of public health prevention (14-17) where an individual’s family, social and physical environment are thought to provide opportunities or capacity for influencing positive health behaviors. This model recognises that individual behaviour changes are unlikely to be sustained unless broader social and environmental factors are in place, providing capacity for such changes (18). For seriously injured trauma survivors, their socio-ecological system involves families and caregivers, peers, supportive social networks, the workplace and health services including community and rehabilitation services (19).

Informal caregivers are an integral part of the patients’ socio-ecological environment and, alongside the patient, are probably the most significantly affected after serious trauma. They have the closest relationship with the injured patient, and play a vital role in facilitating
their physical, psychological, recovery and improving their health-related quality of life. Research literature on caregivers outside of the trauma space show that providing care over prolonged periods of time adversely affects caregivers’ economic productivity and psychological and physical health. (20-23) Caregivers reportedly start to experience stress, burden, depression and anxiety around three months injury, with symptoms lasting for up to 1-7 years. (24) The annual costs of informal care are estimated in Australia to be around $60.3 billion AUD. (25) The costs borne by the caregivers of traumatic injury survivors, in terms of hours of delivered care, diminished quality of life, time off work and health care use have not been quantified, yet probably represent a significant proportion of injury burden. (1)

Caregiver burden is a measure often used in research to depict carers response to the physical, psychological, social, financial demands of caring for someone. (26) Predictors of caregiver burden have been extensively studied across health conditions and include low levels of social support, the severity of patients’ functional status and (27) along with pre-existing depression, poor coping and perceived patient distress. (20) Caregiver burden is possibly an independent predictor of caregiver mortality (28) reduced self-care and health prevention behaviors. (29) However other outcomes important to caregivers, such as their quality of life, beyond the burden of caregiving, have been comparatively less studied, despite the association with adverse health outcomes. (30).

Most of the scholarship in trauma is focused on those caring for patients with significant neurotrauma, such as spinal cord injuries (SCI) or traumatic brain injuries (TBI). Extrapolation of the findings of general caregiver research and even across injury subgroups is not advised because of the diverse range in patients physical and cognitive needs and caregiving characteristics and responsibilities. To that end, relatively little is known about caregiving health for patients in other injury subgroups such as musculoskeletal trauma. Musculoskeletal traumatic injuries are the most common form of trauma in hospitalised
patients, often involving younger adults, and those under 45 who are at the economically productive stage of their lives(31). Traumatic musculoskeletal injuries are associated with prolonged physical dysfunction and psychological disorders(32), pain(33, 34) and delayed time to return to work, particularly in patients with lower extremity trauma. (35) One study reported that, after excluding TBI and SCI injuries from its cohort of patients, severe trauma to the pelvis and limbs accounted for 82% of the disability scores overall, and 90% of the moderate to severe disability scores, five years post-injury.(36)

Unlike patients with severe brain or spinal injuries, there is often a greater expectation that patients with traumatic musculoskeletal injuries will return to work. Re-integration of these patients back to work and society may require different skills in terms of care and multi-disciplinary approaches compared to neurotrauma patients. By default, caregivers of patients with traumatic musculoskeletal injuries are also likely to be comparatively young, yet are almost six times more likely to be out of the labour force compared to non-caregivers. This estimate is substantially higher than for many chronic conditions, including diseases of the respiratory and musculoskeletal system and dementia.(37)

Caregiving is not always associated with negative experiences in the trauma area and variations in the ways in which caregivers respond and adapt to their role have been observed.(38) As such there is an emerging interest in resilience in trauma recovery. Resilience is universally described as positive adaptation, in the face of adversity.(39) Positive adaptation is conceived as maintaining normal development and function (physical or psychological), or even having improved or ‘better than expected’ function(39-43) after significant adversity. Resilience is positively associated with lower depression rates, better physical health, lower burden and stress.(44, 45) Most research reports in trauma focus on patients with severe neuro-trauma, not caregivers.(46-48) Informal caregivers following any
serious trauma suddenly and unexpectedly find themselves in this role. Herein lies the adversity that informal caregivers face in studies of resilience.

Resilience is a ‘construct’ and there is no consensus as to how it should be measured. This has led to great heterogeneity in study designs, measures and disciplinary focus, and has stymied our understanding of the benefits of resilience in health. Despite these obstacles, there are common domains that are seen as evidence of resilience. Furthermore, some methodological guidelines exist that could standardise approaches to resilience research and enable comparison of resilient health outcomes in different populations. For example, there is general consensus that a longitudinal design is warranted to study adaptation to adversity. Personality traits are believed to contribute to resilience. As such psychometric instruments have been developed to capture qualities strongly associated with resilient function, such as include self-esteem, self-efficacy, a sense of control and sense of coherence and optimism. Some of these instruments are reasonably robust but rarely used in studies of resilience.

Resilience can also be ‘inferred’ by assuming outcomes of measurement remain stable after adversity, or are ‘better than expected’. For example, caregivers who maintain from baseline, reasonably low and stable levels of distress in the first 6 months of caregiving, might be described as ‘resilient’. This method acknowledges that resilience is a construct, not a fixed trait and has adaptive qualities. Because these levels are defined by researchers and are subjective, studies using this method would ideally measure baseline (pre-adversity) symptoms and have a clear definition, specified a priori, of the level of adaptive, or ‘better than expected’ response to the adversity that is expected. Finally, socio-ecological systems are thought to be important for resilience and studies of resilience should account for environmental factors that promote or impede resilient function in study population. Evidence for the role of contextual factors shaping resilience is expansive, largely stemming from
studies of environmental factors on childhood adversity(19). Social, physical, cultural, family and community resources are all thought to provide capacity for resilience to prosper(19, 49, 52).

Studies of caregiver resilience in trauma, based on the above methodological criteria, are limited. Study designs are largely cross-sectional yielding low levels of evidence(53) and therefore limiting our understanding of the temporal changes in resilience and health outcomes or the mediating effects of environmental factors. One study of caregivers of patients with TBI identified protective factors aligned with resilience, including coping skills, good family function and social support, yet used no psychometric measure of resilience(54). Another study of a convenience cross-sectional sample of caregivers of patients with neurotrauma reported negative correlations between self-rated resilience and caregiver burden.(55) A longitudinal study examined trajectories of depressive symptoms in caregivers for SCI patients. Here, resilience was inferred, (not measured psychometrically), by the different levels of symptoms over one year, which were defined as ‘chronic’, ‘recovered’ and ‘resilient’.(38)

Of concern is that poor health resulting from caregiving, could adversely affect caregivers’ ability to provide safe, sustainable care for trauma patients(56, 57), yet empirical evidence for this is not available. For patients, quality of life is universally deemed to be an important outcome for trauma survivors.(9, 58-60) and identifying prognostic factors that promote optimal quality of life in patients is a worthy undertaking. There is little, if any, empirical evidence of the role of caregiver resilience on quality of life of patients with musculoskeletal trauma. Some research shows that for patients with severe TBI, family functioning and caregiver social support is associated with improved productivity and social integration in patients.(61)
This study aimed to address some gaps in the evidence of caregiving resilience for patients with severe traumatic musculoskeletal injuries. Drawing on the methodological principles described above, we conducted this research with three main objectives. First, we aimed to quantify changes in resilience, health behaviors, and physical and mental health occurring in the three month period after the onset of caregiving. Second, we aimed to examine the association between levels of caregiver resilience, with caregiver burden and quality of life at follow-up. And finally, we aimed to quantify the association of caregiver resilience with patient quality of life at follow-up.

**Methods**

**Study setting and participants**

A prospective cohort study of acute, severely injured patients with musculoskeletal injuries and their primary informal caregivers was conducted over a 12-month period, commencing 2nd January 2018. Both caregivers and patients were recruited for this study, with the longer-term aim to examine the resilience in patients and the reciprocal relationship of caregiving resilience on the patient. This analysis focuses mainly on resilience in caregivers.

Study participants were recruited from a Tertiary Referral Trauma Centre in South East Queensland. Baseline data collection occurred prior to, or shortly after patients’ discharge (enabling estimation of pre-caregiving exposures) and follow up occurred three months after patients’ discharge from hospital. Eligible patients were adults aged 18 to 80 years, consecutively admitted to the Tertiary Referral Trauma Centre during the study period for acute management of traumatic injuries to at least 2 any of the six body regions defined by the Abbreviated Injury Scale (AIS). Eligible patients were cognitively competent and residents of Australia, with an ISS >12 and requiring a period of informal care upon
discharge. Patients were excluded if they had a clinically diagnosed brain injury of moderate to severe severity (defined by a Glasgow Coma Score of <14 after 24 hours of hospital admission, a spinal cord injury accompanied by sensory or motor loss, or a psychiatric diagnosis. Eligible caregivers were adults identified by patients as the main person who would be supporting and facilitating their care after discharge. They were over 18 years of age, not cognitively impaired, residents of Australia and living with or near the patient after discharge.

The study received full Ethics approval from the Human Research Ethics Committees of the Tertiary Trauma Hospital, the affiliated University. Public Health Act approval was given by the Queensland Government (HREC/QGC/256).

Data collection

All potentially eligible patients could be effectively screened using the Hospital’s the ‘Trauma Alert’ and ‘Trauma Respond’ calls and the Trauma Registry database. The database contains data items from the Australian Bi-National Minimum Trauma Data Set and additional data from the hospital clinical information systems. Data are automatically fed into the Registry from the hospital’s clinical information systems. The Registry is subjected to regular audits and data quality checks, including inter-rater reliability checks.

Patient and caregiver eligibility were confirmed using the electronic medical records, and in consultation with medical, nursing and allied health staff. Following informed consent from both patients and informal caregivers, and shortly before hospital discharge, baseline face-to-face interviews were conducted. The questionnaires for both members of the dyad included items about the pre-injury/pre-caregiving period and demographic details (age, sex, marital status, occupation, household income, and educational level). Information about
dispositional resilience and health related quality of life was collected, where the reference point was the four-week period prior to the injury.

Patients were additionally asked about intentions to return to work, and level of optimism about recovery. Patient data relating to the injury severity and mechanism, hospital length of stay and comorbidity were collected from electronic medical records and the Hospital’s Trauma Registry. The caregiver baseline interview schedule included additional questions about pre-injury health conditions, self-efficacy, coping, family resilience, community support, expectations of their caring role, health behaviors (physical activity, smoking, alcohol intake), health service use (GP, Hospital outpatients visits, hospital stay night, Emergency Department visits).

Follow-up questionnaires were posted (with a reply-paid envelope) to participants approximately three months after discharge. A small number of participants preferred email contact. This was followed up by phone-calls. At follow-up patients and caregivers were asked again, about resilience and quality of life. They were additionally asked about levels of satisfaction in several primary health services, use of health services and work status. Caregivers were additionally asked about caregiver burden, satisfaction with primary health care services whilst caregiving, and perceived work support. The reference point for all participants was during the period they were cared for/were a caregiver.

Socio-demographic and health related factors

Participants were asked standard socio-demographic questions about their age, sex, living situation, work status, household income, highest educational level and area of residence. They were also asked about past illnesses, health behaviors (physical activity, smoking and alcohol intake) and health service use and the extent to which primary health care services met their needs, at follow up. Question items were sourced, where possible,
from the Census of Population and Housing (Australia) and standard survey instruments often used in public health research.

Patient injuries were classified according to the Abbreviated Injury Scale (AIS)(62) that codes injuries according to their anatomic location (head or neck, face, chest, abdominal or pelvic contents, extremities or pelvic girdle and external) and assigns a severity score from 1-6, based on the probability of death or disability. Injuries $\geq 2$ are classified as ‘severe’. Injury severity was examined using the Injury Severity Score (ISS), an ordinal scale ranging from 1 to 75, reflecting the sum of the highest AIS scores for the three most severely injured body regions. Pre-injury patient comorbidity was assessed by the American Society of Anesthesiologists classification (ASA) system.(63)

**Resilience**

The Connor Davidson Psychometric Scale, (CD-RISC 10)(64) was used to measure personal resilience in patients and caregivers. The CD-RISC 10 is a 10-item, validated abbreviated version of the full 25-item instrument, the CD-RISC 25(65) The CD-RISC 10 is reportedly one of only a few resilience scales deemed to be psychometrically robust for research purposes.(43) The CD-RISC 10 is widely used, and has been validated in many community and clinical settings(66) including trauma patients. It measures, on a five-point scale ranging from 0 to 4, five main factors relating to personal competence, tenacity, trust and tolerance and the strengthening effects of stress, positive acceptance of change, secure relationships, and emotional control. A typical question item asks: “I am able to adapt to change” and “I think of myself as a strong person”. The CD-RISC 10 is used in repeated measures research designs because of its capacity to capture changes in resilience over time. (52, 65).

For our study, internal reliability analysis yielded Cronbach’s Alpha scores for the
CD-RISC 10 of 0.88. The Pearson correlation coefficient for test and re-test reliability was 0.65 (p<0.001) and concurrent validity with self-efficacy was demonstrated with a correlation coefficients of 0.70 (p<0.001) at baseline and 0.83 (p<0.001) at follow up.

**Self-efficacy**

Self-efficacy is correlated with health promoting behaviors, medication adherence, active forms of coping and physical activity and emotional and social functioning. The General Self Efficacy Scale (67) was used to measure self-efficacy namely characterize caregivers’ belief in their competence to tolerate, cope with and mobilise resources to meet a broad range of stressful or challenging demands.(68, 69) The General Self Efficacy Scale is a 10-item scale with responses ranging from 1-4, where the range of total scores are from 10-40, where the higher the score the higher the level of self-efficacy. Population norms for the scale do not appear to exist in Australia but have been reported in US-American Adult Populations to be 29.5 (SD 5.13). A typical item in the scale is: “If someone opposes me, I can usually find the means and ways to get what I want and “I am confident I can deal efficiently with unexpected events”.

The General Self Efficacy Scale has is psychometrically sound (70) and has been shown in meta-analyses to be correlated with a number of domains of human functioning, namely optimism(71, 72) emotional and physical health, and health behaviors.(73) For our study, the Cronbach’s alpha score for internal reliability of self-efficacy was 0.88.

**Family Resilience and Social Support**

Family resilience was measured suing the Family Hardiness Index (FHI) (74). Family hardiness refers to the internal strengths and durability of the family unit and characterizes a family’s sense of control over their lives, commitment to family, and confidence that the family will survive no matter what.(75) The FHI conceptualises family resilience as a form of
stress resistance and adaptation resource in families, thereby incorporating the fundamental elements of resilience, adjustment and adaptation. A typical item asks: “We believe that things can work out if we can work together as a family”. Caregivers were asked from a selection of questions, the degree to which each statement describes their current family situation (False, Mostly False, Mostly True, True).

Social support was measured using the Social Support Index(76) which describes the degree to which families find support in their communities. The instrument uses a five point Likert Scale to measure ways in which the community can provide emotional, esteem and network support. A typical question asks: “People can depend on each other in this community”. Internal reliability Cronbach’s alpha scores for family resilience and social support were, respectively 0.94 and 0.84.

**Caregiver strain**

The Modified Caregiver Strain Index(77) was used to evaluate caregiver strain in family caregivers. This is a 13-item tool, containing subjective and objective elements measuring strain related to care provision. While it has been largely used for caregivers of older people, it was chosen for this study, because it was brief and easy for responders to complete. Items cover financial, physical, psychological, social and personal domains. Scoring is for a ‘Yes’ response (2 points), and a ‘Sometimes’ response (1 point) or 0 for ‘No’. Higher scores indicate higher levels of strain. Test-retest reliability date indicate high levels of reliability.(77)

**Quality of life**

The SF-12 Survey tool was used to measure health related quality of life in patients and caregivers.(78) The SF-12 is brief, comprehensive and psychometrically sound(79) with demonstrated utility for measuring health status in a wide range of population groups,
including trauma populations. The domains include physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. ‘Physical functioning’ describes limitations in daily life due to health problems. The ‘role physical’ scale measures role limitations due to physical health problems. The ‘bodily pain’ scale assesses pain frequency and the extent to which pain interferes with usual roles. The ‘general health scale’ measures individual perceptions of general health. The ‘vitality’ scale assesses energy levels and fatigue. The ‘social functioning’ scale measures the extent to which ill health interferes with social activities. The ‘role emotional’ scale assesses role limitations due to emotional problems, and the ‘mental health’ scale measures psychological distress.

Two aggregate summary scores of physical function (PCS) and mental health function (MCS) were computed from these eight domains. Scores range from 0 (lowest) to 100 (highest). Summary scores are based on a mean of 50 and a standard deviation of 10. There is a vast array of evidence reporting strong reliability and validity of the SF-12.(79)

**Satisfaction with primary health care services**

At follow up, caregivers were asked if they visited any community health care services: (General Practitioners, Specialist surgeon, physiotherapist, occupational therapist, psychologist, social workers, community nurse, dietician) and to rate, using a Visual Analogue scale from 1-10 their level of satisfaction with the service. Satisfaction was defined in terms of the extent to which the service responded to, and met their needs as a caregiver.

Table 21 shows questionnaire items for dyad participants, at baseline and at follow up.
Table 21: Questionnaire items for dyad participants, at baseline and at follow up

<table>
<thead>
<tr>
<th></th>
<th>Patient Baseline</th>
<th>Patient Follow up</th>
<th>Caregiver Baseline</th>
<th>Caregiver Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic factors</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Standard survey items</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resilience (CD RISC 10)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Self Efficacy (General Self Efficacy Scale)</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Coping (Brief Cope)</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Family Resilience (Family Hardiness Index)</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Community support (Social Support Index)</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Quality of life Short Form 12</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Caregiver Strain Index</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health behaviors (physical activity, smoking, alcohol intake) Standard survey items</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Health service use</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Satisfaction with Primary Health care VAS 1-10</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Statistical analysis**

SPSS statistical software (IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp) was used for this analysis. The estimated sample size for the study was 95 dyads. Sample size calculations were based on an estimated p value of 0.05, Power of 0.8, effect size for SF-12 PCS and MCS of 0.46,(80) a 2-tailed hypothesis and an attrition rate of 12%.
Norm-based scores are reported for the summary physical and mental component scores of the SF-12. The caregiver sample at baseline was characterized by the use of descriptive statistical analyses using means, standard deviations (SD) for normally distributed data, and medians and interquartile ranges (IQR) for non-parametric distributions, and percentages for categorical variables.

Regression analyses were used to determine bivariate associations between independent variables, (age, income, education, rurality, pre-injury conditions health behaviors, individual and family resilience, and social support) with outcome variables, CSI and the physical and mental health components of the SF-12. Paired sample T Tests was used to determine the mean differences (MD) from baseline to follow up in caregiver resilience, quality of life, self-efficacy, family resilience and social support, health service use and health behaviors.

Multiple regression analyses were performed to examine the independent effect of caregiver factors with the main outcomes of interest. During the modeling procedure, variables were tested for correlations. Caregiver self-efficacy and family resilience were each statistically significantly correlated with caregiver resilience, and were therefore removed as explanatory factors from the multivariate modeling analyses. All tests were two-tailed and statistical significance was set at p<0.05.

**Results**

Figure 9 shows details of the recruitment pathway. Of the 520 patients consecutively admitted to the Hospital over the 12-month study period, 69 participant dyads were eligible, and 53 dyads agreed to participate (77% participation rate). Follow up data was obtained for 38 pairs, yielding an attrition rate of 72%. There were no statistically significant differences
in the remaining study sample and those lost to follow up according to resilience, age and patients’ injury severity.

Figure 9: Recruitment Flow Chart for Patients and Caregivers

Table 22 shows that, for patients, the average age was 47, and median injury severity was 19. Around 90% had injuries graded 'severe' and worse, based on AIS categories.

At baseline (and prior to the onset of caring), most of the informal caregivers (>70%) were female, in a relationship, and lived with the patient. Around 40% had other caring responsibilities besides the patient. Over half of the sample (60%) was working at the time of injury, on average 37 hours/week. Just under half (45%) had not completed schooling to Year 12, and over half (54%) declared a yearly income, before tax, to be less than $60 000. Health related quality of life scores were close to the population norm for physical health, but below the population norm for mental health.(78) The mean resilience score was comparable to population norms.(66)
At follow up, 27 caregivers engaged with at least one PHC or tertiary service. Mean levels of satisfaction with that service ranged from 4.95 (SD) for their General practitioners, 7 (SD 3.5) for specialist surgeon, 7.12 (SD 3.11) for physiotherapist 5.9 (SD 3.3) for occupational therapy, 6.3 (SD 3.65) for psychologists, and 3.83 (SD 3.65) for community nurses.

At baseline, caregiver resilience was positively and statistically significantly associated with physical function (SF-12) (β coefficient = 0.23: 95% CI 0.023-0.436, p=0.03), self-efficacy (β coefficient = 0.88: 95% CI 0.63-1.13, p<.001), family resilience (β coefficient = 0.26: 95% CI 0.001-0.512, p=0.05), community support (β coefficient = 0.43: 95% CI 0.176-0.436, p=0.001), regular gentle exercise (β coefficient = 0.79: 95% CI 0.189-1.39, p=0.01) and patients’ physical function pre-injury (β coefficient = 0.23: 95% CI 0.023-0.436, p=0.03).
Table 22: Baseline characteristics of Caregivers (N=53) and Patients (N=53)

<table>
<thead>
<tr>
<th>Baseline factors</th>
<th>BASELINE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver factors</strong></td>
<td></td>
</tr>
<tr>
<td>Age: Mean (SD)</td>
<td>50.35 (16.14)</td>
</tr>
<tr>
<td>Female Gender: N (%)</td>
<td>38 (72)</td>
</tr>
<tr>
<td>In a relationship: N (%)</td>
<td>39 (75)</td>
</tr>
<tr>
<td>Live with patient N (%)</td>
<td>48 (91)</td>
</tr>
<tr>
<td>Caring for others including patient N (%)</td>
<td>21 (40)</td>
</tr>
<tr>
<td>Work Status: N (%)</td>
<td></td>
</tr>
<tr>
<td>Working at time of injury</td>
<td>31 (60)</td>
</tr>
<tr>
<td>Retired</td>
<td>11 (21)</td>
</tr>
<tr>
<td>Not working</td>
<td>10 (19)</td>
</tr>
<tr>
<td>Working hours/week: Mean (SD)</td>
<td>36.5 (13.74)</td>
</tr>
<tr>
<td>Education: N (%)</td>
<td></td>
</tr>
<tr>
<td>Completed Y12</td>
<td>29 (55)</td>
</tr>
<tr>
<td>Higher education qualifications</td>
<td>39 (74)</td>
</tr>
<tr>
<td>Income N (%)</td>
<td></td>
</tr>
<tr>
<td>&lt;=$60 000</td>
<td>28 (54)</td>
</tr>
<tr>
<td>$60 000-$80 000</td>
<td>7 (14)</td>
</tr>
<tr>
<td>&gt;$80 000</td>
<td>17 (32)</td>
</tr>
<tr>
<td>Quality of Life (Mean, SD)*</td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>49.18 (8.89)</td>
</tr>
<tr>
<td>Mental</td>
<td>45.86 (14.42)</td>
</tr>
<tr>
<td>Resilience (Mean, SD)</td>
<td>32 (5.65)</td>
</tr>
<tr>
<td>Range of Scores (0-50)</td>
<td></td>
</tr>
<tr>
<td><strong>Patient factors</strong></td>
<td></td>
</tr>
<tr>
<td>Age (Mean, SD)</td>
<td>46.65 (17.77)</td>
</tr>
<tr>
<td>Injury Severity Score (Median IQR)</td>
<td>19 (8)</td>
</tr>
<tr>
<td>AIS Score N (%)</td>
<td></td>
</tr>
<tr>
<td>Minor</td>
<td>0</td>
</tr>
<tr>
<td>Moderate</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td>Serious</td>
<td>23 (43.4)</td>
</tr>
<tr>
<td>Severe</td>
<td>17 (32.1)</td>
</tr>
</tbody>
</table>
Table 23 shows the mean differences (MD) in outcome variables, resilience factors and health behaviors from baseline to follow up. Each baseline value represents caregivers’ and patients’ estimates of their status in the four weeks prior to the patients’ injuries. The mean value of the SF-12 mental health function decreased from baseline to follow up by 10.41 points on average, which was clinically and statistically significant (95% CI 4.70-16.13, p=0.001). For patients, this pattern was more severe with a decrease of, on average, 32 points (95% CI 26.78 – 38.04). Similar significant trends, but to a lesser extent based on the MD values, were shown for both caregiver (MD 2.81, 95% CI 1.19-4.42) and patient resilience (MD 2.85 94% CI 0.55 – 5.15), caregivers’ perceived community support (MD 2.84, 95% CI 0.80-4.89) and exercise levels (MD 1.32, 95% CI -0.02-2.18). Caregivers also reported a three-fold increased use of health services, (for their health), from baseline (MD 15.11, 95% CI 0.058). There is an apparent increase in the MD from baseline to follow up in
SF-12 physical function (MD 4.27, 95% CI -9.91-1.38), but this did not reach statistical significance. For patients, physical function appeared to improve, over time with a mean increase of 9.5 points of the PCS (95% CI -14.2 - -4.80).

Table 23: Changes in caregiver and patient factors from baseline to follow-up

<table>
<thead>
<tr>
<th></th>
<th>Baseline (Mean, SD)</th>
<th>Follow up (Mean, SD)</th>
<th>Mean Difference (95% CI)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregivers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life (PCS)</td>
<td>48.41 (9.40)</td>
<td>52.68 (10.50)</td>
<td>-4.27 (-9.91-1.38)</td>
<td>0.13</td>
</tr>
<tr>
<td>Quality of life (MCS)</td>
<td>46.78 (12.66)</td>
<td>36.35 (7.23)</td>
<td>10.41 (4.70-16.13)</td>
<td>0.001</td>
</tr>
<tr>
<td>Resilience</td>
<td>33.58 (4.69)</td>
<td>30.78 (6.26)</td>
<td>2.81 (1.19-4.42)</td>
<td>0.001</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>33.97 (4.60)</td>
<td>32.39 (3.93)</td>
<td>1.57 (-0.09-3.23)</td>
<td>0.063</td>
</tr>
<tr>
<td>Family resilience</td>
<td>22.53 (7.13)</td>
<td>22.09 (5.09)</td>
<td>0.5 (-1.75-2.75)</td>
<td>0.66</td>
</tr>
<tr>
<td>Community support</td>
<td>25.90 (5.09)</td>
<td>23.06 (5.53)</td>
<td>2.84 (0.80-4.89)</td>
<td>0.008</td>
</tr>
<tr>
<td>Paid weekly working hours</td>
<td>36.5 (14)</td>
<td>32 (16)</td>
<td>3.34 (-3.73-1.34)</td>
<td>0.34</td>
</tr>
<tr>
<td>Health service visits for caregiver health</td>
<td>7.54 (9.13)</td>
<td>22.64 (40.46)</td>
<td>-15.11 (-30.78-0.54)</td>
<td>0.058</td>
</tr>
<tr>
<td>Gentle exercise (days/week)</td>
<td>5.0 (2.5)</td>
<td>3.7 (2.48)</td>
<td>1.32 (0.36-2.28)</td>
<td>0.008</td>
</tr>
<tr>
<td>Moderate exercise (days/week)</td>
<td>4.14 (2.63)</td>
<td>3.05 (2.36)</td>
<td>1.08 (-0.02-2.18)</td>
<td>0.05</td>
</tr>
<tr>
<td>Vigorous exercise (days/week)</td>
<td>2.03 (2.80)</td>
<td>1.62 (2.33)</td>
<td>1.41 (-0.62-1.43)</td>
<td>0.43</td>
</tr>
<tr>
<td>Alcohol drinks/week</td>
<td>3.27</td>
<td>3.31</td>
<td>-0.04</td>
<td>0.95</td>
</tr>
</tbody>
</table>
At baseline, and before commencing caregiving (Table 24), high levels of caregiver resilience were apparently associated with physical function ($\beta$ coefficient 0.59, $p=0.06$). High levels of health service use were negatively associated with mental health function ($\beta$ coefficient -0.38, $p=0.017$) and positively associated with community support ($\beta$ coefficient 0.56, $p=0.037$).
Table 24: Multiple regression analysis of caregiver and patient factors with caregiver outcomes at Baseline

<table>
<thead>
<tr>
<th>Baseline caregiver variables</th>
<th>Baseline Caregiver Physical Health SF-12 (PCS)</th>
<th>Baseline Caregiver Mental Health SF-12 (MCS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$R^2$</td>
<td>$\beta$ coefficient</td>
</tr>
<tr>
<td>Resilience</td>
<td>0.24</td>
<td>0.59</td>
</tr>
<tr>
<td>Health service use</td>
<td>-0.20</td>
<td>(-0.57 – 0.17)</td>
</tr>
<tr>
<td>Community support</td>
<td>0.32</td>
<td>(-0.31 – 0.96)</td>
</tr>
<tr>
<td>Patients physical function</td>
<td>0.08</td>
<td>(-0.33 – 0.49)</td>
</tr>
<tr>
<td>Patients mental health function</td>
<td>0.05</td>
<td>(-0.34 – 0.41)</td>
</tr>
<tr>
<td>Follow up caregiver variables</td>
<td>Caregiver burden $R^2$</td>
<td>$\beta$ coefficient 95% CI</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Resilience</td>
<td>0.52</td>
<td>-0.74 (-1.33 - -1.46)</td>
</tr>
<tr>
<td>Health service use</td>
<td>0.005 (-0.15 – 0.16)</td>
<td>0.95</td>
</tr>
<tr>
<td>Community support</td>
<td>0.135 (-0.48 – 0.75)</td>
<td>0.65</td>
</tr>
<tr>
<td>Patients physical function</td>
<td>-0.56 (-0.45 – 0.34)</td>
<td>0.77</td>
</tr>
<tr>
<td>Patients mental health function</td>
<td>0.14 (-0.23 – 0.52)</td>
<td>0.43</td>
</tr>
</tbody>
</table>
Finally, (Table 26) we examined the association of caregiver resilience with patient quality of life, while accounting for known factors mediating this association. Caregiver resilience was significantly and positively associated with patients’ physical health. For every 1 point increase in resilience there was a 0.69 increase in physical function (95% CI 0.26-1.11, p=0.03).

**Table 26: Association of caregiver resilience with patient quality of life at follow up**

<table>
<thead>
<tr>
<th>Follow up variables</th>
<th>Patient Physical Health</th>
<th>Patient Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SF-12 (PCS)</td>
<td>SF-12 (PCS)</td>
</tr>
<tr>
<td>Caregiver Resilience</td>
<td>$R^2 = 0.42$</td>
<td>$R^2 = 0.10$</td>
</tr>
<tr>
<td></td>
<td>$\hat{\beta}$ coefficient $95% CI$</td>
<td>$\hat{\beta}$ coefficient $95% CI$</td>
</tr>
<tr>
<td></td>
<td>0.69 (0.26-1.11)</td>
<td>-0.44 (-0.96 – 0.084)</td>
</tr>
<tr>
<td>Patient Injury severity</td>
<td>0.142 (-0.20 – 0.486)</td>
<td>-0.045 (-0.47 – 0.38)</td>
</tr>
<tr>
<td>Patient resilience</td>
<td>0.35 (0.03 – 0.72)</td>
<td>0.11 (-0.35 – 0.57)</td>
</tr>
</tbody>
</table>

**Discussion**

We have examined resilience during the acute stages of caring severely injured traumatic musculoskeletal injuries patients, and analysed the consequences of resilience, according to personal qualities and situational factors on caregiver burden and their quality of life. At baseline and prior to commencing caregiving, there was evidence of socio-ecological systems supporting resilience in caregivers. Caregiver resilience was significantly and positively associated with their physical health, family resilience and community support. Levels of resilience and community support declined over the course of caregiving, as did caregivers’ mental health function and physical activity levels. However caregiver resilience
appeared to be protective against caregiver burden, and could promote patients’ physical function, according to a broad range of functional domains.

The decline in mental health after the onset of caregiving is not unexpected, and is consistent with other published research in trauma.(24) Notably, caregivers in our sample were vulnerable even before commencing care, where the mean MCS score was on average, 4 points lower than the standard population level. Unlike previously published work(24) that reports symptom onset at three months, our data suggest that caregiver psychological symptoms either appear, or worsen earlier than expected, within three months. Declining mental health is related to the nature of the care recipients’ disability, psychological and behavioural disorders, and caregivers’ social isolation.(81) Our data also show clinically significant decreased mental health function in patients, which possibly explains these parallel trends in caregivers’ mental health function.

Reductions in physical activity levels, shown here, by structured days of exercise, have been reported elsewhere for high level caregivers.(29) However, SF-12 physical function (PCS) describes a far broader range of limitations of daily functional life and this appears to increase for caregivers over time, and significantly so, in patients. This is an encouraging, but unusual finding, as existing poor mental health function could potentially adversely affect physical health.(82) Caregiver resilience, which was positively related to caregiver PCS at baseline, could account for these findings. The additive combination of resilience and better physical function in caregivers early on, could be important for maintaining patient physical function.

Of concern however, are the apparent declines in levels of community support over the caregiving period. Social support is defined as ‘support accessible to an individual through social ties to other individuals, groups and the larger community’(83) and is an ecological factor empirically connected to reduced morbidity and mortality for many serious
health conditions. High levels of social support mediate the relationship between resilience and quality of life (84) and have been shown unequivocally to moderate caregivers psychological distress (24, 54, 85). The mechanism of action of social support has neurobiological and epigenetic plausibility based on studies of factors regulating stress responses (86).

Little is known about the specific types of neighborhood social systems that are best equipped to support caregivers in these early stages of trauma care. Cultural groups, religious organisations, or schools and other community networks with shared value systems (87) that enhance access to social networks and facilitate coping strategies (88) could be important for promoting resilient adaptation in caregivers.

Similarly, the declines in resilience, of a similar magnitude, add weight to the theory that resilience is not a fixed trait; it is responsive to adversity, changes over time and is therefore amenable to interventions. Identifying the skills and qualities of caregivers who do not adapt to adversity as successfully as others could inform the design of early interventions for caregivers. This declining pattern of resilience, measured psychometrically, has not been reported in trauma research to our knowledge, and data collection over more than one time point is needed to substantiate these trends and pinpoint other causal factors.

A three-fold increase in the use of health services is another finding that represents a hidden cost of caregiving and, as suggested by our data, this could reflect the mental health consequences of caregiving in this sample. Caregivers were asked to report on the number of times they had visited a health practitioner in the community or a hospital, either for admission, as an outpatient or to receive acute emergency care. We were not able to describe the reasons for increased use of health services. However, as reported above, it is worth noting the range of community services that caregivers sought, and the variations in the ratings of care provided by these health services. Variations in the quality, acceptability and
responsiveness of community services for caregivers have been reported elsewhere (89) and are worthy of further empirical study.

Multivariate modeling results should be interpreted cautiously because of the small sample size at follow up. When resilience is modeled with other factors against the main quality of life outcomes (PCS and MCS) at baseline, data show that caregiver resilience is positively and independently associated with physical function in patients, independently of other contextual factors. This is an important finding as it suggests that targeting resilience in the early stages of caregiving could help to maintain or improve physical function, which in turn, could assist both the carer and the patient. Unsurprisingly, health service support is higher for people who have relatively poor mental health, however higher levels of community support appear to be protective against mental health dysfunction. This aligns with other research about the value of social systems supporting adaptation to extreme stress, and promoting mental health.(90) The exact nature of the type of support is not clear.

At follow up, the main finding was that caregiver resilience was significantly, independently and inversely associated with caregiver burden. This association has been reported in caregivers of patients with Alzheimer’s Disease(44) and in one cross sectional study Australian study of patients with TBI and SCI, where a different resilience metric was used.(55) These findings could influence rehabilitation practices that include standard assessment of the caregivers’ vulnerability in the early stages of care.

Lower levels of patient mental health appeared to have a positive effect on caregivers’ physical function, which is an unusual finding and not reported in the literature. This finding could reflect the buffering effect of caregiver resilience on caregiver burden or family factors unaccounted for, however more data are needed to confirm this theory.
The inverse relationship of caregiver resilience, using an established metric, on patients’ physical function has not been reported in Trauma. Although other factors, unmeasured here, possibly influence patients’ physical function, our model that includes injury severity and patient resilience along with caregiver resilience, accounts for 42% of the variance on patients’ physical function. This is a highly statistically significant finding, and underlies the public health importance of promoting resilience in caregivers of this severe, multi-trauma population subgroup.

**Strengths and Limitations**

This study has bolstered the existing evidence base of resilience in caregivers of an under-studied trauma subgroup, using rigorous observational epidemiological methods. We employed a prospective repeated measures design and examined resilience using psychometric measures that are generalizable across other studies. We reported on outcomes deemed important to caregivers, such as caregiver burden, and quality of life whilst accounting for co-existing socio-ecological factors supportive of caregiving. Estimates of caregivers’ health before the onset of caring enabled a valid comparison of the impact of caregiving over time. Our methods were, where possible, consistent with socio-ecological research principles and recommended for the study of caregivers. (91) This involved recruiting patient-carer dyads, assessing caregiver status prior to the patients’ injury, and co-existing patient factors important to caregiver outcomes.

Because of time constraints and logistic reasons, we were not able to recruit the full sample size required for this analysis and this is a major limitation to the study. We therefore did not have sufficient statistical power to examine the many socio-ecological factors related to caregiver resilience on outcomes. While it is highly likely that statistically significant
findings reported here reject null hypotheses, Type II errors cannot be ruled out, particularly in multivariate modeling, where statistically insignificant results are reported.

To that end, personal resilience measured by the CD-RISC, rather than situational factors, was statistically significantly associated with caregiver and patient outcomes in this study. This pattern has been reported elsewhere, in a study with a sample similar size to ours.(92) Larger datasets are required to properly delineate the role of contextual factors for resilience research in trauma.

Study power limitations meant that we could not perform multi-level modeling, which would have discriminated between the individual and contextual factors important to caregiver and patient outcomes. In this light, we also could not adequately study the independent role of family resilience because of its correlation to caregiver resilience in our study sample. Family resilience is associated with positive psychological symptoms and reduced caregiver burden(55) however the research into family resilience is quite heterogeneous and often includes many different levels of family members or includes the main caregiver in the ‘family’ assessments.(93) For this study, family members were to be studied as a separate entity from the informal caregiver, as they also represent people nested closely within the patients’ socio-ecological system. However our instrument (FHI) was developed 30 years ago and may not have been sensitive to changes in the demographics of Australian citizens where there have been significant reductions in family household size over the last 20 years. Most households now consist of only 2 people (www.quickstats.censusdata.abs.gov.au) and it is possible that most of our caregiver and patient study participants lived together, on their own. As a number of items on the FHI (used here) did not distinguish between the caregiver and the family unit, measurement error cannot be ruled out.
Finally, the measurement of only one time point from baseline meant that we were not able to examine trajectories of factors that either promote or impede caregiver adaptation. Ideally caregivers would be studied over at least one year, with at least three repeated measures on study factors and outcomes, and would additionally include a non-caregiving sample for comparison.

**Implications**

No society can replace the costs of informal care. Caregivers have been described as ‘invisible patients’. In the absence of an ICD-10 code for caregiver burden, it remains unrecognised as a clinical condition. This means that there are few incentives for health services to formally recognise and address caregiver needs.(20) Examining caregiver resilience as we have done here is one step forward in terms of appropriately targeting health and community services that support both caregivers and patients, and developing social and clinical policies in this area.

There are several ways in which screening for ‘at risk’ trauma caregivers could occur soon after or patient discharge. Resilience could be assessed in caregivers prior to discharge, using the CD-RISC 10 instrument. Their physical and mental health along with their social support networks could also be evaluated at this time. As caregiver burden is multifactorial in causation, data from observational studies of caregiving, sourced from trauma populations where possible, could be systematically reviewed to inform the development of clinical guidelines aimed at recognising and managing caregiver burden. This approach should be multi-disciplinary, incorporating psychosocial, environmental factors and psychological descriptors of resilience represented in established metrics.

Models of resilience data often report coefficients of variations that explain only a small to moderate proportion of the variance of resilience on outcomes. This highlights the multifactorial nature of the resilience phenomenon. Many factors purportedly determine
resilience, including psychological, genetic and biological factors,(49) in addition to the socio-ecological factors we have studied here. Research into genetic factors that could mediate biological responses to resilience is underway, particularly in the area of child maltreatment(94) but is still in its infancy. Future research of resilience in trauma should persist in efforts to obtain neurobiological measures of resilience, as this will minimise the subjectivity of self-reported responses that currently predominate resilience research literature. Assuming that genetic variations in resilience exist (95) then ongoing work in this area should maintain its prevention focus, and examine the ‘gene-environment’ interactions, or the ways in which environmental factors mediate resilience and affect downstream health outcomes.

**Conclusion**

Comprehensive, multi-disciplinary programs of research are needed to inform prevention and intervention programs for trauma patients and their caregivers. This preliminary study showed that for caregivers of traumatic musculoskeletal injuries patients, caregiving represents an adversity that negatively impacts on resilience, mental health and support systems during the acute phases. Resilience in informal caregivers appears to protect against caregiver burden and patient’s physical function. At patient discharge, clinical assessment of caregivers’ physical health, resilience, and social support systems could identify caregivers at risk.
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Chapter 8: Conclusion

Introduction

Trauma patients recover in a highly contextual environment, and it is here where solutions to successful adaptation and reintegration into society will be found. This thesis has drawn on socio-ecological systems theory to examine the role of resilience in survivors of acute, severe multiple traumatic injuries. In this regard, resilience was examined in three main areas deemed as important components of the trauma survivors’ eco-system: rehabilitation services, neighbourhood resources, and primary informal caregivers.

In Study 1, resilience was examined in the form of community-based rehabilitation, where the effectiveness of multi-faceted programs targeting resilient qualities and functional outcomes was studied. Studies 2 and 3 examined qualities of ‘place’—namely those aligned with resilient and prosperous neighbourhoods—with a view to facilitating epidemiological surveillance of longer-term outcomes and ultimately informing approaches to patient rehabilitation. Finally, Study 4 examined resilient qualities and resilient resources in the patients’ primary informal caregiver, in which outcomes were measures of caregiver burden and health-related quality of life of both the caregiver and patient.

This chapter begins with a review of the key findings from each of the four studies before discussing the strengths and limitations of the overall program of work. After this, the implications for clinical practice and further research are outlined and recommendations for future study proposed.
Summary of Study 1
The aim of this study was to quantify, for injured adult patients, the effectiveness of resilience-based rehabilitation programs targeting patients’ socio-ecological systems on outcomes of RTW, stress mitigation, and self-efficacy. The hypothesis tested was that socio-ecological resilience rehabilitation programs after severe traumatic injuries result in stress mitigation, reduced time to return to work, and increased self-efficacy when compared to programs providing standard care.

A systematic review and meta-analyses of 19 randomised controlled intervention studies were conducted, and the results showed that socio-ecological resilience rehabilitation programs significantly increased the odds of RTW (OR 2.09 95% CI 0.99-4.44 \( p=0.05 \)), decreased the time taken to RTW by an average of seven days (mean difference -7.80, 95% CI -13.16 – -2.45 \( p=<0.001 \)), and increased mean levels of self-efficacy by five points (mean difference 5.19, 95% CI 3.12 – 7.26 \( p<0.001 \)), while there were no statistically significant changes in stress levels between the two groups.

There was insufficient study power to examine the specific program components affiliated with positive outcomes for all outcome measures in detail. However, subgroup analyses for the RTW outcome found that program components related to positive outcomes were those that harnessed workplace support (\( p<0.001 \)) and that positive RTW outcomes were more common in people with musculoskeletal or orthopaedic injuries than in those with brain injuries (\( p=0.02 \)).

Summary of Study 2
The overarching aim of this study was to examine resilient qualities of ‘place’, specifically patients’ neighbourhoods, in terms of factors thought to make
communities resilient. First, methods were developed to link ecological, multifaceted indices of neighbourhood socioeconomic disadvantage and residential geographic remoteness to trauma inpatients, which was done by obtaining geocoded patient residential data and computing robust, multifaceted indices of neighbourhood disadvantage (IRSD) and an ecological index of geographic remoteness. These ecological ‘exposures’ were then linked to individual patients on the hospital’s trauma registry, thereby assigning each patient neighbourhood exposures of relative disadvantage and remoteness from services.

Second, this study aimed to quantify the relationship between relative socioeconomic disadvantage and remoteness of residence admitted to a tertiary referral trauma centre over four years (2014–2017). The hypothesis was that for severe traumatic injury survivors, there would be a statistically significant association between neighbourhood disadvantage and remoteness of residence, independent of other ecological factors related to the injury itself and patient factors such as injury severity, comorbidity, and age.

Using a retrospective cross-sectional study design, bivariate analysis results showed that, along with the number of comorbidities (KW H Statistic.11.26, p=0.01), relative socioeconomic disadvantage was statistically significantly and positively associated with a number of dimensions of ‘place’, including remoteness of residence ($\chi^2$.41.61, p<0.001), remoteness of injury location ($\chi^2$.19.73, p<0.001), and receipt of initial trauma care at a regional hospital ($\chi^2$.14.14, p=0.003). After adjusting for age, sex, injury severity, and remoteness of injury location, logistic regression modelling showed a positive gradient of increasing disadvantage according to geographical remoteness of residence, with a six-fold increase in the odds of being in
the most disadvantaged category when compared to the least disadvantaged (OR 6.21, 95% CI 3.07-12.57, p<0.001).

**Summary of Study 3**

The aim of this study was to apply the methods established for Study 2 and evaluate the independent effects of neighbourhood on outcomes—namely neighbourhood relative socioeconomic disadvantage and remoteness of residence—on early morbidity and mortality outcomes for severe, acutely injured adult inpatients. The hypothesis was that patients’ ‘place’ of residence defined by neighbourhood socioeconomic disadvantage and remoteness would predict hospital outcomes for severely injured, hospitalised patients in a Level 1 trauma centre independent of patient factors such as age, injury severity, and comorbidity.

Using a retrospective cohort design and negative binomial regression modelling methods, the model of best fit included age, AIS, head and extremity injuries, ISS, and discharge disposition. Increased risk for longer ALSD was evident for: older age groups, i.e. 65–74 (RR 1.37, 95% CI 1.10–1.83), head injury (HR 1.36 95% CI 1.15–1.62, p<0.001), extremity injuries (RR 1.62 95% CI 1.36–1.94 p<0.001), higher ISS (RR 2.05, 95% CI 1.76–2.39, p<0.001), and discharge to rehabilitation facility (RR 1.75 95% CI 1.43–2.14, p<0.001).

For the mortality outcome, Cox proportional hazards regression modelling was used. The final model of best fit included age, ISS, injury mechanism, head injury, and remoteness of injury location. Compared to patients injured in urban areas and hospitalised, those injured in more remote areas were nearly twice at risk of dying in hospital (HR 1.75, 95% CI 1.15–3.12). These findings were independent of older age (HR 3.53, 95% CI 1.77–7.11), higher ISS (HR 5.279, 95% CI 2.78–10.02), and head
injury (HR 2.53 95% CI 1.38–4.62). A finding that warrants further investigation was that injury mechanisms that included intentional self-harm or assault was independently related to the increased risk of inpatient death (HR 2.73, 95% CI 1.48–5.03).

**Summary of Study 4**

This study aimed to examine caregiver resilience for caregivers of patients with severe, multiple musculoskeletal trauma. In this sense, the objectives were to quantify changes in caregiver resilience, resilient socio-ecological resources, and quality of life (community, family, health service, and workplace) during the acute phase of caring for patients with severe traumatic musculoskeletal injuries; and to evaluate the independent role of resilience using a valid metric and resilience resources on caregiver burden and caregivers’ and patient’s quality of life. The hypotheses were that:

- Caregiver resilience and socio-ecological resilient resources, physical health, and mental health would be significantly decreased from baseline;
- Caregiver resilience and resilience resources would be independently protective of caregiver burden;
- Caregiver resilience and resilience resources would be independently and positively associated with physical and mental function; and
- Caregiver resilience and resilience resources would be independently and positively associated with patient physical and mental health function.

A prospective cohort study of 53 caregiver and patient dyads was implemented. Patients were recruited over a 12 months period, with follow-up at three months. At
baseline, before commencing caring, caregiver resilience was positively and independently associated with physical health, while a resilience resource—community support—was positively and independently associated with mental health function. Because of the significant correlations with caregiver resilience, self-efficacy and family resilience were excluded from multivariate analyses.

The findings for the main hypotheses at follow-up were:

1. **Hypothesis 1:** Statistically significant reductions from baseline were found at follow-up for caregiver levels of resilience (MD 2.81 95% CI 1.19–4.42), mental health (MD 10.41, 95% CI 4.70–16.13), physical activity levels (MD 1.32 95% CI 0.36–2.28), and community support (MD 2.84, 95% CI 0.80–4.89). Of these findings, decline in mental health function of over ten points on the MCS of the SF-12 is clinically important.

2. **Hypothesis 2:** Caregiver resilience predicted lower caregiver burden (β= -0.74, p=0.008), independent of their resilient resources and patient physical and mental health function.

3. **Hypothesis 3:** Caregiver resilience and resilient resources did not statistically predict their quality of life (physical and mental health function).

4. **Hypothesis 4:** Caregiver resilience predicted higher levels of patients’ physical health and function (β= -0.69, p=0.003), independent of injury severity and patient factors. This finding could be mediated, in part, by patient resilience (β= -0.35, p=0.07).

The study was not able to reach the required sample size, and Type 2 errors could not be ruled out for the many non-significant associations.
**Strengths of This Body of Work**

This program of work has several positive qualities that enable it to contribute to the knowledge of resilience in trauma outcomes. For example, it is the first to explicitly address patients’ socio-ecological systems involved with trauma recovery and show that solutions will probably be found in these systems by targeting components of the system and tapping into the scholarly disciplines of public health, epidemiology, and sociology.

In the absence of a universally accepted definition for study, resilience was defined quite broadly in this work, however, core elements were retained based on concepts related to ‘adversity’, ‘adaptation’, resilient qualities, and socio-ecological resilient resources. Resilience was studied in terms of known individual qualities using valid psychometric instruments where possible, and by way of positive health outcome responses. Resilient resources existing in the patients’ eco-system, such as their neighbourhood, community rehabilitation services, and informal caregivers were also examined.

Gaps in current registry-based surveillance systems were identified, and methods were developed to incorporate geocoded residential data in the trauma registry and create ecological variables characterising patients’ place of residence. In doing so, this work acknowledges the importance of ‘place’ to trauma outcomes and has described the complex relationship between remoteness of residence and socioeconomic disadvantage for trauma populations. Preliminary analysis uncovered variations in mortality and acute length of stay according to remoteness factors but not socioeconomic disadvantage, suggesting that geographical distance from care overrides this factor. These methods will further enable spatial analysis of variations...
in outcomes according to neighbourhood factors and the identification of areas where inequalities exist. Meanwhile, the finding that geographical remoteness of residence impacts adversely on hospital outcomes—particularly inpatient mortality—is notable and worthy of further investigation.

There are novel aspects to the caregiver research study, which lie predominantly in the examination of under-studied trauma subgroups, i.e. people with severe musculoskeletal injuries and the resilience of their informal caregivers. As discussed in Chapter 7, there is emerging evidence that people with severe trauma to the pelvis and lower extremity injuries in particular have ongoing pain and disability five years post-injury. The expectation of these people to recover and return to work is greater than for patients with neurotrauma.

Despite the study’s small sample size, resilience is clearly important for caregivers. The co-efficient of determination ($R^2$) for the multivariate models of best fit showed that these resilient explanatory variables explained over half of the observed variation for the outcomes of caregiver burden and SF-12 physical function. Caregiver resilience is clearly related to their physical health and, to some extent, patients’ physical health, which provides avenues for early intervention.

Also, where the focus of Study 4 was on exploring caregiver resilience, the methods also established feasibility and laid the groundwork for further detailed study of aspects of caregiver resilience on patient outcomes where gaps in evidence exist and preliminary findings suggest caregiver causal patterns.

Methodologically, each study aimed to be as robust as possible in its methods. A program of research was identified and study designs were chosen that were best equipped to answer the research questions. Sampling for the prospective study was
carried out consecutively, and not by means of convenience methods, and non-participation and losses to follow-up were accounted for and analysed according to differences in the primary explanatory factors of caregiver resilience.

**Limitations**

The limitations of this work are primarily concerned with the study of resilience as a somewhat new and emerging area of interest in trauma, and statistical issues concerning study power.

Resilience research is in its infancy, and there are no clear guidelines as to how it should be studied with regard to trauma patients. In the absence of an acceptable and standard measure, it thus remains somewhat vulnerable to subjective inference. As discussed in Chapter 2, resilience has been studied as predictive traits, as outcomes, and as confounders or mediators of other explanatory factors on injury outcomes, such as depression.¹ This has led to significant heterogeneity in study designs and has limited our understanding of resilience mechanisms.

For the systematic review of resilience-based rehabilitation programs, there was no explicit mention of ‘resilience’, even though known resilient qualities were examined and incorporated as components into the programs. Further, no programs used validated resilient measurement instruments. Unsurprisingly, given the view held by many about the limitations of adopting individual-level, randomised approaches to research in complex systems²,³, statistical analyses showed heterogeneity of the studies.

For Studies 2 and 3, inferences were made about ‘resilient’ neighbourhoods in relation to inpatient trauma outcomes. Many qualities aligned with resilient neighbourhoods were encapsulated in both the IRSD index and remoteness index,
including economic prosperity, education and occupation, health status, employment opportunities, ability to connect to others, and access to resources that include health, education, and other community support. However, there are other unmeasured underlying qualities related to social capital that were not adequately captured—including social norms such as social cohesion, values, beliefs, and other cultural and religious networks—that are thought to be important components of resilient communities.4

This study focused on psychosocial and environmental components of resilience and was not able to examine the genetic and biological factors that could also explain variations in outcomes attributed to resilient qualities. Our understanding of the complex pathway to resilience is not complete without this component.

The study of gene-environment interactions is gaining prominence in resilience and is key to explaining why people respond differently to environmental stressors. Genetic variations in resilience are thought to exist,5 which could protect people against harsh environmental exposures related to trauma, such as severe childhood maltreatment.6 Most of the early research focused on central nervous system transmitters, where a range of human genes and polymorphisms have been linked to resilient responses to psychological trauma and stress. For example, polymorphisms in the noradrenergic and dopaminergic systems are associated with vulnerability to depression and PTSD.7 Psychological and environmental factors can also interact with an individual’s biological and genetic factors to shape resilient function.6,8–10 Studies of neural plasticity and epigenesis following maltreatment in children add weight to the theory that adverse, external experiences can affect the structure and function of the brain, which potentially distorts subsequent behaviours and social
interactions, thereby increasing adverse experiences. Research into gene environment interactions further highlights the importance of understanding how life experiences and environmental and social exposures can enable resilient adaptation.

Study power issues constrained our understanding of resilience mechanisms and the conclusions about many of the study’s findings. For the meta-analysis, analyses of a wider range of outcomes including quality of life and resilient program components was not possible because of insufficient numbers of studies and heterogeneity of outcome measures.

Ideally, Study 3 should have been analysed using multi-level modelling methods, where isolated effects of neighbourhoods could be determined independently of patient effects. However, this was not possible because of the insufficient number of outcomes (deaths) and areas that could capture sufficient variations in the neighbourhood factors of interest. Finally, Study 4 was also underpowered, and the full extent of multi-level statistical associations between caregiver resilience, resilience resources, and outcomes important to caregivers could not be determined. Furthermore, the dyad study sample was not large enough to enable structural equation modelling analysis, which would have yielded important information about the components of resilience as a latent construct in caregivers and patients.

**Public Health Implications**

There is still much to be learned in terms of addressing the public health burden of severe, non-fatal trauma. At the forefront is the need for effective resilience-based rehabilitation programs that target the complexity of trauma rehabilitation and address prevention at the secondary and tertiary levels. These levels of prevention
involve minimising or eliminating emerging psychological and physical disabilities after trauma, enabling work participation, or managing persistent pain and the permanent irremediable effects of trauma.

There is a well-recognised ‘over-emphasis’ on clinical trials to provide definitive answers to health interventions. For complex and chronic health problems, these studies can result in a somewhat reductionist approach to understanding the effectiveness of a limited number and type of program components. Reliance on clinical trials of single- or even multi-component rehabilitation programs to understand resilience in trauma rehabilitation may not ever fully inform us as to how complex systems function to improve trauma outcomes. As Rutter notes, research in areas like trauma recovery is probably best done in ways that take into account the real-world circumstances in which people live and consider whether an intervention changes the system favourably rather than for individual outcomes. Wilson supports this notion, arguing that systems science involves mapping all the inter-related parts and identifying elements in the system for leverage and intervention. To some extent, this is what was carried out in this thesis, which involved a detailed study of parts of the patients’ eco-system and identified components of the system (caregivers, neighbourhoods, and rehabilitation) where changes could be made to improve outcomes.

To advance prevention at the secondary and tertiary levels, new approaches are required that could, for example, enable a trauma service to expand its scope and oversee prevention activities in trauma patients’ socio-ecological environments. This may involve advocating for more financial and workplace support for, and explicit clinical recognition of, primary informal caregivers. It could also involve working
with community services to develop and deliver health promotion and prevention programs aimed at supporting caregivers’ physical and mental health and resilience at the onset of caregiving. Focusing on prevention and rehabilitation strategies in under-served rural and regional areas where there are known socioeconomic disadvantages are other examples where trauma services could take preventive action for serious trauma survivors.

**Clinical implications**
This research suggests that there is a need to explicitly involve caregivers in the patients’ rehabilitation journey, which requires having formal clinical interactions with them and screening them for resilience and adverse outcomes, such as caregiver burden. Adelman\textsuperscript{15} proposes an excellent framework for assessing caregiver burden in a general practice setting, where caregivers are asked a number of questions related to the context of their caregiving, including items such as their perception of the patients’ overall health, their values, norms, self-rated health and quality of life, their knowledge and skills about caregiving, and resources for caregiving. Additional questions about caregiver resilient qualities and resilient support systems could be asked, with attention directed towards their physical health. However, the tool will have limited use if solely used by general practitioners and should therefore be used by all clinical staff involved in the care of patients and their families after traumatic injury.

Finally, if resilience is to be incorporated into trauma rehabilitation, then clinical, academic, and public health partnerships are required. A multi-disciplinary model of resilience educational training could be designed to teach medical students and other trauma health professionals about resilience, i.e. how to screen for it and take a
detailed history that fully captures the patients’ resilient resources, including those of the informal caregiver.

**Future research**

This study has several important implications for further research:

**Trauma Registries and methods for surveillance**

Trauma registries have the capacity to generate timely, large-scale population-level data on patient-reported outcomes. As evaluation of trauma outcomes shift from acute settings to communities, methodological approaches will not be as straightforward as those used for acute care outcomes, where registry and clinical information systems provide easily accessible data that lends itself to clinically driven, biomedical regression modelling methods.

However, there is currently no standard or routine approach to collecting information about trauma outcomes beyond the acute care setting. Furthermore, there is no standard, agreed metric for outcomes related to longer-term disability, including psychosocial dysfunction. For example, functional measures at discharge do not predict long-term functional outcomes, and while an argument is emerging that quality of life is deemed to be the most important metric,\(^{16}\) consensus is still needed as to the most appropriate metric to use. In this regard, innovative work is currently underway at the Gold Coast University Hospital to further develop systems to enable sustainable long-term trauma outcome assessments.

**Further examination of rural and urban variations in trauma outcomes**

The data from Studies 2 and 3 needs further unpicking to understand more about patterns of regional trauma care, triage systems, and trauma causal mechanisms that
confer additional risk of inpatient mortality for rural patients. The prognostic risk for rural patients may not be adequately defined by traditional measures of injury severity and type of injury, such as head injuries. In this sense, further research is needed to examine the severity and mechanism of these injuries, including complications, and the clinical patterns of care involving resuscitation, retrieval, and regional and tertiary trauma management.

**Measuring integrated care in objective ways**

Integrated care is care that crosses the boundaries between primary, community, allied health, and hospital care, in addition to also extending into social care and support. Integrated care is the ‘holy grail’ of health systems aiming to ensure equitable health care delivery and outcomes for patients. The Primary Health Networks currently exist to coordinate primary health care, but data showing the extent to which PHC services deliver timely, equitable, and optimal evidence-based PHC is lacking.

Because of the many services that provide community care, building data systems that link with others and capture the ways in which trauma patients and their families move through the health system are important priorities for research. In this regard, one small step could be using established trauma cohorts to link claims for medical and pharmaceutical care using data from the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS). For example, the Medicare Benefits Schedule (MBS) contains items that support different types of primary care services, many of which encompass multi-disciplinary care.17

Other key research priorities should be based on strengthening the evidence base for the effectiveness of the multi-disciplinary community care of people with trauma.
disabilities, particularly for those who are socioeconomically disadvantaged or living in areas where access to primary care services is limited.

**Study of resilience in trauma using the bio-psychosocial paradigm**

Resilience is of increasing interest because of the notable individual differences in the ways that people respond to similar levels of trauma. However, the methodologies used in many of these studies are conceptually poor and results are limited in their generalisability. Further, empirical research on protective factors remains limited, and their inter-relationships to risk factors and exposure factors are unclear.

Of concern is that studying resilience using ‘inference’ methods means that outcomes attributed to ‘resilience’ are simply masking other unmeasured risk or protective factors. Research into resilience will need to develop sophisticated methodologies and measurement strategies that incorporate many disciplines and professionals. These include trauma clinicians, basic scientists, geneticists, psychologists, sociologists, epidemiologists, and biostatisticians. All should work collaboratively to develop and validate resilience measures across a range of populations.

**Recommendations**

1. Expand the caregiver/patient cohort study to a fully powered study that enables an informative and detailed multi-disciplinary and comprehensive study of the resilience and the relationship between caregiver resilience and caregiver and patient outcomes.

2. Expand the scope of activities of a trauma service to advocate for prevention at the secondary and tertiary levels of all of its patients in communities using
socio-ecological systems theories and acknowledging trauma outcome inequalities.

3. For ongoing trauma cohort studies, consider the feasibility of linking data to PBS and MBS in order to enable a comparative objective evaluation of the quality and extent of integrated care in addition to patient-reported outcomes.

4. Audit the patients who died in the trauma data set for Study 3 to identify possible clinical and injury-related explanations for higher rates of deaths in rural patients. If possible, expand this work to the regional hospital point of care, if relevant.

5. Include the IRSD scores and the remoteness index in the trauma registry data set and develop ways to integrate these components with national trauma data sets in order to evaluate and compare spatial variations in trauma outcomes according to these ecological indices.

6. Work with other trauma research centres to define a set of standard and acceptable outcome measures for non-fatal trauma survivors.

7. Define a standard and acceptable metric of resilience for trauma research and for screening patient and caregivers. Ideally, this should be one that considers resilient qualities and family, social, and community resilient resources.

8. Consider incorporating resilience education and screening methods into the academic programs for trauma and medical health professionals.

9. Conduct further research aimed at validating resilient metrics with biological measures of resilience in order to advance our understanding of resilient recovery in trauma populations.
Summary
This chapter has summarised the aims, hypotheses, and results of this thesis and reported the main findings from each of the four studies. Further, the strengths and limitations of the work have been critically discussed, and implications for clinical practice and ongoing research areas have been outlined in detail. Finally, the chapter concluded with a series of recommendations for the advancement of research into resilience promotion for severely injured multiple trauma patients using public health principles.
References


Appendices

Appendix A: Ethics Approvals

Queensland Health

District Research Governance

Dear Professor Martin Wulfshlem
Principal Investigator
Gold Coast University Hospital
1 Hospital Boulevard
SOUTHPORT QLD 4215

HREC reference number: HREC/17/QGC2/266
SSA reference number: SSA/17/QGC2/263
Project title: “Surviving traumatic physical injuries: quantifying the socio-ecological factors related to health, and well-being and recovery.”

Thank you for submitting an application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Gold Coast Hospital and Health Service

Ethics approval for this project was granted on 31 October 2017 by the Gold Coast Hospital and Health Service Human Research Ethics Committee and the approval letter contains a list of all the approved documents.

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

1) Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project are to be submitted to the HREC for review. A copy of the HREC approval/rejection letter must be submitted to the ROO.

2) Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to the research governance officer;

3) Proposed amendments to the research protocol or conduct of the research which may affect both the ongoing ethical acceptability of the project and the site acceptability of the project are to be submitted firstly to the HREC for review and then to the research governance officer after a HREC decision is made.

Office
Officer for Research Governance & Development
Level 2, Pathology and Education Building
1 Hospital Boulevard
Southport QLD 4215

Phone
(07) 5657 3800

Queensland Government

Enquiries to
Research Governance Leader
(+61) 7 5657 3800
Our Number
SSA/17/QGC2/263

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<td>Public Health Act approval</td>
<td>RD0037132</td>
<td>24 November 2017</td>
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<td>Research Collaboration Deed – Project Schedule</td>
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Queensland Health

District Research Governance

Enquiries to: Research Governance Leader
Phone: (07) 5517 1883
Our Net: SSA/17/QGC/263

A/Professor Martin Wulschleger
Principal investigator
Gold Coast University Hospital
1 Hospital Boulevard
SOUTHPORT QLD 4215

Dear A/Professor Wulschleger

HREC reference number: HREC/17/QGC/266
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Office
Office for Research Governance & Development
Level 2, Pathology and Education Building
1 Hospital Boulevard
Southport QLD 4215

Phone: 617 5517 3209
Dear A/Professor Wulschleger,

HREC reference number: HREC/17/QGC/256
SSA reference number: SSA/17/QGC/263
Project title: “Surviving traumatic physical injuries: quantifying the sociological factors related to health, and well-being and recovery.”

Thank you for submitting an application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Gold Coast Hospital and Health Service

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Office
Officer for Research Governance & Development
Level 2, Pathology and Education Building
1 Hospital Boulevard
Southport QLD 4215

Please
01 7 5587 3550
Dear APro Jing Sun

I write in relation to your application for ethical clearance for your project "Surviving traumatic physical injuries: quantifying the socio-ecological factors related to health, and well-being and recovery." (GU Ref No: 2017/879). The research ethics reviewers resolved to grant your application a clearance status of "Conditionally Approved".

This decision is subject to:

Condition 01: As per the expectations articulated in the National Statement on Ethical Conduct in Human Research (2007) and Booklet 8 of the Griffith University Research Ethics Manual, because of the prior review by another HREC, this research has been subject to a special administrative review.

Condition 02: Please provide an assurance that the Manager, Research Ethics, Griffith University will be notified promptly if any adverse events occur or if any concerns or complaints are received about the ethical conduct of this research, or if the project is suspended or discontinued for any reason.

Condition 03: Please provide your response to the conditions raised by the Committee in the body of an e-mail to research-ethics@griffith.edu.au or in a separate document forwarded by e-mail (please do not try to amend the RIMS application). Please ensure you respond directly to each condition.
However, you are authorised to immediately commence this research, in full, on the strict understanding that these matters are addressed and that you provide details of how they were addressed.

Please note that failure to provide a timely response to these matters may result in this authorisation being suspended or withdrawn.

It would be appreciated if you could give your urgent attention to the issues raised by the Committee so that we can finalise the ethical clearance for your protocol promptly.

Regards

Mr Rick Williams
Manager Research Ethics and Integrity
Office for Research
Bray Centre, Nathan Campus
Griffith University
Tel: +61 (0)7 373 54375
Email: Rick.Williams@Griffith.edu.au
Appendix B: Questionnaires and Study Forms (For Study 4).

“Survivors of traumatic physical injury and their primary caregivers: quantifying factors related to health and well-being.”

Community Referral Information

People who volunteer to care for people at home are providing a very important service for the injured patient, and for society. Yet they are often caught unprepared for this task.

Our research is attempting to understand how caregivers of injured people cope with challenging situations and the types of support networks that are most useful to them in this role. We also wish to collect information about caregivers’ physical health and psychological wellbeing and their general experience of the caregiving role.

As a carer you might find that you need further information or emotional support. The following information could be helpful.
### Community support services for people providing informal care

<table>
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<tr>
<td><strong>Your General Practitioner</strong></td>
<td>As a first step, we suggest that you contact your General Practitioner for support, and for information about relevant support services in your local area. If it is an emergency or if assistance is urgently required, ring 000 or present to the Emergency Department of the hospital that is closest to you.</td>
</tr>
<tr>
<td><strong>A psychologist</strong></td>
<td>If you are already connected with a mental health professional in your community or through a hospital service, we suggest you contact them. Otherwise, the APS “Find a Psychologist Service” is an online, telephone and email referral service for the general public, GP’s and other health professionals who are seeking the advice and assistance of a qualified APS psychologist.</td>
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|                                              | • Phone: 1800 333 497 (Outside Melbourne) or 03 8662 3300 (in Melbourne)  
|                                              | • Email: referral@psychology.org.au  
|                                              | • Operating Hours: 8:45am to 5:15pm Monday to Friday |
| **Your local community health service (Qld)** | Your local community health service can provide you with information or support about mental health issues.                                                                                                                                 |
|                                              | • Phone Call 13HEALTH (13432584)  
| **Your local community health service (NSW)** | If you live in NSW, eight local health districts (LHD) cover the Sydney metropolitan region, and seven cover rural and regional NSW. Community Health Services operate within these LHDs Click on this link to locate your Local Health District (LHD). [http://www.health.nsw.gov.au/lhd/Pages/default.aspx](http://www.health.nsw.gov.au/lhd/Pages/default.aspx) From here, you can navigate your way to the Community Health Centre for your LHD |
| **Caregivers Australia, and associated organisations** | Caregivers Australia is the national peak body representing Australia’s caregivers, advocating on behalf of Australia’s caregivers to influence policies and services at a national level. It works collaboratively with the Network of state and territory Caregivers Associations, to deliver a range of essential national carer services. |
|                                              | • Phone: 1800 242 636  
| **Caregivers Qld**                           | Caregivers Queensland is the peak Qld body of Caregivers Australia, representing and advocating on behalf of caregivers throughout Queensland.                                                                                                                                 |
|                                              | • Phone: Carer Advisory Service. Call 1800 242 636 for information, support, planning and referral advice to help you in your caring role. Operating Monday to Friday, 9:00am to 5:00pm  
|                                              | • Website: [http://caregiversqld.asn.au/about-us](http://caregiversqld.asn.au/about-us) |
| **Carer Information Support Services (CISS)** | The CISS provides a co-ordination pathway for caregivers to access services and other forms of support that are most appropriate to their individual needs and circumstances. Services include access to counselling, carer support groups, carer education and training, advocacy, respite services and guided referral, where appropriate.  
|                                              | CISS is delivered through Caregivers Australia’s network of Carer Associations in each state and territory.                                                                                                                  |
|                                              | • Phone: For more information or to make an appointment call 1800 242 636.                                                                                                                                               |
### National Carer Counselling Program (NCCP)

The NCCP provides short term counselling, emotional and psychological support services for caregivers in need of support. The NCCP is delivered through Caregivers Australia’s network of Carer Associations in each state and territory.

Counselling can be delivered via the telephone, face to face, via Skype, email or in a group.

- **Phone:** 1800 242 636 (free call from a landline). Operates only during business hours. Mobile calls at mobile rates.

### Carer Respite and Carelink (CRCC)

Commonwealth Respite and Carelink Centres (CRCCs) support caregivers’ needs and circumstances, and the needs of the people they care for. CRCCs can facilitate access to information, respite care and other support appropriate to caregivers.

- **Phone:** in Business hours, phone 1800 052 222 for information about your nearest CRCC, during business hours. (Freecall except from mobile phones)

### Lifeline

Lifeline is a national charity that provides 24/7 crisis support and suicide support prevention service for all ages.

- **24 Hour Telephone Crisis Line** is open 24/7 by calling 13 11 14.
- **Lifeline Crisis Support Chat** is open 7:00am to 4:00am (AEST/AEDT) 7 days a week and can be accessed from: [https://www.lifeline.org.au/Get-Help/Online-Services/crisis-chat](https://www.lifeline.org.au/Get-Help/Online-Services/crisis-chat).
- **Phone:** 13 11 14
- **Website:** [https://www.lifeline.org.au/](https://www.lifeline.org.au/)

### Beyond Blue

Beyond Blue is an Australian non-profit independent organization that promotes good mental health, tackles stigma and discrimination, and provides support and information on anxiety, depression and suicide to everyone in Australia.

- **Phone:** 1300 224636, 24 hours, 7 days a week.
- **Website:** [https://www.beyondblue.org.au/get-support/get-immediate-support](https://www.beyondblue.org.au/get-support/get-immediate-support)
- **Chat online:** 3pm-12am, 7 days a week (click on the link at the above website)
- **Email online and online forums** (click on the link at the above website)
Participant Information Sheet (Caregivers)

Study Title

_Survivors of traumatic physical injury and their primary caregivers: quantifying factors related to health and well-being._

Principal Investigators

- Associate Professor Jing Sun, Griffith University  
  j.sun@griffith.edu.au, 07 5678 0924
- Associate Professor Martin Wullschleger, Gold Coast Health  
  martin.wullschleger@health.qld.gov.au, 07 56870231
- Ms Katharine Heathcote, Griffith University  
  k.heathcote@griffith.edu.au, 0413 585 724

What is this study about and why is it important?

Surviving a traumatic injury can be a significant event for people, requiring long periods of rehabilitation and care and time off work. People who volunteer to care for injured patients are providing a very important service for the injured patient, and for society. Yet they are often caught unprepared for this task. Some report feeling
overwhelmed and unsupported, yet others find the caregiving experience very rewarding.

Many factors can affect the ways in which people recover. These can be directly related to the injury, the various ways in which people are able to cope, and to the availability of family, work and other support networks. The relative importance of each, or all of these factors in terms of promoting long term recovery is not certain.

We are asking you to participate in a research study about caregiving and patient recovery following significant physical injury. Participation in the study requires both you and the patient you are caring for to participate.

Your involvement, as an informal caregiver, is important, and will help us to better understand the wide range of factors that can influence patient recovery. Your involvement will also help clinicians design programs that can assist caregivers support patients in the recovery.

**Who is involved?**

A research team consisting of members of the Trauma Service, Gold Coast University Hospital, and the School of Medicine, Griffith University invite you to take part in a research study that is examining the long term health and well-being of people who have suffered physical traumatic injuries. The study is being coordinated by Ms Kathy Heathcote, a PhD student who is working with the research team.

Once you understand what the research project is about and if you agree to take part in it, you will be asked to sign the Consent Form. You will be given a copy of this Participant Information and Consent Form to keep.
What is involved in the study?

In order to fully understand the ‘bigger picture’ of what is involved with injury recovery and caregiving, we need to study both you and the injured person you will be caring for, over a period of time. This will enable us to see how things change in your circumstances and how these changes affect a number of other important factors related to your general wellbeing. We will be asking you about your health, coping ability, caregiving tasks, quality of life and your work and family situation.

Your participation will therefore involve the following:

- Completing a survey questionnaire with a member of our research team, just before you are discharged home or as soon as possible after discharge. This will enable us to obtain baseline measures before you commence caring for the injured person. *This should take about 20 minutes of your time.* We will conduct the interview with you and the injured person you are caring for separately.

- Participating in two follow up surveys that will be mailed to you at approximately 6 and 12 months after the baseline survey. These should take about 20 minutes of your time.

We can help you complete the questionnaires if required. Or you can ask a friend or a family member to help you complete the form.

Up to 200 people will be invited to participate in this project: 100 caregivers and 100 care recipients (injured patients).
Why have I been chosen?

You have been chosen for this study because you and the injured person in hospital, have identified you as the main person who will be supporting and facilitating the care of the patient.

Do I have to participate?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your relationship with members of the Trauma Team or other clinical personnel managing the care and rehabilitation of the injured patient you are looking after.

As we are studying both you and the injured person you are caring for, it is important that both of you understand that the study will be conducted over the next 12 months, and will require completing brief questionnaires at the follow-up time point.

It is also important that your decision to participate is made independently, by you and not by anyone else. To assist with this, we will meet with you and the person you are caring for, separately, to answer any questions you might have about this study requirements, to obtain your consent and to conduct the baseline interview.

Withdrawal from the study will also mean that the injured person you are caring for will need to withdraw as well. This decision will not affect the relationship between you and the health care professionals looking after the person that you are caring for.

We suggest you discuss any decisions about withdrawing from the study, together before contacting a member of the study team. If this is not possible, we can contact the patient on your behalf, to inform them of your decision.
If you decide to withdraw from this study, please notify a member of the research team.

**Are there any risks?**

There are no identified risks associated with the project. If you find any of the questions distressing, you can contact your GP, or a counsellor. You can withdraw from the study at any time if you wish. Alternatively you can contact Lifeline on 13 14 11 ([www.lifeline.org.au](http://www.lifeline.org.au)) or Beyond Blue (03) 9810 6100 ([www.beyondblue.org.au](http://www.beyondblue.org.au))

**Are there any benefits?**

If you agree to take part in this study, it is likely that your participation will help us understand the factors that are important for the health and wellbeing of caregivers of people who have suffered acute traumatic injury. This information could also assist people involved in public health policy and decision-making to plan for services and design programs that support informal caregivers and patients

**What are the costs?**

There will be no cost to you for participating in this study and you will not receive any payment for participating in this study.

**Financial disclosure**

This project is not currently receiving an external source of funding.
Access to the results of the study

We will send you a report of the study’s findings once the study has been completed.

What about confidentiality?

We will not share any of your information with the person you are caring for, or with members of their clinical team managing their rehabilitation and medical care.

At the start of the study, we will require your name, email address and some identifying information as this will enable us to contact you at follow up. However, for all other purposes, your information will be ‘de-identified’, that is you cannot be identified. You will be given a unique, identifying code and any information that is sent out to you to complete will contain this code. This unique code will only be available to members of the research team and will also be used for data management and analysis. This code means that you cannot be identified on any databases or reports arising from the research. In other words, your responses will be ‘de-identified’.

De-identified data from the questionnaires will be entered into a database and stored in a password protected file on the Griffith University Research Drive. Hard copies of the questionnaires will be stored in locked filing cabinets in Ms Heathcote’s office accessible, only by members of the study team. Data analysis will be conducted by a member of the study team who is not directly involved with the clinical management of you or the injured patient you are caring for.

In any publication of this study, information will be reported in such a way that you cannot be personally identified.
Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this study have been approved by the Gold Coast Hospital and Health Service Human Research Ethics Committee HREC/17/QGC/256

If you have any questions please contact the research team

Ms Katharine Heathcote | Research Investigator. K.heathcote@griffith.edu.au.

Phone 0413 585 724. Or you can contact Ms Heathcote at the Griffith University School of Medicine. Ph 07 5678 0504.

Should you have any problems or queries about the way in which the study is conducted, and do not feel comfortable communicating with the staff conducting this survey, please contact: Gold Coast Hospital and Health Service Human Research Ethics Committee, Level 2, E Block, Gold Coast University Hospital, Telephone: (07) 5687 3879 or GCHEthics@health.qld.gov.au
Consent Form for Participation in a Research Project

Title
“Survivors of traumatic physical injury and their primary caregivers: quantifying factors related to health and well-being”

Location
Gold Coast Hospital and Health Service

Research Team
Associate Professor Jing Sun, Associate Professor Martin Wullschleger, Ms Kathy Heathcote
School of Medicine, Griffith Health Centre,
Griffith University.
Contact: 617 567 80924
Email: j.sun@griffith.edu.au

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will include completing three survey questionnaires over a 12-month period.
- I understand that my information remains confidential, and is accessible only to the study team.
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time, without explanation or penalty;
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 4375 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and

- I agree to participate in the project.

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Participant Information Sheet
(Patients)

Study Title

Survivors of traumatic physical injury and their primary caregivers: quantifying factors related to health and well-being.

Principal Investigators

- Associate Professor Jing Sun, Griffith University j.sun@griffith.edu.au, 07 5678 0924
- Associate Professor Martin Wullschleger, Gold Coast Health martin.wullschleger@health.qld.gov.au, 07 56870231
- Ms Katharine Heathcote, Griffith University. k.heathcote@griffith.edu.au 0413 585 724

What is this study about and why is it important?

Surviving a traumatic injury can be a significant event for people, requiring long periods of rehabilitation and care and time off work. People who volunteer to care for
injured patients are providing an important service for the injured patient, and for society. Yet they are often caught unprepared for this task.

Many factors can affect the ways in which people recover. These can be directly related to the injury, the various ways in which people are able to cope, and to the availability of family, work and other support networks. The relative importance of each, or all of these factors in terms of promoting long term recovery is not certain.

We are asking you to participate in a research study about factors that influence peoples’ recovery from physical injuries. Participation in the study requires both you and your nominated caregiver to participate.

Your involvement, as a patient, is important, and will help us to better understand the wide range of factors that can influence patient recovery. Your involvement will also help clinicians design programs that can assist caregivers support patients in their recovery.

**Who is involved?**

A research team consisting of members of the Trauma Service, Gold Coast University Hospital, and the School of Medicine, Griffith University invite you to take part in a research study that is examining the long term health and well-being of people who have suffered physical traumatic injuries. The study is being coordinated by Ms Kathy Heathcote, a PhD student who is working with the research team.

Please take time to read the following information carefully and ask the study team any questions about the study.
Once you understand what the research project is about and if you agree to take part in it, you will be asked to sign the Consent Form. You will be given a copy of this Participant Information and Consent Form to keep.

**What is involved in the study?**

In order to fully understand the ‘bigger picture’ of what is involved with injury recovery and caregiving, we need to study both you and your caregiver over a period of time. This is so we can see how things change in your care circumstances and how these changes affect a number of other important factors related to you and your caregivers’ wellbeing. We will be asking you about your health, coping ability, quality of life, your living circumstances and your work.

Your participation will therefore involve the following:

- Completing a survey questionnaire with a member of our research team, just before you are discharged home or as soon as possible after discharge. This will be conducted between you and Ms Heathcote, and will enable us to obtain baseline measures before your rehabilitation period commences. *This should take about 20 minutes of your time.*

- Participating in **two** follow up surveys that will be mailed to you, approximately 6 and 12 months after you have been discharged from hospital. We can help you complete the questionaries if required. Or you can ask a friend or a family member to help you complete the form.

- Permitting a member of the research team to access your medical records to obtain information about your injury, your recovery in hospital, and any co-existing health conditions you had prior to the injury.
We can help you complete the questionaries if required. Or you can ask a friend or a family member who is not your primary caregiver, to help you complete the form.

Up to 200 people will be invited to participate in this project: 100 caregivers and 100 care recipients (injured patients).

**Why have I been chosen?**

You have been chosen for this study because you have suffered a physical injury, have been hospitalised for that injury and require a period of informal care after discharge. Also you have identified a person as your caregiver; who will be the main person supporting and facilitating your care during rehabilitation.

**Do I have to participate?**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your relationship with members of the Trauma Team or other clinical personnel who manage your care and rehabilitation.

As we are studying both you and the person who is caring for you, it is important that both of you understand that the study will be conducted over the next 12 months, and will only require completing short questionnaires at the follow-up time points.

It is also important that your decision to participate is made independently, by you and not by anyone else. To assist with this, we will meet with you and your designated caregiver, separately, to answer any questions you might have about this study requirements, to obtain your consent and to conduct the baseline interview.
Withdrawal from the study will also mean that your caregiver will need to withdraw as well. This decision will not affect the relationship between you and the people looking after the person that you are caring for. We suggest you discuss any decisions about withdrawing from the study, together before contacting a member of the study team. If this is not possible, we can contact the caregiver on your behalf, to inform them of your decision.

If you do decide to withdraw from this study, please notify a member of the research team.

**Are there any risks?**

There are no identified risks associated with the project. If you find any of the questions distressing, you can contact your GP, or a counsellor. Alternatively you can contact Lifeline on 13 14 11 (www.lifeline.org.au) or Beyond Blue (03) 9810 6100 (www.beyondblue.org.au)

You can withdraw from the study at any time if you wish.

**Are there any benefits?**

If you agree to take part in this study, it is likely that your participation will help us understand the factors that are important for the health and wellbeing of caregivers of people who have suffered acute traumatic injury. This information will also likely assist people involved in public health policy and decision-making to plan for services and design comprehensive programs that support informal caregivers and patients.
What are the costs?

There will be no cost to you for participating in this study and you will not receive any payment for participating in this placement program.

Financial disclosure

This project is not currently receiving an external source of funding.

Access to the results of the study

We will send you a report of the study’s findings once the study has been completed.

What about confidentiality?

We will not share any of your information with your caregiver or with members of the clinical team managing your rehabilitation and medical care.

At the start of the study, we will require your name, email address and some identifying information as this will enable us to contact you at follow up. However, for all other purposes, your information will be ‘de-identified’, that is you cannot be identified. You will be given a unique, identifying code and any information that is sent out to you to complete will contain this code. This unique code will only be available to members of the research team and will also be used for data management and analysis. This code means that you cannot be identified on any databases or reports arising from the research. In other words, your responses will be ‘de-identified’.

De-identified data from the questionnaires will be entered into a database and stored in a password protected file on the Griffith University Research Drive. Hard copies of
the questionnaires will be stored in locked filing cabinets in Ms Heathcote’s office which will only be accessed, by members of the study team. Data analysis will be conducted by a member of the study team who is not directly involved with the clinical management of you or the injured patient you are caring for.

In any publication of this study, information will be reported in such a way that you cannot be personally identified.

**Ethical Guidelines**

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

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Location  Gold Coast Hospital and Health Service

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School of Medicine, Griffith Health Centre, 

Griffith University. 

Contact: 617 567 80924 

Email: j.sun@griffith.edu.au

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that the research investigators will be obtaining access to my medical information relating to this current hospitalisation;
- I understand that my involvement in this research will include completing three survey questionnaires over a 12 month period;
- I understand that my information remains confidential, and is accessible only to the study team.
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time, without explanation or penalty;
• I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 4375 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and

• I agree to participate in the project.

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| Name (Researcher)                         |
| Signature                                 |
| Date                                      |
Protocol for managing Caregiver Distress

- The Participant Information Form states that some questions might cause concern of discomfort.

- A **Community Referral Plan** has been developed (see Appendix 3) and this will be given to **all** participants, along with the Participant Information Form, prior to interview or self-completion of the questionnaires.

- If a participant becomes distressed during a phone or face to face interview, the researcher who is conducting the interview will take the following steps:
  - Acknowledge their distress, and ask if they would like to take a break.
  - Inform the participant that they do not have to answer any question that causes distress
  - Terminate the interview if distress is significant eg if the participant is having difficulty answering questions because of apparent distress.
  - Otherwise, discuss the Community referral plan protocol (see below) with the participant at the completion of the interview.
- If the participant is significantly distressed and the interview is conducted at the hospital, prior to patient’s discharge, inform the Research Supervisor (and Director of Trauma Services), and relevant members of the Trauma team, including the Trauma Nurse Practitioner and Social Worker. Advice about appropriate management will be sought.

- If interview is conducted after patient’s discharge from hospital, ie at home, over the phone, discuss the Referral plan with the participant. Seek advice from members of the Trauma Team. Follow up the participant within 24-48 hours.

- Record all concerns, follow-up and referrals during the study
The questions in this form mostly relate to the time period before you were hospitalized for your injuries. If there is no specific time period specified in the question, just answer the question as to how you **USUALLY** felt or functioned before your injury.

Please try and answer every question.

Thank you for participating in our research.

To help us read you answers, please write as clearly as possible using a BLACK or BLUE pen.

Please put a cross in the appropriate box(es) ☒ Yes ☐ No

### Section 1: Some general details about you

1. **In the week prior to your injury** what best described your current living situation?
   - Single
   - Married
   - Widowed
   - Divorced
   - Defacto/living with partner
   - Separated

2. **What is your age?**

3. **What is your current postcode of residence?**
   
4. **What is the name of the suburb or town in which you live?**

5. **What is your ancestry? You can tick up to 2 boxes**
   - English
   - Irish
   - Scottish
   - Italian
   - German
   - Indigenous or Aboriginal
   - Chinese
   - Australia
   - Other: (please specify)

6. Please complete the table about the country of birth of yourself, your mother and your father

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7. What is the highest year of primary or secondary school that you completed?
- Never attended school
- Year 8 or below
- Year 9 or equivalent
- Year 10 or equivalent
- Year 11 or equivalent
- Year 12 or equivalent

8. Have you completed a trade certificate, diploma, degree or any other educational qualification?
- Yes (please specify) __________________________
- No

9. I would now like to ask you about your household income in the month before your injury. What was your annual household income before tax?
- Less than $20 000
- $20 000-$40 000
- $40 000-$60 000
- $60 000-$80 000
- More than $80 000

Section 2: Your ability to cope, and accomplish things

10. We would now like to ask you some questions about your belief in your ability to accomplish things, as well as your general wellbeing prior to this hospitalization episode. Please circle the response most applicable. Answer options are listed as follows:

I am able to adapt to change?
0 1 2 3 4

I can deal with whatever comes?
0 1 2 3 4

I try to see the humorous side of things?
0 1 2 3 4

Coping with stress can strengthen me?
0 1 2 3 4

I tend to bounce back after illness or hardship?
0 1 2 3 4

Section 3: Your general wellbeing

The next section concerns your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

1. In general, would you say your health is:
- Excellent
- Very good
- Good
- Fair
- Poor

The following questions are about activities you might do during a typical day. In the 4 weeks before your injury, did your health limit you in these activities? If so, how much? Answer options are listed as follows:

(1- YES limited a lot, 2- YES limited a little, 3- NO not limited at all).

2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf?
1 2 3

3. Climbing several flights of stairs?
1 2 3
During the past 4 weeks before your injury, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. Accomplished less than you would like?
   □ Yes   □ No

5. Were limited in the kind of work and other activities?
   □ Yes   □ No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like?
   □ Yes   □ No

7. Did work or activities less carefully than usual?
   □ Yes   □ No

8. During the past 4 weeks before your injury, how much did pain interfere with your normal work (including work outside the home and housework)?
   □ Not at all   □ A little bit   □ Moderately   □ Quite a bit   □ Extremely

These questions are about how you have been feeling during the past 4 weeks before your injury. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

Please circle the response most applicable.

(1- All the time, 2- Most of the time, 3- A good bit of the time, 4- Some of the time, 5- A little of the time, 6- None of the time).

9. Have you felt calm and peaceful?
   1 2 3 4 5 6

10. Did you have a lot of energy?
    1 2 3 4 5 6

11. Have you felt down-hearted and blue?
    1 2 3 4 5 6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
    □ All of the time
    □ Most of the time
    □ Some of the time
    □ A little of the time
    □ None of the time

Section 4: The following questions relate to how productive you were in your general daily activities in the month before your injury.

During the past month have you had difficulties with:
Please circle the response most applicable. Answer options are listed as follows:

(4- Usually did with no difficulty, 3- Some difficulty, 2- Much difficulty, 1- Usually did not do because of health, 0- Usually did not do for other reason).

1. Taking care of yourself, that is eating, dressing, bathing?
   4 3 2 1 0

2. Moving in and out of a bed or chair?
   4 3 2 1 0

3. Walking indoors such as around your home?
   4 3 2 1 0

4. Walking several blocks?
   4 3 2 1 0

5. Walking one block or climbing one flight of stairs?
   4 3 2 1 0

6. Doing work around the house such as cleaning, light yard work, or home maintenance?
   4 3 2 1 0

7. Doing errands such as grocery shopping?
   4 3 2 1 0

8. Driving a car or using public transportation?
   4 3 2 1 0
Section 5: Your work

1. What best described your working status in the 4 weeks BEFORE your injury (you can tick more than one box)
   - Full time paid work
   - Part time paid work
   - Completely retired/pensioner
   - Disabled/sick
   - Self-employed
   - Doing unpaid work
   - Studying
   - Looking after home and family
   - Unemployed
   - Other _______________________

2. The following questions concern your views about your ability to work at some stage after your injury.
   Please circle the response most applicable.
   (1- Very good chance, 2- Good chance, 3- Neither, 4- Small chance, 5- Very small chance, 6- I am not in work).

2. How great are your chances to be in work within 6 months?
   1  2  3  4  5  6

3. What was your main occupation in the month before your injury?
   __________________________________________

4. Considering your health now, do you think you'll be back at work in your current occupation in 2 years?
   - No
   - Maybe
   - Yes, probably
   Please circle the response most applicable.
   (1- Often, 2- Quite often, 3- Now and then, 4- Relatively seldom, 5- Never).

5. During the last month have you felt optimistic about the future?
   1  2  3  4  5  6

Please indicate (by putting a cross in the box), if someone else has helped you complete this questionnaire   

Thank you for taking the time to complete this survey

If you have any questions about the Study or require assistance to complete the questionnaire, please ring Kathy Heathcote on 0413 585 724.

If any of these questions has caused you to feel distressed, please contact your General Practitioner.

You can send your questionnaire using the envelope provided (no stamp required).
Survivors of traumatic physical injury and their primary caregivers: quantifying factors related to health and well-being.

This research is a joint initiative of the Trauma Service, Gold Coast University Hospital and Griffith University. Professor Martin Wullschleger, Medical Director of the Trauma Service is a principal investigator, along with Ms Kathy Heathcote who coordinates the study and is the main contact person for any queries related to the study. Her contact details are on the last page of this questionnaire.

The questions in this form mostly relate to the time period before the patient you are caring for was hospitalized for their injuries. If there is no specific time period specified in the question, just answer the question as to how you usually felt or functioned before the person’s injury.

Please try and answer every question. Thank you for participating in our research.

To help us read your answers, please write as clearly as possible using a BLACK or BLUE pen.

Please put a cross in the appropriate box(es)    Yes     No

Section 1: Some general details about you

1. What is your age? ________________ (years)

2. What is your gender?
   Female    Male

3. What is your current postcode of residence?
   __________(postcode)

4. What is the name of the suburb or town in which you live?
   _______________________(suburb)

5. In the week prior to your injury what best described your current living situation?
   □ Single
   □ Married
   □ Widowed
   □ Divorced
   □ Defacto/living with partner
   □ Separated

6. What best described your working status in the 4 weeks BEFORE your injury (you can tick more than one box)
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   □ Disabled/sick
   □ Self-employed
   □ Doing unpaid work
   □ Studying
   □ Looking after home and family
   □ Unemployed
   □ Other__________________

7. If working, prior to injury: What was your main occupation in the month before your injury?

______________________________

8. In the month prior to the hospitalization of the person you will be caring for, about how many hours each week did you usually spend doing the following? (please put ‘0’ if you do not spend any time doing it)

Paid work___________ hours/week
Unpaid work___________ hours/week (this does not include an informal caregiving role)
9. What is your ancestry? You can tick up to 2 boxes

- English  - Irish  - Scottish
- Italian  - German  - Indigenous or Aboriginal
- Chinese  - Australia
- Other ____________________

10. Please complete the table about the country of birth of yourself, your mother and your father

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11. What is the highest year of primary or secondary school that you completed?

- Never attended school
- Year 8 or below
- Year 9 or equivalent
- Year 10 or equivalent
- Year 11 or equivalent
- Year 12 or equivalent

12. Have you completed a trade certificate, diploma, degree or any other educational qualification?

- Yes (please specify) ____________________________
- No

13. How many times did you do each of these activities in the LAST WEEK, that is the week prior to this hospitalization episode? Please tick the response most applicable.

- Walking continuously for at least 10 minutes
  - (for recreation, exercise to get from places)
  - Did not do activity
  - 1
  - 2
  - 3
  - 4
  - 5
  - 6
  - 7 or more

- Moderate physical activity
  - (like gentle swimming, social tennis, vigorous gardening or work around the house)
  - Did not do activity
  - 1
  - 2
  - 3
  - 4
  - 5
  - 6
  - 7 or more

- Vigorous physical activity
  - (made you breathe harder, or puff and pant, like jogging, cycling, aerobics – not housework or gardening)
  - Did not do activity
  - 1
  - 2
  - 3
  - 4
  - 5
  - 6
  - 7 or more

14. Have you ever been a regular smoker?

- Yes  - No

15. If YES: How old were you when you started smoking regularly?

__________ years old

16. Are you a regular smoker now?

- Yes (If YES skip to question 18)
- No

17. If NO: How old were you when you started smoking regularly?

__________ years old
18. About how much do you smoke on average each day? (If you are an ex-smoker, how much did you smoke on average when you smoked?)

_______ cigarettes a day

_______ Pipes and cigars per day

19. About how many alcoholic drinks do you have each week?
One drink = glass of wine, middy or beer or nip of spirits. (put '0' if you do not drink or have less than one drink per week)

_______ alcoholic drinks each week.

20. On how many days each week do you usually drink alcohol?

_______ days each week.

21. Has a doctor EVER told you that you have any of the following conditions? If yes, please tick the box in Column 2 and give your age when the condition was first diagnosed. Please also tick the box (next to age) for any conditions for which you were treated for in the LAST MONTH.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Have been diagnosed</th>
<th>Age at diagnosis</th>
<th>Received treatment in within last month?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart disease</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>High blood pressure</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Stroke</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood clot</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical disability:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

22. Are you now suffering from any OTHER important illness? (If YES, please describe the illness and its treatment)

[ ] Yes  [ ] No

23. I would now like to ask you about your household income. What is your annual household income before tax?
- Less than $20 000
- $20 000-$40 000
- $40 000-$60 000
- $60 000-$80 000
- More than $80 000

24. Which of the following do you have? (excluding Medicare)
- Private health insurance (with extras)
- Private health insurance (without extras)
- Department of Veterans Affairs white or gold card
- Health care concession card
- None of these

Section 2: Your support networks and your belief in your ability to accomplish things

Please circle the response most applicable.

0- Not true at all
1- Rarely true
2- Sometimes true
3- Often true
4- True nearly all of the time

I am able to adapt to change?

0  1  2  3  4

I can deal with whatever comes?

0  1  2  3  4

I try to see the humorous side of things?

0  1  2  3  4

Coping with stress can strengthen me?

0  1  2  3  4

I tend to bounce back after illness or hardship?

0  1  2  3  4
I can achieve goals despite obstacles?
0 1 2 3 4

I can stay focused under pressure?
0 1 2 3 4

I am not easily discouraged by failure?
0 1 2 3 4

I think of myself as a strong person?
0 1 2 3 4

I can handle unpleasant feelings?
0 1 2 3 4

Please circle the response most applicable.
1- Not true at all
2- Hardly true
3- Moderately true
4- Exactly true

I can always manage to solve difficult problems if I try hard enough?
1 2 3 4

If someone opposes me I can find the means and ways to get what I want?
1 2 3 4

It is easy for me to stick to my aims and accomplish my goals?
1 2 3 4

I am confident that I can deal efficiently with unexpected events?
1 2 3 4

Thanks to my resourcefulness I know how to handle unforeseen situations?
1 2 3 4

I can solve most problems if I invest in the necessary effort?
1 2 3 4

I can remain calm when facing difficulties because I can rely on my coping abilities?
1 2 3 4

When I am confronted with a problem I usually find several solutions?
1 2 3 4

If I am in trouble, I can usually think of a solution?
1 2 3 4

I can usually handle whatever comes my way?
1 2 3 4

STYLE
Please circle the response most applicable to you in the period since the person’s injury.

1- I haven’t been doing this at all
2- I’ve been doing this a little bit
3- I’ve been doing this a medium amount
4- I’ve been doing this a lot

I have been turning to work or other activities to take my mind off things?
1 2 3 4

I have been concentrating my efforts on doing something about the situation I’m in?
1 2 3 4
Section 3a: Your Family

1- I haven’t been doing this at all
2- I’ve been doing this a little bit
3- I’ve been doing this a medium amount
4- I’ve been doing this a lot

I’ve been getting emotional support from others?

1 2 3 4

I’ve been taking action to try to make the situation better?

1 2 3 4

I’ve been getting help and advice from others?

1 2 3 4

I’ve been trying to come up with a strategy about what to do?

1 2 3 4

I’ve been getting comfort and understanding from someone?

1 2 3 4

I’ve been expressing my negative feelings?

1 2 3 4

I’ve been thinking about what steps to take?

1 2 3 4

Directions: Please read each statement below and decide to what degree each describes your family.

0- False,
1- Mostly False
2- Mostly True
3- True

Please circle the response most applicable.
Please respond to each and every statement.

Our work and efforts are not appreciated no matter how hard we try and work?
Section 3b: Your Community

The following questions relate to the extent to which you feel your family finds support in your community.

Please indicate how much you agree or disagree with each of the following statements about your community.

Read the statements below and decide for your family whether you:

0- Strongly Disagree  
1- Disagree  
2- Neutral  
3- Agree  
4- Strongly Agree

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I had an emergency, even people I do not know in this community would be willing to help?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People here know they can get help from the community if they are in trouble?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have friends who let me know they value who I am and what I can do?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People can depend on each other in this community?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My friends in this community are a part of my everyday activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in this community gives me a secure feeling?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel secure that I am as important to my friends as they are to me?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section 4: Your use of health services

These questions relate to the ways in which you have used health services for your health in the last 6 months. **Tick if not applicable**

<table>
<thead>
<tr>
<th>In the last 6 months</th>
<th>Number of times (please write a number)</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many times did you consult with your GP about your health?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times did you consult with any other health professional about your health? (this can include a nurse, physiotherapist, dentist, specialist, psychologist or counsellor or any other health practitioner)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times have you visited a hospital outpatient clinic?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times have you been admitted to hospital as a day case patient (not kept over night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times have you visited emergency or casualty at a hospital, but not been admitted?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many nights, overall, have you stayed in hospital?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. In the last 6 months: did you have difficulty getting health care when you needed it?

- Yes  
- No  
- Do not need health care

If YES to Q5, was this for any of the following reasons: (you can tick more than one box)

- Could not afford it  
- Too far to travel  
- Could not get transport  
- Family responsibilities  
- Caregiving responsibilities  
- Work responsibilities  
- Other reason: please specify:
**Section 5: Your views about caring for the injured person**

1. What relation are you to the person you will be caring for?
   - Spouse/partners
   - Father
   - Mother
   - Son
   - Daughter
   - Son-in-law
   - Daughter-in-law
   - Brother
   - Sister
   - Friend
   - Other _______________________

2. Do you plan to live in the same household as the injured person?
   - Yes  
   - No

3. How many hours per week do you expect to be caring for this person?
   ___________________________ hours/week

4. Do you have other people that you will be caring for at the same time? For example, your parents, children or anyone else?
   - Yes  
   - No

4.1. If yes, how many? _____________

5. Please list the ways in which you expect to be caring for the injured person?
   (you can tick more than one box)
   - Moving about the house
   - Transportation out of the home to other places
   - Showering/bathing
   - Dressing
   - Eating meals
   - Toilet/hygiene needs
   - Other _________________________

6. Is there anyone else who will be providing an equal amount of informal care to this person?
   - Yes  
   - No

7. If Yes please list the number of other people who will also provide care to this person
   ________ (NUMBER)

**Section 6: Your quality of life**

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

In general, would you say your health is:
   - Excellent
   - Very good
   - Good
   - Fair
   - Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Please circle the response most applicable.

1. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf?
   1- YES limited a lot
   2- YES limited a little
   3- NO not limited at all

2. Climbing several flights of stairs?
   1 2 3

Have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

Accomplished less than you would like?
   - Yes  
   - No

5. Were limited in the kind of work and other activities?
   - Yes  
   - No
During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- Accomplished less than you would like?
  - Yes  [ ]  No

- Did work or activities less carefully than usual?
  - Yes  [ ]  No

8. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?

  - Not at all  [ ]
  - A little bit  [ ]
  - Moderately  [ ]
  - Quite a bit  [ ]
  - Extremely  [ ]

These questions are about how you have been feeling during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks… Please circle the response most applicable.

1- All the time
2- Most of the time
3- A good bit of the time
4- Some of the time
5- A little of the time
6- None of the time

Have you felt calm and peaceful?

1  2  3  4  5  6

Did you have a lot of energy?

1  2  3  4  5  6

Have you felt down-hearted and blue?

1  2  3  4  5  6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

  - All of the time
  - Most of the time
  - Some of the time
  - A little of the time
  - None of the time

13. Are you currently enrolled in any other research study from the Gold Coast University Hospital?

  - Yes: (Name of the study) ________________________
  - No

(Researcher: please tick if the caregiver referral resource was given: [ ])

Please indicate (by putting a cross in the box), if someone else has helped you complete this questionnaire [ ]

Thank you for taking the time to complete this survey

If you have any questions about the Study or need assistance to complete the questionnaire, please ring the study coordinator, Kathy Heathcote on 0413 585 724.

If any of these questions has caused you to feel distressed, please contact your General Practitioner.

If you have completed this questionnaire on your own, at home, please mail it back to us as soon as possible, using the envelope (no stamp required) provided.
Survivors of traumatic physical injury and their primary caregivers: quantifying factors related to health and well-being.

This research is a joint initiative of the Trauma Service, Gold Coast University Hospital and Griffith University.

Professor Martin Wullschleger, Medical Director of the Gold Coast University Hospital Trauma Service is a principal investigator, along with Ms Kathy Heathcote who coordinates the study and is the main contact person for any queries related to the study. Her contact details are on the last page of this questionnaire.

The questions in this form relate to the last few months, or the time period since we last spoke to you. Please try and answer every question. Thank you for participating in our research.

Section 1: Some general details about you

1. What best describes your CURRENT living situation?
   - Single
   - Married
   - Widowed
   - Divorced
   - Defacto/living with partner
   - Seperated

2. What is your CURRENT postcode of residence?  
   ___________ (postcode)

3. What is the name of the suburb or town in which you CURRENTLY live?  
   ______________________ (suburb)

4. The following questions ask about your general ability to cope with problems. Please circle the response most applicable.

   0. Not true at all
   1. Rarely true
   2. Sometimes true
   3. Often true
   4. True nearly all of the time

   I am able to adapt to change 0
   1 2 3 4

   I can deal with whatever comes 0
   1 2 3 4

   I try to see the humorous side of things
   0 1 2 3 4

   Coping with stress can strengthen me
   0 1 2 3 4

   I tend to bounce back after illness or hardship
   0 1 2 3 4

   I can achieve goals despite obstacles
   0 1 2 3 4

   I can stay focused under pressure
   0 1 2 3 4
This survey asks for your CURRENT views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

1. In general, would you say your health is:  
   - Excellent  
   - Very good  
   - Good  
   - Fair  
   - Poor

   The following questions are about activities you might do during a typical day. In the 4 weeks before your injury, did your health limit you in these activities? If so, how much?

   1- YES limited a lot  
   2- YES limited a little  
   3- NO not limited at all

2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf

   1 2 3

3. Climbing several flights of stairs

   1 2 3

4. Have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

5. Accomplished less than you would like

   Yes  No

6. Were limited in the kind of work and other activities

   Yes  No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

7. Accomplished less than you would like

   Yes  No

8. Did work or activities less carefully than usual

   Yes  No

9. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?

   Not at all  A little bit  Moderately  Quite a bit  Extremely

10. These questions are about how you have been feeling during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

   Please circle the response most applicable.

   1- All the time  
   2- Most of the time  
   3- A good bit of the time  
   4- Some of the time  
   5- A little of the time  
   6- None of the time

Have you felt calm and peaceful?

   1 2 3 4 5 6

Did you have a lot of energy?

   1 2 3 4 5 6
### Section 3: The following questions relate to how productive you were in your general daily activities in the month before your injury

1. The following questions relate to how productive you have been in your general daily activities in the last month? Please circle the response most applicable.

<table>
<thead>
<tr>
<th></th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing work around the house such as cleaning, light yard work, or home maintenance?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Doing errands such as grocery shopping?</td>
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<tr>
<td>Driving a car or using public transportation?</td>
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</tr>
</tbody>
</table>

Have you felt down-hearted and blue?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

---

### Section 4: Your use of health services

These questions relate to the ways in which you have used health services for your health in the last 3 months

<table>
<thead>
<tr>
<th>In the last 3 months:</th>
<th>Number of times (please write a number)</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Approximately how many times did you see a health care practitioner for your injury?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(for example, a physiotherapist, an occupational therapist, a dietician, a psychologist, social worker)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How many times did you consult with a health professional for other reasons, ie for reasons NOT related to your injury?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(this can include a doctor, nurse, physiotherapist, dentist, specialist, other health practitioner)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How many times have you visited an outpatient clinic?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In the last 3 months: Number of times (please write a number) Not applicable

4. How many times have you been admitted to hospital as a day case patient (not kept over night) 

5. How many times have you visited emergency or casualty?

6. How many nights have you stayed in hospital?

7. In the last 3 months: did you have difficulty getting health care when you needed it?
   - Yes
   - No
   - Do not need health care

If YES to Q7, was this for any of the following reasons: (you can tick more than one box)
- Could not afford it
- Too far to travel
- Could not get transport
- Family responsibilities
- Caregiving responsibilities
- Work responsibilities
- Other reason: please specify:

The following questions list a number of health professionals that you might have come into contact with during your rehabilitation period.

We would like to know who was most helpful to you during this time. Being 'helpful' in this sense means: helping you recover from, or manage your injuries.

The scale show ranges from 1 to 10 and provides you with a continuum with which to reply. A '0' means that you do not think that particular health professional was helpful to you at all while a '10' means that you think the professional was extremely helpful.

If you did not see this person at all, just circle N/A, ie 'not applicable'.

<table>
<thead>
<tr>
<th>Professional</th>
<th>Not at all</th>
<th>Extremely helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioner</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>A Medical Specialist, eg Surgeon</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Community Nurse</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Dietician</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Your Primary Informal Caregiver</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
<tr>
<td>Other: please specify</td>
<td>1 2 3 4 5 6 7 8 9 10 N/A</td>
<td></td>
</tr>
</tbody>
</table>
Section 3: Your work

1. What best describes your CURRENT working status? (you can tick more than one box)
   - Full time paid work
   - Part time paid work
   - Completely retired/pensioner
   - Disabled/sick
   - Self-employed
   - Doing unpaid work
   - Studying
   - Looking after home and family
   - Unemployed
   - On workers compensation
   - Other ____________________

2. Please list the number of times you have attempted to return to work since your injury. Just put a '0' if you have not attempted to return to work
   ____________ (times)

3. If you are currently working in a paid job, please give the date that you commenced that job after your injury. If you can’t remember the exact date, just write the month and year. Date________________________

4. If you are currently working: please describe the nature of work that you returned to after injury (you can tick more than one box)
   - Full duties
   - Modified duties
   - Full time
   - Part time

5. For your current job, was it necessary for your employer to provide any special equipment, modify the work environment or make special arrangements for you because of your condition?
   - Yes
   - No

6. Were any other special arrangements made for you to return to work?
   - Yes
   - No

7. For your current job, was it necessary for your employer to provide any special equipment, modify the work environment or make special arrangements for you because of your condition?
   - Yes
   - No

If YES: please tick which applies (you can tick more than one box)
   - Sick leave
   - Flexible hours
   - Recreation/annual leave
   - Leave without pay
   - Casual
   - Part time hours
   - Workcover/Workers Compensation (Duration: _________________months)
   - Other_____________________________

Thank you for taking the time to complete this survey.

If you have any further comments you’d like to make, please use the space below to write them down.

If any of these questions has caused you to feel distressed, please contact your General Practitioner.

You can send your questionnaire using the envelope provided (no stamp required.)
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This research is a joint initiative of the Trauma Service, Gold Coast University Hospital and Griffith University.

Professor Martin Wullschleger, Medical Director of the Gold Coast University Hospital Trauma Service is a principal investigator, along with Ms Kathy Heathcote who coordinates the study and is the main contact person for any queries related to the study. Her contact details are on the last page of this questionnaire.

The questions in this form mostly relate to time period since we last interviewed you, in other words, the last few months. Please try and answer every question.

Thank you for participating in our research.

To help us read you answers, please write as clearly as possible using a BLACK or BLUE pen.

Please put a cross in the appropriate box(es) × Yes □ No

Section 1: Some general details about you

1. What best describes your CURRENT living situation?
   □ Single
   □ Married
   □ Widowed
   □ Divorced
   □ Defacto/living with partner
   □ Separated

2. What best described your working status in the 4 weeks BEFORE the patient’s injury (you can tick more than one box)
   □ Full time paid work
   □ Part time paid work
   □ Completely retired/pensioner
   □ Disabled/sick
   □ Self-employed
   □ Doing unpaid work
   □ Studying
   □ Looking after home and family
   □ Unemployed
   □ Other ________________

3. About how many hours each week do you usually spend doing the following? (please put '0' if you do not spend any time doing it)
   Paid work___________ hours/week
   Unpaid work___________ hours/week (this does not include an informal caregiving role)

4. What is your CURRENT postcode of residence?
   _______________(postcode)

5. What is the name of the suburb or town in which you CURRENTLY live?
   _______________________(suburb)

6. Since commencing caregiving, do you receive any Government assisted funding to support you in your caregiver role?
   □ Yes □ No
7. How many times did you do each of these activities in the last week, ?

Please tick the response most applicable.

Walking continuously for at least 10 minutes
(for recreation, exercise to get from places)

- Did not do activity
- 1
- 2
- 3
- 4
- 5
- 6
- 7 or more

Moderate physical activity (like gentle swimming, social tennis, vigorous gardening or work around the house)

- Did not do activity
- 1
- 2
- 3
- 4
- 5
- 6
- 7 or more

Vigorous physical activity (made you breathe harder, or puff and pant, like jogging, cycling, aerobics – not housework or gardening)

- Did not do activity
- 1
- 2
- 3
- 4
- 5
- 6
- 7 or more

1. Are you a regular smoker now?
- Yes  (If YES skip to question 7)
- No

2. About how much do you smoke on average each day? (If you are an ex-smoker, how much did you smoke on average when you smoked?)

_________ cigarettes a day

_________ Pipes and cigars per day

3. About how many alcoholic drinks do you have each week? One drink = glass of wine, middy or beer or nip of spirits.

(put '0' if you do not drink or have less than one drink per week)

_________ alcoholic drinks each week.

4. On how many days each week do you usually drink alcohol?

_________ days each week.

5. Since we last spoke to you, has a doctor told you that you have any of the following conditions? If yes, please tick the box in Column 2 and give your age when the condition was first diagnosed.

Please also tick the box (next to age) for any conditions for which you were treated for in the last month.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Have been diagnosed</th>
<th>Age at diagnosis</th>
<th>Received treatment in within last month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer: Type</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Heart disease</td>
<td></td>
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<td></td>
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<tr>
<td>High blood pressure</td>
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<td></td>
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<tr>
<td>Stroke</td>
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<tr>
<td>Diabetes</td>
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<tr>
<td>Blood clot</td>
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<tr>
<td>Asthma</td>
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<tr>
<td>Depression</td>
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<td></td>
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<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Physical disability:</td>
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<td></td>
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</tbody>
</table>
## Section 2: Your support networks and your belief in your ability to accomplish things

**Please circle the response most applicable.**

0 Not true at all  
1 Rarely true  
2 Sometimes true,  
3 Often true  
4 True nearly all of the time

| I can always manage to solve difficult problems if I try hard enough? | 1 2 3 4 |
| I can deal with whatever comes? | 0 1 2 3 4 |
| I try to see the humorous side of things? | 0 1 2 3 4 |
| Coping with stress can strengthen me? | 0 1 2 3 4 |
| I tend to bounce back after illness or hardship? | 0 1 2 3 4 |
| I can achieve goals despite obstacles? | 0 1 2 3 4 |
| I can stay focused under pressure? | 0 1 2 3 4 |
| I am not easily discouraged by failure? | 0 1 2 3 4 |
| I think of myself as a strong person? | 0 1 2 3 4 |
| I can handle unpleasant feelings? | 0 1 2 3 4 |
I can usually handle whatever comes my way?
1 2 3 4

Please circle the response most applicable to you, over the last 3 months.

1- I haven't been doing this at all
2- I've been doing this a little bit
3- I've been doing this a medium amount
4- I've been doing this a lot

I have been turning to work or other activities to take my mind off things?
1 2 3 4

I have been concentrating my efforts on doing something about the situation I'm in?
1 2 3 4

I've been getting emotional support from others?
1 2 3 4

I've been taking action to try to make the situation better?
1 2 3 4

I've been getting help and advice from others?
1 2 3 4

I've been trying to come up with a strategy about what to do?
1 2 3 4

We strive together and help each other no matter what?
1 2 3

I've been thinking about what steps to take?
1 2 3 4

Section 3a: Your Family

Directions: Please read each statement below and decide to what degree each describes your family.

0. False
1. Mostly False
2. Mostly True
3. True

Please circle the response most applicable.

Our work and efforts are not appreciated no matter how hard we try and work?
0 1 2 3

I've been getting comfort and understanding from someone?
0 1 2 3

Many times I trust that even in difficult times things will work out?
0 1 2 3

While we don't always agree, we can count on each other to stand by us in times of need?
0 1 2 3

We believe that things will work out if we can work together as a family?
0 1 2 3

We strive together and help each other no matter what?
0 1 2 3

We listen to each other's problems, hurts and fears?
0 1 2 3
<table>
<thead>
<tr>
<th>We seem to encourage each other to try new things and experiences?</th>
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</thead>
<tbody>
<tr>
<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>Being active and learning new things are encouraged?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>We work together to solve problems?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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</table>

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Section 3b: Your Community

The following questions relate to the extent to which you feel your family finds support in your community.

Read the statements below and decide for your family whether you:

0. Strongly Disagree
1. Disagree
2. Neutral
3. Agree
4. Strongly Agree

<table>
<thead>
<tr>
<th>If I had an emergency, even people I do not know in this community would be willing to help?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>People here know they can get help from the community if they are in trouble?</th>
</tr>
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<tbody>
<tr>
<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>I have friends who let me know they value who I am and what I can do?</th>
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<tbody>
<tr>
<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>People can depend on each other in this community?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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</table>

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Section 4: Your use of health services

These questions relate to the ways in which you have used health services for your health in the last 3 months, or since we last spoke to you.

<table>
<thead>
<tr>
<th>In the last 3 months</th>
<th>Number of times (please write a number)</th>
<th>Not applicable (Please tick)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many times did you consult with any health professional about your health? (this can include a nurse, physiotherapist, dentist, specialist, psychologist or counsellor or any other health practitioner)</td>
<td></td>
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</tr>
<tr>
<td>How many times have you visited a hospital outpatient clinic?</td>
<td></td>
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<tr>
<td>How many times have you been admitted to hospital as a day case patient (not kept over night)</td>
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<tr>
<td>How many times have you visited emergency or casualty?</td>
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<tr>
<td>How many nights have you stayed in hospital?</td>
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</tbody>
</table>
6. In the last 3 months: did you have difficulty getting health care when you needed it?

- Yes
- No
- Do not need health care

If YES to Q6, was this for any of the following reasons: (you can tick more than one box)

- Could not afford it
- Too far to travel
- Could not get transport
- Family responsibilities
- Caregiving responsibilities
- Work responsibilities
- Other reason: please specify:

Section 5: Your caregiving role

The following questions refer to the period of time you cared for this person, since their discharge from hospital.

1. Please tick the following box that best indicates the period of time you were the primary caregiver for the injured person, commencing straight after hospital discharge

- Less than 1 month
- 1-2 months
- 2-3 months
- 3-4 months
- More than 4 months

2. If you are no longer acting as an informal caregiver to the injured person, please give reasons as to why this is the case. You can tick more than one box

- Patient recovered /Did not need care
- Our relationship did not work out (eg separation, divorce)
  - Please specify____________________
- I moved away
- The person I cared for moved away
- Financial difficulties
- Family difficulties
- Work difficulties
- Other: ____________________________

3. During the period of time you were the caregiver, did you both share the same GP?

- Yes
- No

4. If Yes: please list the following reasons for sharing the same GP (you may tick more than one box).
If no, please proceed to question 5.

- Convenience
- Affordable
- Waiting time is not too long
- Accessibility (transport, distance)
- Our GP is supportive to the person I care for
- Our GP is supportive of my caregiving needs
- Our GP is supportive to my own health needs
- Our GP supports us both
- Other: ____________________________

5. If No to Q3: please tick the boxes that best describe the reasons for NOT sharing the same GP as the person you cared for (you may tick more than one box)

- Convenience
- More affordable
- Waiting time is not too long
- Accessibility (transport, distance)
- My GP is not that supportive to the person I cared for
- My GP is more supportive to my caregiving needs
- My own GP is supportive to my own health needs
- Privacy of my own medical information
- Other reasons? ____________________________

6. During your time as a caregiver to the injured person: (please also answer these questions if you are still caring for this person)

6.1. Did you live in the same household?

- Yes
- No

6.2. Were you the person who provided the MOST informal care for this person?

- Yes
- No

7. If 'No' to 6.2 above, please list the number of other people who also provide/provided care to this person?

_____________(NUMBER of other informal caregivers)

7.1. In the last 3 months did you contact any of the agencies or health professionals listed on the caregiver referral resource document that we gave you?

- Yes
- No

- Other reason (please specify)____________________
7.2. If you did use this caregiver resource form, did you find it helpful in terms of supporting you in your caregiver role?

- Yes
- No
- Other reason (please specify)____________________

8. How many hours per week, on average, did you spend caring for this person?

___________________ hours/week

9. Please describe the main caregiving tasks that you performed while you were caring for the patient (you can tick more than one box)

- Moving about the house
- Transportation out of the home to other places
- Showering/bathing
- Dressing
- Eating meals
- Toilet/hygiene needs
- Other ________________________

10. We would like to know the extent to which different health professionals were helpful to you during your time as a carer.

Being ‘helpful’ in this sense means supporting you in your role as a carer, providing you with information and resources or helping you to manage your own health.

The scale shows ranges from 1 to 10 and provides you with a continuum with which to reply. A ‘0’ means that you do not think that particular health professional was helpful to you at all while a ‘10’ means that you think the professional was extremely helpful.

Please circle the number that best corresponds to the degree of support you obtained for each professional.

If you did not see this type of health professional at all, just circle N/A ie ‘not applicable’.

Please circle.....

**Your General Practitioner**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Social worker**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Physiotherapist**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Occupational therapist**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Surgeon or other medical specialist**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Community nurse**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Dietician**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Psychologist**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**The patients General Practitioner (if different to your own GP)**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

**Other: please specify _________________**

(not at all) (extremely helpful)
1 2 3 4 5 6 7 8 9 10 N/A

11. Here is a list of things that other caregivers have found to be difficult. Please circle the appropriate answer which applies to you now, as a carer, or did apply while you were a caregiver.

1- Yes on a regular basis
2- Yes, sometimes
3- No

**My sleep is disturbed** (for example the person I care for is in and out of bed or wanders around at night)

1 2 3
There have been work adjustments (for example; I have to take time off for caregiving duties)

1- Yes on a regular basis
2- Yes, sometimes
3- No

Caregiving is inconvenient (for example helping takes so much time or it’s a long drive over to help)

1 2 3

Caregiving is a physical strain (for example lifting in or out of a chair, effort of concentration is required)

1 2 3

Caregiving is confining (for example helping restricts free time or I cannot go visiting)

1 2 3

There have been family adjustments (for example, helping has disrupted my routine; there is no privacy)

1 2 3

There have been changes in personal plans (for example I had to turn down a job; I could not take holidays)

1 2 3

There have been other demands on my time (for example other family members need me)

1 2 3

There have been emotional adjustments (for example severe arguments about caregiving)

1 2 3

Some behavior is unsettling (for example incontinence; the person I care for has trouble remembering things, or the person I care for accuses people of taking things)

1 2 3

It is upsetting to find the person I cared for has changed so much from his/her former self (for example he/she is a different person to what they used to be)

1 2 3

Section 6: Your quality of life

This section asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Please circle the response most applicable.

1- YES limited a lot
2- YES limited a little
3- NO not limited at all

1. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf?

1 2 3

2. Climbing several flights of stairs?

1 2 3
Have you felt down-hearted and blue?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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</table>

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

Section 7: Your work

1. During the period of time you were caring for the injured person, did you do any form of paid work?

- Yes
- No

Please continue:

The following questions relate to your ability to work whilst caring for the injured person.

Please answer all questions even if you are not currently working.

If the question is not applicable to you, just tick the 'Not applicable' box.

2. My care-giving responsibilities restricted the type of work I was able to do

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable
3. My care-giving responsibilities restricted the number of hours that I could work

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable

4. My employer was supportive of my caregiver role

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable

5. My work colleagues were supportive of my caregiver role

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable

6. My workplace provided financial assistance to support me as a caregiver, (such as tax and insurance, cash and subsidies)

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable

7. My workplace provided services on site, to directly support my caring responsibilities, (such as child care, wellness programs, family counseling, support groups, private rooms for phone calls)

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable

8. My workplace provided resources for people with care-giving responsibilities, such as education and training programs, toolkits, networks and forums

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Not Applicable

Thank you for taking the time to complete our survey.

If you would like to add any further information, please use the space provided below.