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Measuring long-term outcomes after injury: current issues and future directions

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SUMMARY

Maximizing long-term outcomes for patients following injury is the next challenge in the delivery of patient-centered trauma care. The following review outlines three important components in trauma outcomes: (1) data gathering and monitoring, (2) the impact of traumatic brain injury, and (3) trajectories in recovery and identifies knowledge gaps and areas for needed future research.

For the past 50 years, improvements in the delivery of trauma center care have markedly decreased mortality after injury. Unfortunately, our knowledge of what happens to survivors once they leave the hospital is limited. The reasons for this are multifactorial. For many years, 'discharged alive' was sufficient and in-hospital mortality was the metric on which trauma center care was judged. There was also little interest or regulatory requirement to collect data beyond discharge.

There has been increased recognition that inpatient trauma care makes up only a very small, although vital, part of a patient's recovery. The focus on long-term outcomes is necessary to begin to understand the degree of disability our patients experience and how these outcomes may be modulated following discharge to optimize recovery.[1 2] In 2021, at the annual meeting of the American Association of the Surgery of Trauma, a panel of experts provided an overview of some the important issues that need to be addressed when considering long-term outcomes following injury. The following paper outlines three important components in trauma outcomes: data gathering and monitoring, the impact of traumatic brain injury, and trajectories in recovery. More importantly, it begins to identify those gaps in our knowledge and those areas which require further investigation and study. The overall focus on these outcomes must become the next frontier in overall patient-centered trauma care. It is hoped that these types of future investigations will ultimately improve our patients' quality of life (QoL) and reintegration back to family and society similar to the impact past studies had on improving overall inpatient survival after injury.

DATA GATHERING AND MONITORING

Data are the key to understanding and improving patient care. This concept began with the mandatory requirement for all trauma centers to have individual registries and has further expanded into the robust and important Trauma Quality Improvement Project. However, these data comprise prehospital and in-hospital events with minimal collection of postdischarge data.

One of the longest and most successful endeavors in tracking long-term trauma outcomes is the Victoria State Trauma Registry (VSTR) in Australia; under the direction of Gabbe *et al*.[3–7] In addition to the standard inpatient trauma registry data, the VSTR re-engages patients at 6, 12, and 24 months after injury to collect health-related QoL, function, disability, pain, and return to work outcomes. These longitudinal data on physical and behavioral health, social, and cognitive impairments uncovered by this population-based registry have provided tremendous insights into the outcome of trauma patients in that province. One of the key findings from this work demonstrates that there is significant impairment in all domains which does not substantially improve for the 3 years postdischarge.[8] These data paint a rather bleak picture of life following major trauma and provide an impetus to formulate interventions that can positively impact the recovery of trauma patients. It is these data gathering models which will be able to assess the impact and potential successes of these interventions.

In the USA, two similar longitudinal studies have been launched over the past 20 years including the Functional Outcomes and Recovery after Trauma (FORTE).[9–11] Similar to the VSTR, the FORTE project is a collaboration between three level 1 trauma centers in Boston to determine the feasibility, sustainability, and value of the routine collection of long-term outcomes after injury. With data collected at 6 and 12 months postinjury from over 4500 patients, the FORTE project is one of the largest repositories for long-term trauma outcomes in the USA. Some of the key observations suggest and reiterate the findings of others, that patient factors (age, gender, race, education) rather than injury-related factors (injury severity or location) are more predictive of long-term outcomes[12–15] and that poor long-term outcomes tend to be associated with each other within and across different health domains (behavioral health (eg, post-traumatic stress disorder (PTSD)), physical, social).[16 17] Potentially modifiable factors such as social support were found to potentially influence the recovery trajectories of these patients.[18 19]

The impetus and momentum for US trauma centers to collect long-term outcomes has been slow but there has been a small increase in the number of published research articles over the last several years. Unfortunately, there is considerable variability in the metrics used to measure outcomes. In 2019, a consensus conference of key stakeholders was convened to propose the optimal metrics to assess

long-term outcomes as well as the appropriate instruments with which to measure them.[20] Subsequently, the National Trauma Research Action Plan collaborative has proposed 14 patient-reported outcome measures (PROMs) across 13 core domains including activities of daily living, alcohol and substance use, behavioral health metrics (such as PTSD and depression), and measures of general and trauma-specific QoL.[21] One substantial concern is that these quantitative metrics, while useful for many surgical conditions may fail to capture the true picture and nuances of outcomes in trauma patients. More importantly, they do not provide insight into potential solutions to modulate outcomes. A recent descriptive study by Rosenberg *et al* demonstrated that recovery of both the physical body and the 'self', a composite of one's roles, values, identities, and beliefs was essential to achieving favorable subjective outcomes.[22] These complex qualitative findings which may not be reflective of quantitative ordinal scales in the same patients have been suggested by others[23] and it is likely that to obtain a true assessment of long-term outcomes following trauma will require both qualitative and quantitative measures.

Unfortunately, obtaining high-quality data are both costly and labor intensive. Interest has recently emerged in other fields in measuring long-term outcomes through indirect measures such as digital phenotyping; a technique of passively collecting data through an individual's smartphone sensors and use.[24–26] This methodology offers the possibility of obtaining objective data without the manpower needed for telephone surveys. For example, the collection of global positioning system data might possibly be used to study physical mobility and community integration after trauma based on examining how a person spends their time at different locations.

Determining the best methodology to gather these data is an area of ongoing research and will need to meet the aims of long-term outcome data collection: (1) low cost, (2) minimal burden to patients and data registrars, and (3) production of sufficiently granular and high-quality data that can be used to measure outcomes that matter. The best strategy may in fact be a combination that deploys surveys and tasks via email, text, and apps with phone interviews to collect PROMs data. Recently, the VSTR has demonstrated that on-line report was almost as good as phone interviews.[27] However, as outlined above, the issue of human contact and obtaining more qualitative information may ultimately be necessary in truly assessing recovery.

TRAUMATIC BRAIN INJURY

Traumatic brain injury (TBI) remains a huge public health problem which accounts for 80 000 permanently disabled individuals each year in the USA.[28] Additionally, TBI disproportionately affects certain groups that suffer from healthcare disparities such as racial and ethnic minorities and people living in rural areas.[29–33] The impact of TBI on overall trauma outcomes cannot be underestimated. In a retrospective study of severe trauma patients by Livingston *et al*, those patients with a TBI did substantially worse at 3.3 years than those free of brain injury.[34] In addition, survivors of TBI are at an increased risk of depression and PTSD, suicide, and substance abuse.

There is a well-described natural history of an acute severe TBI, but the ultimate recovery and outcome of an individual patient is exceedingly variable which can appear random to the lay public and even to medical personnel. Determining the recovery of a patient following moderate-to-severe TBI is difficult and fraught with uncertainty.[35] Prognostic models have been created such as 'Crash' and 'Impact TBI' that are able to provide reasonable predictions for unfavorable outcome at 2 weeks and/or 6 months and death based on clinical and radiographic variables.[36 37] One systematic review of 27 studies demonstrated that early imaging and evaluation of the deep cerebral structures can yield significant prognostic information.[38] It is advisable to be extremely cautious as these tools only provide early and somewhat gross prognostic information.

There is no question that many patients with moderate-to-severe TBI make great strides in the first year following injury.[39] Unfortunately, TBI is a chronic disease with the best data on longitudinal follow-up coming from the TBI models systems from the National Institute on Disability and Rehabilitation Research. Unfortunately, the data from 1 to 5 years do not paint a promising picture for long-term improvement.[40] In these data, only 25% of patients had any improvement over time. For the remaining 75%, one-third die and one-third suffer marked deterioration.

Even if we were able to prognosticate with some measure of certainty following TBI, defining a 'favorable' outcome following a TBI is subjective and dependent on the outcome scales used. In many studies, the Glasgow Outcome Scale (GOS) or GOS-extended version is used to define a 'favorable' outcome. However, these scales have an exceedingly low threshold for what is considered 'favorable' to an individual patient or family. For example, being unable to shop without assistance, not being able to return to work, and severe restrictions in social and leisure activities are all considered 'favorable' outcome by these scales but would not likely be favorable by most people.

Patients who sustain a moderate or severe TBI have a reduced life expectancy by 9 years. Survivors alive 5 years after a TBI suffer a litany of ongoing medical and social problems; 57% are moderately or severely disabled, 55% who were previously employed are unemployed, 50% require at least one hospital readmission, 33% are dependent for their activities of daily living, 29% are not 'satisfied' with life, 29% have substance use disorders, and 12% reside in chronic care facilities.[41–43] Physical symptoms, often lifelong, such as headache, dizziness and nausea, fatigue, and lethargy are common as well as cognitive deficits such as disturbances of attention and memory, slow cognition, inability to multitask, increased distractibility, and impaired executive function.[44] Memory failure is the most commonly reported cognitive issue following TBI, while mental slowness and attention disorders are the next most common occurring in 57% and 52% of patients.[45–47] Fatigue is extremely common and is reported by 30%–70% of patients.[48 49] Additionally, 'anosognia' or lack of awareness of cognitive and behavioral disorders occurs in 76%–97% of patients following severe TBI, which contributes to difficulty in treatment and poor outcomes.[47 50–52] Behavioral disturbances such as personality changes, depression, anxiety, impulsivity, irritability, emotional lability, apathy, and depression occur frequently as well.[44] In one study, 2 years after TBI, irritability was found in 67% of patents, a lack of initiative in 44%, and socially inappropriate behavior in 26%.[52] Nearly 60% of patients experienced personality change after an acquired brain injury which is associated with a high subjective burden for the patients' caregivers.[52 53]

Therefore, we must ask ourselves whether any of these outcomes are currently modifiable. Is a poor outcome or a 'favorable' outcome with severe personality and cognitive disturbances a forgone conclusion following TBI? Without long-term longitudinal data, these answers will never be known. We believe that there may be opportunities both in inpatient and outpatient treatments that may affect outcomes. At present, social factors such as educational attainment[54] and preinjury employment[55]

seem to be the best predictors of functional recovery after controlling for severity of injury. This implies that social factors are potentially modifiable factors that could be leveraged to improve outcomes for patients with severe TBI in the future. These data clearly suggest that overall impact and trajectory of recovery for patients with and without TBI are very different. In contrast to other trauma studies which mix patients with and without TBI, we would strongly suggest that studies examining long-term outcomes following injury should separate these populations.

TRAJECTORIES AFTER INJURY

It is increasingly clear that recovery after injury is a complex and dynamic process with many factors that influence how fully an individual patient may recover. To better understand recovery and to design interventions that may be effective in improving long-term outcomes, it is imperative that we reconsider the underlying assumptions that we have regarding recovery. The most common assumption as described by Iwashyna is that most patients follow a 'Big Hit' trajectory following injury.[56] In this model, patients have a severe and sudden decline in function followed by a slow recovery over several months until reaching a new baseline. But data from several studies indicate that this may not be the prevailing or the only trajectory followed during recovery.

Until recently, most of the statistical methods used to analyze retrospective and prospectively collected long-term outcomes force all the data used to fit a model in which a mean curve is constructed with the variance of the curve made up of random and systemic error. This approach to analysis forces outliers to fit the underlying shape of the outcome curve which could obscure the existence of other recovery trajectories. One way to overcome this problem is to use group-based trajectory modeling (GBTM). GBTM is a type of finite mixture modeling that does not make assumptions about the number or shape of trajectories that may exist in longitudinal data. When applied to longitudinally collected data among injured people, several possible trajectories of recovery following injury emerge (figure 1).[57]

Using the data from the Health and Retirement Study, which surveys a cohort of people 50 and older every 2 years, Bell *et al* applied GBTM to a measure of functional limitation 2 years before and 8 years after a reported injury.[58] The analysis demonstrated that five different trajectories existed in the longitudinal functional limitation data. Only 46% of the cohort followed the 'Big Hit' trajectory. Three other trajectories were identified that changed over time: the 'slow burn', the 'long-term improvement', and the 'low functioning'. The 'slow burn' trajectory was characterized by an initial steep decline in function followed by a less severe, but still declining trajectory. The 'long-term improvement' trajectory improved slowly after an initial decrease in functional status. Finally, the 'low functioning' trajectory was characterized by low functioning at the time of injury and suffered a decrease in function but improved over time.

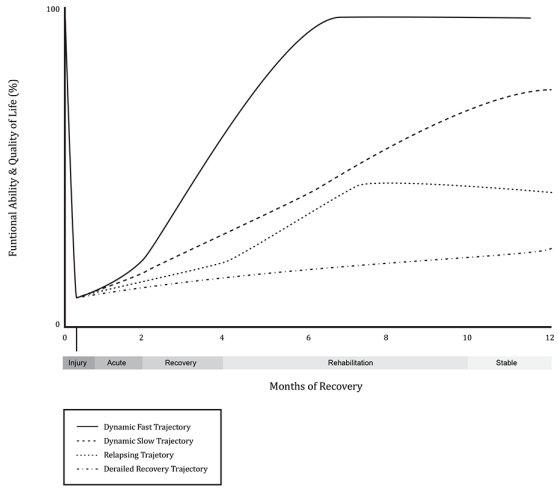

Figure 1 Various trajectory models for trauma recovery.

While these data demonstrate the existence of different recovery trajectories, there was no information available regarding the type or severity of injury that the people in the Health and Retirement Survey cohort suffered. In the Socioeconomic Status and Post-Injury Quality of Life and Functional Ability Study, 500 non-TBI or spinal cord injury survivors were followed for 1 year. GBTM was used to identify classes of individuals within the study sample that had varying and distinct recovery patterns over 12 months.[59] This analysis used the Short Form-36 as the outcome measures for functional and psychological outcomes and identified three physical and five behavioral health trajectories. For the physical outcomes, only 24% of patients followed the expected recovery trajectory which has a sharp decline followed by rapid recovery. The remainder followed worse trajectories. For the behavioral health outcomes, a similar pattern was observed. Only 23% followed the expected trajectory with one-third of patients following a resilient recovery

Box 1 Challenges and future directions for optimizing trauma outcomes

Data collection

1. How best to capture high-quality data at the lowest possible cost?
2. What standardized and validated screening tools should be used to detect changes in psychological status (eg, post-traumatic stress disorder (PTSD)), physical function, caregiver burden, sleep disturbances, and perceived social support?
3. How to incorporate qualitative data into a measure of trauma outcomes?
4. How long should trauma patents be followed to determine 'final outcome measures'?

Traumatic brain injury

1. The recognition that the outcomes of patients with traumatic brain injury (TBI) are so different that they should not be mixed with non-TBI patients.
2. Identify and define favorable outcomes in TBI.
3. Can the TBI outcomes be modified during inpatient care?
4. Can TBI outcomes be modified and improved with targeted outpatient care?

Trajectory and interventions

1. Identification of which groups may benefit the most from post-trauma center discharge intervention?
2. How often should behavioral health (eg, PTSD and depression) screening be done?
3. What is the optimal composition of the outpatient team to provide comprehensive collaborative care?
4. How does discharge location affect trajectory and outcomes?
5. What is the effect and impact of caregivers on trauma outcomes?
6. Does caregiver support improve outcomes?
7. What is the effect of peer support programs on trauma outcomes?

trajectory in which no decrease in behavioral health outcomes was observed. In summary, in this vulnerable population, over 75% of the non-neurological injury survivors followed suboptimal physical recovery trajectories and nearly 50% suffered a long-term decrease in psychological recovery. This was true even after accounting for differences in injury severity. The important underlying question in these observational database studies is 'Can these poor trajectories be modified through intervention?'

Identifying those who might benefit from an intervention to improve outcomes is problematic. Similar to other medical interventional studies there exist three populations: those who are destined to improve, and which interventions will have no harm but may offer no benefit, those who are destined to do worse and which interventions are doomed to fail, and the target group where the interventions may improve outcomes. It is also important to recognize that not all outcomes may be modifiable in the same way. In terms of outcome trajectories after injury, we would like to be able to identify the last group so that we can have the most impact. Unfortunately, at the present time, no good screening criteria exist to indicate which patients will follow one of the dynamic recovery trajectories following injury. However, data are emerging that indicate certain groups may be at higher risk of suffering a poor outcome trajectory than others. Older patients, women, and those with multiple medical comorbidities are at risk for following one of the less desirable outcome trajectories.[59] Pre-existing psychological comorbidities and substance abuse are also an indication of poor functional and psychological outcomes.[17 60 61] There is mounting evidence that poor perceived social support is associated with following a suboptimal outcome trajectory.[19 62 63]

Taken together, the data from cross-sectional and longitudinal outcome studies indicate that there are persistent impairments of physical and psychological outcomes for patients after injury.[7 9 34 58 59 64] While some patients follow the 'Big Hit' outcome trajectory, more have a very different recovery experience. Also, biopsychosocial impairment persists for many months after injury in a time where patients are in an outpatient setting and not readily available for screening and intervention. Injury survivors are also at risk from fragmentation of care which is a major factor in poor outcomes in patients with complex biopsychosocial needs. More worrisome are those who follow one of the trajectories that are initially high functioning and then suffer some setback weeks after their injury that leads to a worsening of their overall QoL. Ultimately, recovery from injury is a dynamic process that occurs over many weeks to months with most people reaching a steady state at some point 1 year after injury.

There are evidence-based interventions that exist from which we can learn about how to improve long-term outcomes after injury. Screening for post-traumatic stress in the inpatient setting following injury and following a stepped care pathway that includes prescribing medications reduces the risk of the development of PTSD and depression in the months after injury.[65 66] Despite limitations, this type of screening and treatment should be a part of any comprehensive program to improve the overall QoL of injured patients.

To augment inpatient focused interventions, we need to consider the fact that recovery takes many months to years, that it is a dynamic process, and that care fragmentation and social isolation are significant threats to achieving ideal outcomes after injury. To address these threats, new and novel approaches to the outpatient management of injury survivors must be considered. Furthermore, trauma surgeons and trauma centers are in an ideal position to implement programs for the long-term care of trauma patients. A type of intervention that may hold promise is a collaborative care intervention. Collaborative care interventions are designed to meet the needs of biopsychosocially complex patients who are at particular risk from fragmented care in the outpatient setting. There have been several randomized controlled trials that demonstrate the effectiveness of improving outcomes or delaying decline in patients with dementia, multiple comorbidities, social frailty, and in the recovery from critical illness.[67–69] The collaborative care delivery model is a multidisciplinary process to standardize and streamline care for selected case types—particularly for those with complex cognitive, physical, or psychological morbidity. Care coordination includes these features: (1) a patient-centered approach focused on the goals of the patient; (2) team and measurement-based care plan with each team member having the appropriate skills and resources to carry out their role; (3) a process to track the efficacy of a personalized care plan to meet the complex cognitive, physical, and psychological morbidity of each patient longitudinally to inform care decisions and to facilitate communication and coordination of care across team members and across sites of care; (4) a stepped care approach that provides the patient with the dose and duration of evidence-based treatment necessary to meet their goals of care; and (5) access to specialty care or community resources for those patients whose goals are not being met with current interventions. There are no clear data regarding how frequently follow-up should occur nor how long it should continue but all should recognize that serious injury is a life-changing event.[70–72]

CONCLUSION

We believe that maximizing long-term outcomes is the next challenge that trauma centers must face. The data presented (box 1) attempts to outline both the current state of knowledge and areas where future study is required.

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