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Experiences of care reported by adults with traumatic brain injury.

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Abstract

This paper investigates the continuum of care experienced by adults and their significant others following a moderate to severe traumatic brain injury (TBI) in Victoria, Australia. Clinical care guidelines exist defining best practice in TBI rehabilitation, but little is currently known about the experiences of those who sustain a TBI, their needs and the barriers they encounter when attempting to access services. This paper presents the journeys of 202 Victorians admitted for acute care following a moderate to severe TBI over four years. Results of this study indicate very few participants report receiving services in line with recommendations made in clinical care guidelines. In addition reported access to services was noted to vary according to allocated healthcare funding (i.e., compensable vs. private vs. public). Clinicians' consideration of healthcare consumers' experiences are essential if services provided are to match consumers' needs.

Keywords: *Traumatic brain injury (TBI), best practice, consumer preferences, clinical care guidelines, healthcare funding.*

Introduction

In recent years there has been a move towards the application of clinical care guidelines based on evidence best practice in the provision of health services. Health services, departments and clinicians have been encouraged to use guidelines to formulate service specific protocols, clinical pathways and care plans which help ensure efficient and effective service provision. The availability and implementation of these guidelines has been shown to lead to significant improvements in the processes as well as the outcomes of care (Bulger et al., 2002; Fakhry, Trask, Waller, & Watts, 2004; Faul, Wald, Rutland-Brown, Sullivent, & Sattin, 2007; Spain et al., 1998).

In the area of TBI evidence based guidelines, otherwise referred to as clinical care guidelines, are “systematically developed statements devised to assist practitioners and client decisions about appropriate healthcare for specific clinical circumstances” (Feild & Lohr, 1990, p. 99). Their successful implementation should improve quality of care by decreasing inappropriate variation and expediting the application of effective advances in every day clinical practice (Cabana et al., 1999).

There are several clinical care standards or guidelines that now reportedly define best practice in TBI. Examples of these include:

- Guidelines for the Surgical Management of Traumatic Brain Injury (2006), Guidelines for Pre-hospital Management of Severe Traumatic Brain Injury (2008) and Guidelines for the Management of Severe Traumatic Brain Injury (2007), all devised by the American Association of Neurological Surgeons and the Congress of Neurological Surgeons in association with the Brain Trauma Foundation (Brain Trauma Foundation, 2006, 2007, 2008a)

- Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation (2006), devised by the New Zealand Guidelines Group on behalf of the Accident Rehabilitation and Compensation Insurance Corporation and the National Health Committee in New Zealand (Accident Rehabilitation and Compensation Insurance Corporation, & National Health Committee, 2006),
- Multidisciplinary Rehabilitation for Acquired Brain Injury in Adults of Working Age (2005), devised by the Cochrane Collaboration (Turner-Stokes, Disler, Nair, & Wade, 2005),
- Clinical Practice Guidelines for the Care of People Living with Traumatic Brain Injury in the Community (2004) (Trevena, Cameron, & Porwal, 2004) and Guidelines for Mild Traumatic Brain Injury Following Closed Head Injury: Acute/Post Acute Assessment and Management (2008), both funded by the Motor Accident Authority of Australia (Motor Accident Authority NSW, 2008),
- Adult Trauma Clinical Practice Guidelines: Initial Management of Closed Head Injury in Adults (2006), devised by the New South Wales Institute of Trauma and Head Injury Management (Institute of Trauma and Health Injury Management, 2006),
- Rehabilitation Following Acquired Brain Injury: National Clinical Guidelines (2003), devised by the British Society of Rehabilitation Medicine and the Royal College of Physicians (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003),
- Guidelines for the Management of Severe Head Injury in Adult's (1997), devised by the European Brain Injury Consortium (Maas et al., 1997), and

- Head Injury: Triage, Assessment, Investigation and Early Management of Head Injury in Infants, Children and Adults (2007), devised by the United Kingdom's National Institute for Clinical Excellence (National Institute for Clinical Excellence, 2007).

A summary of the contents of these eleven guidelines is beyond the scope of this article. However a table listing the specific guidelines aims, targeted client type, outcomes and methods of creation, are provided in Appendix A.

Clinical care guidelines while beneficial in their potential to improve the quality of health services by assisting clinicians in decision making about the management of adults with TBI based on research evidence, should not be used uncritically for they are not always methodologically sound. For example, the EBIC guidelines are based solely on expert opinion and consensus (Frattali et al., 2003). Before using guidelines, clinicians need to understand the methodology used to create the guideline recommendations. The strength of a recommendation is said to be dependent on the method used for the literature reviewed. A common misconception exists among health professionals that guidelines pertain only to the results of randomised control trials (RCT) (Turkstra, & Kennedy, 2008). However, Maas (2002) argued that the results of RCT are not enough. Guidelines should be based on the integration of RCT, high quality clinical research, which may or may not involve randomisation, caregiver experience, and client preferences (Maas, 2002).

The guidelines listed above were formed in the United Kingdom, United States, Australia and New Zealand. Each targets a slightly different stage of the continuum of care provided to an adult following TBI. One targets the pre-hospital care of an adult with

TBI, six target the acute stage, one targets the non-residential or community based stage of rehabilitation, another targets recommendations for multidisciplinary rehabilitation across all stages, and the final two guidelines target the entire continuum of care an adult should have access to following TBI. Given the aim of this article is to present the continuum of care experienced by adults with TBI, only two guidelines, those which describe the entire continuum of care Rehabilitation Following Acquired Brain Injury: National Clinical Guidelines (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003) and Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation guidelines (New Zealand Guidelines Group, 2006) will be referred to throughout the remainder of this article.

Current Service Utilisation Patterns of Clinical Care Guidelines

Clinical care guidelines were initially created to assist health professionals' decision making regarding client assessment and management. However recently they have been adopted by insurance companies and lawyers who use current international guidelines as directives which in all instances should be followed (Maas, 2002). For example, in the US many state health plans and private insurance companies will not cover the costs associated with cognitive rehabilitation, given the lack of "good evidence" (i.e., RCT) which demonstrate its efficacy (Turkstra, & Kennedy, 2008, p.10).

Multiple studies have been completed in the United States to measure the implementation of acute care guidelines formulated by the Brain Trauma Foundation (Bulger et al., 2002; Fakhry et al., 2004; McIlvoy et al., 2001). These studies have identified that adherence to acute care protocols based on guidelines has resulted in

reduced client mortality, reduced length of stay of clients in the acute stage of their care and hospital cost savings due to reduced length of stay. In one particular US study (Faul et al., 2007) cost savings said to be achieved if treatment guidelines were used routinely were estimated to be as high as \$262 million in annual medical costs, \$43 million in annual rehabilitation costs and \$3.84 billion in lifetime societal costs (Faul et al., 2007).

While these cost savings resulting from the routine implementation of clinical care guidelines appear impressive, the ability of Australian services to comply with these guidelines is unknown. Therefore, care needs to be taken that achieving best practice according to the guidelines does not become the ultimate or only goal of health professionals, departments, services, insurance bodies and lawyers. Clinical care guidelines should never be considered the sole influence in facilitating a client's best outcome following TBI.

Consumer preferences

As stated above before being directed by clinical care guidelines, it is important for clinicians to be aware of the research evidence on which clinical guidelines are based. According to Maas (Maas, 2002), guidelines should also include consideration of high quality clinical research, with or without randomisation, caregivers' experiences and clients' preferences. However, very few currently utilised clinical practice guidelines consider the preferences of consumers in their recommendations. In fact, Nelson (2007) went so far as to state that health professionals do not routinely recognise the potential for assessing consumers' preferences. Consumers' preferences and experiences along a continuum of participation in health and healthcare can act as a stimulus and roadmap for

improvement in healthcare policy and delivery (Nelson, 2007). Clinical practice guidelines are increasingly affecting the quality of healthcare and have the potential to affect the availability of healthcare options for consumers. Deciding what guidelines will cover, how they will be developed and what they will say is therefore an issue in which consumers have a considerable stake (Bastian, 1996).

As stated earlier, the implementation of clinical care guidelines helps to standardise service delivery, ensuring the development of equitable and efficient TBI services through the implementation of best practice. While the importance of providing services is noted, it is imperative to recognise that the provision of a health service does not guarantee that those who need the service will use it (Humphreys & Mathews-Cowey, 1997). In order for a health service to be utilised consumer preferences must be considered. Formal methods to incorporate consumer preferences in the development of clinical care guidelines have been limited in the past (Institute of Medicine, 1992). Systematic involvement of consumers in the development, dissemination and use of clinical care guidelines in the management of chronic conditions, such as TBI, continues to be slow to evolve (Rao, Myers, Smith, & Andreou, 1995).

Consumers' preferences for and experiences of the delivery of health services, have been explored in the literature (Humphreys, Mathews-Cowey, & Weinand, 1997; Rankin, Newell, Sanson-Fisher, & Girgus, 2000). Factors underpinning consumer preferences and experiences of medical services been identified. They include availability, accessibility, accommodation, affordability and acceptability (Penchansky & William Thomas, 1981). Consumers' preferences for, experiences of and satisfaction with the delivery of TBI services are, however, largely unknown. No national and few

international studies have been completed to date reflecting the experiences of, satisfaction with and preferences for the receipt of services from the perspective of adults with TBI and their families (LeFebvre, Pelchat, Swaine, Gelinas, & Levert, 2005; Muus, Cogan, Offutt, & Medalen, 2006; New Zealand Guidelines Group & Accident Compensation Corporation, 2004).

Canadian researchers LeFebvre, Pelchat, Swaine, Gelinas and Levert (2005) used semi-structured interviews to investigate the experiences of eight individuals who had sustained a TBI, their families and the physicians and health professionals involved in their care. This study reviewed the experiences of consumers from the acute care management through to their subsequent rehabilitation. LeFebvre et. al., (2005) found that the majority of participants included in this study were satisfied with the availability of services during the acute care phase. However, they found that this situation differed once the people with TBI and their families returned home. Adults with TBI and their families criticised the lack of resources available to them after discharge from residential care. They voiced their belief that the lack of human resources available results in exhaustion amongst professionals which compromises quality of care for them as recipients of TBI services. The opinions of physicians and health professionals mirrored patients' and families' comments in this study.

The findings of Muus, Cogan, Offutt and Medalen's (2006) research were consistent with those of LeFebvre et al. Muus et al. surveyed 117 North Dakotans with TBI. In this study Muus et al. aimed to identify the major barriers to access to health and social services from the perspectives of healthcare consumers. They found that the commonly cited barriers to access and service utilisation were: shortages of TBI

advocates, inadequate knowledge of available services, no centralised source of information, inadequate financial resources and lack of individualisation of TBI programs. Although they cited that the majority of barriers experienced were due to poor advocacy efforts and a lack of information, they reported many of the cited barriers could be lessened or alleviated through increased effort at the state level to address the needs of people with TBI.

Another survey of TBI consumers preferences for, experiences of and satisfaction with services was employed by the Medical Research Institute of New Zealand (2004). The aim of this, and a second survey of TBI service providers was to allow comparison of international best practice as described in TBI guidelines with TBI service provision in New Zealand. The responses of 420 adults with TBI (response rate of 21%) were analysed as part of the New Zealand study. The results indicated that a large number of consumers (40%) were not satisfied with services that were provided. Gaps identified in service provision included:

- a perceived lack of knowledge of TBI among service providers which affected the way adults with TBI were treated,
- difficulty finding available services, which were often self sourced rather than offered or suggested by service providers,
- fragmented and/or poorly coordinated services,
- poor access to services, which appeared to be compounded by degree of rurality,
- preference for perceived specialist services even if required to travel,
- variable case manager services with high staff turn over, and

- perception that the New Zealand health system was geared toward resolution of physical injuries, not remediation of cognitive, emotional or lasting impairments commonly experienced by those with TBI (McNaughton, 2004).

These three studies, while offering important initial research which assists in the evaluation of TBI consumers' care from their perspectives and the perspectives of their families, are all internationally based (i.e., Canada, US and New Zealand). In addition, most of the participants included in the studies had sustained their TBI up to 12 years prior to being surveyed or interviewed (indicating that while the publication the studies are based on appear recent). The experiences of care reflected upon occurred up to 17 years ago. Therefore their experiences may not reflect the current reality of service provision in those countries.

No Australian study investigating consumer preferences with regard to TBI service planning, utilisation or evaluation has been published to date. It is the aim of this article to present consumers preferences and experiences of healthcare following TBI to determine whether Australian adults with TBI receive services in line with clinical care guidelines. In addition this paper aims to provide adults with TBI and the opportunity to express satisfaction or dissatisfaction with the services they receive, offering their perceptions of potential barriers to access, which could be removed once known.

Method

This project involved two separate research stages. The first involved the dissemination of two state-wide surveys; the first of these surveys targeted adults with moderate to severe TBI of working age and the second targeted a significant other of the

person with TBI. The second stage of the project involved seventeen in-depth interviews involving the first author, an adult with TBI and their significant other. This research project aimed to answer following research questions:

1. What is the reported continuum of care experienced by adults with TBI and their significant others in Victoria?
2. What is the recollected impact of location on the continuum of care experienced by adults with TBI and their significant others in Victoria?
3. What is the recollected impact of funding on the continuum of care experienced by adults with TBI in Victoria?
4. What other reported factors influence the continuum of care experienced by adults with TBI and their significant others in Victoria?

Victoria was chosen as the state for this research as it is one of the smallest geographical states in Australia, yet it is the second most populated.. Therefore, findings relating to difficulties in access according to geographical isolation (research Questions 2 and 5) could be easily generalised to other larger states and territories. Victoria is one of six states in Australia.

The data presented in this paper reflect the results of the first stage of this research from the perspective of adults with moderate to severe TBI. It specifically addresses research questions one and three. Further data from this project will be published in subsequent journals.

Participants

Individuals targeted for inclusion in this project were those of working age (i.e., 18-65 years) with a moderate to severe TBI, who had undergone initial acute trauma care at one of two major Victorian trauma centres between July 2001 and June 2005. June 2005 was selected as the latest acute admission date to ensure that all participants had had an opportunity to complete their continuum of care and experience life back in the community prior to completing the questionnaires utilised in the first stage of this research. Of the 1,771 eligible individuals invited to take part in this research 202 participants responded (response rate = 11.4%). The mean age range of these 202 individuals with TBI was 36-45 years (range: 18 - 66 years or older). The majority (23%) were adults between 26-35 years, while 22% were under 25 years, 17% were 36-45 years, 21% were 46-55 years and 13% were 56 years or older. Sixty-eight percent were male. With respect to education, 44% had a high school education or less, 27% had some kind of TAFE certification, while 27% had graduated from university with at least a bachelor's degree. Educational data was missing for 4% of participants.

The perceived severity of injury for the 202 participants represented primarily the moderate, severe to very severe range (83%). The majority of participants sustained their TBI in a car or motor bike accident (54%), while 17% reported sustaining their TBI in a fall and 7% reported being assaulted. Thirty five percent of participants were younger than 25 years of age when they sustained their head injury, 36% were aged between 26-45 years, while 28% were 46 years or older.

Of the 202 (57%) adults with TBI who took part in this study, 115 reported that they were currently employed in paid work. The majority of these stated they worked at least 33 to 38 hours per week (67%). Of those who were in paid employment, reported

hours working were: less than 8 hours (4%), 9 – 16 hours per week (8%), 17 – 24 hours (9%), or 25 – 32 hours per week (13%).

Instrument

A questionnaire devised by the first author based on clinical experience, an extensive literature review and consultation with specialist TBI services, was the research instrument in this study. This survey was specifically formulated to collect information on, and survey opinions of participants with regard to the recollected continuum of care they experienced.

A questionnaire was chosen as the research tool for this study as questionnaires are low-cost in terms of time and money; they are an easy way to obtain information relatively quickly from a large sample of people; they are completed by participants at a time that suits them; they are easy to analyse, particularly closed-ended questions; they place less pressure on participants to provide immediate responses, giving them time to think about the questions they are being asked; participants can remain anonymous; interviewer bias is reduced; questions asked are standardised and they provide initial data that can be followed up and examined in more detail (Gillham, 2000; Jackson & Furnham, 2000).

The survey entitled Investigating Your Experiences of Health Care – A Survey for People who have a Traumatic Brain Injury was broken into five sections representing each stage of their continuum of care. The sections were named as follows: Acute medical care, Rehabilitation in hospital, Leaving hospital based rehabilitation, Rehabilitation outside hospital, and What are you doing now? The survey was made up

of 69 items distributed throughout 21 pages. The items included in the survey took open and closed ended forms with the occasional visual analogue scale. All items included within this survey were researched in order to determine their purpose, necessity and accuracy, and were piloted to determine their content validity.

Questionnaires were piloted firstly with allied health therapists working within specialised traumatic brain injury units (South West Brain Injury Rehabilitation Service [SWBIRS] and Ivanhoe Private Hospital) and then with ex-SWBIRS and Ivanhoe TBI survivors and their families within their homes. The researchers were present on all piloting occasions to receive feedback and to modify the questions as needed.

Given the page length of the survey and the time need for its completion, as well as potential cognitive-communication or literacy impairments of participants secondary to their TBI, participants were provided with the option to complete the questionnaires with the assistance of a significant other. Participants also were prompted to take regular rest breaks throughout the surveys completion. If surveys were too deemed to long by participants, information sheets distributed with the surveys made participants aware they were under no obligation to take part in the research.

Data collection & analysis

Data were collected through one postal survey sent twice. The survey was first sent with an accompanying easy to read information sheet explaining the purpose of the research, its benefits, issues of confidentiality, the time taken to complete the survey, and the investigators' and ethics committees' contact details. Four weeks after the initial mail out, follow-up letters were sent to participants. The need for follow-up letters was

established because less than 30% of potential participants responded. These follow-up letters were accompanied by another copy of the survey. The follow-up letters reiterated the importance of the research and thanked those that had already replied. All self-administered surveys were returned via pre-paid envelopes. Return of the survey was taken as an indication of voluntary consent to participate. All surveys were disseminated between November 2007 and July 2008.

Data arising from the survey were entered into a spreadsheet and analysed using the Statistical Package for the Social Sciences (SPSS) and QSR NVivo 7. Analysis of closed-ended questions using SPSS contained both descriptive statistics (i.e., frequency and percentage distributions, measures of central tendency and cross tabs) to describe the experiences of adults with TBI throughout their continuum of care. Open-ended questions were coded using NVivo through content analyses to identify common trends expressed by TBI survivors when reflecting back on their continuum of care.

Results and Discussion

Access to Stages of Continuum of Care as Reported by Adults with TBI

All adults with TBI in this study reported accessing acute care. This is not surprising given participants were sourced via their acute care provider. However, their access to care following this point drops. One hundred and twenty four participants with TBI (61%) reported receiving inpatient rehabilitation services. Participation increased slightly to 142 participants with TBI (70%) receiving outpatient rehabilitation. However, only 50 participants with TBI (25%) stated they were receiving therapy services at the time they completed the questionnaire and only 44 participants with TBI (22%) reported

they received ongoing monitoring. This means that over half of the participants with TBI (n= 106 or 53%) reported that they were neither receiving therapy nor ongoing monitoring at the time of questionnaire completion. This is concerning, given repeated acknowledgement of the needs for long term support for adults with TBI and their families (Avesani et al., 2005; Coetzer & Rushe, 2005; Karlovits & McColl, 1999).

Over time the needs of adults with TBI and their families has been shown to change and in some instances significantly increase as they adjust to altered occupational roles and life circumstances (Brooks et al., 1986; Brooks et al., 1987; Brooks, & McKinlay, 1983; Marsh et al., 1998; Marsh et al., 2002). According to rehabilitative guidelines (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003; New Zealand Guidelines Group, 2006) adults with TBI and their families require information, practical support, continued education and easy access to health and social services to combat isolation, emotional distress, stress and practical overload which occur over time. Ongoing support is reportedly required following discharge from formal based services in order to maximise the independence and quality of life for adults with TBI for what may be the next 50 or more years of their lives (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003).

Some participants in this study made comments congruent with the need for long term support in open ended questions that asked whether access to services could have been improved. The majority of the comments made related not to participants' ability to access hospital based services, but to the lack of services available to them on discharge. This is illustrated with the quotes from four participants below.

Nothing [needs to be done] in [the] rehab hospital but ongoing longer term support would have been extremely beneficial.

After being discharged from the [specialist acute hospital], there were no follow-up visits or checkups as was promised when discharged.

The need for services following discharge from residential rehabilitation has also been identified in international research. A Canadian study of 16 consumers (eight adults with TBI and eight family members) and 31 health professionals, conducted by LeFebvre, Pelchat, Swaine, Gelinias and Levert in 2005, found that the majority of participants in their study were satisfied with the availability of services during the acute phase of their care. However, they reported this situation differed when they returned home. Once at home the Canadian consumers criticised the lack of professional resources available to them. The opinions of health professionals mirrored consumers' comments in this study.

Table 1 provides a summary of the rehabilitation pathways participants with TBI in this study recollected receiving following their TBI. According to TBI rehabilitative guidelines (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003; New Zealand Guidelines Group & Accident Compensation Corporation, 2004) there are four distinct stages in the rehabilitation of adults following moderate to severe TBI. Each of these stages is distinct and has differing aims in relation to TBI recovery. The first stage in TBI recovery is acute neurosurgery care, the second is residential rehabilitation (i.e., inpatient rehabilitation), the third is non-residential rehabilitation (i.e., outpatient rehabilitation) and the fourth is longer term community support (i.e., ongoing therapy and monitoring) (New Zealand Guidelines Group, 2006). According to the

recollections of participants in this study, only 41 adults with TBI (20%) received a continuum of care in line with clinical care guidelines (i.e., received acute care, inpatient and outpatient rehabilitation and either ongoing therapy or monitoring). Other rehabilitation pathways recollected can be seen in Table 1.

INSERT TABLE 1 HERE

Access to specialist services

Of the 137 participants with TBI who reported receiving inpatient rehabilitation, only 91 (66%) reported that they accessed specialist neurorehabilitative services; and of the 142 adults with TBI who reported receiving outpatient rehabilitation, only 45 (28%) reported receiving home based, context specific therapy. This indicates that although significant numbers of adults with TBI reported accessing services (i.e., 61% of participants accessed inpatient rehabilitation and 70% accessed outpatient rehabilitation) following discharge from their acute medical provider, few adults with TBI reported receiving specialist or contextually specific services as recommended in clinical care guidelines (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003).

The findings in this stage of the research replicate those found in a practice review of TBI rehabilitation in New Zealand (New Zealand Guidelines Group & Accident Compensation Corporation, 2004). According to this review residential rehabilitation services in New Zealand tend to be low volume (for TBI clients) and not specialised, a combination that would suggest that most people with (severe) TBI are being managed in

environments that might not be ideal for TBI clients and by staff who do not see TBI clients as their “main business” and/or for whom they have special training (New Zealand Guidelines Group & Accident Compensation Corporation, 2004).

Happiness with services accessed

Regardless of the fact that few adults recalled receiving specialist services in appropriate contextual settings, a large number of participants with TBI in this study reported they were either *very happy* or *extremely happy* with the care they received throughout their healthcare journey (see Table 2).

INSERT TABLE 2 HERE

Participants with TBI made comments in open ended questions relating to their degree of happiness with services. These comments reflected initial happiness with acute care which appears to reduce as adults with TBI make their way through their healthcare journey. For example two adults with TBI wrote:

In critical care the nurses and doctors were good. They not only looked after me but Mum and Dad as well. In the general ward the care was very poor. [I was] left in [a wet] bed for at least an hour [and was] not fed at times.

The emergency care [and] surgery [teams] were excellent. ICU [was] okay. The neurosurgery ward was extremely bad at the [specialist acute hospital].

Involvement of Adults With TBI in Guiding Their own Rehabilitation

Tables 3 to 5 document the involvement of participants with TBI in activities which helped guide their rehabilitative care. For example, Table 3 shows that just over 55% of adults with TBI who received inpatient rehabilitation in this study can remember taking part in regular progress meetings. Progress meetings are held in inpatient rehabilitative services to bring therapists, family members and a client together to discuss a client's injuries, their prognosis and progress to date, future goals and discharge planning. A client's involvement in these meetings helps to inform them of their current status, likely improvement and future plans. Ultimately it ensures clients' active participation and involvement in planning their care.

INSERT TABLE 3 HERE

Another way clients can help guide their care is through their active involvement with their therapists in setting goals. However, half of participants with TBI (50%) in this study stated that they did not set any goals in inpatient rehabilitation. They reported that either therapists set the goals for them (42%) or they didn't set any goals at all (7%). This finding improves in outpatient settings, with the majority of participants with TBI reporting they set their own goals with the support of their family and therapists (see Table 4).

INSERT TABLE 4 HERE

According to the BSRM and the RCP (2003), goal oriented rehabilitation programs have gained international acceptance as a means of demonstrating progress and improving communication. If a person with TBI, their family and their treating team are all working towards the same agreed goals, rehabilitation effectiveness and a satisfactory client outcome is said to be more likely. Given this statement and the numbers of participants reporting involvement in joint goal setting in this study, the effectiveness of their rehabilitation may be questioned.

In addition to client involvement in goal setting, another way clients can help guide their care is through joint discharge planning. However, not unlike the involvement of participants with TBI in goal setting, in inpatient rehabilitation, participants with TBI reported decision making regarding their discharge was largely left to medical, allied health and mental health staff. According to frequency data tabulated in Table 5, over 56% of adults with TBI cited their therapists' or doctors' decisions as the reason for their discharge from inpatient rehabilitation.

INSERT TABLE 5 HERE

The reported limited involvement of participants in this study in guiding their own rehabilitation is of concern. According to the World Health Organisation (1998), positive health outcomes are increased when people take an active role in their own healthcare. Researchers support the need for an individual to take control of their health (Newberry, 2001; Seligman, 1993; Stringer, 1999). Newberry (2001) stated that in order for a person with an acquired brain injury (ABI) to feel empowered, they must be involved in the

decision making process throughout their healthcare. If they are not, their lack of control may result in learned helplessness (Seligman, 1993).

Dependency is one of the major barriers to independence and empowerment. The “patient” or “sick” role often adopted by people in acute care has been described as one of dependency on others (MacPhail, 1998). When this occurs, control is transferred from the individual to others (i.e., healthcare providers). In order for clients to be empowered, control needs to be shifted from others back to individuals as they transition through their continuum of care (Newberry, 2001). In order to facilitate positive health outcomes, adults with TBI and their families must be able to participate in family meetings, select their own options for treatment, formulate their own goals for rehabilitation, take responsibility for the achievement of those goals and make decisions about appropriate times to cease therapy. Newberry (2001) stated that people with ABI need to be involved in the design and direction of their services, to ensure that services are responsible to them rather than to the needs of funders or healthcare providers.

Healthcare Funding Models Reported by Participants

The majority of participants (57%) in this study were allocated compensable funding. These compensable funds were provided primarily by the Traffic Accident Commission (TAC) (51%) and Workcover (6%). The high level of compensable participants in this study is representative of the adult TBI population as a whole given the majority of TBIs sustained occur as a result of a motor vehicle accident (MVA) (O'Connor, 2002). The care for people who sustain a TBI as a result of an MVA in Victoria is funded by the TAC, which pays “the reasonable costs of medical treatment,

rehabilitation services, disability services, income assistance, travel and house hold support services” that a person may need as a result of TBI (Traffic Accident Commission, 2003). Other participants in this study had their services paid for by public (32%) or private funds (7%). Private funds accessed to pay for participants’ care included private health insurance bodies such as the Hospital Benefits Association (HBA), Medibank Private and Australian Unity.

Patterns Identified Between Funding Allocation and Cause of TBI

As stated above, the majority of participants with TBI in this study received compensable funding. By completing cross tabulation to compare the patterns between funding and received services a number of trends were noted. Not surprisingly, allocation of compensable funding appears to be related to the initial cause of the TBI. For example, 86% of participants in this study who sustained their TBI in a road accident were allocated compensable funding (see Table 6). Given the Traffic Accident Commission’s (2007) commitment to funding care following head injuries sustained either on a Victorian registered road or in a Victorian registered car, this pattern between cause of TBI and funding allocation was expected.

INSERT TABLE 6 HERE

Patterns Identified Between Funding Allocated and Received Rehabilitation Services.

Trends were also noted when the patterns between funding allocation and received rehabilitation services were examined. For example, allocation of compensable

funding appears to be related to increased received services in inpatient and outpatient rehabilitation settings. For example, 71% and 81% of adults with TBI with compensable funding in this study reported accessing inpatient rehabilitation services and outpatient rehabilitation services respectively (see Table 7). Those who were allocated public funding appeared to be the least well served (i.e., only 49% of publicly funded participants reported accessing inpatient rehabilitation, with 52% reporting being able to access outpatient services). While just over 60% of those who were allocated private funding reported receiving both inpatient and outpatient rehabilitation services.

INSERT TABLE 7 HERE

These findings are congruent with those of a US study completed by Nabors, Seacat and Rosenthal (2002) who, in the discussion of their findings, reported that the poorer the healthcare payer source (i.e., limited private health insurance or public funds), the less access to resources for the person with TBI. Nabors et al. specifically stated that “persons who sustain a TBI who have limited insurance should be less likely to receive outpatient therapy, vocational services, access to transitional living, adequate transportation and equipment” (Nabors et al., 2002, p. 1047).

Another study completed by Rosenthal, Dijkers, and Harrison-Felix (1996) suggested that a lack of resources post injury is associated with lower total community integration for people with TBI one year post injury, as measured by the Community Integration Questionnaire (Kaplan, 2001). These findings suggest that limited financial

resources may directly impact upon client outcomes. Further research is required to examine this area more fully.

Conclusion

The majority of adults with TBI involved in this research reported being able to access acute, inpatient and outpatient rehabilitation services. This level of reported access seems appropriate when taken at face value, in that all participants received acute care, 61% of participants received inpatient rehabilitation and 70% received outpatient rehabilitation. However, upon closer inspection, just over half of all participants reported accessing specialist TBI services with fewer than 30% of participants reporting that they received context specific outpatient services. These findings indicate significant variations in service provision and delivery when compared to the recommendations of existing clinical care guidelines. In addition, the reported low levels of participants' involvement in guiding their care is concerning. Surprisingly, regardless of the limited involvement in guiding their own care, participants' level of satisfaction with services, particularly those provided in residential settings, remains strong.

An examination of the patterns between received services, length of stay in services and funding was undertaken. The findings of these research questions indicated variations in received rehabilitation and case management services dependent upon funding allocation, although no pattern between funds and reported length of stay was noted. This may indicate that clients' reported funding allocation affects access to services, not provision of services once admitted. The impact allocated funding has on access to services for adults following TBI require further investigation.

The data reported in this chapter have a number of important clinical implications which should be considered when planning services in consultation with adults following TBI. The first of these relates to the fact that participants with TBI in this study reported adequate access to TBI services following head injury. However, the services they received were perceived to be non-specialist, with limited flexibility regarding appropriate methods of service delivery. The efficacy of providing such rehabilitation services can be questioned. According to clinical care guidelines, the provision of specialist community based, context-specific rehabilitation is essential to achieve a maximum degree of return to pre-morbid level of functioning for adults with TBI (Khan et al., 2003).

Participants in this study also played very minor roles in guiding their own care. The limited role healthcare consumers play in guiding their care may be acceptable in acute settings where medical management is key. However, in rehabilitation settings, where the aim is achieving client goals, participants' reportedly limited involvement is concerning. The empowerment of clients and their families to manage their own care in hospital based settings is important to not only ensure that therapy targets individual needs, but also to ensure that once discharged, adults with TBI and their families have the skills and information needed to continue to access services as appropriate.

Finally, the consideration of received services dependent on healthcare funding needs to be planned for in service allocation. If TBI services are to be provided equitably to all Victorian adults following TBI, and in line with clinical care guidelines, the services provided must be available to all those who choose to access them, regardless of funding. Given the healthcare funding model currently utilised in Victoria, it is unlikely

that this will be the case, as financially restricted health services prioritise compensable and private clients because of their potential to generate hospital income (McAuley & Menadue, 2007).

In order to resolve this conflict, the Australian Centre for Policy Development (2007) advocated that universalism should be restored and embedded. In this context, the term universal simply means that regardless of means or location, all people have access to the same professional staff, clinics, pharmaceuticals and other resources. According to this centre, a universal system will not only ensure fair access to health services; it is also the most affordable in terms of private and public spending. A universal system is not necessarily a free system: people in differing socioeconomic groups may pay differing amounts to have access to the universal system, but the wealthy and the poor should not have separate providers. All should share one, high quality system (McAuley & Menadue, 2007).

In the interpretation of this study's results its limitations must be noted, including the number of participants who responded to the questionnaire. As stated earlier questionnaires were mailed to the home addresses (as recorded in hospital files upon admission to acute care) of 1,771 adults with moderate to severe TBI. In all, 202 adults returned the questionnaire, an 11.4% response rate. However, of the possible 1,771 questionnaire distributed 256 were returned to author unopened. This means the response rate from participant groups increases slightly to 13.3%. While it is acknowledged the response rate is low, according to Nabors, Seacat and Rosenthal (2002, p. 1043) a response rate of "approximately 15% is comparable to other mail surveys of clinical populations."

In addition the findings reported in this study reflect the experiences of adults with TBI when accessing healthcare following head injury in Victoria. The experiences reported are participants' perceptions of the events that occurred following their TBI. They do not necessarily reflect the reality of the services that were provided. Large scale studies reviewing trends in TBI service provision based on prospective client medical records have been conducted both within Australia and internationally (see for example, (Hodgkinson et al., 2000; Schootman & Fourtes, 2000; Tooth et al., 2001)). These studies have aimed to investigate client outcome based on services received, client service utilisation patterns and client demand on services following TBI. These studies while useful for identifying current services accessed by adults with TBI do not consider the unmet needs highlighted by participants in this study. Data collected on trends in services accessed are also vulnerable to measurement inaccuracies (i.e., coding errors in client databases, missing data) and are often service specific (i.e., acute services collect their own data, as do residential services and non-residential services). Therefore they reflect that only snap shots of the continuum of care of adults with TBI. These problems are being rectified by national (i.e., National Research Trauma Institute) (National Trauma Research Institute, 2009) and international research programs (i.e., American Traumatic Brain Injury Model Systems) (Bushnick, 2003) which are currently being devised to collect consistent and comprehensive data from all stages in a client's continuum of care. These data are yet to be published in Australia.

In the absence of a useful system to investigate current trends in service provision this study relied on service users' perceptions of care. However, this was not the only reason why perceptions were investigated. By investigating consumers' perceptions this

paper uncovered consumers experiences of care, their satisfaction with services and the barriers to access they experienced. Implementing improvements in healthcare based on these needs and preferences requires concentrated effort by researchers, healthcare professionals and policy makers. This study ensured that consumers were engaged as vital participants in healthcare delivery rather than passive recipients of information. Engagement of consumers in this way is beneficial, as indicated by the growing literature which indicates that consumer involvement in care is associated with enhanced health outcomes (Ergh, Rapport, Coleman, & Hanks, 2002; Kaplan, Greenfield, & Ware, 1989).

Table 1
Rehabilitation Pathways Recollected by Adults with TBI (n = 202)

Rehabilitation Pathways Recollected by Adults with TBI	Number	Percentage
Acute only	38	18.8
Acute and inpatient rehabilitation	17	8.4
Acute, inpatient and outpatient rehabilitation	65	32.2
Acute, inpatient rehabilitation and ongoing therapy	1	0.5
Acute, inpatient and outpatient rehabilitation and ongoing therapy	8	4.0
Acute, inpatient and outpatient rehabilitation, ongoing therapy and monitoring	29	14.4
Acute, inpatient and outpatient rehabilitation and monitoring	4	2.0
Acute and outpatient rehabilitation	26	12.9
Acute, outpatient rehabilitation and ongoing therapy	3	1.5
Acute, outpatient rehabilitation, ongoing therapy and monitoring	7	3.5
Acute and ongoing therapy	1	0.5
Acute, ongoing therapy and monitoring	4	1.0
Acute and monitoring	1	0.5

Table 2
Degree of Happiness of Adults with TBI With Care Provided

Degree of happiness	Acute (n = 202)		Inpatient rehabilitation (n = 137)		Outpatient rehabilitation (n = 202)	
	n	%	n	%	n	%
Extremely unhappy	6	3.0	8	5.8	8	3.9
Not happy	10	5.0	6	4.3	10	5.0
Okay	44	21.8	32	23.4	52	25.7
Very happy	69	34.2	52	38.0	63	31.2
Extremely happy	45	22.3	36	26.3	29	14.4
Missing data	28	13.9	3	2.2	40	19.8

Table 3
Attendance of Adults with TBI in Their Progress Meetings in the Inpatient Rehabilitation Setting (n = 137)

Attendance at progress meetings	n	%
Attended	75	54.7
Did not attend	47	34.3
Can't remember	15	10.9

Table 4
Involvement of Adults with TBI in Goal Setting Throughout Rehabilitation

Involvement in goal setting	Inpatient rehabilitation (n = 137)		Outpatient rehabilitation (n = 141)	
	n	%	n	%
Yes, I set my goals by myself	29	21.2	38	26.8
Yes, I set my goals with help from my family and therapists	40	29.2	75	52.8
No, I didn't set goals. My therapist set them for me.	58	42.3	16	11.3
No, I didn't set any goals.	10	7.3	14	9.2

Table 5
Reported Reasons for Discharge From Inpatient Rehabilitation (n = 137)

Reported reasons for discharge from inpatient rehabilitation	n	%
Don't know	12	8.7
I chose to go	27	19.7
Therapist's/doctor's decision	77	56.2
My goals were achieved	13	9.4
Other	8	5.8

Table 6
Relationship Between Cause of TBI and Funding Allocated

Funding Model	Cause of TBI			
	Road accident	Fall	Assault	Other
	%	%	%	%
Public funding	7.9	39.7	14.3	36.5
Private funding	0.7	38.5	23.1	30.8
Compensable funding	85.8	4.4	0.0	9.7
Other	20.0	0.0	40.0	40.0

Table 7
Funding Allocation by Reported Rehabilitation Services Received

Funding allocated	Received services		
	Received	Did not receive	Missing data
	%	%	%
Inpatient rehab.			
Public funding	49.2	49.2	1.6
Private funding	61.5	38.5	0.0
Compensable funding	70.8	27.4	1.8
Other	20.0	80.0	0.0
Outpatient rehab.			
Public funding	52.4	42.9	4.8
Private funding	61.5	38.5	0.0
Compensable funding	81.4	16.8	1.8
Other	80.0	10.0	10.0

Appendix 1. Summary of clinical care guidelines for adults with TBI

EBP guidelines	Client type	Outcomes	Method of creation	Comments
Multidisciplinary rehabilitation for acquired brain injury in adults of working age – Cochrane Collaboration (2005)	<p>People with acquired brain injury (from any cause) aged 16-65 years.</p> <p>Aim: To assess the effects of a multidisciplinary rehabilitation following ABI in adults and to explore approaches that are effective in different settings and the outcomes that are affected.</p>	<p>Strong evidence to suggest that:</p> <ul style="list-style-type: none"> - adults with mild ABI make good recovery with provision of appropriate information, without additional specific intervention. - more intensive rehabilitation programs are associated with earlier functional gains for those with moderate-severe ABI. <p>Moderate evidence suggests that:</p> <ul style="list-style-type: none"> - continued outpatient therapy can help to sustain post acute rehabilitation gains following moderate-severe ABI. <p>Limited evidence suggests that:</p> <ul style="list-style-type: none"> - specialist in-patient rehabilitation and specialist multi-disciplinary community rehabilitation may provide additional functional gains. 	<p>Literature search of: Cochrane central register of controlled trails, MEDLINE, EMBASE, CINHAL, PsycLIT, AMED, the national research register and ISI science citation index.</p> <p>Literature reviewed included: randomised controlled trails (RCT), quasi-randomised and quasi experimental designs.</p>	<p>These guidelines are based on ABI research outcomes, not specific TBI studies.</p>
Initial management of closed head injury in adults – Institute of trauma and injury management (2007)	<p>Adults with mild, moderate or severe TBI</p> <p>Aim: Formulate recommendations on the initial acute management of adults following TBI</p>	<p>Mild TBI:</p> <ul style="list-style-type: none"> - Defined condition - Specified clinically important complications - Specified how patients should be assessed. - Identified which patients require CT scans and what to do with “high risk” patients when CT scans are unavailable. <p>Moderate –severe TBI:</p> <ul style="list-style-type: none"> - Defined proven acute treatments - Defined when patients should be transferred to acute hospitals with neurosurgical facilities 	<p>The literature reviewed according to NHMRC (1999) levels of evidence (i.e., Level I – systematic review of RCTs; Level II – RCT; Level III – pseudo-RCT, etc.)</p> <p>Literature search: MEDLINE, EMBASE, Cochrane Database of Systematic Reviews (CDSR) and the Cochrane Library.</p>	<p>Those with penetrating head injuries were excluded from this study as their acute care management varies.</p> <p>Focussed purely on acute care medical management</p>

EBP guidelines	Client type	Outcomes	Method of creation	Comments
TBI: Diagnosis, acute management and rehabilitation – New Zealand Guidelines Group (2008)	<p>Guidelines applied to any New Zealand resident who sustained a TBI.</p> <p>TBI was broadly defined as an injury to the brain resulting from externally inflicted trauma.</p>	<ul style="list-style-type: none"> - Clear definition of TBI - Clear description of severity levels for TBI - Description of who should be admitted in emergency department - Recommendations about who should receive CT scans - Recommendations about when it is safe to discharge adults, children and young people from acute care - Description of the types of rehabilitation services available for people with TBI - Recommendations about organisation of rehabilitation services and approaches to rehabilitation - Recommendations about which interventions for people with TBI are appropriate 	<p>Literature was graded using the system detailed in the “Handbook for the preparation of explicit evidence-based clinical practice guidelines” (NZGG,2001). Levels of evidence were rated as:</p> <ul style="list-style-type: none"> - strong (study met all or most of the validity criteria) - fair (not all validity criteria were met, but the study was not influenced by bias) - weak (very few of the validity criteria were met) <p>Informed by the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001).</p>	<p>These guidelines were based not only on epidemiological studies where no evidence was available, but guidance was needed, recommendations for the guidelines were developed through systematic group consensus based on the experience of the guideline development team.</p>
Clinical practice guidelines for the care of people living with TBI in the community – Motor Accident Authority (MAA, 2004)	<p>Adults with TBI who are residing in the community following resident rehabilitation</p> <p>Aim: Summarise the best available evidence about the longer term care of people with TBI.</p>	<p>Evidence from guidelines was grouped into five categories:</p> <ul style="list-style-type: none"> - common health issues in TBI (e.g., seizures, somatic complaints, post concussive syndrome) - mental healthcare needed (e.g., depression, anxiety, schizophrenia) - cognitive and behavioural sequelae (e.g., cognitive impairment, personality and behaviour changes) , - lifestyle issues and quality of life (e.g., functional status; issues for carers, friends and family), and - substance abuse. 	<p>Literature searched included: MEDLINE, Health Star, PsychInfo, CINAHL, EMBASE, SPORTS discuss, CDSR, American College of Physicians Journal Club, Database of Reviews and Abstracts of Effectiveness, and Cochrane Control Trail Register.</p> <p>Strength of evidence of literature reviewed was based on NHMRC criteria.</p>	<p>Targeted to inform the practice of GPs in the community.</p> <p>Largely recommends pharmacological interventions; little attention paid to non-medical interventions</p>

EBP guidelines	Client type	Outcomes	Method of creation	Comments
Guidelines for mild TBI following closed head injury: Acute/post acute assessment and management – MAA (2008)	Guidelines target adults (>16 years) with mild TBI during the first 6 months following closed head injury. Aim: Improve early identification and management of mild TBI.	Provides recommendations to clinicians in three practice areas: - pre-hospital - emergency departments and - general practice In the domains of assessment and diagnosis, management and prognosis.	Developed following review of international guidelines for mild TBI, together with a systematic review and appraisal of literature. Literature was appraised using the NHMRC criteria. Informed by the ICF.	Doesn't contain recommendations for mild penetrating TBI.
Guidelines for the management of severe head injury in adults – European Brain Injury Consortium (EBIC, 1997)	Guidelines target acute management of adults following severe TBI. Aims: improve the outcome of people with TBI by optimising resources and organisation.	Provides recommendations for treatment from accident site to the intensive care unit, including: - early management of head injury, - referral policy and admission care in neurotrauma centres, - transportation, and - ICU care.	Guidelines are based on consensus and expert opinion.	EBIC is an organisation of more than 100 European centres committed to research targeted to improving the outcome of patients with head injury. Does not consider research outcomes reviewing severe TBI outcomes following specific forms of acute management.

EBP guidelines	Client type	Outcomes	Method of creation	Comments
Rehabilitation following ABI: National clinical guidelines – BSRM & RCP (2003)	<p>Guidelines target adults, primarily of working age, with ABI of any cause (including trauma).</p> <p>Aim: provide guidance regarding the general principles of service provision and specific advice on the clinical management of people with ABI.</p>	<p>Provide recommendations in eight areas, including:</p> <ul style="list-style-type: none"> - principles and organisation of services (e.g., the provision of specialist services, staffing levels to meet demands of intensive treatment, coordinating services), - approaches to rehabilitation (i.e., teamwork and communication, assessment and outcomes), - involvement of carers and families in care, - early discharge and transition to rehabilitation services, - inpatient clinical care, preventing secondary complications in severe brain injury (i.e., optimising respiratory functioning, swallowing management, nutrition and hydration, bladder and bowel, prolonged coma, seizures, etc) - rehabilitation setting and transition phases (i.e., referral, assessment and review), - rehabilitation interventions (i.e., continence, motor function and control, sensory disturbance, cognitive, emotional and behavioural management, etc), and - continuing care and support (i.e., joint health and social service provision). 	<p>Guidelines were based on: pre-existing reviews of ABI care and pre-existing guidelines. A Cochrane Systematic Review was also used and a systematic search of literature on brain injury rehabilitation was undertaken. Databases searched included: Medline, EMBASE, AMED and CINAHL.</p> <p>Literature was critiqued according to own classification of levels of evidence (i.e., Ia – meta-analysis of RCT; Ib – RCT; IIa – well designed control study; IIb – quasi-experimental design, etc.)</p> <p>In areas where gaps in literature were identified, guidelines were based on expert opinion and consensus-based documents.</p>	<p>Guidelines were proposed to be reviewed at three yearly intervals. However, they are yet to be reviewed.</p> <p>Based on ABI rehabilitation, not specifically TBI.</p>

EBP guidelines	Client type	Outcomes	Method of creation	Comments
Guidelines for the surgical management of TBI – American Association of Neurological Surgeons and the Congress of Neurological Surgeons (AANS & CNS, 2006)	Aim: present rigorous literature-based recommendations for the surgical management of people with posttraumatic intracranial mass lesions.	Provide recommendations regarding surgical management of: <ul style="list-style-type: none"> - acute epidural hematoma, - acute subdural hematoma, - traumatic parenchymal lesions, - posterior fossa mass lesions, and - depressed cranial fractures. 	Literature used in the formation of these guidelines were reviewed according to authors own scale (i.e., Class 1 evidence – RCT; Class II – nonrandomised cohort studies, RCT with design flaws; case-control studies; Class III – case series/expert opinion).	<p>Only focuses in lesions which develop within 10 days of injury, therefore guidelines do not cover conditions such as subdural hematomas which take longer to develop.</p> <p>In addition guidelines only refer to people who have sustained closed head injuries.</p> <p>No recommendations made in these guidelines at the level of Class I evidence (i.e., RCT).</p>
Guidelines for pre-hospital management of TBI – AANS & CNS (2007)	<p>Guidelines target adults and children who have sustained a severe TBI (as measured by a GCS of 3-8)</p> <p>Aim: To clearly delineate the current scientific basis for emergency medical services pre-hospital practice in managing people with severe TBI.</p>	Provide recommendations regarding pre-hospital management, including: <ul style="list-style-type: none"> - assessment of oxygenation and blood pressure, - use of GCS, - use of pupil examination, - airway, ventilation and oxygenation treatment, - fluid restriction treatment, - cerebral herniation as a treatment technique, and - hospital transport conditions. 	<p>Guidelines were formulated according to current evidence base.</p> <p>Literature was critiqued according to association specific “level of evidence scale” (i.e., Class 1 evidence – RCT; Class II – nonrandomised cohort studies, RCT with design flaws; case-control studies; Class III – case series/expert opinion)</p>	<p>Created specifically for emergency medical staff (i.e., paramedics).</p> <p>Medically based.</p>

EBP guidelines	Client type	Outcomes	Method of creation	Comments
Guidelines for the management of severe TBI – Brain trauma foundation, AANS & CNS (2007)	<p>Target audience: adults with severe TBI classified by a GCS of 3-8. Acute phase only</p> <p>Aim: to clearly articulate the current scientific basis for clinical practice when working with adults with severe TBI.</p>	<p>Comprised of 15 topics:</p> <ul style="list-style-type: none"> - Blood pressure and oxygenation, - Hyperosmolar therapy, - Prophylactic hypothermia, - Infection prophylaxis, - Deep vein thrombosis prophylaxis - Indications for intracranial pressure monitoring, - Intracranial pressure monitoring technology - Intracranial pressure thresholds - Cerebral perfusion thresholds - Brain oxygen monitoring and thresholds, - Anaesthetics, analgesics and sedatives, - Nutrition, - Antiseizure prophylaxis, - Hyperventilation, and - Steroids. 	<p>Used own classification system to assess the value of therapies or interventions (i.e., Class I – RCT; Class II - observational studies, cohort studies, prevalence studies and case control studies; Class III – case reviews, case reports, expert opinion etc).</p> <p>Studies were reviewed in terms of design and quality.</p>	<p>Initially published in 1995, reviewed in 2000 and again in 2007.</p> <p>Do not consider all aspects of acute management for adults with severe TBI. Also excluded studies in review with participants with multiple pathologies.</p>

EBP guidelines	Client type	Outcomes	Method of creation	Comments
<p>Head injury: Triage, assessment, investigation and early management of head injury in infants, children and adults - National institute for clinical excellence (2007)</p>	<p>Audience targeted: all people aged over 1 year of age who sustain a head injury. Head injury in the context of this guideline is defined as any trauma to the head,</p> <p>Aim: offer best practice in the assessment, investigation and early management of head injury.</p>	<p>Provides recommendations for the care provided by primary care, ambulance and emergency department staff, including:</p> <ul style="list-style-type: none"> - assessment and pre-hospital management, - transfer to hospital, - assessment and investigation in the emergency department, - admission to sub-acute care, - transfer to neuroscience unit, and - discharge to the community of people following head injury. 	<p>The classification of evidence for this study was based on the Oxford Centre for Evidence-based Medicine Levels of Evidence (May, 2001).</p> <p>Databases searched include: MEDLINE, EMBASE, the Cochrane Library, Health Technology Assessment Database, National Health System Economic Evaluations Database, System for Information on Grey Literature in Europe and the Health Management Information Consortium.</p> <p>Consensus for all recommendations (even those based on level 1 evidence) was also sought to ensure guidelines were “taken up” once devised.</p>	<p>Does not address the rehabilitation or long term care of people with TBI.</p> <p>Guidelines were initially published in 2003, and were then updated in 2006 and 2007.</p>

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