Provision of Information to Patients and Relatives after Traumatic Brain Injury

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ABSTRACT

It is estimated that Traumatic Brain Injury (TBI) affects over 9000 people in New Zealand every year. This study aimed to describe the information and resources available to patients and their families after a TBI in New Zealand. A survey was sent to a sample of General Practitioners and hospital Emergency Departments asking about what information and other resources they had available for patients. Results showed that, of those who responded, all hospitals but less than half the General Practitioners had a patient information sheet on TBI. The quality of content and appearance of the leaflets was highly variable, but generally the presentation of the hospital information sheets was better. Individuals who had recently sustained a TBI and their relatives were also given a questionnaire about the information they received while in hospital and how satisfied they felt with it. Due to small numbers of respondents, no generalisations could be made from this part of the study.

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CHAPTER ONE

Overview

Being admitted to hospital can be a very confusing and stressful time. This is increased when the event that precipitates the hospital visit is sudden and unexpected as is usually the case with Traumatic Brain Injury (TBI).

1.1 Background

On several occasions, as a nurse, I have had the opportunity to talk to people about their experience of TBI either from a personal perspective or as a friend or relative of someone who has had a TBI. A common theme was that they felt very well cared for and looked after in the early stages but felt isolated and less satisfied over time. It was also apparent that people either did not fully understand how long-term the injury would be, or hadn't recognised that some of the problems that they were experiencing were as a consequence of the TBI.

1.2 Patient Information Provision

There are several possible reasons that people lack understanding about TBI when they leave hospital. These include not being provided with information about their condition and the consequences of TBI in a form that they can understand, or in some cases not being provided with information at all. At the same time, it is also possible that people are not ready to listen to and comprehend what they are being told at that time. Whatever the reason, it remains important that people know who to contact if and when they need help.

Professional groups also need education to enable them to recognise the symptoms of TBI and provide appropriate education and support for the patient and their relatives. People may present to their General Practitioner (GP) some time after the original injury and may not necessarily view their current difficulties as sequelae of the TBI. They may not have sought any treatment or advice at the time of the injury and so do not even perceive themselves as having had a TBI. Families who did receive information in hospital at the time of the injury may only become receptive to further education as the reality of their situation becomes more apparent.

The process of adjustment to a traumatic event or significant health condition is often slow and needs to be a compromise between the reality of the situation and the ability to maintain hope for the future. This process has been likened to the stages of bereavement. Friends and relatives, as well as the individual affected, go through a time of mourning for their loss. They commonly experience periods of shock or disbelief, grief and despair, anger, guilt and self-blame, and finally acceptance of the loss and adjustment to the changes to their life. The role of the GP as a co-ordinator of services, information and resources has increased over time as hospital services become less able to respond flexibly to the needs of those in community not directly under their care.

1.3 TBI Outcome and Recovery

As accidents are the most common cause of TBI many people sustain other physical injuries at the same time as the TBI. Physical injuries generally heal, and with good treatment and rehabilitation most people recover well and are able to return to many of their former activities. By comparison, TBI is much less visible and its subtle effects are often overlooked especially when the person is in hospital. Often it is not until the person with TBI returns home that others comment that the person is characterologically changed. Difficulties with everyday activities also become more apparent in an environment that requires them to be more independent than in hospital. Problems with memory, attention and concentration, reasoning and decision making, planning and organising, impulsivity and emotion, coupled with a lack of awareness of difficulties, combine to make the return to family, community and work activities difficult. It can take families years to come to the realisation that the next specialist that they visit won't have a magical cure and that any progress is likely to be slow and that a full recovery may be an unrealistic goal.

Families may voice dissatisfaction with the information they were given about their relative's condition and recovery many weeks or months after their discharge from hospital. Their experience of the recovery process is often at odds with their expectations. In this situation people's coping skills are challenged, as their need for clear, concise information about what to expect is not met. However, as with many other areas of health, recovery from TBI is not straightforward and can be difficult to predict. Although as a general rule, the severity of the TBI is related to the success of the outcome, it remains difficult to predict the pattern of recovery in individual cases. A person with a mild TBI may have distressing symptoms that continue for months or years and appear to be at odds with the initial assessment of the severity of the TBI.

1.4 The Current Study

While anecdotal evidence from a small number of people can be very compelling, it may not provide a realistic representation of the situation. This study aimed to overcome the limitations of anecdotal evidence by examining formally the extent to which the experience of dissatisfaction with information provision described by these individuals was widespread. The first goal was to clarify what information and resources had been provided to people with TBI and their relatives about their current situation and the future consequences with regard to the TBI, and to determine at what stage after their injury these resources are available and how they are accessed. It was hypothesised that people who have access to good resources and information would cope better with the process of adaptation to their new situation, than those without access to or utilising such information.

The study was designed to be in two parts. In Part One, staff representing Hospital Emergency Departments and General Practitioners would be asked what information they routinely gave to people who presented with a probable TBI, and what other resources they had available to provide to patients over time. The second part of the study involved the administration of a questionnaire to a group of people who had just sustained a TBI, as well as to a relative of theirs, in order to determine whether the trends found when talking to people were actually present in a wider sample.

Background to the current study commences in Chapter Two, with an account of the literature concerning information provision in healthcare settings. There is a large body of evidence regarding the provision of information to patients and relatives before procedures and after diagnosis to improve understanding and compliance with treatment instructions. Chapter Three will examine the current understanding of TBI and its consequences for individuals and their families. Chapter Four will outline the current study in more detail and relate it to both the current literature and the New Zealand healthcare situation. Chapter Five will provide details of the methodology used in the study. The results will be presented in Chapter Six, and a discussion of those results will appear in Chapter Seven.

CHAPTER TWO

Patient Information Provision

2.1 Introduction

There is a large body of evidence regarding the benefits of providing patients and their families with information about the procedures they are about to undergo and the stages in the process of recovery (e.g., Hathaway, 1986; Mumford, 1997). This has been shown to be valuable in many areas of healthcare including surgery, medicine, mental health. Such information improves compliance with medicines and other treatment interventions (Buck, 1998; Vam, 1995).

Provision of appropriate information at a time and in a format that patients and their families can understand, has been shown to reduce anxiety and improve recovery times (Curran, Ponsford & Crowe, 2000; Hathaway, 1986; Levin-Zamir & Petersburg, 2001; Mumford, 1997). The provision of patient information can also be used as an effective coping strategy to reduce distress by promoting the use of problem solving strategies in preference to wishful thinking and blaming. Patient education that incorporates self-management concepts has been shown to be cost effective by reducing the use of health services by 7-17% (Aldana, 2001; Morrison & Lift, 1990; cited in Levin-Zamir & Petersburg, 2001). This type of education helps patients and their families to understand what is happening and gives them a sense of control over their future.

However, despite the recommendation on many occasions that an information booklet be routinely given to TBI patients upon discharge from hospital (e.g., Crawford, 1983;

Junque, Bruna, & Mataro, 1997; Leathem, Heath & Woolley, 1996; Morris, 2001), this process remains rather haphazard (Genuardi & King, 1995; McPherson, McNaughton & Pentland, 2000).

The increase in technology over recent times has improved survival rates for a number of diseases and procedures (Schootman & Fuortes, 2000). In turn, this has placed an added burden on the healthcare system by increasing clinical caseloads and the number of people requiring long-term care. In order to try to cope with the situation there has been an increasing emphasis on self-management in health (Fries, 1998). This will in turn mean an increased need for information provision.

This chapter will discuss both the situational and informational factors that are important when educating patients and their families in healthcare settings. Barriers to optimal information provision will also be examined together with the educational needs of healthcare professionals. Finally, the situation in New Zealand for people who have sustained a TBI will be discussed.

2.2 Patient Education

Results of a meta-analysis of studies examining the effect of pre-operative instructions has shown a positive effect on operative outcomes regardless of the method used to aggregate effect sizes (Hathaway, 1986). Level of patient fear or anxiety was found to be an important factor. Patients with higher levels of anxiety benefited from a focus on psychological factors that aimed to enhance exploration of their feelings and attitudes towards the surgery. Those with lower levels of anxiety benefited from a combination of a psychological focus as well as information about procedural aspects of their care including factual information about their physical care regime and the sensations they might see, feel, taste or smell. However, this does not imply the need for two education programmes. Rather, it is recommended that a pre-operative education programme should include content on both procedural aspects and psychological components. More emphasis should be placed on one aspect or the other depending on the assessment of the patient's fear or anxiety levels. Individual instruction also appears to be more beneficial than group education sessions. A focus on an individual's specific learning needs, produces a more positive outcome, and overall a greater consistency in the effectiveness of pre-operative instruction.

2.3 Barriers to Information Provision

Several studies (e.g., Foltz & Sullivan, 1999; Holland & Shigaki, 1998; Meredith, Emberton & Wood, 1995; Mumford, 1997) have identified barriers to families and individuals receiving the education and information they need in acute healthcare settings. These can be broadly divided into situational and informational factors. Situational factors include greater use of ambulatory care settings, patients staying in hospital for a shorter length of time and being discharged at an earlier stage of recovery, and clinical staff taking greater caseloads, which leads to the risk of families receiving less face-to-face time with a clinician. Informational variables include intrinsic factors pertaining to the information itself for example, readability and applicability (Meredith, Emberton & Wood, 1995). If people are to develop self-management skills, it is essential that they have access to health information, which is relevant and applicable to their personal situation. Information that has not been tailored for the purpose or audience it will be used for may be clinically accurate as well as being unacceptable and possibly incomprehensible.

2.3.1 Literacy and Readability of Patient information

Literacy levels have been shown to affect the ability to access health care, understanding of treatments and consent forms, and compliance with medication and other treatment interventions (e.g., Baker et al., 1996; Davis et al., 1996; Meade & Howser, 1992; cited in French & Larrabee, 1999). Embarrassment and shame often prevent people from disclosing their literacy problem, thus compounding the problem. French and Larrabee (1999) found that number of years of schooling is not a good indicator of reading ability. They suggest that the reading level of all written communication for distribution to the public should be calculated to ensure that it is appropriate for the mean reading level of their population. Procedures designed to optimise information absorption should be used including sending materials home with the patient, utilizing audiotapes and videotapes, developing computer-assisted instruction and using limited literacy materials (Foltz & Sullivan, 1999).

Much research that has examined the readability of patient information sheets has found they are written at university or postgraduate level and/or are so technical that very few people are able to understand them (e.g., Mumford, 1997; Payne, Large, Jarett & Turner, 2000). There are various readability formulae available that examine different aspects of written communication and assess the reading level of the piece of writing. Two of the most common are the Flesch Reading Ease (FRE) (Gilliland, 1972) and the Simple Measure of Gobbledygook (SMOG) (Payne et al., 2000).

The FRE formula systematically selects 100-word samples from a passage of text. It uses the number of syllables per 100 words (wl), and the average sentence length in words (sl) in the following formula to calculate reading ease and yields a score between 0 and 100:

$$\text{Reading Ease (RE)} = 206.835 - 0.846(\text{wl}) - 1.015\ (\text{sl})$$

The lower the score, the harder the piece is to read. A score of 61 or higher is estimated to be able to be read by at least 70% of the population (see Table 2.1). The factors measured by the FRE formula reflect aspects of the difficulty of reading single words and sentences. Longer words tend to have higher syllable counts that reflect rarity of words and therefore difficulty of meaning. The sentence length measure is a reflection of memory span, since the longer a sentence is, the more difficult it is to remember the parts and so the more difficult it is to understand (Gilliland, 1972).

Table 2.1: Flesch reading ease scoring system (adapted from Payne et al.; 2000)

FRE Scores	Difficulty	Example Text	% Who understand
0-30	Very difficult	Scientific journals	4.5
31-50	Difficult	Academic journals	24.0
51-60	Fairly difficult	Quality magazines	40.0
61-70	Standard	Reader's digest	70.0
71-80	Fairly easy	Slick fiction	80.0
81-90	Easy	Pulp fiction	86.0
91-100	Very easy	Comics	90.0

The SMOG measure uses regression analysis to simplify the method of reaching a reading grade. To calculate a SMOG grade, the number of words with more than three syllables per 30 sentences is counted and applied to the following formula:

$$3 + \sqrt{\ } \text{polysyllable count}$$

Ten sentences are chosen near the beginning of the text, ten from the middle and ten from the end of the passage (Gilliand, 1972). SMOG grades indicate the reading grade that a person must have reached if they are to understand fully the text being assessed. SMOG grades of 13-16 indicate the need for tertiary education to understand the material, 17-18 the need for graduate training, and above 19 indicates the need for a higher professional qualification (Payne et al., 2000). This formula directly assesses the skills used in the identification and processing of words. It indirectly assesses the semantic difficulty of text through the use of word length, but sentence length is not used in the calculation.

A recent survey of patient information leaflets in palliative care units in the UK found that 64% of the leaflets had a FRE score less than 60, which indicates that they could only be understood by around 40% of the population (Payne et al., 2000). Only 1.5% of the leaflets had a SMOG score of 10 or below, which is the level recommended to be generally understandable. Their survey revealed inadequacies in legibility, including font size, contrast between text and paper colours, use of illustrations, and justification of text. Dating of information leaflets to ensure they are kept up-to-date was also a problem, with only 19.5% of leaflets having a date on them somewhere. The leaflets scored well on the use of headings and bullet points, low levels or no medical jargon, personal style of writing, and clarity of content.

Healthcare staff need appropriate training if they are to produce readable patient information. Although nurses spend a proportion of their time explaining and translating medical terms into everyday language for patients, a study by Mumford (1997) showed that nurses are equivalent to other healthcare professionals in their skills at writing readable patient information. She used a convenience sample of 24 leaflets designed by nurses from 12 broad speciality areas and found that the readability scores were equivalent to those in other studies. Nurses and other health professionals often receive training in verbal communication with patients, but have little or no training in how to write at an appropriate readability level. They may be accustomed to reading academic journals and may not realise that others may easily misunderstand their writing. The challenge is to learn to write clearly without being condescending.

Continuing medical education for health professionals is also an issue. There are constant changes within healthcare and keeping up to date with the latest advances and best practice in a range of specialties is a major challenge. Although many organizations offer programmes of continuing medical education, there are always more topics than time, so professionals must have other ways to access the latest information and advice. A survey of New Zealand family practitioners asked about their need for medical information and their use of resources to fulfil this need (Cullen, 1997). The results showed a preference for textbooks, colleagues and specialists as sources of immediate, reliable and useable information. These results reiterate those from similar studies in other countries (e.g., Connelly, Rich, Curley, & Kelly, 1990; Verhoeven, Boerma, & Meyboom-de Jong, 1995). Cullen found that while respondents made greater use of textbooks, they considered that they were more likely to find the information they sought by asking colleagues and specialists. They also reported greatest satisfaction with information provided by specialists. Interestingly, satisfaction levels with each of the sources did not correlate with high or low use of a source.

2.3.2 Situational Factors

Although hospitalisation is a common outcome for people with TBI, a significantly larger number of TBI patients are treated in ambulatory care settings including general practitioners' offices, emergency departments, and accident and medical centres (Schootman & Fuortes, 2000), or fail to present for medical care at all. Even among mild TBI patients, there is a risk of ongoing neurobehavioural symptoms for some months following the injury. It is estimated that 40-80% of people who suffer a mild brain injury will develop Post-Concussive Syndrome (PCS) symptoms, ranging from headaches and dizziness to trouble performing cognitive tasks and intolerance to sensory stimuli (Bazarian et al., 1999). It is therefore important in ambulatory care settings to appropriately manage and refer on those with mild TBI in order to reduce possible future problems. The provision of educational material that emphasises aspects of self-management and where to get assistance if necessary is a valuable tool to reduce ongoing problems.

A follow-up visit within one month of the injury is an effective way to identify and treat PCS before it becomes a persistent problem. In New Zealand, guidelines produced by the ACC for providers of healthcare services for people with mild TBI, recommend that all patients should be screened for PCS and provided with information and intervention to help them minimise their risk of developing on-going difficulties in the long-term (www.acc.co.nz). They accept that PCS may occur even after relatively minor TBI and may slow recovery.

2.4 Information as a Coping Strategy

The need for information is a common coping strategy for patients and their families regardless of the illness or disease concerned. Information provision prior to surgery has been shown to improve operative outcome and reduce anxiety (Hathaway, 1986). The provision of an information booklet for patients and relatives of TBI patients before discharge from hospital has been recommended on many occasions (e.g., ACC, 2000; Crawford, 1983; Junque, Bruna, & Mataro, 1997; Leathem, Heath & Woolley, 1996; Morris, 2001). A study of the discharge instructions given to youth athletes hospitalised for a TBI, found that only 30% received appropriate discharge instructions regarding return to participation in sport (Genuardi & King, 1995). This was despite the publication of Guidelines for the Management of Concussion in Sports, which have been endorsed by a number of medical organizations including the American Academy of Pediatrics. This is of concern as one of the most important factors in preventing serious sequelae from a sports-related TBI is an adequate amount of recovery time before returning to participation in sports. The authors recommended improved education for physicians, coaches, parents and the athletes.

Holland and Shigaki (1998) have proposed a three-phase model for the provision of a comprehensive information and education package for families of those with TBI. The model emphasises the need to ensure that family education is delivered throughout the course of recovery. The programme has been developed to satisfy both the family's acute information needs as they arise and ensure that specific knowledge criteria were met in a standardised manner. The material is presented in the form of "guided study" modules structured into three parts to coincide with the patient's time in acute care, rehabilitation, and community re-entry. A combination of written material and videotaped information was used, together with face-to-face time with the rehabilitation psychologist to discuss important ideas and clarify issues. This enables the standardised package of information and education to be personalised to the needs of each family. The combination of written and videotaped material allows for different learning styles and literacy levels as well as taking less staff time and being a cost effective method of delivery. The follow-up meeting with the psychologist allows the family time to discuss personal issues and so make better use of staff time. This type of programme is most suited to patients with a moderate to severe TBI, although appropriate information is also important for those with less severe injuries.

A relationship has been found between family member's needs for information about TBI and their perceptions of changes in their relative's behavioural and affective symptoms and quality of life following moderate and severe long-term TBI (Junque, Bruna & Mataro, 1997; Wallace et al., 1998). These findings are consistent with other studies, which have reported that behavioural, and personality changes are the most stressful aspects of TBI for relatives to cope with. Leathem, Heath and Woolley (1996) interviewed relatives of people with TBI and concluded that the amount, quality and accessibility of information about current condition and possible outcomes of TBI were most important to relatives. They also identified a need not only for a consistent source of information about current condition and outcomes, but also information about hospital procedures, networks and services available in the community as well. They recommended that information be made available in a variety of formats and languages including pamphlets or brochures, books, videos, audiotape and CD Rom. This would allow relatives to absorb information at their own pace and to refer back to it as necessary. Specific areas of educational need identified included instructions for resuming activities such as driving, riding, and sport, the importance of avoiding another TBI, the effects of alcohol, recovery rates and the significance of headaches and behavioural changes.

Although the severity of the TBI affects the content of the information requested by patients and relatives, the need for information and education is not related to the severity of the injury or the level of functional deficits. McPherson, McNaughton, and Pentland (2000) interviewed the carers of people who had been hospitalised with a head injury 6 weeks after their discharge. They found that immediately or soon after discharge, carers wanted more information. They also found that although many carers did not spontaneously request information, when prompted they expressed a need for more information.

2.5 Assessment Feedback

Many patients with a moderate or severe TBI will undergo a neuropsychological assessment to describe and measure their difficulties. This can be affected by expectations and preparation, perceived relevance, length, and the provision of useful feedback (Bennett-Levy, Klein-Boonschate, Batchelor, McCarter & Walton, 1994). Psychologists, like other health professionals, have an ethical responsibility to provide feedback to clients about the results of tests or procedures they have undergone (American Psychological Association Ethical Principles of psychologists & Code of Conduct, Section 2.09, 1992). Feedback has been shown to be beneficial to clients in a number of settings (Finn & Tonsager, 1992; Gass & Brown). However, it can be difficult for the practitioner as well as their client and the client's family particularly when negative results have to be presented. This needs to be done in a sensitive way in order to reduce harm and maximise the chance that the test feedback can provide valuable material for further treatment or rehabilitation sessions (Gass & Brown, 1992). The way in which test results are framed and the implications are explained can influence the meaning that a client places on them (Bennett-Levy et al., 1994). Feedback must acknowledge potential sources of bias or error, and it is the clinician's responsibility to ensure that the client understands their results and any specific reservations about the validity, reliability, meaning and implications of specifics findings (Pope, 1992).

Neuropsychological test feedback provides additional difficulties, as the client is likely to have some cognitive deficits, which may make it more difficult for them to understand the interpretation of results (Gass & Brown, 1992). Lack of awareness of deficits is not uncommon with moderate to severe TBI. This makes it even more important to discuss feedback with the patient's relatives as appropriate. Face-to-face feedback offers an opportunity to discuss the results and implications of any assessments performed and to help explain any problem behaviours that may be confusing or distressing for family and friends (Gass & Brown, 1992).

It appears that despite many recommendations for improved education of TBI patients and their families, still more needs to be done make this a standard procedure. There is clear evidence that the provision of information to patients and relatives after a TBI is important to that person's recovery. Information helps to reduce anxiety and promote positive coping strategies. As an increasing number of injuries are dealt with in ambulatory care settings, it is important to warn patients that some post-concussion symptoms are to be expected and to emphasize when the presence of ongoing symptoms is significant. Information should also be provided about return to work, sport, driving and other activities, avoidance of further TBI, and the use of medication, alcohol and other drugs.

CHAPTER THREE

Traumatic Brain Injury

It is difficult to know how many people in New Zealand sustain a TBI each year. The Brain Injury Association of New Zealand estimates that more than 9000 people in New Zealand are admitted to hospital with a TBI each year (http://www.brain-injury-nz.org/). Half these people will be aged between 15 and 34 years, and the most common cause of injuries are motor vehicle accidents (MVA). Many more people each year sustain a concussion or mild TBI and are not admitted to hospital or do not seek medical advice. In 2000, the ACC recorded over 12,000 new claims for concussion and TBI. Evidence suggests that an accurate diagnosis of TBI may be difficult to establish for a number of reasons (McNaughton & Wadsworth, 2000). These include the effects of alcohol intoxication and other drugs, inconclusive symptomology, and a system of discharge coding that is ambiguous and potentially misleading.

TBI has consequences for the individual, their family and friends and for society. For the individual, consequences may range from headaches and dizziness for a few hours or days to serious disability for the rest of their life. Common consequences of TBI include impaired attention, concentration, learning, memory, speed of information processing and communication. Changes to sensory functioning are also common in moderate and severe TBI. The most distressing aspect for relatives and friends is often the impact on social functioning including impulsive behaviour, mood swings, anger outbursts, fatigue and depression and an impaired ability to interpret and respond appropriately to social signals (Tate & Broe, 1999; Wallace & Bogner, 2000). The costs for society can be measured both financially and in the social cost of the devastation to so many young lives.

3.1 Epidemiology

Figures from New Zealand public hospitals suggest that more than 6000 people are hospitalised with a brain injury each year (McNaughton & Wadsworth, 2000). It is difficult to accurately quantify this however, as the classification system used to code public hospital admissions and discharges does not have a single code for TBI. In fact up to 12 separate codes could potentially be used ranging from skull fractures after injury to concussion and cerebral contusions and lacerations. These figures also do not include individuals who suffer a concussion or mild brain injury but were not admitted to hospital or never present to a medical professional. A survey in Sweden in 1986 reported that 20% of respondents had received a TBI with loss of consciousness without seeking medical attention (Carlson, 1986). Guerrero, Thurman and Sniezek (2000) estimated the incidence of TBI seen in Emergency Departments in the US, but not requiring hospitalisation, as four times as high as the incidence rate of fatal and hospitalised TBI.

International statistics estimate that the annual TBI incidence rate is between 132 and 430 per 100,000 head of population. New Zealand figures of around 6000 people hospitalised per year with TBI translate to an annual rate of around 180 per 100,000 (ACC Annual Report, 2000). When those who are not admitted to hospital are included in the figures, the rate increases to 618 per 100,000 or approximately 30,000 people in New Zealand who sustain a mild, moderate or severe brain injury each year. The main causes are falls, motor vehicle related accidents and being struck by an object. Males aged 15-30 years are at highest risk of sustaining a TBI, mainly due to the large number of sports and motor vehicle related accidents in this age group. The next highest incidence is for children under 15 years due to falls and sports injuries (ACC, 2000).

In 2000, the New Zealand Accident Compensation Corporation recorded 12,953 new claims for concussions and brain injuries at a cost of $3,860,000. They had 2,414 ongoing claims for concussions and brain injuries at an annual cost of $13,296,000. However, the impact is not merely financial and is not restricted to the individual who sustains the injury - family and friends are also affected.

Schootman and Fuortes (2000) investigated the medical records of ambulatory patient visits for TBI in the US in an attempt to explain the decline in hospitalisation rates for TBI. They wanted to differentiate between the several possible explanations for this trend including a decline in the incidence of TBI, fewer people seeking treatment for head injuries or an increase in the number of people being examined and treated in ambulatory care settings. They concluded that the last two reasons were most likely to account for the change in the hospitalisation rate for TBI.

This finding reinforces the need for changes in the way that TBI is managed. Schootman and Fuortes (2000) also found that whereas most people who present to a hospital ED have recently sustained their injury, many individuals with mild TBI who visit their GP do not seek medical attention at the time of their injury but weeks or months later due to persistent symptoms. Greenspan and MacKenzie (2000) found that need for and use of post-acute services for children with TBI was positively correlated with severity of injury. However, they also found that unmet need was the highest for children with the least severe injuries. Unrecognised needs existed for 33% of children with physical limitations and 40% of children with at least 14 identified behaviour problems. Ambulatory care providers and GPs need to become more skilled at identifying individuals at risk of PCS and need to have systems to follow-up on patients with mild TBI to ensure that appropriate services are put in place to reduce stress for the individual and their family (Curtiss, Klemz & Vanderploeg, 2000; Merritt & Evans, 1990).

3.2 Definition and Severity ratings

TBI refers to damage to the brain that is caused by trauma to the head and/or neck. A brain injury is defined according to severity, rather than injury type. The two most common methods of classifying brain injury severity are the Glasgow Coma Scale (GCS) and the length of Post Traumatic Amnesia (PTA) (Lezak, 1995; Zasler, 1994). The GCS is commonly used to triage patients and is based on the presence, degree and duration of coma. The patient receives a score between 1 and 4 for eye opening, 1 and 5 for verbal behaviour; and 1 and 6 for motor response (see Table 3.1). These combine to give a range of 3-15. A score of 13 or greater or coma duration of less than 20 minutes is classified as a mild injury. A patient with a moderate injury receives a score between 9 and 12 or has a coma duration of no longer than 6 hours from the time of admission to hospital. A patient with a GCS score of less than 8 is considered to be in a coma. A GCS of 8 or less or the presence of a coma for more than 6 hours after admission indicates a severe injury.

Trauma can include a direct blow to the head, a penetrating head wound or indirect damage caused by the forces associated with stopping suddenly without a direct blow to the head (e.g., whiplash). Damage may occur at the time of the impact or subsequently due to haemorrhage, brain swelling, changes to blood flow, hypoxia, or chemical changes in the brain (Lezak, 1995). Injuries are classified as closed or open head injuries based on the type of trauma involved. A closed head injury occurs when the brain is caused to strike the bony surface inside the skull for example when the head is hit by a blunt objector when a person stops rapidly, with or without direct external trauma. A penetrating head injury occurs when a fast moving object, such as a bullet, pierces the skull (Zasler, 1994). However, a head injury does not necessarily imply TBI. As well as an injury to the head or neck, there needs to be some combination of PTA, retrograde amnesia, loss of consciousness or decreased level of consciousness in order to meet the definition of TBI. The most common causes of TBI include impacts to the brain from MVA, falls, assaults, and sports injuries.

Although the GCS generally correlates well with outcome, it has a number of specific limitations. Scores taken within the first few hours or the first day post trauma may not always correlate well with eventual outcome. This is due to the failure of the GCS to distinguish between people who have suffered severe trauma but are likely to recover and those who will have a permanent serious brain injury (Richardson, 1990). It also fails to identify individuals who have little or no loss of consciousness but have significant deterioration over the following 48 hours due to internal bleeding. Alcohol intoxication may also lower the GCS initially, although assessments after 6 hours usually improve if alcohol is the main reason for the low score. Distortions may also occur due to the fact that loss of consciousness is generally shorter when injuries are mainly localised to the right hemisphere rather than the left hemisphere.

A second measure of TBI severity, duration of PTA, refers to the period between the time of injury until the patient registers a continuous stream of conscious experience, including any period of coma. Estimates of severity of injury are shown in table 3.2. The practical usefulness of using PTA as a measure of injury severity has been questioned due to difficulties in defining the duration of PTA, especially when patients are aphasic or confused (Lezak, 1995). Further, many patients with a mild brain injury are discharged home while still in PTA with estimates having to be made later based on the reports of relatives. The broad time frames shown in table 3.2 usually suffice for clinical purposes and can be estimated from relative's reports of patient behaviour.

Table 3.1 Glasgow Coma Scale (after Lezak, 1995)

Glasgow Coma Scale Response Chart		
Test	Patient's Response	Score
Eye Opening	Opens eyes on his own	4
	Opens eyes when asked to in a loud voice	3
	Opens eyes to pain	2
	Does not open eyes	1
Verbal Response	Carries on a conversation correctly and is oriented to place and time	5
	Seems confused or disoriented	4
	Talks to examiner, can follow directions, but speech makes no sense	3
	Makes unintelligible sounds	2
	Makes no noise	1
Best Motor Response	Follows simple commands	6
	Pushes examiner's hand away on painful stimuli	5
	Pulls body part away on painful stimuli	4
	Flexes body inappropriately to pain	3
	Decerebrate posture	2
	Has no motor response to pain	1

The level of disability from TBI is highly variable. Most people with a moderate TBI take at least six months to recover and begin to resume their usual activities. However, up to two thirds of people may be unable to return to work a year after their injury (Colins et al., 1999; Tate & Broe, 1999). Most brain injury is classified as mild. Individuals with mild TBI often receive little or no medical attention and usually return to usual activities in less than 5 days. However up to 10% of people with mild TBI will have ongoing symptoms and a small number may not be able to maintain their pre-injury performance level (ACC, 2000).

Table 3.2 Severity of TBI based on PTA duration (from Lezak)

PTA Duration	Severity
< 5 minutes	Very mild
5-60 minutes	Mild
1-24 hours	Moderate
1-7 days	Severe
1-4 weeks	Very Severe
More than 4 weeks	Extremely severe

In a New Zealand study conducted by McNaughton and Wadsworth (2000) problems were identified in establishing a diagnosis of TBI in hospitals, and ensuring accurate hospital discharge coding for TBI. They used a standard definition for diagnosis of TBI from a large American study, that included evidence of damage to brain tissue due to external mechanical forces with loss of consciousness, PTA, or objective neurological findings. In their study, 32.3% of patients admitted with a diagnosis of TBI met the criteria for 'definite TBI', while a further 18 patients were not admitted for TBI but met the criteria. Approximately 2/3 of people who fitted the 'definite TBI' category were correctly identified at discharge, and a further 34 people were given a discharge diagnosis of TBI who did not meet the criteria for 'definite TBI'. Finally, 6 people who met the 'definite TBI' criteria were not identified by either admission or discharge diagnosis.

Previous studies show that up to two thirds of TBI individuals have a detectable alcohol level (Gale, Dikmen, Wyler, Temkin & McLean, 1983; Murray, 1977; Rimel & Jane, 1983; cited in Dikmen, et al., 1993), and a third to half are intoxicated when they arrive in the ED. A pattern of chronic pre-injury alcohol abuse is over-represented in this population, with more than a third of head trauma victims being diagnosed as alcohol dependent (Brismar, Engstrom & Rydberg, 1983; O'Shanick, Scott & Peterson, 1984; cited in Dikmen et al., 1993). Alcohol use among those with a pre-injury pattern of abuse often continues after the injury and can exacerbate the effects of the brain injury due to decreased tolerance to alcohol and the effects of mixing alcohol and medications, particularly anti-convulsant medications.

As alcohol intoxication can make the diagnosis of TBI more difficult by mimicking some of the symptoms, McNaughton and Wadsworth recorded the number of individuals affected by alcohol at the time of admission. Nearly half (46%) of the hospitalised TBI patients showed clinical evidence of being affected by alcohol, and 2/3 of patients admitted with a diagnosis of TBI, but not meeting the criteria for 'definite TBI' due to lack of definite neurological deficit, were intoxicated. Alcohol intoxication is known to make GCS assessments unreliable and to overrate the incidence of TBI (Lezak, 1995). Pre-injury alcohol abuse is associated with reduced neuropsychological functioning and increased severity of injury (Dikmen et al., 1993). However, although there was strong evidence that the degree of alcohol use was related to neuropsychological impairment, the mechanism responsible for alcohol-related impairments was said to be complex.

3.3 Post Concussive Syndrome

It is estimated that approximately 15% of people who sustain a mild brain injury continue to experience negative consequences 1 year post-injury (Alexander, 1995). Studies have shown that up to half the patients treated in the Emergency Department (ED) with a minor head injury will develop post-concussive symptoms within 1 month of their injury (Binder, 1986; cited in Bazarian, Hartman, & Delahunta, 2000; Bazarian et al., 1999). Under half of these patients are likely to comply with instructions to see their doctor for a follow-up check within the next month even though follow-up is important to detect any intracranial injuries previously missed, offer advice about return to driving, sport, work and other everyday activities, and to identify Post Concussive Syndrome (PCS).

Whether classified as PCS or not, the presence of a range of symptoms including headaches, dizziness, lack of energy, fatigue, poor memory, and loss of concentration following mild TBI has been confirmed by a large number of studies (e.g., Rimel, 1981; Levin et al., 1987). Signs of emotional distress including irritability, depression and anxiety are also common following mild TBI. While these deficits are mild and transient they have an impact on everyday functioning including return to work. Individuals may experience difficulties recalling information completely and accurately, attending to tasks for more than a short period of time, and attending to more than one task at the same time.

The concept of PCS as a short-term problem remains controversial, however neurobehavioural testing in the ED has been shown to be helpful in predicting patients who are at risk of developing PCS at 1 month. Two neurobehavioural tests were found to be associated with PCS. High scores on the Digit Span Forward and the Hopkins Verbal Learning test are associated with a decreased incidence of PCS developing (Bazarian et al., 1999). The incidence of PCS is also lower at 1 month among people injured during sport and males. However, this may be because of gender differences in the method of injury such that more males are injured in sports and more females in motor vehicle accidents.

3.4 Injury Severity and Consequences

The behavioural consequences of brain damage vary with the nature, extent, location and duration of the lesion; as well as with the age, sex, physical condition and psychosocial background and status of the patient; and with individual neuroanatomical and physiological differences (Lezak, 1995). Not only is the pattern of deficits displayed by each individual likely to differ due to damage involving anatomically and functionally different areas, but patients with similar lesions may differ in presentation and patients with damage at different sites may present similar deficits. TBI is associated with impairment of memory, judgement, planning and organization, and reduced information processing speed. These difficulties are often compounded by personality changes and reduced awareness of behavioural limitations (Hanks, Temkin, Machamer & Dikmen, 1999). Lack of awareness of difficulties (anosognosia), is associated with damage to the frontal lobes and presents major difficulties both in rehabilitation and everyday functioning (Leathem, Murphy, & Flett, 1998; Wallace & Bogner, 2000).

Approximately three quarters of all TBI's are classified as mild. Patients have a low risk of intracranial injury, and most make a complete and uneventful recovery. Many people with mild TBI do not seek medical attention. The most common complications of mild TBI are psychosocial problems and work difficulties (ACC, 2000). Moderate and severe TBI are associated with much higher risks of long-term disability. Approximately 23% of all TBI are classified as being of moderate severity and only 2% are classified as severe.

Due to advances in medicine, many patients who would have previously died of complications of severe brain trauma are surviving today. This has resulted in a new phenomena of physically fit children and young adults with significant brain damage (Lezak, 1995). Behavioural, personal and social consequences have far-reaching effects. Very few patients with severe TBI are able to return to work except in the most supportive settings. Quality of life for the individual and their family is compromised and results in distress and dissatisfaction (Tate & Broe, 1999).

Diffuse damage tends to result in compromised mental speed, attentional functions, cognitive efficiency and when severe, high-level concept formation and complex reasoning abilities. These problems are often expressed as inability to concentrate, confusion, irritability, fatigue and inability to perform activities as before the injury. Direct blows to the head result in discrete impairment to functions mediated by the cortex at the site of the lesion. This results in specific impairments as the sole or predominant difficulties. Bruising of the brain due to deceleration effects most commonly affects the frontal and temporal lobes due to the brain bouncing within the skull. Problems may be seen with regulation and control of activity, conceptual and problem solving behaviour, and aspects of memory and learning. Damage to the frontal and temporal lobes can also affect personality and social adjustment. These difficulties may impede the patient's return to independence than cognitive or physical impairments.

A review of the literature on family psychosocial outcome after TBI has revealed a mixed picture, and a bias towards measuring negative rather than positive outcomes (Perlesz, Kinsella & Crowe, 1999). Although the cognitive, behavioural, and personality changes following TBI are likely to have a significant and often negative impact on family members, this experience is not universal. Studies frequently report the number of relatives that describe symptoms of stress, depression or anxiety, but fail to highlight the large proportion of relatives who do not report high levels of psychological distress or family and marital dysfunction after TBI. Longitudinal research shows that community reintegration is a particularly stressful time, but also that distress may increase over time, especially in relatives with less realistic expectations.

3.5 Sources of information in New Zealand

Clinicians also need to be aware of how patients are accessing information in the absence of an appropriate education programme. Although there are some excellent resources available to help explain TBI, its consequences and the recovery process, the patient or their family first need to be able to access such information. A search of the Internet for resources on TBI revealed an enormous number of sites with information from health professionals, patients, brain injury organizations, lawyers and other sites whose authorship was uncertain. The accuracy and relevance of the information contained on these sites is often difficult to verify. A list of recommended resources that patients and families can refer to can aid the self-management process. Such a list needs to cover a variety of resources in terms of content and presentation. The following resources were identified by the researcher.

3.5.1 Written Material

A number of books are available that help explain TBI and its consequences. It can be useful for patients and relatives to be able to take information home to read and absorb. Written resources also have the advantage that they can be referred back to at a later date. The following books and brochures are available in New Zealand. Many can be borrowed from local Brain Injury Organisations or local libraries.

- Gronwall, D., Wrightson, P., & Waddell, P. (1998). *Head Injury: The facts, a guide for families and care-givers.* (Oxford University Press).
- Johnston, G. *TBI Survival Guide*. Available to be downloaded off the Internet.
- Winslade, W.J., & Brady, J. S. (1999). *Confronting Traumatic Brain Injury: Devastation, hope, healing.* Yale University Press.
- Stoler, D. R., & Hill, B. A. (1998). *Coping with Mild Traumatic Brain Injury.* Avery Publishing Group.
- ACC Booklets. Available from ACC, GP, Health Professionals.
- New Zealand Guidelines Group – Traumatic Brain Injury Rehabilitation Guidelines. These are now only available to be downloaded from the Internet. However, many organizations have a “hard copy” available.

3.5.2 Internet Sites

Given that TBI patients are overly represented in lower socio-economic groups, access to the Internet may be difficult due to lack of availability of a computer or the skills to use one. A search for New Zealand Internet sites for TBI found over 18000 potential matches. Some of the sites with accurate, verifiable information include:

- www.acc.co.nz This site gives information about how to access ACC services and what to expect.
- www.head-injury.org.nz This is the website of the New Zealand Head Injury Society. It offers information, personal stories from patients and families, as well as suggestions for support.
- www.nzgg.org.nz/library/gl-complete/tbi This website has a PDF format copy of the TBI rehabilitation guidelines. These guidelines are no longer available in hard copy.
- www.ranworth.co.nz/framelinks Ranworth Healthcare is a private provider of residential and day rehabilitation services. This page on their website has links to a number of other sites with information on TBI. Some of the overseas sites may be less relevant to the New Zealand scene (e.g., An American site about the Law and TBI)
- www.lapublishing.com This company produces a range of brochures about TBI and children and young people. There is information about school, activities, care etc.
- www.neuroskills.com This is the website of an American TBI rehabilitation provider. While not all information may be directly relevant to New Zealand, there is plenty of information, latest updates, news and educational resources available as well as a "book of the week" recommendation.

3.5.3 Advocacy and Support

- Brain Injury Association of NZ
- Head Injury Society
- Neurological Foundation
- Patient Advocacy Service
- Stewart Centres – 12 nationwide
- Citizens Advice Bureau

3.5.4 Medical Information

- GP
- Other medical specialists (e.g. Neurologist, Neuropsychologist)
- Concussion Clinic – available in most main urban centres

3.5.5 Auckland Resources

The following resources are available in Auckland. There are similar resources available in other parts of the country.

- Stewart Centre – offer social rehabilitation and support
- Ranworth Healthcare
- Laura Fergusson Centre
- Concussion Clinic

A list of recommended resources that patients can refer to can aid the self-management process. Such a list needs to cover a variety of resources in terms of content, format and presentation. Table 3.3 shows a summary of the advantages and disadvantages of various resources about TBI available in New Zealand. It includes written, verbal, and videotaped information, as well as sources of support, advocacy and advice.

Table 3.3: Sources of information about TBI for patients and families

Source	Advantages	Disadvantages
Personal Advice from Healthcare Professionals	• Face to face, can have questions or concerns addressed at the time • Professional is able to give advice and information specific to the person and their functioning	• Often difficult to access one-on-one time with a professional. May be expensive if not covered by ACC or other insurance • Person may not be ready to absorb the information. Denial is a common initial reaction
Books	• Can be re-read as often as needed to absorb the information • Low cost – often books can be borrowed from the library or local brain injury organisation	• Information in books is not personalised to the individual • May be difficult to know what information is applicable initially. • Books written overseas may not be applicable to the New Zealand healthcare situation • Information becomes out-of-date very quickly
Other Written Material	• Often summarises the important information • Initially more easily digested rather than books that take time to read and understand	• Writing style not always clear, many booklets are written at a level above what most people can understand
Internet Sites	• Latest information and advances	• Can be difficult to verify the source of information • Need to have access to a computer and the internet, not always easy in smaller towns or rural areas and for lower SES groups • Huge number of sites around – need to have the skills to search for relevant information
CD Rom	• Usually have excellent multimedia and graphics • Good alternative for low literacy • Easy to understand	• Need a computer with CD Rom drive
Videotape & Audiotape	• Good for low literacy	• Need appropriate equipment • Can be expensive to buy

CHAPTER FOUR

Formulation

As previously stated, the idea for this study came after talking to several patients with TBI, and their families. There seemed to be an almost universal theme that they wanted more information about TBI and its consequences, and what to expect for the future. This need was apparent in people with mild TBI as well as those with moderate and severe brain injuries. Even several years after the accident many family members did not make the connection between difficulties their relative was having and their previous TBI. This was compounded by a lack of awareness of deficits on the part of the person with TBI.

A subsequent search of the literature reported in previous chapters has revealed a growing body of evidence regarding the benefits of providing patients with information before medical procedures, and after illness or accidents. More specifically, several studies have recommended that patients with TBI should have an information booklet to take with them at discharge. That booklet should provide information about TBI and its consequences, about what to expect with rehabilitation and recovery as well as suggestions of other resources that they may find useful. GPs also need access to such resources, as they are often the most easily accessible health provider. Patients often find it difficult to know where to find information and advice after they are discharged from hospital. It may be weeks or months before the reality of their situation begins to "sink in" and they start to notice the effects on their everyday life. At this point, people are often more receptive to information about TBI than immediately after their accident or injury.

This study aimed to investigate what types of information are given to people who sustain a TBI in New Zealand, who gives them that information, when and how well do they consider that it meets their needs. Differences between health providers in the quantity and quality of information provided will also be examined. Finally, how much of the information they receive do people with TBI and their families understand at the time?

There were several major hypotheses guiding the study:

- That there will be great variability in the number and quality of resources available to General Practitioners around New Zealand.
- That there will be more resources available in larger urban centres than in rural areas.
- That notification of GPs by a hospital when a patient has attended ED would be variable over the country.

Specifically, the following hypotheses were formulated:

1. That all hospitals and most (over 70%) GPs would have a written information sheet about TBI to give to any patients with a confirmed or suspected brain injury. This would contain advice about the recovery process and what signs and symptoms to be concerned about, and where to go for assistance.
2. That hospitals would have a firm policy of whether GPs are notified when a patient attend the ED.
3. That information sheets produced by hospitals would be more legible, have more up-to-date and accurate information and have better readability scores.

4. That few hospitals and GPs would have TBI information in a format other than written or verbal information (such as audiotape, videotape, or CD Rom).
5. That GPs in urban areas would have access to greater numbers of resources for people with TBI in their local community than GPs in rural areas.

CHAPTER FIVE

Method

5.1 General Practice and Emergency Department Questionnaire

5.1.1 Participants

The participants were representatives of Public Hospital Emergency Departments (EDs) and a random sample of General Practitioners (GP's) in New Zealand. The sample of Public Hospitals were taken from the Telecom White Pages, Hospitals and other Health Service Providers section, and the GP sample was also drawn from the Telecom White Pages, either the 1999 or 2000 edition; depending on what was current as at March 2000. Every fifth GP in the "Registered Medical Practitioners" section of every phone book in New Zealand was included in the sample.

In total 487 questionnaires were sent out (38 to EDs and 449 to GPs). Eight questionnaires were returned due to incorrect mailing information or because the practice was no longer operating, and 244 valid questionnaires were returned, giving a return rate of 50.1%, (229 questionnaires from GPs and 15 from hospital EDs). Practitioners and hospitals in urban areas comprised 65% of the sample (66.8% GPs and 33.3% EDs), with 15% from rural areas (15.3% GPs and 20.0% EDs), and 20% served a mix of urban and rural areas (17.9% GPs and 46.7% EDs).

5.1.2 Procedure

A copy of the questionnaire (Appendix A) was mailed to the sample of hospitals and GPs, with an information sheet (Appendix B) and a reply paid envelope in which to return the questionnaire. The information sheet explained the aims of the study and how the information collected would be used. Participation in the study was voluntary and there was no incentive offered to those who returned the questionnaire. It was assumed that consent had been given if the questionnaire was returned. Participants were assured that any information collected would remain anonymous and individual hospitals or GP practices would not be able to be identified.

5.1.3 Measure

The Hospital and General Practice Questionnaire was designed to determine what information was routinely given to patients with a suspected or confirmed TBI who came to the ED or visited their GP, and what knowledge doctors had of the resources available for patients with ongoing problems related to their injury in their local community. The questionnaire was based conversations with GPs and hospital ED staff, as well as research findings presented in previous chapters. In order to increase the response rate, the questionnaire was designed to be completed in 10-15 minutes.

Respondents were asked for some general demographic information about the number of TBI patients they had seen in the last month and the ratio of male to female patients. They were also asked about other sources of information they used and the services they had available to them for referral and community support services, where they felt this was appropriate. As well as completing the questionnaire, respondents were asked to indicate whether they had an information sheet or other written information that they routinely gave to patients with a suspected or confirmed TBI, and if so to include a copy when they returned the questionnaire.

5.2 Patient and Relative Questionnaire

5.2.1 Participants

The participants were patients (who had been recently hospitalised with a TBI), and their relatives. A total of 40 patients gave initial consent to participate in the study and agreed to complete and return the questionnaires. They were given a copy of the questionnaire and some information and a questionnaire for their relative. Only six patients and two relatives returned the questionnaires, giving a return rate of 15% and 5%, respectively (overall return rate of 10%). The sample consisted of equal numbers of male and female participants. One-third of participants identified themselves as Maori and two-thirds were of European origin.

5.2.2 Procedure

Suitable potential participants who were identified while still hospitalised, were initially approached by one of their key workers, usually their Occupational Therapist. Some participants were approached directly by the researcher's supervisor in her capacity as a Neuropsychologist at the Massey University Psychology Clinic. If the patient indicated they were interested, the researcher, or her supervisor met with them to give them an information sheet (Appendix C), explain the study in more detail and invite them to participate. If a patient agreed to participate, their relative, usually their partner or parent was also invited to participate. All participants were required to sign a consent form (Appendix D) prior to completing the questionnaire. Participants who had difficulty writing were able to have the researcher or another person complete the questionnaire according to their instructions.

5.2.3 Instruments

The questionnaires for Part Two were created for the purposes of this study. There were separate questionnaires for the clients (Appendix E) and their relatives (Appendix F), which asked similar questions about what had happened during the patient's time in hospital and how much they remembered or knew about brain injury around the time of discharge from hospital when completed the questionnaire. The questionnaires were based on the Client Satisfaction Questionnaire (Larsen, Attkisson, Hargreaves & Nguyen, 1979) and a questionnaire developed by Heath (1997), as well as research findings presented in previous chapters about the common consequences of TBI for clients and their relatives and friends. The questionnaire took 20-30 minutes to complete, depending on the abilities of the client. It was designed according to guidelines covered in previous chapters, to require minimal writing. Putting a tick in a box or circling the appropriate option could answer most of the questions.

5.3 Ethical Issues

The study was approved by both the Massey University Human Ethics Committee in Albany (Appendix G) and by the Auckland Ethics Committee (Appendix H), which was administered by the Health Funding Authority, now the Ministry of Health.

The main ethical considerations were:

- How participants would be first contacted and who would identify suitable potential participants,

- Timing of the introduction of research – are clients well enough, can they consent, and this is a busy time.
- Provision of a support system and procedure for participants,
- Provision of cultural support and advice for the researcher throughout the research, but particularly during the interpretation stage.

Several steps were taken to address these issues. The client's key worker was chosen to make the initial contact with potential participants as the key worker was considered to be in a position to assess when the client has recovered enough to be able to comprehend and respond to the questionnaire. Further, as they were independent of the research, they would be able to inform people about the study without risk of putting pressure on them to participate. The key worker did not receive any incentive for recruiting participants. Clients then only needed to be contacted if they expressed some degree of interest. Clients were therefore entirely free to choose whether or not to participate in the study, with their decision not affecting their treatment in any way. A list of suitable/possible support people was available for participants who were concerned or required support during or after the study. They included the client's GP, ACC case manager, patient advocates and their key worker while they were in hospital. A cultural advisory group was formed to assist the researcher with advice on cultural matters. This group included representation from Maori, Pacific Nations, and Asian advisors.

CHAPTER SIX

Results

Part One: General Practice and Emergency Department Questionnaire

6.1 General Summary Statistics

Of the 244 General Practice and Emergency Department Questionnaires returned, 93.9% (229) were from General Practitioners (GPs) and 6.1% (15) from hospital Emergency Departments (ED). The sample consisted of 64.8% (158) urban GPs and hospitals, 15.6% (38) from rural areas and 19.7% (48) from a mixture of rural and urban areas. This is broken down by hospitals and GPs in Figure 6.1, which shows that GPs were more likely to be situated in urban areas and hospitals were more evenly distributed among the community.

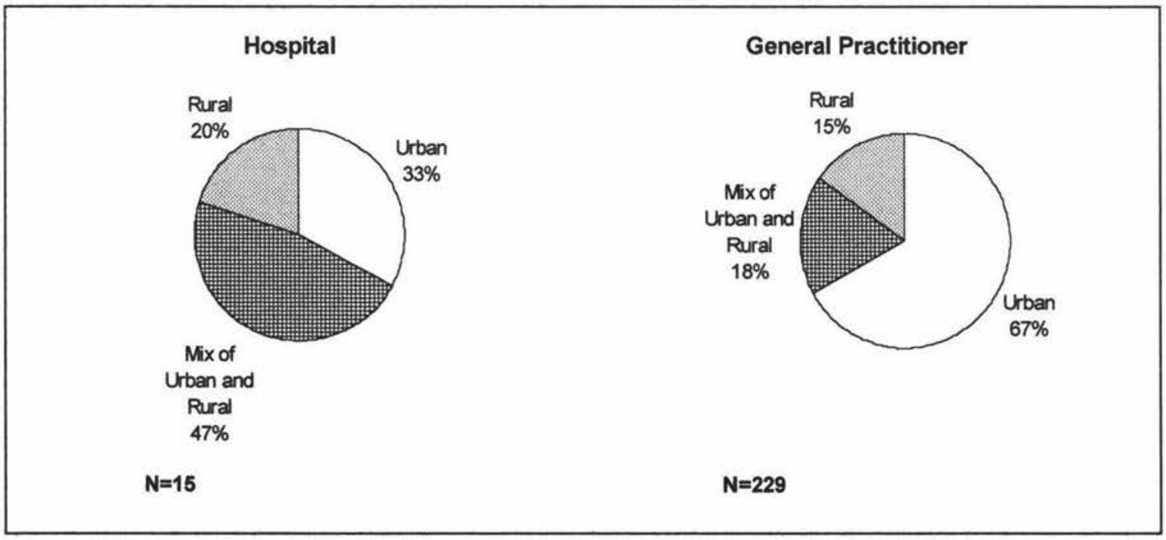

Figure 6.1: Urban and Rural distribution of participants

As can be seen in Figure 6.2, hospitals saw more TBI patients than GPs. The mean number of new presentations in the past month was 1.45, ranging from 0 to 58. There were a total of 69% (89) male patients with a new brain injury and 31% (40) female patients with a new brain injury.

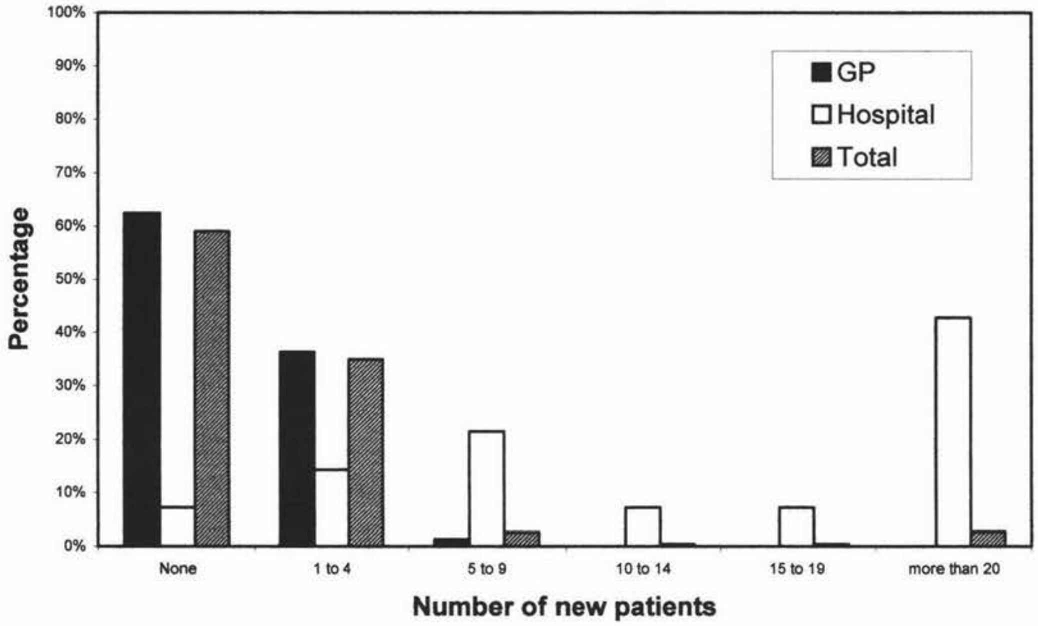

Figure 6.2: New TBI presentations in the past month for GPs and Hospital EDs

6.2 Notification from hospital

Of the GPs, 58.9% (132) reported that they received notification from hospital if one of their patients presented to the Emergency Department with a diagnosed or suspected TBI and were discharged home the same day. A further 21.4% (48) sometimes received notification and 19.6% (44) never received notification from the hospital Emergency Department (see Figure 6.3). Five GPs did not answer this question.

Hospitals were asked if they always sent a discharge summary if the patient identified a GP. Two-thirds of hospitals (8) always notified GPs, 17% (2) sometimes notified, and 17% (2) did not inform GPs if their patients presented at ED. Three hospitals did not answer this question.

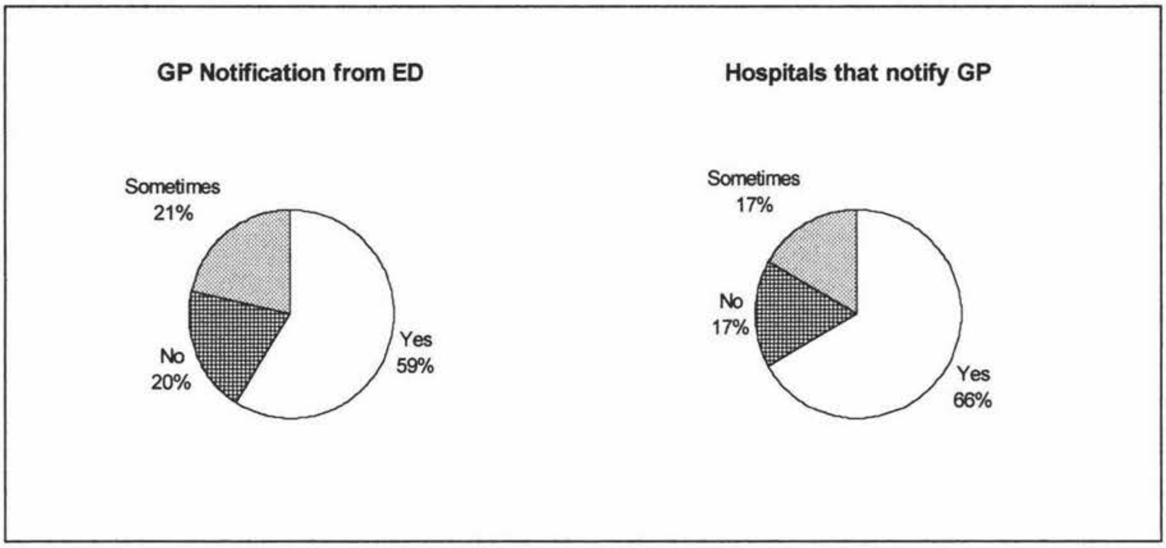

Figure 6. 3: GP notification by hospitals when a patient comes to ED with a suspected or confirmed TBI

6.3 Information Sheet

Most hospitals (93.4%), and nearly half (42.8%) the GPs reported that they gave an information sheet to patients with a confirmed or suspected TBI. Participants were also asked to enclose a copy of their advice sheet when returning the questionnaire. Of those who had a patient information sheet about TBI, 77% (75) of GPs and 71% (10) of hospitals returned a copy with their questionnaire. Generally, these contained information about signs and symptoms to watch for, when to call the hospital or GP, and advice about pain relief, driving, alcohol and rest (see Appendix I for examples).

However, there was great variability in many aspects of the information sheets, as detailed further below.

6.3.1 Readability

All the leaflets were written in English. The FRE measure was used to calculate the readability of the information sheets. This measure was chosen, as over 50% of the information sheets did not contain the required 30 sentences to perform SMOG analysis. The mean FRE score was 67.81 for the hospital information sheets and 61.02 for the GP information sheets. The maximum score (most readable) was 80.2 for a hospital leaflet and 73.7 for a GP leaflet, and the minimum score (least readable) was 51.0 for a hospital leaflet and 34.6 for a GP leaflet. Table 6.1 shows a comparison of FRE scores for Hospital and GP information sheets.

Table 6.1 FRE Scores of Hospital and GP TBI Information Leaflets

FRE Score	Difficulty	Percentage of Leaflets	
		Hospital	GP
0-30	Very difficult	0	0
31-50	Difficult	0	14.7
51-60	Fairly difficult	7.1	29.3
61-70	Standard	64.4	36.6
71-80	Fairly easy	21.4	19.4
81-90	Easy	7.1	0
91-100	Very easy	0	0

While 92.9% of the hospital information sheets had a FRE score of over 61 (the level recommended to be able to be read by 70% of the population), only 56% of the GP leaflets were in this category. The passive voice was used in 92.9% of hospital, and 70.7% of GP information sheets. A mean of 15.9% of hospital, and 13.3% of GP leaflets were in the passive voice.

6.3.2 Legibility and Presentation

The information sheets were assessed for legibility based on the criteria of the Royal National Institute for the Blind (Payne et al., 2000). In this sample, almost all (91.9%) the information sheets satisfied the recommendations to use at least 12-point font. It is recommended (Payne et al., 2000) that the right margin should not be justified in order to make the text easier to read. There were 25.7% of the leaflets in the sample that justified the right margin. Headings and bullet points were used to emphasize important information and guide the reader in 86.5% of the information sheets. Few sheets (17.6%) used illustrations or diagrams to enhance the information they were providing. Approximately one-third (33.8%) of the leaflets contained a spelling error or misuse of a word. The most common spelling mistakes were “vomitting” and “persistant” and arouse was most commonly used instead of rouse.

In general, the quality of the paper and photocopying of the hospital information sheets was of a better quality than the GP information sheets. The quality of the photocopying in some of the information sheets was so poor that some of the words could not be read and others were distorted or unclear. Only 28.6% of the hospital information sheets were of poor quality photocopying, compared with 53.3% of GP information sheets. Thermal fax paper was used to copy 6.7% of the GP information sheets. The lines and marks transferred from the fax, as well as the distortion of the typeface lead to very poor legibility. In contrast, 21.4% of the hospital leaflets were produced by professional printers.

6.3.3 Content

Information sheets ranged from ½ a page to 10 pages in length (see table 6.2). The hospital information sheets were generally longer with a mean of 33.6 sentences, compared with 12.9 sentences for GP information sheets. However, both groups had a similar sentence length, with a mean of 14.6 words per sentence in the hospital information sheets and 13.2 words per sentence for the GP information sheets.

Only 14.9% of the information sheets had a date on them, and of those that were dated, one had not been revised for over 10 years. In addition, 5% (3) of the information sheets had no date on them but were clearly out-of-date as the phone numbers were incorrect, (i.e., the phone numbers had only 6 digits indicating that they had not been revised for over 15 years).

Table 6.2 Length of TBI information sheets from Hospitals and GPs

Length	Percentage	
	Hospital	GP
Half a page or less	0%	21.7%
Up to 1 page	21.4%	48.3%
1 ½ to 2 pages	64.3%	23.3%
More than 2 pages	14.3%	6.7%

Most of the leaflets were simply titled "Head Injury", or "Advice for Head Injury Patients", and 22.9% of the information sheets explained what was meant by head injury or concussion. All the information sheets returned gave advice about important symptoms to watch for, such as severe headache, vomiting, weakness of arms or legs, visual disturbances or uneven pupil size, and the patient being unable to be roused. A small number (5%) gave no advice about what to do if you noticed these symptoms and 4% of information sheets advised to call an ambulance if the person was unconscious. Advice about the appropriate use of pain relief medication was given in 71.7% of the information sheets.

About half the information sheets mentioned returning to usual activities. This included 61.7% that gave advice about when the person could start driving again, 58.3% mentioned returning to sport or exercise, 40% that provided information about returning to school or work and 38.3% that gave advice about drinking alcohol. Once again the quality of the information varied. Many advised not to start driving again for at least 24 hours, but some left the judgment up to the individual as to when they were ready to start driving with statements such as "Do not drive your car or motorcycle until such time that you feel that your ability to judge distances and unexpected hazards have improved."

The likelihood of ongoing problems for some weeks or months was identified in 43.3% of the information sheets, and 10% gave advice about what to do or who to contact if you were concerned. There was one sheet (1.7%) that left spaces for the doctor to insert information specific to the individual regarding the use of pain relief, returning to school, physical activities and sport.

6.4 Sources of information for patients

As can be seen from table 6.3, 77.4% of GPs were able to identify up to 3 resources (mean 2.81) that they knew of and were able to access locally for their patients. Most commonly, patients were spoken to by the GP (88.1%), or their practice nurse (54.1%) about brain injury. Giving patients information in the form of a discharge summary or summary of treatment was also identified by 48.4% of respondents as a method that they would use, and 37.3% knew of a Head Injury Support Group that they could refer a patient to or tell a patient about if they felt it was appropriate.

Table 6.3 Number of resources for patients that respondents could identify

Number of Resources identified	Frequency	Percent
0	4	1.6
1	29	11.9
2	79	32.4
3	71	29.1
4	31	12.7
5	15	6.1
6	7	2.9
7	2	0.8
8	1	0.4
9	0	0.0
10	0	0.0
11	1	0.4

There were 9% of respondents who would use library or Internet resources as a source of information for patients. Some of the information sheets that were returned provided evidence to support this, as a search of the Internet had been used to find information for patients.

Figure 6.4 shows the differences between rural and urban GPs in their ability to identify resources for people with TBI in their local community. Rural GPs were slightly less likely to be able to identify any resources in their local community for people with TBI. There were 5.7% of rural GPs and 1.3% of urban GPs who were unable to identify any local resources. GPs who were based in a mixed urban and rural area were least likely to be able to identify 3 or more resources, with 39% (16) of those GPs able to identify 3 or more resources, compared with 54.7% (82) of urban GPs and 57.2% (20) of GPs from rural areas.

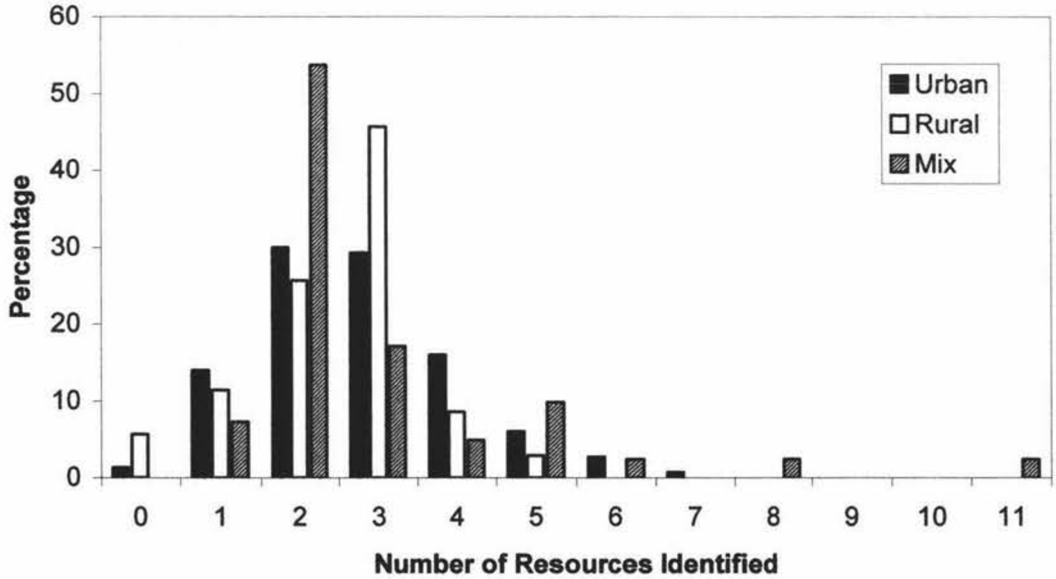

Figure 6.4: GP awareness of local resources for people with TBI

6.4.1 Access to other resources

Most GPs and EDs could identify 1 or 2 other resources that they could refer patients to including hospital outpatient clinics (73.0%) and Community activity or support groups (43.0%). A small number of respondents (11.5%) were able to identify other community resources, for example a residential placement service for people with brain injuries, and community neurobehavioural treatment team.

Part Two: Patient and Relative Questionnaire

6.5 Summary

A total of 38 patients gave initial consent to participate in the study and agreed to complete and return the questionnaires. They were given a copy of the questionnaire and some information and a questionnaire for their relative. Only six patients and two relatives returned the questionnaires, giving a return rate of 15.8% and 5.3%, respectively, and an overall return rate of 21.1%.

6.5.1 Patient Responses

The mean age of the clients who completed and returned the questionnaire was 28 years, ranging from 18 to 54 years. All participants had been working prior to the accident that caused their TBI, with a mean of 29.6 hours worked pre-accident. Motor vehicle accidents (MVA) were the cause of 83.3% of the hospitalisations with TBI. The participants stayed in hospital for a mean of 20 days, with 50% of the patients staying for 7 days or less. Their main physical injuries, apart form their TBI, were bruising (100%) and fractures (83.3%). The participants had a range of cognitive difficulties associated with the TBI. At the time of the questionnaire, 66.7% of participants described fatigue and difficulties with planning and organising as moderate or severe. Difficulties with memory, attention and frustration were described as moderate or severe by 50% of participants.

All participants received verbal information about TBI in general, their current condition and possible outcomes of TBI. Doctors and Occupational Therapists (OTs) provided this information most frequently. Written material such as booklets or brochures was received by 50% (3) of patients. Half the patients also had a family meeting to discuss their condition and rehabilitation. Of the information provided, 66.7% (4) said they understood some of it, and 16.7% (1) understood most of it. Two-thirds (4) of patients were either neutral or satisfied with the amount of information they were given about TBI. However, 66.7% (4) were not satisfied that they were kept sufficiently informed about changes in their condition or treatment and rehabilitation plans.

6.5.2 Relative Responses

Both the relatives who completed and returned the questionnaire, were parents of teenage children with TBI. Both families had quite different experiences while in hospital. General comments included that there were too many people giving different information and it was difficult to know who to listen to, and that there were vastly different experiences between hospitals and between ICU and the general hospital ward.

CHAPTER SEVEN

Discussion

7.1 Introduction

This study aimed to investigate the provision of information to patients and their relatives after a TBI. To accomplish this, the study was designed in two parts. Part One investigated the information provided by GPs and hospital EDs, while Part Two asked a number of recent patients with TBI and their relatives about their experiences.

This chapter will present a discussion of the findings of the current study in relation to the specific hypotheses proposed in Chapter Four, and the findings of similar research in the published literature. The strengths and limitations will be noted. Finally, conclusions and recommendations for future research will be made.

Part One: Information Provision by Hospitals and General Practitioners

7.2 Information Provision

There are no available statistics in New Zealand about the number of hospitals and GPs that produce patient information literature. While recommendations are frequently made that patients should be provided with written information about their condition and any treatment they may receive, there are no regulations to monitor the quality of such information. In general, individual hospitals and practices are left to make the decision about what topics they need to have written patient information.

It was hypothesized that all hospitals and most GPs would provide a basic information sheet about TBI to patients. This was only partly supported by the current study. Over 90% of hospitals reported that they provided an information sheet and 66.7% enclosed a copy, while 42.8% of GPs reported that they provided written advice about managing TBI to patients, and 32.8% enclosed a copy of the sheet. In total, less than half the hospitals and GPs questioned gave an information sheet to patients with a confirmed or suspected TBI. Many GPs commented that they saw very few patients with acute TBI as they generally sent their patients to hospital or Accident and Medical Centre if they were concerned. This perception of lack of need on the part of GPs may explain the small numbers that were able to provide patient information on this topic. However, given that many patients with minor TBI are advised to return to their GP for a check-up or if they are concerned, it is likely that GPs will see these patients later in the recovery process. At this stage patients, and particularly their relatives, may need reassurance and advice about symptoms and may be more receptive to education about TBI. It is important that GPs have current information available to assist these families.

Alternative methods of presentation of information, such as audiotape, videotape, or CD Rom, did not feature in the information stated or returned. There were no GPs or hospital EDs that had access to such information. It is unlikely that this type of patient education video would be presented in a setting such as a hospital ED as there is generally not the time or facilities available for staff to spend with patients. Within the hospital setting this type of resource may be available through the OT department, Concussion Clinic, or other Outpatient setting. Depending on the size and location of the practice, GPs may have difficulty justifying the purchase of such resource for a limited number of their patients. However, many local Head Injury Societies are able to loan such resources to patients and their families. The important role for the GP is to recognise when patients and their families are having difficulties and being able to direct them to an appropriate source of assistance. The finding that even in the first few weeks after the injury many family members will not spontaneously ask for more information about TBI, but when prompted express a need for such education, suggests that GPs are well positioned to explore this need with families.

Many GPs are part of organizations called "Independent Practitioner Associations" or IPAs. These organizations function to assist GPs to collectively access resources for their patients in the local community. For example, they may organise a contract with a local podiatrist to access foot checks for patients with Diabetes. The IPA would have funding to enable this service to be free to patients, and GPs who are members of the IPA would be eligible to refer their patients to the service. IPAs could also compile a list of local resources for people with TBI that GPs could use when appropriate. Unfortunately, the drive for such projects comes from the members, and the evidence from this study suggests that among GPs the perceived need is low.

7.3 Notification from Hospital

When a patient is discharged from hospital, the responsibility for their ongoing medical care is transferred back to their GP, if they have one. Again, it was difficult to find any statistics about the number of hospitals that provide some form of notification to a patient's GP when they have been in hospital. There appears to be no mandatory standards and so the process remains haphazard. There was some support for the hypothesis that hospitals would have a firm policy about notifying GPs, as only 17% of hospitals reported that they sometimes notified GPs when a patient of theirs attended

ED, indicating that they did not have a firm policy in this area. The majority (83%) of hospital EDs either always notified GPs (66%), or had a policy of not notifying GPs (17%).

7.4 Information Sheet

The readability of the information sheets, as measured by FRE score, was in line with Mumford's (1997) study and slightly better than those reported by Payne et al., (2000). However, it was still disappointing to see that 34.5% of the information sheets were written at a level that could not be understood by the general population. Given that patients and families are often under stress at the time of injury, information that is difficult to understand is easily disregarded.

The data supported the hypothesis that patient information sheets produced by hospitals would be more accurate and more professionally presented. It seems logical that as hospital EDs see the majority of acute TBI patients who come to medical attention, they would have the greatest demand for information about TBI and its consequences. As larger organizations, hospitals are also more able to access the expertise and resources needed to produce such information sheets. However, although readability is relatively simple to assess (most word processing programs will do so automatically), unless the writer is aware of the need to be mindful of this, results are not guaranteed. The finding that over 90% of hospital TBI information sheets were written at a level that at least 70% of the population could read is an improvement on the results of Mumford's (1997) study. As awareness of the need to produce patient information that is understandable increases, these results should continue to improve.

Two of the hospital information booklets used information adapted from a booklet produced by Dr D Gronwall, and Mr P Wrightson, from the Department of Neurosurgery at Auckland Hospital[1]. These were the most comprehensive booklets in the sample. They gave clear advice about what to do and what not to do while recovering from TBI and when to seek help and who to approach if you do need it. While providing in-depth information about TBI, they also conveyed the message that with time, most people recover to have their same level of intelligence and functioning as prior to their injury. The knowledge that this is a temporary condition, and that while symptoms are distressing they do not indicate 'brain damage', is reassuring for patients and families. Although evidence is limited at this time, it is believed that providing information about recovery can help prevent the development of long-term disability as a consequence of mild TBI in some people.

Poor quality photocopying was an issue for both GPs and hospitals. Even the best, most readable information is only useful if it is legible. In several instances the quality of copying was so poor that it was difficult or impossible to read some sections. This may be due to something as simple as not keeping a master copy of the document or poor photocopier maintenance. Several information sheets also were so crooked that sentences were cut off, leaving the reader to try and guess what was missing. An issue unique to the GPs in this study was the use of thermal fax paper to copy information sheets. The use of this type of paper lead to very poor quality copying, with lines and distortion of text resulting in a product that was, in some instances, almost illegible. These comments are made on the assumption that the quality of the copies received during this study is similar to that produced for patients. It seems reasonable that if a

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[1] This appears to be a different entity to the book authored by Gronwall, Wrightson & Waddell (1990).

GP copied an information sheet on the fax to return with the questionnaire, he or she might also do that if they have run short of photocopied sheets.

7.5 Community Resources

The hypothesis that GPs in larger urban centres would have access to more resources than those in rural areas was not supported by this study. Both groups were able to identify a median of three resources in their local community for people with TBI that they had knowledge about and access to. A small number of the information sheets gave contact details for the local Head Injury Association or similar organization that was able to provide support for patients and families.

Several of the hospitals commented that they routinely notified a specialist staff member, such as an Occupational Therapist, Head Injury Nurse, or Paediatric Outreach service, in case further follow-up was required. Some of these services, mainly in paediatrics, automatically contacted patients within 48 hours to assess the need for further assessment or intervention, while others were available only if the patient or their family sought further advice or assistance. However, the majority of hospital EDs referred the patient back to their GP for any ongoing care required. At the time of the survey, a lack of funding had closed an outpatient concussion clinic at one of the hospitals, which had previously provided a reliable "safety net" for mild TBI patients who were not admitted to hospital.

Part Two: The Experience of TBI Patients and their Relatives

The small number of patients and relatives that were recruited into Part Two of the study has made it difficult to draw any conclusions from this part of the study. One of the aims of this study was to overcome the difficulties associated with anecdotal evidence and to get a large enough sample of participants to enable some conclusions to be drawn. Unfortunately this was not possible. There was not enough evidence to provide support for or against any of the hypotheses proposed. A number of factors contributed to this situation, and will be detailed within the limitations section.

7.6 Limitations

As previously stated, the major limitation of this study was the small number of participants in Part Two. Potentially there were a number of explanations for this. Difficulties arose during the process of gaining ethical and institutional approval for the study. There was concern from the Massey Ethics Committee that the study should not be conducted in the hospital where the researcher worked, due to a potential for conflict of interest. Another hospital that was approached had concerns that although the questionnaire was anonymous, the results would be biased because there would be a tendency for patients who were dissatisfied with their treatment to choose to participate in the study. Other institutions agreed to participate but could not allow staff time to assist with the identification of potential participants or the distribution of information sheets. Due to the restrictions imposed by the Privacy Act and the Health Information Code, this made it nearly impossible to recruit participants from these establishments.

To overcome these difficulties, alternative methods of recruitment of participants or research design could have been used. An alternative would have been to use a qualitative research design and interview a small number of participants in depth. These interviews could then have been analysed using a number of qualitative methodologies. However, this would have been difficult with patients who were still experiencing post concussive symptoms such as tiredness and poor concentration. Relatives are often feeling very stressed at this time and may not be inclined to participate.

It may have been more practical to attempt to recruit participants during the first six weeks after their discharge from hospital, rather than while still admitted. Gaining permission to advertise at Concussion Clinics, Head Injury Associations, and working with hospital staff such as Head Injury Nurse Specialists and OTs, private rehabilitation providers and GPs might have made this possible.

The period around discharge and immediately after leaving hospital is often very busy for patients and families and there are many demands on that time. This study aimed to recruit participants close to the time of their discharge from hospital so that some of the difficulties associated with previous research that had asked participants to remember events from months or years previously could have been overcome. Attempting to recruit participants during a busy and stressful period in their lives contributed to the low response rate. A compromise between the current process and previous methodologies needs to be found.

However, none of these changes in methodology would have overcome the inherent self-selection bias. In a research design such as the one used, and with a vulnerable population of patients and families who have recently suffered a TBI, it would be unethical to use many other forms of participant selection. However, recruiting participants from as wide a range of sources as possible would have provided a more balanced view, and the concerns of institutions that their service was being targeted may have been reduced. Unfortunately the resource costs and complexities of such a study would make it difficult for a first time researcher to attempt, and a significant level of research funding would need to be accessed.

Another limitation, from Part One of the study, was the depth of information that could be established from a brief questionnaire. When designing a questionnaire for GPs it was necessary to compromise between the content to be covered and the length of the questionnaire. Many previous studies that have included GPs as participants have suffered from a low response rate, which has made it difficult to draw valid conclusions from the data. For this reason, the results of this study have raised as many questions as they have answered. By keeping the questionnaire no longer than two pages it was possible to improve the response rate and therefore have some valid data from which to draw conclusions. Unfortunately it also left many questions unanswered. For example, what Continuing Medical Education (CME) about TBI had participants been involved in over the past 2 years, at what stage of recovery do GPs generally see people with TBI, if they do receive notification from the hospital ED do they follow-up the patient and if so how?

7.7 Conclusions and Recommendations

This study aimed to investigate the provision of information by hospital EDs and GPs, to patients and relatives after TBI. Support was provided for the hypotheses that all hospitals would have an information sheet to give to patients with a confirmed or suspected TBI, and that these would be more legible and have better readability scores than those from GPs. The proportion of GPs that had a similar information sheet was less than expected and of highly variable quality. As expected there were no participants who identified any alternative formats for TBI information apart from verbal or written information. People with TBI appear to be equally well supported in urban and rural communities. GPs in urban and rural areas were able to identify the same number of local resources for people with TBI.

Ongoing research in the area of TBI is important for a number of reasons. Frequently TBI patients are young people, with many productive years ahead of them. Research that can help to educate all healthcare providers about ways to optimise the recovery process for these patients will benefit not only the individuals affected and their families, but also society as a whole. The ongoing cost, in both financial and social terms, of young people with permanent disability resulting from TBI is growing each year.

This study has raised a number of issues that could be investigated by further research in the area of TBI. It appears that hospitals frequently refer mild TBI patients back to their GP for ongoing monitoring and advice. Further studies could examine how well equipped GPs are to take on this role. This could include an assessment of the continuing education that GPs have received in this area and the degree of clinical risk that this exposes them to as well as how well they are supported and resourced to assess the sometimes complex and ongoing needs of these patients.

Another area that requires further work is the investigation of how well the needs of patients with mild to moderate TBI and their families are met. A study that is able to recruit participants from a variety of sources in the first 6-8 weeks after their discharge from hospital would be invaluable for those planning and managing services for people with TBI.

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APPENDIX A

Client and Relative Satisfaction following Traumatic Brain Injury

HOSPITAL AND GENERAL PRACTICE QUESTIONNAIRE

Please take a moment to answer this questionnaire by ticking the best answer or answers. When you have finished it can be returned in the prepaid envelope provided together with any other materials. Thank you for your co-operation.

1. Is your hospital/practice mainly:
   - ☐ Rural
   - ☐ Urban
   - ☐ Mix of rural & urban

2. How many new Traumatic Brain Injury (TBI) clients have you had in the past month?
   - ☐ None
   - ☐ 1-4
   - ☐ 5 - 9
   - ☐ 10 – 14
   - ☐ 15 - 19
   - ☐ 20 +

3. How many were
   - ☐ Male _____
   - ☐ Female _____

4. Do you get notification from the Emergency Department when a patient has a concussion or head injury but is not admitted to a ward (or do you notify GPs)?
   - ☐ Yes
   - ☐ No
   - ☐ Sometimes (please specify)

     ____

5. Do you have an information sheet/brochure that you generally give to TBI patients?
   - ☐ Yes
   - ☐ No

If yes, please enclose a copy when you return this questionnaire.

6. What other sources of information for patients do you generally use?

- ☐ Verbal advice from
  - ☐ Doctor
  - ☐ Nurse
  - ☐ Physiotherapist
  - ☐ Other (please specify)

  ____
- ☐ Discharge summary notes
- ☐ Other hand-written notes (please specify)

  ____
- ☐ Other Printed material (please specify)

  ____
- ☐ Referral to support group
  - ☐ Head Injury organisation
  - ☐ Other (please specify)

  ____
- ☐ Library or Internet resources
- ☐ Other (please specify)

  ____

7. What other resources do you have available to you?
   - ☐ Outpatient hospital clinics
   - ☐ Community support groups
   - ☐ Other (please specify)

   ____

8. Any other comments you would like to make

Thank you for completing this questionnaire and including any Information Sheet or leaflet about head injury that you provide for patients.

APPENDIX B

Client and Carer Satisfaction following Traumatic Brain Injury

HOSPITAL AND GENERAL PRACTICE INFORMATION SHEET

My name is Catherine Moore. I am completing a Master of Science in psychology at Massey University under the supervision of Professor Janet Leathem, Director of the Psychology Clinic at Massey University.

I am writing to invite you to take part in a study to evaluate levels of client and carer satisfaction with various clinical services and with the information provided after traumatic brain injury (TBI). As part of this, copies of the enclosed questionnaire have been sent to all Public Hospitals with an Emergency Department in New Zealand, and to a random sample of General Practices and Private Accident and Emergency Clinics selected from the Telecom white pages. The questionnaire asks about the nature and extent of information provided to and access for clients with TBI and their families. It is hoped that the feedback that results from this research will assist healthcare providers in their efforts to provide the best information for such clients.

Please find enclosed a short questionnaire, which I invite you to complete and return in the reply paid envelope provided. The questionnaire should not take longer than 15 minutes to complete and is anonymous.

If you choose to take part in the research, your organisation has the right to

- Refuse to answer any questions and to withdraw from the study at any time during the study
- Ask any further questions about the study at any time during the study
- Provide all information on the understanding that it will remain confidential to the researcher and her supervisor. It will not be possible to identify your organization in any reports that arise from the study.
- Be given a summary of the findings from the final report. These will be posted to you when they are available.

This research project has the approval of the Massey University Human Ethics Committee. Please feel free to contact the chair of the committee, Dr Michael O'Brien, if you have any questions or concerns about the ethics of this research. You can phone him on (09) 4439700. This study also has the approval of the Auckland Ethics Committee. The Health Advocates Trust can be contacted on 0800 205 555 if you have any concerns about this research.

Please feel free to contact me at any time if you have any further questions or concerns about this research. You can leave a message for me at the psychology office ph (09) 443 9700. You can also contact my supervisor, Janet Leathem, on (09) 443 9799 ext 5196.

Thank you for your consideration. We appreciate you taking time to read this information and think about taking part in this research.

Yours sincerely

Catherine Moore Janet Leathem

APPENDIX C

Client and Relative Satisfaction following Traumatic Brain Injury

CLIENT INFORMATION SHEET

My name is Catherine Moore. I am completing a Master of Science in psychology at Massey University under the supervision of Professor Janet Leathem, Director of the Psychology Clinic at Massey University.

You are invited to take part in a study about brain injury to find out what you know about it and what information you have received about it. I would like to give this questionnaire to people who have had a brain injury while they are in hospital or soon after they get home. I hope that the results of this study will help healthcare providers in their efforts to provide the best information for people with brain injuries and their families.

People who have been in hospital recently after having a brain injury have been given this information sheet about the study so that they can decide if they are interested in taking part. If you choose to take part in this study it would involve completing a questionnaire. The questionnaire should take less than 15 minutes to complete.

If you choose to take part in the research, you have the right to

- Refuse to answer any particular questions and to withdraw from the study at any time during the study,
- Ask any further questions about the study at any time during your participation,
- Provide information on the understanding that your name will not be used unless you give permission to the researcher. Only the researcher and her supervisor will see all records. It will not be possible to identify you in any reports that result from the study.
- Have your questionnaire kept in a safe place and destroyed after the study has finished.
- Be given access to a summary of the findings from the final report, which will be posted, to you when it is available.

The Massey University Human Ethics Committee has approved this research project. Please feel free to contact the chair of the committee, Dr Michael O'Brien, if you have any questions or concerns about the ethics of this research. You can phone him on (09) 4439700. The Auckland Ethics Committee has also approved this study. The Health Advocates Trust can be contacted on 0800 205 555 if you have any concerns about this research.

Please feel free to contact me at any time if you have any further questions or concerns about this research. You can leave a message for me at the Psychology office on (09) 443 9799 ext. 2040. You can also contact my supervisor, Janet Leathem, on (09) 443 9799 ext. 5196 if you have any concerns.

Thank you for your consideration. We appreciate you taking time to read this information sheet and think about taking part in this research.

Yours sincerely

Catherine Moore Janet Leathem

Client and Relative Satisfaction following Traumatic Brain Injury

RELATIVE INFORMATION SHEET

My name is Catherine Moore. I am completing my Master of Science in psychology at Massey University under the supervision of Professor Janet Leathem, Director of the Psychology Clinic at Massey University.

You are invited to take part in a study about brain injury to find out what you know about it and what information you have received about it. I would like to give this questionnaire to relatives of people who have had a brain injury while their relative is in hospital or soon after they return home. I hope that the results of this study will help healthcare providers in their efforts to provide the best information for people with brain injuries and their families.

A relative of everyone who has agreed to take part in this study has also been given this information sheet about the study so that they can decide if they are interested in participating. If you choose to take part in this study it would involve completing a questionnaire. The questionnaire should take less than 15 minutes to complete.

If you choose to take part in the research, you have the right to

- Refuse to answer any particular questions and to withdraw from the study at any time during the study,
- Ask any further questions about the study at any time during your participation,
- Provide information on the understanding that your name will not be used unless you give permission to the researcher. Only the researcher and her supervisor will see all records. It will not be possible to identify you in any reports that result from the study.
- Have your questionnaire kept in a safe place and destroyed after the study has finished.
- Be given access to a summary of the findings from the final report, which will be posted, to you when it is available.

The Massey University Human Ethics Committee has approved this research project. Please feel free to contact the chair of the committee, Dr Michael O'Brien, on (09) 443 9700, if you have any questions or concerns about the ethics of this research. The Auckland Ethics Committee has also approved this study. The Health Advocates Trust can be contacted on 0800 205 555 if you have any concerns about this research.

Please feel free to contact me at any time if you have any further questions or concerns about this research. You can leave a message for me at the Psychology office on (09) 443 9799 ext. 2040. You can also contact my supervisor, Janet Leathem, on (09) 443 9799 ext. 5196 if you have any concerns.

Thank you for your consideration. We appreciate you taking time to read this information sheet and think about taking part in this research.

Yours sincerely

Catherine Moore Janet Leathem

APPENDIX D

Client and Relative Satisfaction following Traumatic Brain Injury

CLIENT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time before the final statistics have been calculated and analysed and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission. The information will only be used for this research and publications arising from this research project.

I agree to participate in this study under the conditions set out in the Information Sheet.

English	I wish to have an interpreter	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	Ae	Kao
Samoan	Oute mana ‘o ia iai se fa’amatala upu	Ioe	Leai
Tongan	Oku ou fiema ‘u ha fakatonulea	Io	Ikai
Cook Island	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakhokohoko kupu	E	Nakai

Signed: ………………………………………………

Name: ………………………………………………..

Date: ………………………………………………..

Client and Relative Satisfaction following Traumatic Brain Injury

RELATIVE CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time before the final statistics have been calculated and analysed and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission. The information will only be used for this research and publications arising from this research project. I understand that I may request a summary of the research findings when they are available.

I agree to participate in this study under the conditions set out in the Information Sheet.

English	I wish to have an interpreter	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	Ae	Kao
Samoan	Oute mana 'o ia iai se fa'amatala upu	Ioe	Leai
Tongan	Oku ou fiema 'u ha fakatonulea	Io	Ikai
Cook Island	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakhokohoko kupu	E	Nakai

Signed: ....

Name: ....

Date: ....

APPENDIX E

Client and Relative Satisfaction following Traumatic Brain Injury

CLIENT QUESTIONNAIRE

Please answer the following questions by ticking the box beside the best answer or answers, or by writing in the space provided. Thank you for your time and cooperation.

1. How old are you?

   ____

2. Are you
   - ☐ Male
   - ☐ Female

3. What ethnic group do you identify with?

   ____

4. What was your occupation at the time of your accident/ illness?

   ____

5. How many hours per week did you spend in paid employment?

   ____

6. What was the cause of your current hospital admission?
   - ☐ Motor vehicle accident
   - ☐ Workplace accident
   - ☐ Other accident
   - ☐ Sport injury
   - ☐ Infection
   - ☐ Tumour
   - ☐ Other, please specify

     ____

7. How long were you in hospital for?

   ____

8. What physical injuries did you receive at the same time as your brain injury?
   - ☐ No other injuries
   - ☐ Fractures/Broken bones
   - ☐ Bruising, cuts
   - ☐ Internal injuries
   - ☐ Breathing difficulties
   - ☐ Infection
   - ☐ Other, please specify

     ____

9. How much difficulty do you have in each of the following areas at the moment?

	No Difficulty	Very Mild	Mild	Moderate	Severe	Very Severe
Memory						
Attention and Concentration						
Reasoning and Decision Making						
Planning and Organization						
Frustration and Loss of Temper						
Impulsivity						
Difficulty getting started with tasks						
Depression or Anxiety						
Fatigue or Tiredness						
Headaches						
Coordination and Balance						
Reading, Writing, finding the right words or understanding others						

10. What format was the information you received about current condition, possible outcomes or brain injury in general in?
    - ☐ Verbal, by

    ____

    - ☐ Handwritten notes
    - ☐ Booklet or brochure
    - ☐ Video
    - ☐ Tape or CD
    - ☐ Family meeting
    - ☐ Other, please specify

    ____

11. Which of the following professional groups of services have you used while in hospital?

Service	Which services have you used?	What information did you receive? e.g. pamphlets, verbal, video etc
Intensive Care Department		
Surgeon		
Neurosurgeon		
Orthopaedic Surgeon		
Nurse		

Service	Which services have you used?	What information did you receive? e.g. pamphlets, verbal, video etc
Neurologist		
Neuropsychologist		
Psychologist		
Psychiatrist		
Physiotherapist		
Occupational Therapist		
Speech Language Therapist		
Pain Service		
Social Worker		
Chaplain		
Other, please specify ______		

12. Who were the three main people that you received information from about your physical injuries?

    ______

    ______

    ______

13. Who were the three main people that you received information from about your brain injury?

    ______

    ______

    ______

14. When did you receive the most information about your brain injury?
    - ☐ At admission
    - ☐ On the ward
    - ☐ Small amounts throughout
    - ☐ At discharge
    - ☐ Only when I asked questions
    - ☐ Other, please specify

      ______

15. What would have been the best time for you to be given information about your brain injury?
    - ☐ At admission
    - ☐ On the ward
    - ☐ Small amounts throughout
    - ☐ At discharge
    - ☐ Only when I asked questions
    - ☐ Other, please specify

      ______

16. How much of the information you were given about your brain injury did you understand?
    - ☐ All
    - ☐ Most
    - ☐ Some
    - ☐ None

When you think about your time in hospital, how satisfied do you feel about each of the following areas?

	Very Satisfied	Satisfied	Neutral or Don't Know	Not Satisfied	Not Satisfied At All
Information about physical injuries					
Information about current condition					
Information about possible outcomes of brain injury					
Information about brain injury in general					
Amount of information received					
Ease of getting questions answered by staff					
Kept informed about changes in condition or treatment plans					

18. What instructions were you given about returning to work, sport, driving and other activities?

19. Any other comments you would like to make

Thank you for taking the time to complete this questionnaire. We appreciate your time and effort.

APPENDIX F

Client and Relative Satisfaction following Traumatic Brain Injury

RELATIVE QUESTIONNAIRE

Please answer the following questions by ticking the box beside the best answer or answers, or by writing in the space provided. Thank you for your time and cooperation.

1. How old are you?

   ____

2. Are you
   - ☐ Male
   - ☐ Female

3. What ethnic group do you identify with?

   ____

4. What is your occupation?

   ____

5. How many hours per week do you spend in paid employment?

   ____

6. What is your relationship to ______________?
   - ☐ Husband/Wife
   - ☐ Partner
   - ☐ Parent
   - ☐ Brother/Sister
   - ☐ Grandparent
   - ☐ Friend
   - ☐ Other, please specify

     ____

7. What services that __________ did not receive would you have liked him/her to receive?
   - ☐ Neurologist
   - ☐ Neuropsychologist
   - ☐ Psychologist/ Psychiatrist
   - ☐ Physiotherapist
   - ☐ Occupational Therapist
   - ☐ Speech Language Therapist
   - ☐ Pain Service
   - ☐ Social Worker
   - ☐ Chaplain
   - ☐ Other, please specify

     ____

8. How much difficulty has ______________ experienced in each of the following areas since his/her injury?

	No Difficulty	Very Mild	Mild	Moderate	Severe	Very Severe
Memory						
Attention and Concentration						
Reasoning and Decision Making						
Planning and Organization						
Frustration and Loss of Temper						
Impulsivity						
Difficulty getting started with tasks						
Depression or Anxiety						
Fatigue or Tiredness						
Headaches						
Coordination and Balance						
Reading, Writing, Finding the right words or Understanding others						

9. Who were the three main people that you received information from about physical injuries?

____

____

____

10. Who were the three main people that you received information from about ___________ current condition?

____

____

____

11. Who were the three main people that you received information from about possible outcomes?

____

____

____

12. Who were the three main people that you received information from about brain injury in general?

____

____

____

13. When did you receive the most information about ___________ brain injury?
    - ☐ At admission
    - ☐ On the ward
    - ☐ Small amounts throughout
    - ☐ At discharge
    - ☐ Only when I asked questions

14. What would have been the best time for you to be given information about ___________ brain injury?
    - ☐ At admission
    - ☐ On the ward
    - ☐ Small amounts throughout
    - ☐ At discharge
    - ☐ Only when I asked questions

15. In general, how much of the information that you were given did you understand well?
    - ☐ All
    - ☐ Most
    - ☐ Some
    - ☐ None

16. How satisfied are you with how easily you were able to contact staff members when needed?
    - ☐ Very satisfied
    - ☐ Satisfied
    - ☐ Neutral or don't know
    - ☐ Not satisfied
    - ☐ Not satisfied at all

17. How satisfied are you with how easily you were able to have your questions answered by staff?
    - ☐ Very satisfied
    - ☐ Satisfied
    - ☐ Neutral or don't know
    - ☐ Not satisfied
    - ☐ Not satisfied at all

18. How satisfied are you with the information you were given about each of the following areas?

	Very Satisfied	Satisfied	Neutral or Don't Know	Not Satisfied	Not Satisfied at all
Physical injuries					
Possible outcomes of brain injury					
Brain injury in general					
Amount of information received					
Timing of information received					
Changes in ___________ condition or treatment plan					

19. Any other comments you would like to make

Thank you for taking the time to complete this questionnaire.

APPENDIX G

Massey University

Office of the Principal
Massey University
Albany Campus
Private Bag 102 904,
North Shore MSC,
Auckland,
New Zealand
Principal: 64 9 443 9799 ext 951
Campus Registrar: 64 9 443 979
ext 9516
Facsimile: 64 9 414 0814

15 August 2000

Catherine Moore
C/o Dr. Janet Leathem
School of Psychology
Massey University
Palmerston North

Dear Catherine,

HUMAN ETHICS APPROVAL APPLICATION – MUAHEC 00/048
"CLIENT AND CARER SATISFACTION FOLLOWING TRAUMATIC BRAIN INJURY"

Thank you for your amended application details, which we recently received and have been placed on our files.

The amendments you have made now meet the requirements of the Massey University, Albany Campus, Human Ethics Committee and the ethics of your application, therefore, are approved.

Yours sincerely

Mike O'B

Dr Mike O'Brien
CHAIRPERSON,
MASSEY UNIVERSITY, ALBANY CAMPUS
HUMAN ETHICS COMMITTEE

cc. Dr. Janet Leathem, School of Psychology, Palmerston North

Te Kunenga ki Pūrehuroa
Inception to Infinity: Massey University's commitment to learning as a life-long journey

APPENDIX H

Auckland
Ethics Committees

Delivery Address:
C/O Health Funding Authority
Level 3, Columbus Building
650 Great South Road, Penrose
Private Bag 92522
Wellesley Street
Auckland
Phone (09) 580 9105
Fax (09) 580 9001
Email: pat.chainey@hfa.govt.nz

Please include the reference number and study title in all correspondence/telephone queries

10 November 2000

Ms Catherine Moore
26 Seine Road
Milford
Auckland

Dear Catherine,

2000/189 Client and carer satisfaction with information provision following traumatic brain injury

Thank you for your letter dated 6 November 2000.

We are pleased to inform you that this study has received ethical approval until 10 November 2001, at which time a final summarised report/ abstract is required to be presented to the committee for consideration. It is certified as not being conducted principally for the benefit of the manufacturer and will be considered for coverage under ACC.

Please note that the Committee grants ethical approval only. If management approval from the institution/organisation is required, it is your responsibility to obtain this.

If the study is not completed by November 2001, a progress report will be required by 10 November 2001. Approximately two months prior to the end of this period you should receive a progress report form from our database that is required to be completed and submitted to the Ethics Committee one month before the expiry date. However, it is your responsibility to ensure that a yearly progress report is submitted to the Ethics Committee.

The Committee wishes you well with your research

Yours sincerely

Pat Chainey
Administrator

Auckland Healthcare

APPENDIX I

HEAD INJURY INFORMATION

In a small number of minor head injuries,symptoms may develop which need Medical attention.

Signs to watch out for (especially in the first 24 hours) are:

1. An increasingly severe headache
2. Nausea and Vomitting
3. Progressive drowsiness
4. Confused or irrational behaviour
5. Blurred or double vision
6. Weakness of the arms or legs

If any of these symptoms appear contact

Head Injury Advice

- The patient should be watched for any increase in drowsiness for the next 6 -12 hours. This may mean waking them every hour to check on drowsiness for at least the first 6 hours following the injury.
- Check that both arms and legs are moving normally.
- Only give pain relief if GP advises
- Phone the surgery if the patient vomits, if their headache becomes worse or if you have any other anxieties.

The afterhours Dr can be contacted on 434- 9444

AFTER A HEAD INJURY

Advice for relative or friend of any person who has suffered a head injury

A person who has suffered a head injury can take several hours to recover.

They should not be left alone.

They should not be allowed to drive a vehicle or ride a bicycle.

They should not drink alcohol.

They should not use strong pain killers or sedatives unless advised by a doctor.
-usually Paracetamol (Panadol, Pamol, etc.) is safe and effective.

We have found no evidence of serious head injury at this examination. However you must watch for the following :

Drowsiness or difficulty arousing the patient.
Any irritable or unusual behaviour.
Repeated vomiting.
Headache which is getting worse.
Any fit or seizure.

Should any of the above occur please contact your doctor or the After Hours Surgery.

IMPORTANT ADVICE
AND INSTRUCTIONS CONCERNING
HEAD INJURIES

Any person who has suffered even a minor head injury can take some time to recover. Complications are uncommon but can be serious.

PATIENTS SHOULD NOT;

BE LEFT ALONE
BE ALLOWED TO DRIVE A MOTOR VEHICLE OR RIDE A BICYCLE
DRINK ALCOHOL

On examination today we have found no evidence of serious injury, however, should any of the following be noted the patient should be seen by a doctor immediately.

1. Confusion, drowsiness, or difficulty in rousing the patient.
2. Irritability or unusual behaviour
3. Repeated vomiting
4. Increasing, persistent headache
5. Patient has a fit, or seizure

If it is after hours, the After Hours Surgery is located on the corner of Bealey Avenue and Colombo St, the phone number is 365-7777, or the patient can be taken straight to the Emergency Department at Christchurch Hospital.

ADVICE FOR PEOPLE CARING FOR SOMEONE WHO HAS HAD A HEAD INJURY

The person who has had a head injury has been examined by the Doctor and it is considered safe for that person to return home, we ask that you keep a close eye on the head injured person and watch carefully for the following signs:

☐ SEVERE HEADACHE

If headache persists or gets worse, medical advice should be sought.

☐ EXCESSIVE DROWSINESS

It is expected that people who have had a head injury to feel exhausted after what has happened but it is important that you are able to rouse them easily if they are asleep. Seek medical advice if the person is difficult to rouse.

☐ PERSISTANT VOMITING

People may vomit once or twice after a head injury has occurred however, if vomiting continues or begins again hours after it has ceased medical assistance should be sought.

☐ CONFUSION

Seek medical advice if person becomes increasingly confused or behaves abnormally

☐ LIMB WEAKNESS

Seek medical advice if there is weakness of an arm or leg.

☐ FLUID LEAKAGE

Seek medical advise if fluid leaks from the nose or ear.

H:\A&E:7297

INSTRUCTIONS FOLLOWING HEAD INJURY

19/11/91

A. OBSERVATION : For the next 24 hours keep a careful watch over the patient who should be checked regularly - 1 / 2 / 4 HOURLY (circle one). The patient must be brought back to this Clinic or a Hospital Emergency Department immediately if you notice any of the following :

1. The patient becomes unconscious or difficult to rouse completely.
2. The patient becomes confused, irrational or delirious
3. Fits, convulsions or spasms of the face and limbs occur.
4. The patient complains of persistent headache or neck stiffness.
5. Persistent vomiting, especially not related to food intake.
6. Bleeding or recurrent watery discharge from ear or nose.

B. PAIN RELIEF : Some headache is common after head injury. You may give paracetamol (Panadol, Disprol) but should avoid anything containing aspirin (Aspro, Disprin). If the headache becomes severe see above.

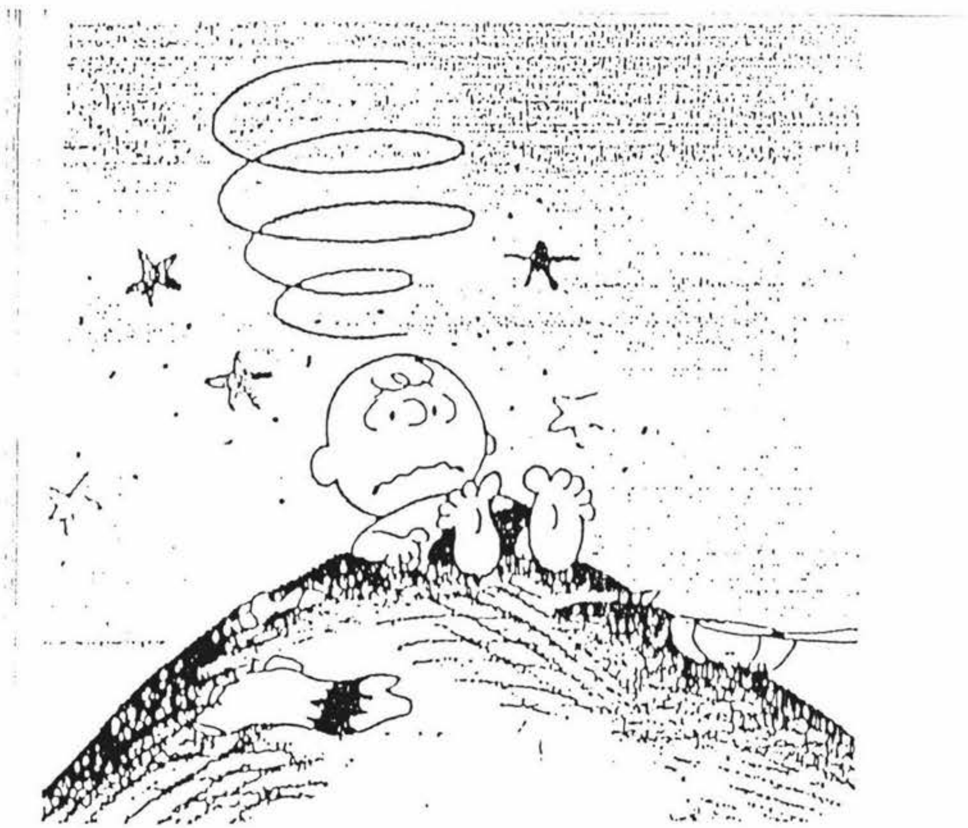
C. CONCUSSION : This may occur after head injuries with or without knockout or skull fracture. Patients often have mild headache for a few days which may become worse with exercise. They may also feel a little giddy and unsteady. Concentration and reaction time may be poor for this period. In addition or as a result, they may be easily irritated.

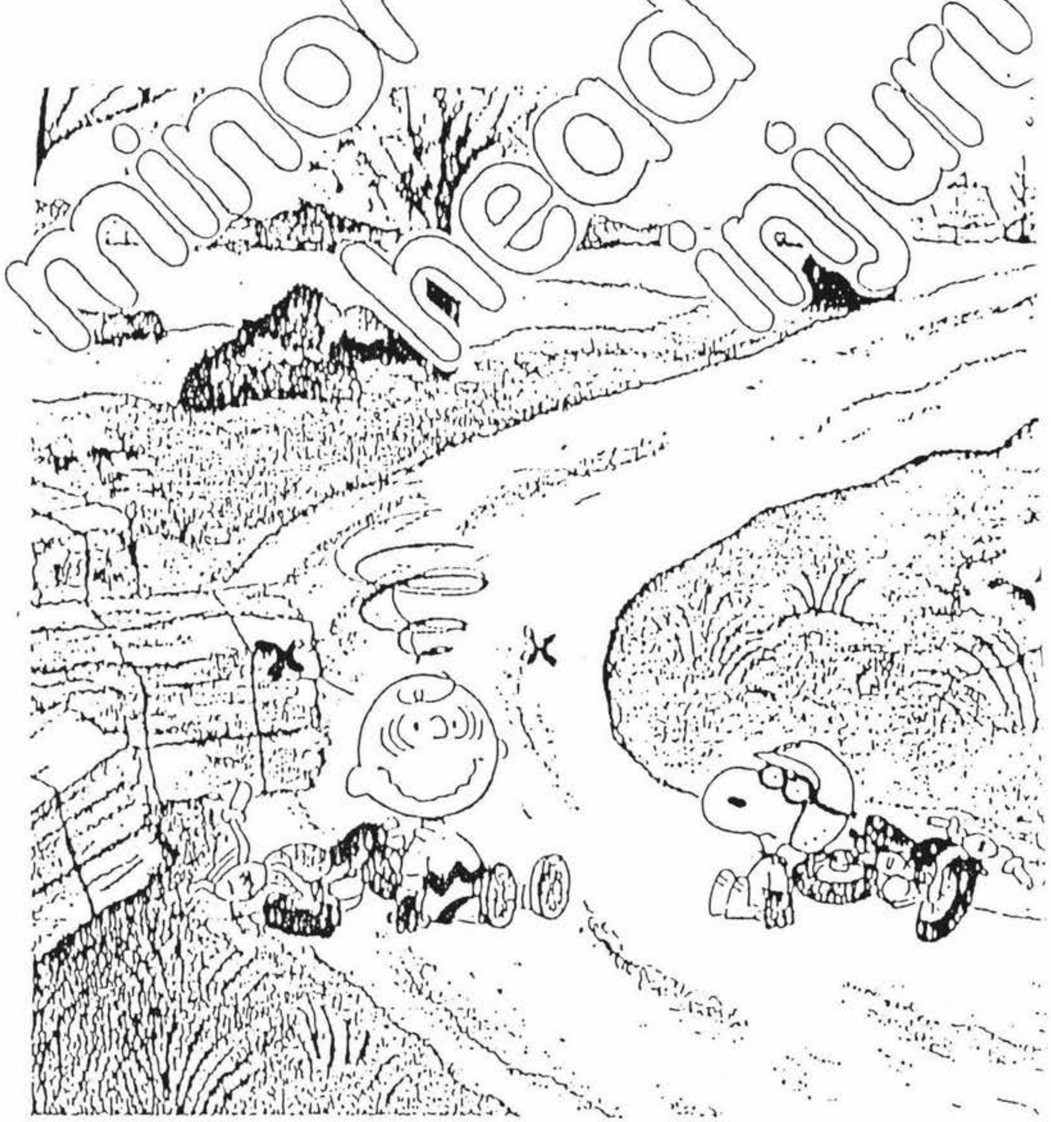
1. Driving : You should not drive for at least 24 hours after a significant head injury due to poor reaction time.
2. Work : If you do not feel well and can't concentrate, you are unlikely to be much use at work and should stay off a day or two. You are also likely to tire easily and may find it better to start again with half a day.
3. Sport : Ordinary exercise can commence when you feel well. Sports with a risk of further concussion should not be played for at least a month. For some sports (e.g. NZRFU) there is a compulsory period of time off.

Hospitals

North Shore 486-1491   Auckland 379-7440   Middlemore 276-1999

Children often progress very quickly but if there are on-going problems that you are concerned about, such as your child not coping well with school or not seeming to play as well as usual, it may be helpful to ask to see your doctor or contact the Visiting Neurodevelopmental Therapist.





If your child develops any of the following symptoms it is MOST IMPORTANT that you call your own Doctor or return to the Hospital IMMEDIATELY:

- Severe headache
- Continued dizziness
- Vomiting
- Double or blurred vision

Although a concussion injury may affect children in a similar way to adults, children, especially at pre-school age, may not be able to verbally express some of the effects very well.

Most of the time, any difficulties will be noted by observing the child's behaviour in play, school activities or with the family.

Some possible problems that can occur as a result of a mild concussion injury are:

1. Mild headaches.
2. Disturbed sleep and fatigue - do not settle as well as usual, wake often and get tired more easily.
3. Concentration - become tired more quickly at activities normally concentrated on without difficulty, tend to 'flit' from one toy to another.
4. Memory - tend to forget things eg. what happened during the day.
5. Irritable/frustrated - annoyed by noise or other children playing, unable to cope with not instantly succeeding at an activity.
6. Behaviour - tend to be more restless/active or unusually quiet.
7. Emotional - tend to be more insecure and may go back to earlier behaviour patterns.

All these problems may not be present in all children and many may resolve very quickly.

Ordinary exercise can start when symptoms such as headache, dizziness and tiredness have disappeared. Contact sports (where another head injury is possible) should not be played for at least three weeks For some sports bodies (eg. NZRFU) this time off is compulsory.

One head injury - no contact sports for 3 week
Two head injuries - no contact sports for rest of season.
Three head injuries - no contact sports for ever

SOME POINTS TO REMEMBER while a child recovers from a head injury:

- May need more rest-time ie. in the morning as well as the afternoon.
- Don't let the child become overtired, ie. encourage a rest or quiet activity before the child becomes overexcited.
- Realise unusual behaviour patterns may be related to the injury.
- Child may be more fresh in the morning, a rest in the afternoon may be necessary.
- Concentration and attention may decrease as he tires and he may tire more easily.
- Return to school/pre-school should be gradually increased according to the child's ability to manage.
- Classmates may not understand if there is no obvious injury.
- It is a good idea to make the teacher aware also.

BEHAVIOUR

Has become:

- More demanding and easily frustrated
- More fearful and anxious
- More easily tired

Changes in sleeping pattern

Complains of headaches

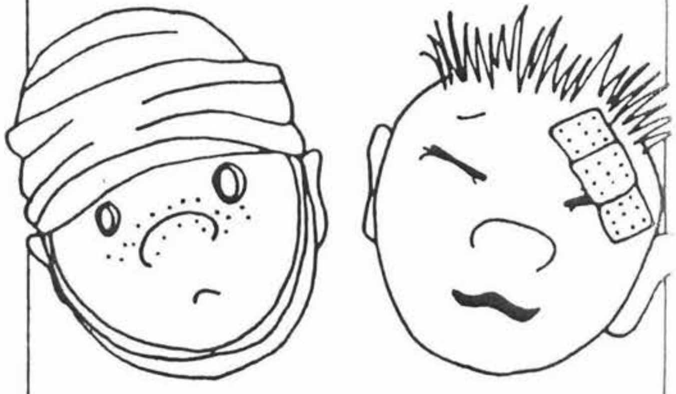
After your child has been back at school for one month, we suggest you talk with the teacher about whether there have been any changes in your child's performance since the head injury.

If you have any concerns please contact:

YOUR FAMILY DOCTOR

CHILDREN WITH HEAD INJURY

A GUIDE FOR PARENTS



Head Injury ranges from minor bumps to loss of consciousness!

HEAD INJURY

Even though most children with Head Injuries make a full recovery,

please read this carefully so that you are aware of the signs

that may indicate further investigation.

SIGNS TO LOOK FOR

EARLY ON

If your child has suffered a head injury, however minor, and develops any of the following symptoms:

1. Headache
2. Giddiness
3. Nausea or Vomiting
4. Drowsiness

Report immediately to the hospital or to your local medical practitioner.

Do not delay, especially if the symptoms get worse.

If you are concerned phone your local Doctor

LATER ON

You may notice some changes in your child's behaviour and/or physical ability at home or at school, even though the child may not have stayed in hospital. Some of the following changes may be noticed by the family or the teacher during the months after a head injury.

PHYSICAL

Change in the ability to:

- Do physical activities such as sport, gymnastics, climbing, hopping and catching
- Join in games
- Do everyday activities such as dressing, using a knife & fork and writing

SPEECH AND LANGUAGE

Change in the ability to:

- Understand what is said
- Follow a conversation
- Re-tell the day's events
- Find the right word

Change in the amount or style of speech

MEMORY AND LEARNING

Difficulty with new school work or new activities.

Problems with concentrating or remembering instructions.

Slowness to think about new things.

Symptoms remaining after 48 hours

Where to seek help !!!

- Tiredness
- Poor memory
- Clumsiness
- Poor concentration
- Irritability
- Vision problems
- Severe Headaches
- Dizziness

These symptoms are temporary but can last up to three weeks. If you continue to suffer from any of these symptoms or have concerns, please contact the paediatric outreach nurse for help or for further information.

Tamariki Ora

Tamariki Ora

CHILDREN WITH

HEAD INJURY

MILD / MODERATE

For children aged 0-15 years

A GUIDE FOR PARENTS

FOR FIRST 24-48 HOURS

Head injury ranges from minor bump to loss of consciousness

INSTRUCTION SHEET

For first 24 to 48 hours following a blow to the head

Some of the symptoms you may experience are ... headache, dizziness, fatigue, nausea or vomiting.

Mild symptoms are to be expected
They may last for several days and are no cause for alarm.

DO'S ✓

- ✓ A parent/caregiver needs to stay with the child (at least for the first 24 hours.
- ✓ Your child can go to sleep but should be roused every 1-2 hours for the first 12 hours.
- ✓ Your child can eat lightly beginning with liquids, soup and soft solids.
- ✓ Pamol/paracetamol can be given for headache as prescribed by the Doctor.
- ✓ A cold pack may be used.

DON'TS ✗

- ✗ Do not put your child in a position where he/she is likely to get another bang on the head.
- ✗ Your child should not return to playgroup/school until symptoms have cleared.
- ✗ Your child should not take part in any contact sport or practice for 3 weeks or until symptoms are clear.
- ✗ Your child should avoid TV and Video games for at least 48 hours.

You should return to the Emergency Department <u>IMMEDIATELY</u> if your child has any of the following ...

1. Frequent vomiting
2. Bleeding or discharge from the ear or nose
3. Severe or persistent headache
4. A fit or spasms of the face or limbs
5. Unusual or confused behaviour
6. Difficulty in waking up

The Paediatric Outreach Nurse will phone you within 24-48 hours after discharge from hospital.
