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**Provision of Information on Concussion
to Patients and Families
by Videotape**

A thesis presented in partial fulfilment of the requirements for the degree of
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ABSTRACT

Traumatic brain injury (TBI) is a major health problem in New Zealand that results in death and disability as well as a substantial number of mild injuries. Information provision is an important part of interventions that can help to prevent long-term difficulties from developing after mild TBI. This study investigated whether information provision by videotape can be a useful part of interventions for mild TBI. The research was in the form of a pilot study in that a videotape and a brochure were produced as part of the study. The participants were clients of a concussion clinic and the people who accompanied them to the clinic and they were divided into three different groups. One group received the videotape and brochure, a second group received the brochure only and the third group received neither of these resources. Specific questions about information provision were developed to gather data for the study which formed part of a larger survey of client satisfaction. The number of responses from people who accompanied the clients was insufficient and that data was therefore omitted from the study. There were no significant differences between the three groups of clients in their satisfaction with information provision or the perceived level of help they received from information provision in understanding concussion. Clients who reported that they received an appropriate rather than an insufficient or excessive amount of information were significantly more satisfied with information provision. The results also suggested that clients who did not receive the resources may not have received enough information. The majority of clients preferred to receive information on both videotape and brochure compared to either resource on its own or other options and most clients who received the information resources referred to them more than once. The findings support the use of videotapes in information provision for clients of concussion clinics when they are used alongside written resources rather than replacing them. Limitations in the study and directions for future research are discussed.

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CHAPTER ONE

Introduction

1.1 Background

The original idea for this research was initiated by a recent masterate study by Moore (2001) which investigated the nature of information made available to patients and their families by general practitioners (GPs) and hospitals after traumatic brain injury (TBI) in New Zealand. Moore reported that over 90% of the hospital emergency departments who responded had a patient information sheet on TBI but less than half of the GPs had such an information sheet. The quality of the content and appearance of the information sheets was found to be highly variable and it was noted that none of the respondents had access to information in non-written formats such as audiotape, videotape or CD-ROM. This latter finding provided the impetus for an investigation into the use video in information provision for TBI.

There were a number of reasons why this topic appealed to me. I have previously worked in video production and I am still interested in video as a communication medium. My first career was in secondary education and I have maintained an interest in education in other areas both as a volunteer and paid tutor. More recently I have been studying psychology with a particular interest in clinical neuropsychology and TBI. The topic for this research provided an opportunity for me to use my experience and skills with video production and education in a study involving TBI.

1.2 Traumatic Brain Injury

Traumatic brain injury is a major health problem in developed countries like New Zealand. It places great demands on all levels of health services because it not only causes death and disability but it also results in a large number of mild injuries. The consequences of TBI for the person injured can include difficulties in many different areas of physical, cognitive, behavioural, emotional and social functioning. The most common age group affected by TBI are those aged 15 to 24 years (Naugle,

1990). These young people can face many years of disability and lost productive capacity which underlines the impact of TBI on the people injured, their families and society.

Although the injuries involved in mild TBI may appear to be minor they can nonetheless have a substantial impact on health services because they affect a large number of people and can result in long-term disability. The type of problems that can occur after mild TBI are numerous and wide ranging. They include headaches, fatigue and sleep disturbances, as well as problems with memory, attention and concentration and slowness in reactions and information processing (Goldberg, 2001). There can also be emotional and behavioural problems such as irritability, anger outbursts, mood swings, depression, anxiety and social difficulties. These difficulties can hinder return to work and disrupt family and social relationships and this highlights the importance of developing effective interventions for people with mild TBI (Fabiano & Daugherty, 1998).

People with mild TBI and their families can be better prepared to cope with any difficulties after the injury if they are aware of the possible consequences. Research has indicated that interventions which provide information, support and reassurance soon after injury can be effective at reducing the risk of long-term disability after mild TBI (Wade, King, Wenden, Crawford, & Caldwell, 1998). In New Zealand, the Accident Compensation Corporation (ACC) has recommended in its guidelines to clinicians that people with mild TBI be provided with information as part of interventions to enhance recovery and improve outcomes (Accident Compensation Corporation, 2001).

1.3 Patient Information Provision

Information provision is an important intervention to aid recovery from any medical event. The principal method for health consumers to receive information is from discussion with health professionals but recent health policies have encouraged health professionals to spend less time with their patients. This has led to a growth in other means of information provision particularly pamphlets and information sheets (Rankin & Stallings, 2001). The value of information sheets lies in their ability to supplement and reinforce verbal education from health workers. They can correct

any misunderstandings and can be read as often as needed to help patients to retain information and learn more (Rankin & Stallings, 2001).

Patient information can also help to reduce anxiety and can lead to greater adherence to treatment and more appropriate use of health services (Wyatt, 2000). Many patients actively seek information as a coping strategy that helps to reduce the stress and anxiety surrounding their illness (Van der Molen, 1999). The desire for information is not just restricted to patients. The family members of people with TBI report that information is one of their highest needs following the injury (Sinnakaruppan & Williams, 2001).

However, there are deficiencies in many pamphlets and health consumers are often dissatisfied with the information they receive from health professionals (Meredith, Emberton, & Wood, 1995; Van der Molen, 1999). Many patients have limited reading skills and written information is often incomprehensible to them because of inadequate legibility and high reading levels (Arthur, 1995). Some people learn better from non-written material and it has been recommended that information be provided on videotape for people who do not respond well to written information including those with limited reading skills (Holland & Shigaki, 1998; Tooth, Clark, & McKenna, 2000).

1.4 Information Provision by Videotape

Video is used widely in health settings to convey information. An advantage of using video to provide information is its greater ability to attract and maintain the attention of people compared to printed material or audiotapes (Dowrick & Associates, 1991). The popularity and almost universal use of television and video indicates that people generally prefer viewing over reading even when they are literate.

Video can involve viewers personally by encouraging them to identify with the experiences and actions of those on screen. This facility can be used to make information relevant to patients by presenting realistic accounts from people with the same health condition and by modelling health care behaviours (Rankin & Stallings, 2001). Video can also present information in two modes, vision and sound, and this allows for dual coding which can be more effective than single coding in helping

people with TBI who have memory difficulties to learn and retain information (Wilson, 1992).

Research has shown that video is effective at increasing patient knowledge but, in general, it is not more effective than print media (Gagliano, 1988). The use of videotapes in patient education has been associated with increased patient satisfaction (Rankin & Stallings, 2001) and the advantage of video may lie in its greater acceptability and therefore greater use by many patients and their families. Research on the use of video in information provision has involved many different medical conditions but there appears to be a lack of research involving TBI. A search of electronic databases which included PsycInfo, Web of Science, Medline, ERIC, CINAHL, SportDiscus and Dissertation Abstracts produced no relevant research on information provision by videotape in relation to TBI.

1.5 The Current Study

The objective of the current study was to address the lack of information available on videotape for people with TBI and their families in New Zealand and the lack of research into the use of video for information provision in relation to TBI. To address the first issue, a videotape containing information on concussion (mild TBI) was produced as part of the study. The second issue was addressed by investigating the perceived utility of information provision by videotape among people with mild TBI and their families.

With such a high incidence of mild TBI, there are potentially clear benefits to the people injured, their families and society from research that seeks to improve the effectiveness of information provision for this group. The term families or family members will generally be used in this study to refer to those persons who are involved in supporting and caring for people with TBI. However, in situations where a particular relationship such as parent, sibling, partner or friend is relevant, the appropriate term will be used.

In seeking possible participants to receive the videotape, contact was made with staff at the Midcentral Health Concussion Clinic which was established in association with Massey University. During these discussions it was apparent that the first priority of the clinic staff in relation to information provision was to have a

specifically designed brochure containing information about concussion and the clinic's assessment processes to give out to clients and their families. At the same time, a survey of client satisfaction was being planned for the clinic and questions about information provision could be included in that survey. These circumstances provided the framework under which the design of the current study took shape.

A brochure and a videotape containing information about concussion were produced as part of the study and were given to people who attended the Midcentral Health Concussion Clinic. In developing these two resources, the study sought to make a useful contribution towards information provision for people with mild TBI and their families.

In the investigative part of the study the people who attended the Concussion Clinic were surveyed about various aspects of information provision. The aim of the survey was to compare the participants' perceptions about information provision depending on whether they received the videotape and brochure, the brochure only or neither of these two resources. The aspects of information provision investigated were (a) satisfaction with information provision, (b) amount of information received, (c) understanding of concussion, (d) preference for type of information media, and (e) number of times information was referred to.

The thesis is organised into seven chapters. This section, Chapter One, introduces the study and its aims and gives background information on TBI and information provision. A more comprehensive examination of the literature on TBI follows in Chapter Two and on information provision in Chapter Three. Chapter four outlines the development of the current study as it relates to the literature reviewed in previous two chapters and presents the study's hypotheses. The methodology used in the study is described in Chapter Five and the results of the research are reported in Chapter Six. The discussion of these results and their implications is presented in Chapter Seven.

CHAPTER TWO

Traumatic Brain Injury

2.1 Definition

There have been many attempts to provide a definition for traumatic brain injury (TBI) but these efforts have not produced a consensus on how to define TBI (Elovic & Antoinette, 1996). However, there is general agreement about the type of event that results in TBI. The brain can be damaged in many different ways and a number of terms have been used to describe or categorise these different types of injury. In this respect, traumatic brain injury refers to an injury to the brain caused by an external physical force (D'Amato & Rothlisberg, 1997; Elovic & Antoinette, 1996). This definition of TBI includes injuries from accidents and assaults but excludes injuries from causes not involving trauma such as infections, toxins, strokes, anoxia and tumours. It also excludes congenital and degenerative injury as well as injury due to birth trauma (Elovic & Antoinette, 1996). In some of the literature most injuries have been included under the term acquired brain injury which primarily excludes only congenital injuries (D'Amato & Rothlisberg, 1997).

The main difficulty in defining TBI is the lack of consensus over what conditions constitute evidence of brain injury following head trauma (Bigler, 1990; Elovic & Antoinette, 1996). There are some conditions that are accepted as signs of TBI including reduced level of consciousness, amnesia, skull fracture and objective neurological and neuropsychological abnormality (Elovic & Antoinette, 1996). These criteria provide a useful basis for definitions of TBI but they are less effective for detecting minor injuries. The difficulty of differentiating between head trauma that causes minor damage to brain tissue and that which does not underlines much of the lack of agreement among definitions of TBI.

Most definitions include loss of consciousness or an alteration in the level of consciousness as a sign of brain injury but brain injury can occur without a major alteration in the level of consciousness (Bigler, 1990). Superficial head wounds or

minor blows to the head may not affect the brain and yet a sudden movement of the head without it being struck can cause brain injury. It is unlikely that a practical and inclusive definition of TBI can be developed that includes the many minor cases and this makes it difficult to determine the number of people who sustain a TBI (Elovic & Antoinette, 1996).

2.2 Epidemiology

Traumatic brain injury is a major health problem in western countries (Jennett, 1996). It places great demands on all levels of health services because it is not only a leading cause of death and disability but it also leads to a substantial number of minor injuries (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). However, the impact of TBI and other accidental injuries on western health systems is a relatively recent phenomenon. It was only during the middle of the 1900s that trauma replaced contagious fevers as a major health issue (Miller, 1961). From that time the rates of deaths and hospital admissions for TBI continued to increase but they peaked in the mid 1970s and over the last two decades these rates have fallen considerably (Thurman et al., 1999).

It is clear that TBI affects a large number of people each year but there is often a wide variation in the number reported to be involved. Estimates of the number of people sustaining a TBI each year in the United States have varied from 1.5 million to nearly 8 million (Conboy, Barth, & Boll, 1986; Thurman et al., 1999). In New Zealand, the Accident Compensation Corporation (ACC) recorded more than 14,000 new claims for concussion in the year ended June 30, 2002 (J. Visch, personal communication, April 16, 2003) whereas the Head Injury Society of New Zealand (1993) has estimated that 9,000 people are admitted to hospital with a head injury each year.

Epidemiological studies generally report the incidence of TBI, which is the rate at which new cases occur. This statistic varies considerably between different countries, different regions within a country and different studies (Jennett, 1996). Variations in national and regional characteristics contribute towards this variability but there are other reasons as well. Differences in definitions of TBI, hospital admission policies, methods for collecting data, access to medical care and the way people seek or do not seek treatment all act to produce variability in reports of the

incidence of TBI (Jennett, 1996). Many estimates only include people hospitalised with TBI and they are much lower than estimates that include people who were not admitted to hospital. Another factor is that TBI is not a diagnostic category in hospital classification systems like the International Classification of Diseases (ICD) and this can lead to variations in the number of admissions to hospital attributed to TBI (Tate, McDonald, & Lulham, 1998).

Reports from different countries giving the incidence of TBI admissions to hospital per year have varied from 91 to 403 per 100,000 people although most are in the range of 200 to 300 per 100,000 (Jennett, 1996). However, a much greater number of people with TBI are treated in ambulatory care settings including emergency departments, accident and medical centres, concussion clinics and general practitioners' offices (Schootman & Fuortes, 2000; Wrightson & Gronwall, 1998). Data from a self-report survey in the United States reported that the incidence of mild and moderate TBI with loss of consciousness was 618 per 100,000 (Sosin, Sniezek, & Thurman, 1996). In this survey 25% were admitted to hospital, 35% had emergency department care, 14% received non-hospital care and 25% did not seek medical care.

A New Zealand study which investigated mild head injury reported an incidence rate for those seen at hospital but not admitted of 654 per 100,000 and a rate of 689 per 100,000 when those admitted for up to 48 hours are included (Wrightson & Gronwall, 1998). The rate of hospitalisations for TBI has declined over time and a recent survey of visits to emergency departments found that only 17.6% of patients with TBI were hospitalised (Schootman & Fuortes, 2000). In New Zealand, the number of hospital admissions for mild TBI fell by approximately 40% between 1984 and 1993 (Wrightson & Gronwall, 1998).

The prevalence of TBI, which is the proportion of people with TBI at any one time, is even harder to estimate but some studies suggest it may be four times the incidence (Naugle, 1990). Studies of non-clinical populations of college or university students have reported prevalence rates of mild TBI for this group of between 3% and 37% with self-report rates giving the higher estimates (Laforce & Martin-MacLeod, 2001). In a recent survey, 34.9% of university students reported that they had sustained a mild TBI in the past and almost half (47.5%) of them did not seek

medical attention (Laforce & Martin-MacLeod, 2001). It appears that a substantial number of cases of mild head trauma go unreported although just how many of these cases involve mild brain injury depends on the definition used (Bernstein, 1999).

The occurrence of TBI is not random because some individuals are more susceptible to head trauma than others. Epidemiological studies consistently report that the age group with the highest incidence of TBI overall is people aged between 15 to 24 years (Naugle, 1990). However, those aged 75 years and over have been found to have the highest incidence of TBI that results in hospitalisation and death (Thurman et al., 1999) and some studies have found that children aged up to 14 years have the highest incidence of mild TBI (Guerrero, Thurman & Sniezek, 2000; Schootman & Fuortes, 2000). The ratio of males to females who sustain a TBI varies but researchers commonly report that it happens to twice as many males as females (Naugle, 1990; Thurman et al., 1999).

Reports on TBI from different countries consistently agree that the main causes are traffic accidents, falls and assaults although there are considerable variations in the percentage attributable to each cause in different places (Jennett, 1996; Naugle, 1990). Traffic accidents are the main cause of severe and fatal injuries and falls are the main cause of TBI in young children and the elderly (Jennett, 1996; Naugle, 1990). Sports and physical activities join traffic accidents, falls and assaults as prominent causes of mild TBI particularly among young people (Schootman & Fuortes, 2000; Sosin et al., 1996). Alcohol has a prominent role in the occurrence of TBI and it has been estimated that alcohol has been consumed before one third to a half of all TBIs (Dikmen, Donovan, Loberg, Machamer, & Temkin, 1993; Naugle, 1990).

Mortality records indicate that there has been a decline in deaths due to TBI (Sosin, Sniezek, & Waxweiler, 1995). The decline in the death rate was mostly due to a reduction in deaths caused by traffic accidents, which have been overtaken by firearms as the leading cause of deaths from TBI in the United States (Sosin et al., 1995). Survey data also shows a decline in the incidence of mild and moderate TBI which when considered with the mortality data suggests that there has been a decline in the overall incidence of TBI (Sosin et al., 1996). Hospitalisation rates for TBI have declined by nearly 50% in the United States since 1980 and this may be attributable

to successes in injury prevention and changes in hospital admission policies that encourage outpatient care for less severe injuries (Thurman et al., 1999).

2.3 Diagnosis

A major difficulty in determining the number of TBIs that result in hospital admission is that TBI is not a diagnostic category in hospital classification systems such as the ICD (Tate et al., 1998). There are at least twelve ICD codes that can specify TBI and this makes it difficult to identify possible cases of TBI from medical records. Furthermore, these codes describe the occurrence of head injury which does not necessarily involve injury to the brain (Tate et al., 1998). This can lead to inaccuracies in the diagnosis of TBI in hospitals and can have important implications for clinical management and public health planning systems (McNaughton & Wadsworth, 2000; Tate et al., 1998).

A New Zealand study that investigated this issue found substantial inaccuracies in hospital diagnoses of TBI at admission and discharge (McNaughton & Wadsworth, 2000). The study reported that only 32% (21) of the patients admitted with a diagnosis of TBI met the study definition for a 'Definite TBI' and another 18 patients not admitted for TBI did meet the definition. Of those patients discharged with a diagnosis of TBI, only 43% (26) met the definition for 'Definite TBI' (McNaughton & Wadsworth, 2000).

This study examined alcohol consumption because it can also affect the accuracy of diagnosis for TBI. Alcohol excess can imitate the characteristics of TBI and often occurs alongside TBI (Dikmen et al., 1993; McNaughton & Wadsworth, 2000). It was found that almost half (46%) of the patients admitted with a diagnosis of TBI were affected by alcohol. Two thirds of the patients admitted with a diagnosis of TBI but who did not meet the criteria for 'Definite TBI' were intoxicated. This study points out the need for clearer criteria for diagnosing TBI including the measurement of blood alcohol concentration (McNaughton & Wadsworth, 2000).

2.4 Classification

The injuries that result from head trauma can be categorised in different ways. Head injuries and brain injuries can be classified according to the nature of the injury and they can be further classified in relation to the way the injury develops over time. There are also several methods for classifying the severity of the initial injury.

2.4.1 Nature of the injury.

In broad terms, a head injury can be classified as either open or closed (Lezak, 1995). An open head injury involves damage to the skull in which the brain is exposed. In these injuries the skull is usually crushed or penetrated. Most penetrating head wounds are caused by bullets. In closed head injury, which is also called blunt head injury, the brain is not exposed and the skull is generally intact. Open head injuries tend to be more serious and they lead to the majority of fatalities in cases of head trauma (Lezak, 1995).

There are also two broad concepts that are commonly used to describe the nature of any damage to the brain. Damage that is restricted to a discrete region of the brain is referred to as focal injury whereas damage that is spread throughout the brain is referred to as diffuse injury (Lezak, 1995). In practice, the distinction between these two concepts in the injury itself tends to be unclear. Diffuse injuries seldom affect all areas of the brain evenly and most focal injuries occur alongside diffuse effects (Lezak, 1995).

The nature of TBI is also categorised by what occurs over time. There are two main stages in the development of brain injury after head trauma. The first stage is the primary injury which involves the damage caused by the initial trauma to the head. Primary injuries initiate another set of processes in the brain that lead to secondary injuries. These later injuries can be just as damaging as primary injuries and are often more damaging (Lezak, 1995).

The main mechanisms of primary injury are impact force and sudden acceleration or deceleration of the brain (Graham, 1996; Marion, 1996). In most impact injuries both mechanisms cause damage, but the brain can be damaged by sudden movement alone through whiplash of the head, which mainly results in mild or moderate injury (Halliday, 1999). A third and rare mechanism of primary injury

occurs when a trapped head is gradually fractured or crushed by a slow moving load (Halliday, 1999).

The main types of primary injury are contusions (bruises), fractures, lacerations, bleeding and damage to the connections (axons) between brain cells known as diffuse axonal injury (Graham, 1996). Contusions are a form of focal injury caused mainly by contact between the surface of the brain and the skull. They typically occur in the frontal and temporal regions of the brain where it is flung around against the bony protuberances on the base of the skull (Graham, 1996; Lezak, 1995). Bruises at the site of impact are called coup contusions and those that occur at the opposite side of the brain when it rebounds are called contrecoup contusions (Graham, 1996; Lezak, 1995).

At the site of the impact there may be lacerations of the scalp, which can bleed profusely, skull fractures and lacerations of brain tissue and blood vessels (Graham, 1996). Penetrating objects destroy brain tissue along their path and can produce a clean wound with damage restricted to the pathway or more widespread damage due to shock waves and pressure effects (Lezak, 1995). Bleeding can occur in and around the brain (intracranial haemorrhage) and may lead to swellings filled with blood (hematomas) at various places inside the skull (Graham, 1996).

Diffuse axonal injury (DAI) is caused by rotational acceleration of the brain and can produce strain deep within the brain (Halliday, 1999). It plays an important role in TBI because it is a leading cause of severe injury and death (Graham, 1996) as well as being the main form of injury in mild TBI (Alexander, 1995; Goldberg, 2001).

The secondary injuries that occur in TBI include swelling, blockages to blood flow and oxygen supply and increased pressure inside the skull (Graham, 1996). Swelling in the brain is caused by higher blood volume from haemorrhages and fluid which collects (oedema) at damaged tissue. The swelling can lead to an increase in intracranial pressure and the resulting compression of blood vessels can cause blockages in the blood supply (ischemia) and reductions in the flow of cerebral spinal fluid (Lezak, 1995). Ischemia produces an undersupply of oxygen (hypoxia) to sick tissue that badly needs it. Swelling and compression also damages brain tissue and

structures and if the lower brain stem structures concerned with vital functions are compromised this can cause death (Lezak, 1995).

Secondary injuries also result from infections such as meningitis that enter through open head wounds and from changes in neurochemicals that become toxic to brain tissue (Marion, 1996). The division of TBI into primary and secondary injury helped to raise awareness of the role of secondary injury in the complications that occurred after minor head injuries such as when people who were able to talk after the initial injury deteriorated later and developed severe disability or died (Graham, 1996). Much of the progress that has been achieved in improving outcomes after TBI in the last 30 years has been due to advances in medical care that have reduced the impact of secondary injury (Gentleman, 1999).

2.4.2 Severity ratings.

Classification of the severity of the initial injury in TBI is important for treatment procedures and outcome prediction (Lezak, 1995). Severity ratings for TBI commonly focus on the effects of the injury on consciousness, memory, responsiveness and orientation. The severity of TBI has generally been based on a combination of ratings including the Glasgow Coma Scale, the duration of post-traumatic amnesia and the duration of loss of consciousness (Goldberg, 2001). These measures all have limitations in their ability to provide accurate clinical observations. In particular, the ratings often rely on responses from the person injured and the circumstances of the injury can make it difficult or impossible to gauge these responses (Lezak, 1995).

The Glasgow Coma Scale (GCS) is the most commonly used clinical method for measuring the severity of brain injury (Jennett, 1996). It was developed in the 1970s as a clinical scale to provide a measure of the depth and duration of impaired consciousness and coma (Teasdale & Jennett, 1974). Prior to its development there was no commonly recognised way to classify severity of head injury and many of the measures that were used were either too crude or too complex (Gentleman, 1999). The GCS overcame these failings and has become widely accepted (Gentleman, 1999; Lezak, 1995). It provides a classification of the whole range of altered consciousness from confusion to deep coma (Lezak, 1995).

The GCS measures three behavioural responses: eye opening, verbal response and motor response (see Table 1). The total score is the sum of the scores from the three dimensions and it ranges from 3 to 15. A score between 3 and 8 is classified as severe TBI, between 9 and 12 as moderate TBI and between 13 and 15 as mild TBI. The main advantages of the GCS are that it is simple enough to be used by different medical personnel and it is a useful predictor of outcome (Lezak, 1995; Lucas, 1998). However, it does have some inherent limitations. It is less sensitive to injuries in the mild range and people affected by alcohol or drugs can produce unreliable scores (Lezak, 1995). Also, the measurement of some behavioural responses may not be possible because of the injuries or medical procedures. For example, tubes may prevent speech, eyes may not open because they are swollen and limbs may be paralysed or restrained (Lezak, 1995).

Table 1

Glasgow Coma Scale (from Ghajar, 2000).

Eye opening	Score	Motor response	Score	Verbal response	Score
Spontaneous	4	Obeys	6	Oriented	5
To speech	3	Localises	5	Confused	4
To pain	2	Withdraws	4	Inappropriate	3
None	1	Abnormal flexion	3	Incomprehensible	2
		Extensor response	2	None	1
		None	1		

Duration of post-traumatic amnesia is another accepted method for classifying severity of TBI. Post-traumatic amnesia (PTA) refers to a disruption of memory for new information and events that occur after the injury (Lucas, 1998). Duration of PTA is the time period between the injury and the moment when the injured person regains a continuous memory for new events. This method usually classifies a duration of PTA of less than 1 hour as mild TBI, between 1 and 24 hours as moderate TBI and longer than 24 hours as severe TBI. Extensions of this system have been made that have finer gradings for mild and severe (see Table 2). There is also support

for mild TBI to include a duration of PTA of up to 24 hours (Kay et al., 1993; Wrightson & Gronwall, 1998).

Duration of PTA has proven to be useful as a predictor of outcome but it can be difficult to assess accurately and this limits its utility particularly in clinical settings (Binder, 1997). It often needs to be assessed retrospectively such as for people who are discharged before their PTA has ended and these estimates can be unreliable (Bernstein, 1999; Lezak, 1995). Furthermore, it may be difficult to determine when memory for continuous experience returns with people who are confused or have language impairments (Gronwall & Wrightson, 1980, cited in Lezak, 1995).

Table 2

Severity Ratings of TBI Based on Duration of PTA (from Lezak, 1995)

Duration of PTA	Severity
Less than 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

Loss of consciousness (LOC) is a common feature of TBI and the length of time it takes for a person to regain consciousness, or duration of LOC, has also been used to classify severity. In one system for grading duration of LOC, less than 30 minutes represents a mild TBI, up to 24 hours a moderate TBI and more than 24 hours a severe TBI (Kraus, 1999). The injured person may not be able to provide a reliable estimate of the duration of LOC, however, information in accident reports may be useful (Lucas, 1998). The usefulness of this measure of severity is limited by the lack of consensus among the different grading systems that have been published (Lucas, 1998).

The different levels of severity for TBI exist on a continuum without a clear transition between levels and therefore the divisions of severity that have been

specified within the various scales are largely arbitrary (Alexander, 1995). These severity scales correlate fairly well with outcome for moderate and severe TBI but they are less reliable for mild TBI and the wide range of outcomes that follow mild TBI continue to present a challenge for clinicians (Kraus, 1999).

2.5 Consequences

The consequences of brain injury vary widely and are influenced by a number of factors related to the injury itself and the person injured (Lezak, 1995). These factors include the nature, extent and location of the injury, individual differences in brain structure and physiology as well as age, gender, physical condition and psychosocial background and status (Lezak, 1995). The complex nature of these factors means that the consequences of the injury are also complex and difficult to predict. While people with different brain injuries are likely to have different impairments, those with similar injuries may also have different impairments and people with different injuries may have similar impairments (Lezak, 1995). For the injured person, the effects of TBI are seldom limited to one group of symptoms that affect only one part of his or her life (National Institutes of Health [NIH] Consensus Development Panel, 1999). Brain injury can lead to many difficulties in a person's physical, cognitive, behavioural, emotional and social functioning.

2.5.1 Physical impairments.

There are a number of different physical functions that can be affected by TBI and many occur in the sensory and motor domains (Cullum, Kuck, & Ruff, 1990). In the sensory area there may be impairments in vision, hearing and sense of smell as well as a reduced tolerance (hypersensitivity) to various stimuli such as light, noise and heat. Impairments in motor function include different degrees of paralysis (hemiplegia and hemiparesis), gait disturbances and reduced motor speed and coordination (Cullum et al., 1990). Other common physical difficulties after TBI include seizures, headaches, sleep disorders and reduced energy. Physical impairments are generally apparent within the first few days or months after the injury depending on the severity of the initial trauma (NIH Consensus Development Panel, 1999).

2.5.2 Cognitive impairments.

Traumatic brain injury produces a wide range of cognitive impairments that can occur on their own or in combination and they affect each person differently (NIH Consensus Development Panel, 1999). Among the most persistent problems are memory impairments and difficulties in attention and concentration. Impairments in language use and visual perception are also common although they are often not recognised (NIH Consensus Development Panel, 1999). There are a range of skills involved in executive functioning that are also affected by TBI. These skills include information processing, problem solving, abstract reasoning, insight, judgement, planning and organisation (NIH Consensus Development Panel, 1999). Impairments in these skills are associated with injuries to the frontal lobe of the brain. The cognitive consequences of TBI affect extensive areas of functioning and they have a greater impact on outcome than the physical consequences (Dombovy, 1998).

2.5.3 Behavioural and emotional changes.

The behavioural and emotional changes associated with TBI are also referred to as personality disturbances and there is a long list of terms that have been used in the literature to refer to these disturbances (Lezak & O'Brien, 1990; Prigatano, 1992). Most of these difficulties can be classified as active disturbances and they include irritability, agitation, anger, aggressiveness, impatience, impulsiveness, disinhibition, emotional lability, anxiety, paranoia, and inappropriate social responses. Other common difficulties of a passive nature include apathy, withdrawal, blunted affect, and depression (Lezak & O'Brien, 1990; Prigatano, 1992).

There are doubts as to whether many of these emotional and behavioural difficulties are a direct consequence of TBI (Hanks, Temkin, Machamer, & Dikmen, 1999). Injury to the brain can directly affect the control or expression of affective responses and the cognitive processes that some emotional and behavioural responses depend on (Prigatano, 1992). However, the role of these direct effects in personality disturbances is uncertain. Research has found no significant difference between the level of emotional and behavioural difficulties in people with TBI and people with other trauma injuries (Curran, Ponsford, & Crowe, 2000; Hanks et al., 1999). Many personality disturbances may occur more as an indirect consequence of TBI and may

reflect the pre-injury psychosocial characteristics of patients as well as their reactions to the trauma and the resulting impairments (Curran et al., 2000; Hanks et al., 1999).

Although the role of TBI in these difficulties is unclear, their impact on the person injured and their families is apparent. The emotional and behavioural consequences of TBI disrupt family and social relationships and hinder return to work and are considered to be the most enduring and disabling difficulties for the person with TBI and their families (Brooks, 1991; Lezak & O'Brien, 1990).

2.5.4 Social disability.

The impact of TBI extends beyond the initial injury and can affect many areas of social functioning with potentially serious consequences (NIH Consensus Development Panel, 1999). People with high levels of impairment after TBI may become dependent on others for assistance with activities of daily living (Cullum et al., 1990). Many people cannot return to their previous level of employment and there is an increased risk of chronic unemployment after TBI. The emotional and behavioural changes that follow TBI can have an adverse affect on interpersonal relationships and can create difficulties for employment. Children with TBI face barriers to their educational progress, social development and their ability to fulfil their potential because their impairments (NIH Consensus Development Panel, 1999).

These social consequences of TBI can have a spiralling effect. Unemployment places a financial strain on the person with TBI and their families and creates an additional burden for social agencies (NIH Consensus Development Panel, 1999). Relationship difficulties and financial strain can have an adverse affect on marriages. Increased dependence, loss of employment and disturbed relationships can result in social isolation and feelings of alienation (Cullum et al., 1990). These debilitating social consequences place considerable strain on the coping skills of people with TBI and they face an increased risk of drug and alcohol abuse, divorce and suicide (NIH Consensus Development Panel, 1999).

2.5.5 Awareness of impairments.

The consequences of TBI present a challenge for those injured, their families and rehabilitation professionals. The rehabilitation process can be further

complicated because some people show a lack of awareness of their impairments following TBI. This lack of awareness can be due to a loss of insight (anosognosia) as a direct consequence of the brain injury (Prigatano, 1999; Wallace & Bogner, 2000). It can also occur as an indirect consequence of the injury when the person injured denies their impairments as a psychological reaction to these difficulties (Prigatano, 1992). More commonly there is a reduced ability to recognise problems due to a combination of diminished insight and psychologically-based denial (Prigatano, 1992, 1999; Sbordone, Seyranian, & Ruff, 1998).

Studies in this area have shown that people with TBI tend to underestimate their difficulties in certain activities and behaviours compared to the perceptions of their families, partners or significant others (Prigatano, Altman, & O'Brien, 1990; Sbordone et al., 1998; Wallace & Bogner, 2000). People with TBI have been found to report significantly less cognitive, behavioural and emotional problems but no difference in the number of physical problems compared to those observed by significant others (Sbordone et al., 1998). This study supports the role of diminished insight in the under-reporting of problems because the participants were all pursuing financial compensation and would have been more likely to exaggerate their symptoms rather than deny them (Sbordone et al., 1998). The similarity in reports of physical problems may be because they require a lower level of cognitive awareness to identify and describe and because it is more acceptable to complain about them (Sbordone et al., 1998).

The subjective experiences and perceived needs of people with brain injury have received little attention from researchers (Prigatano, 1999). Patients often report being frustrated and confused by their experiences and their families' behaviour and yet these two common problems have been neglected in the literature (Prigatano, 1999). Although the subjective complaints of people with TBI can be unreliable it is also unreliable to rely solely on neuropsychological assessment to quantify a person's degree of disability. (Prigatano, 1999). The results of neuropsychological tests can underestimate the impact of brain dysfunction on a person's daily functioning which involves less structure, more distractions, unusual situations and greater flexibility (Sbordone et al., 1998).

2.5.6 Recovery and outcomes.

The outcomes of brain injury vary widely and range from near complete recovery or mild impairment through to severe disability, vegetative state or death (Kolb & Whishaw, 1996). The number of deaths from TBI has fallen considerably in the last thirty years following dramatic improvements in trauma care (Gentleman, 1999). There were fears that the falling mortality rate would lead to higher numbers of people left in a severely disabled or vegetative state but this has not happened (Ghajar, 2000). The proportion of people in these serious states has remained stable and overall there has been an increase in the proportion of people with better outcomes following severe TBI (Ghajar, 2000).

The rate at which brain function recovers after TBI and the amount of recovery that occurs varies considerably between individuals and is difficult to predict as not enough is yet known about the processes involved (Gronwall, Wrightson, & Waddell, 1990). However, it is known that recovery is related to the location, size, nature and severity of the injury as well as age at injury, time since injury and pre-injury intelligence (Prigatano, 1999). The more serious the initial injury is, the longer it takes to recover and the less complete the recovery is likely to be (Gronwall et al., 1990; Hellowell, Taylor, & Pentland, 1999).

However, the effect of the severity of the initial injury may not be apparent in everyday functioning. In a study of people with moderate and severe TBI, the patterns of the difficulties in everyday functioning reported by relatives were similar regardless of the severity of the injury (Hellowell et al., 1999). In general, most recovery occurs in the first six months after the injury and, although it tends to slow after this, there can continue to be improvement for ten or more years (Gronwall et al., 1990).

2.6 Effects on Family Members

In the early 1970s several studies were instrumental in highlighting the impact that TBI can have on the families of the person injured (Perlesz, Kinsella, & Crowe, 1999). The long-term care of people with TBI is often taken on by family members and most of these carers are women (Perlesz, Kinsella, & Crowe, 2000; Serio, Kreutzer, & Witol, 1997). In a recent study of the impact of TBI on carers one year

after the injury, 47% had experienced some negative impact on their lives and a further 20% had experienced considerable impact (Wallace et al., 1998).

The nature of the effects experienced by families following TBI include increased subjective burden, higher levels of anxiety and depression, reduced support networks, financial strain, relationship problems and deteriorating family functioning (Perlesz et al., 1999). Research has identified differences in the type of effects experienced by partners as compared to parents of the person injured. Partners are more likely to experience greater role changes, less financial and parenting support, losses in sexual intimacy and empathic communication, concerns about their children and little social opportunity to mourn these changes (Perlesz et al., 1999). In contrast, parents tend to face concerns about the long-term future of their adult children with TBI and issues around dependence and independence as their children recover.

However, a review of research on family psychosocial outcome after TBI found that there was a bias in the literature towards viewing family outcome in terms of stress and burden and it emphasised that many families do not experience negative effects (Perlesz et al., 1999). In a study since that review, between 51% and 80% of primary carers (depending on the outcome measure considered) reported that they were satisfied with their families and were not psychologically distressed (Perlesz et al., 2000).

2.7 Mild TBI and Post-Concussion Syndrome

The vast majority of cases of TBI are classified as mild TBI and most do not involve admission to hospital (Goldberg, 2001). By one estimate between 70% and 90% of head injuries are classified as mild TBI (Laforce & Martin-MacLeod, 2001). There is a consensus on some criteria for defining mild TBI including a GCS score of 13 to 15, duration of LOC of less than 30 minutes, brief or no hospitalisation and no abnormal neurological signs or neuroimaging data (Binder, 1997). The accepted duration of PTA for mild TBI is usually either, less than 1 hour or up to 24 hours (Binder, 1997; Kay et al., 1993).

These criteria tend to indicate upper limits of severity for mild TBI but there is less agreement on criteria for detecting minor cases of mild TBI (Elovic & Antoinette, 1996). At the minor end of the spectrum of mild TBI, the American Congress of

Rehabilitation Medicine has determined that an alteration in mental state following head trauma, such as feeling dazed, disoriented or confused, is an acceptable criteria for defining mild TBI (Kay et al., 1993). The criteria used for mild TBI have a number of limitations. In particular, an initial GCS score of 13-15 can involve more severe damage, and estimates of duration of PTA and LOC are more unreliable in mild TBI compared to moderate or severe TBI (Bernstein, 1999).

Mild TBI makes considerable demands on the resources of healthcare systems because of the large numbers of people involved and because many of them go on to develop persistent symptoms that lead to long-term disability (Jennett, 1996). Approximately half of all disability days due to head injury in the United States have been attributed to mild TBI (Fife, 1987). It also causes concern because of the slight but very real danger of serious early complications (Jennett, 1996). Although there can be persistent symptoms after mild TBI, the majority of people recover to levels comparable to their pre-injury functioning without long-term impairment (Bernstein, 1999; Fabiano & Daugherty, 1998). A meta-analytic review examined a number of neuropsychological studies of adults with mild TBI at 3 months to longer than a year after the injury. The results suggested that there was an association between mild TBI and cognitive impairments in about 5% of patients or a reduction of about 5% in cognitive functioning in most patients (Binder, Rohling, & Larrabee, 1997).

There are a variety of symptoms that frequently develop after mild TBI. The physical symptoms include headache, fatigue, sleep disturbance, dizziness, blurred vision and hypersensitivity to light and sound (Bernstein, 1999; Goldberg, 2001). The cognitive complaints involve problems with memory, attention and concentration and slowness in reactions and information processing. Emotional and behavioural symptoms include irritability, anger outbursts, mood swings, depression, anxiety and social difficulties (Bernstein, 1999; Goldberg, 2001). The symptoms are common in the first few days and weeks but they usually resolve over time (Bernstein, 1999; Binder, 1997). In one study, 58% of patients with mild TBI had one or more symptom at 1 month and 25% had symptoms at 6 months after the injury (Bazarian et al., 1999). A literature review of recovery from mild TBI found that there was considerable evidence that symptoms resolve within 6 months but there was also

increasing evidence that these difficulties can be long term or even permanent in some cases (Bernstein, 1999).

When the symptoms associated with mild TBI persist and form a clear symptom complex this is referred to as post-concussion syndrome (PCS) (Goldberg, 2001). The term concussion is often used when describing mild head trauma particularly in relation to sports injuries (Bernstein, 1999). The detrimental consequences of mild TBI can last for months even years. The rate at which symptoms persist is uncertain and studies show a great range in the incidence of reported symptoms after one year (Bernstein, 1999; Binder, 1997). It appears that between 7% and up to 15% of people still have disabling symptoms one year after the injury (Alexander, 1995; Bazarian et al., 1999; Binder, 1997).

The diagnosis of PCS has been controversial for over a century and it is not widely accepted (Binder, 1997; Fabiano & Daugherty, 1998). Although there is general agreement on the symptoms associated with PCS there are those who object to the term post-concussion syndrome because of the heterogeneity of the disorder (Zasler, 1996). Binder (1997) has argued that the symptoms of PCS do not appear together with the consistency associated with the term syndrome and they are not specific to TBI. There are a number of medical conditions such as alcoholism, hypertension, migraine, diabetes, depression, anxiety and chronic pain that can produce the same symptoms as PCS (Alexander, 1995; Binder, 1997). Two of these conditions, alcohol abuse and chronic pain, are common in people with mild TBI (Alexander, 1995; Binder, 1997). In the study by Bazarian et al. (1999) discussed above, 34% of the controls (orthopaedic patients with no head injuries) also had one or more symptoms of PCS at 1 month after their injury.

The factors that may influence the development of chronic PCS are not yet delineated although several factors have been associated with lingering symptoms including lower levels of education, occupational status and pre-injury psychosocial health as well as advanced age and ongoing litigation (Alexander, 1995; Binder, 1997). The role of litigation and financial incentives in the development of PCS has long been a contentious issue but there is increasing evidence that the presence of financial incentives is associated with more symptoms and greater disability (Binder & Rohling, 1996). A meta-analytic review of the effect of financial incentives on the

level of symptoms and disability after TBI found a moderate but significant effect size of 0.47 and the data suggested that the effect was stronger for mild TBI than more severe TBI. (Binder & Rohling, 1996). It is clear that development of PCS following TBI is a complex process that involves many factors and there is much about the nature and influence of these factors that is yet to be discovered (Goldberg, 2001).

Another concern in relation to TBI in general as well as mild TBI is that people who have sustained a TBI are at a greater risk of incurring another TBI (Naugle, 1990). This can have several implications in relation to mild TBI. People who incur a second mild TBI may be at a greater risk of developing the lingering symptoms associated with PCS (Alexander, 1995; Binder, 1997). There is also evidence that a second even mild TBI may lead to greater impairment than if it had been a first injury. An early New Zealand study with a small sample reported that people with a second concussion had delayed recovery and a greater reduction in information procession speed compared to those with a first concussion and this lead the authors to suggest that the effects of concussion were cumulative (Gronwall & Wrightson, 1975).

This topic is important to the management of concussion among sports people but there has been considerable disagreement regarding guidelines for returning to sports after concussion due to a lack of scientific data to guide efforts in this area (Wilberger, 1999). Interest in the topic has grown rapidly and a recent study with a large number of university football players in the United States reported that participants with a history of 2 or more concussions had significantly lower performances on neuropsychological tests than participants with a history of one or no concussions (Collins et al., 1999). A repeated case of concussion can have catastrophic consequences if the second concussion occurs after a relatively brief period of time and before the symptoms from the previous TBI have fully cleared (Cantu & Voy, 1995). Even though the second injury may be minor the person can deteriorate rapidly from a conscious state to a coma within minutes and may die later. This situation is rare and is known as second impact syndrome (Cantu & Voy, 1995).

There is often a delay of weeks or months before people seek help for persistent symptoms following mild TBI (Schootman & Fuortes, 2000; Wrightson & Gronwall, 1998). In some instances this can occur because of delayed diagnosis particularly in cases of multiple trauma. Orthopaedic and tissue injuries are often more apparent and

urgent at onset and mild TBI may be overlooked initially while these other medical problems are attended to (Clements, 1997; Kay et al., 1993).

The key to interventions that can reduce the risk of the symptoms associated with PCS from becoming chronic and intractable is to respond soon after the injury (Goldberg, 2001). A randomised controlled trial with TBI patients reported that those who received an early intervention had significantly less social disability and fewer post-concussion symptoms at six months than patients who did not receive the intervention (Wade et al., 1998). The early intervention provided information, support and advice and further interventions as needed including neuropsychological assessment and therapy. In a study of children with mild TBI, the early intervention group who received an information booklet were reported to have less anxiety and fewer symptoms associated with PCS at three months after the injury compared to those who did not receive the booklet (Ponsford et al., 2001).

There is also evidence that interventions for mild TBI need not be prolonged if they are applied soon after the injury (Paniak, Toller-Lobe, Durand, & Nagy, 1998). In a comparison of two treatment groups, those people with mild TBI who received a brief educational intervention and reassurance did not differ on any outcome variable or satisfaction with service at 3 months and at 12 months compared to those who received more extensive assessment, education and treatment if needed (Paniak et al., 1998; Paniak, Toller-Lobe, Reynolds, Melnyk, & Nagy, 2000). The improvements seen at 3 months in both groups were maintained at 12 months although there was negligible further improvement after 3 months (Paniak et al., 2000).

The research above has revealed that early interventions that include education and information provision can be effective at reducing long-term disability in people with mild TBI. Information provision has become an increasingly important part of health services and these studies underline its value in interventions for mild TBI. Further research that seeks to improve the effectiveness of information provision has an important role to play in efforts to reduce the impact of mild TBI on the people injured, their families and health services.

CHAPTER THREE

Patient Information Provision

3.1 Patient Education

Patient education has become a central aspect of the care provided by health services (Rankin & Stallings, 2001). The aim of patient education is to improve the health outcomes of patients by promoting healthy behaviour and by involving patients in their own care (Rankin & Stallings, 2001). At its centre is the recognition that the best case managers for patients are the patients themselves. Recent reforms in health care delivery that have produced shorter hospital stays and increasing use of ambulatory and office-based care have also emphasised that health is an individual responsibility (Krouse, 2001; Wyatt, 2000). In this respect, education has a role in strategies that aim to promote informed choice by the patient and increase adherence to treatment.

A patient's ability to cope during an illness can be undermined by a feeling of powerlessness. Education can help to combat feelings of helplessness by increasing the ability of patients to make decisions about their care (Rankin & Stallings, 2001). Patient education is also at the core of discharge planning. People are now spending less time in hospital and are leaving earlier in the recovery process. This has raised the importance of discharge planning and education in helping patients and their families to develop and implement a plan of care. Patient education has a vital role throughout the health care system and it is an important feature of quality health care (Rankin & Stallings, 2001).

3.2 Information Provision

A fundamental role of patient education is for the health consumer to gain knowledge and the provision of information is at the core of this process (Foltz & Sullivan, 1999). Health consumers primarily receive information from discussion with health professionals but this approach has come under pressure from recent health policies which encourage health professionals to spend less time with their

patients (Rankin & Stallings, 2001). This has led to a growth in the importance of other methods of information provision particularly pamphlets and information sheets which are the most common forms of patient information (Kenny et al., 1998; Meredith et al., 1995). Other types of media used for delivering information include audiocassettes, videotapes, computer tutorials, internet resources, videodisks and visual displays such as posters and bulletin boards.

The value of patient information lies in its ability to supplement and reinforce verbal education from health workers (Arthur, 1995; Dixon & Park, 1990; Rankin & Stallings, 2001). Patients frequently forget or misunderstand much of what is discussed with health professionals and patient information has a role in helping them to retain what they are told (Kenny et al., 1998). A New Zealand study of stroke survivors reported that 18% of the participants asked similar questions about stroke at different survey times over two years despite having received careful explanations each time they asked (Hanger, Walker, Paterson, McBride, & Sainsbury, 1998). Patient information can act as a back-up system that can be referred to whenever necessary to help people to clarify and retain information and to correct any misconceptions they may have (Wiles, Pain, Buckland, & McLellan, 1998).

Information taken home by patients and their families can be absorbed later at a time and pace that suits the individual. It can also include additional information that allows people to learn more about their health condition. Some health situations and problems only become apparent after discharge such as baby care and feeding and information provision is particularly important for those circumstances (Rankin & Stallings, 2001). The act of giving a pamphlet may be received positively by patients and may enhance their relationship with health providers (Kenny et al., 1998). The knowledge gained from patient information can help to reduce anxiety, improve adherence to treatment and lead to more appropriate use of health services (Buck, 1998; Mumford, 1997; Wyatt, 2000).

The demand for health information from patients has been increasing (Krouse, 2001; Meredith et al., 1995). Information-seeking behaviour is an important strategy that helps many patients to cope with and reduce stress (Van der Molen, 1999). Information provides knowledge that helps them to manage the physical effects of their illness and treatment and this can increase their feeling of having control and

ease their feelings of vulnerability and confusion. Access to appropriate and understandable information at the right time for people with TBI can alleviate distress by promoting the use of problem solving strategies and a positive outlook in preference to wishful thinking or blaming (Curran et al., 2000).

With TBI the importance of providing information to caregivers as well as patients has been increasingly recognised (Junque, Bruna, & Mataro, 1997; Wallace et al., 1998). Family members of people with a brain injury consistently report that information is one of their greatest if not their most important need following the injury (McPherson, McNaughton, & Pentland, 2000; Serio et al., 1997; Sinnakaruppan & Williams, 2001). In many cases the carer's need for information is not related to the severity of the injury or the degree of impairments (McPherson et al., 2000). The potential long-term consequences of TBI mean that the need for information by families can continue long after the injury. In one study of families of people with TBI at 1 to 24 years after injury, 43 out of 63 of the relatives reported a high need for information, another 14 had some need and only 6 had no need (Junque et al., 1997).

The importance of information provision has been acknowledged in New Zealand through the development of the Code of Health and Disability Services Consumers' Rights (Health and Disability Commissioner, n.d.). The right of every consumer to information is outlined in Right 6 of the Code. Information provision is also an essential part of Right 7, which grants consumers the right to make an informed choice and give informed consent. There is considerable evidence that patients want more information to assist them to make decisions about treatment options (Barry, 2002; Deyo, 2001). This is consistent with the goal of patient education to involve the patients as key decision makers in their own treatment (Deyo, 2001; Rankin & Stallings, 2001).

Information provision is also being emphasised for financial reasons. The cost of health care has increased greatly in recent years and the challenge for health providers is to find the optimum use of limited health resources (Levin-Zamir & Peterburg, 2001). This has led to a greater emphasis on self-management and individual responsibility in health care (Fries, 1998; Wyatt, 2000). An important aspect of efforts to promote self-management skills in health is the provision of

information (Levin-Zamir & Peterburg, 2001). Research has shown that health education programmes that promote healthy lifestyles, individual responsibility, self-management skills and appropriate use of health services can produce savings in health services well in excess of the cost of the education (Aldana, 2001; Fries, 1998).

The benefits of information provision for patients are apparent in the literature and yet there may be some drawbacks as well. A greater focus on informing patients about various health issues may create a society of worried well (Wyatt, 2000). Contact with health professionals may be prolonged because patients have more questions or have received misleading information that needs to be countered. From another perspective, an increased reliance on providing information outside of clinical contact may undermine the doctor-patient relationship (Wyatt, 2000). There is also the possibility that information providers may manipulate health consumers to suit their own ends. Although these drawbacks do not negate the clear need to provide health information to patients and their families, it is important that information providers aim to limit any disadvantages of doing so (Wyatt, 2000). Just as important is the need to ensure that information provision is effective at what it aims to achieve.

3.3 Limitations in Information Provision

There have been numerous reports in the literature of shortcomings in the communication of information and dissatisfaction among patients with information they have received from health professionals (Meredith et al., 1995; Van der Molen, 1999). A recent audit of a stroke service found that 40% of patients and carers were dissatisfied with the information they received during hospital care (Rodgers, Bond, & Curlless, 2001). Inadequate communication skills in health workers can be a cause of dissatisfaction (Van der Molen, 1999). In some cases people report that they were not given enough information. A study of 62 patients with a variety of common medical conditions reported that most of the patients had wanted more information about their condition and treatments than they had received (Coulter, Entwistle, & Gilbert, 1999). However, it is also important not to overwhelm patients with too much information and finding the right balance can be difficult (Coulter et al., 1999).

Many health consumers receive information that may be accurate but is not relevant to their situation (Levin-Zamir & Peterburg, 2001). Patient information is often based on what health workers perceive is needed rather than what patients and carers want (Rodgers et al., 2001; Van der Molen, 1999). This can lead to the inclusion of technical details that are not helpful to health consumers (Coulter et al., 1999). Although these limitations in patient information have been identified there is still not enough known about the most effective and acceptable way to provide information to patients and carers (McPherson et al., 2000; Rodgers et al., 2001).

Information providers face a number of challenges in meeting the information needs of people with TBI and their families. The heterogeneity of the concerns that arise after a brain injury makes it difficult to provide material relevant to all patients and their families (McPherson et al., 2000). This situation is further complicated by the fact that the kind of information needed by people with TBI and their carers tends to change over time (Holland & Shigaki, 1998). In one study of the information needs of carers of people with a brain injury, the majority of carers reported that they wanted more information even though the patient had recently been discharged from a comprehensive rehabilitation programme that included patient and carer education (McPherson et al., 2000).

Despite the difficulties of meeting the information needs of some health consumers there is evidence that information provision can be effective. Two literature reviews of written patient information have reported that written information can increase knowledge, aid recall of advice, reduce anxiety and contribute to increased patient satisfaction and improved outcomes (Arthur, 1995; Kenny et al., 1998). In a recent study of information provided to carers of people with TBI, the great majority of carers (20 out of 26) reported that an information booklet they received was very helpful and only one carer reported that it was not helpful (Morris, 2001). However, there is an important limitation that is specific to written information. Many health consumers cannot read the patient information they receive (Levin-Zamir & Peterburg, 2001). This issue has focused attention on the literacy levels of health consumers and the readability and legibility of printed health information.

3.4 Literacy and Readability of Patient Information

People who use health services are required to read increasing amounts of written information (Dixon & Park, 1990; Murphy, Chesson, Walker, Arnold, & Chesson, 2000). However, the provision of written materials to health consumers does not necessarily mean that knowledge is transferred (Rankin & Stallings, 2001). The ability of patients to understand written information is hampered by limited literacy skills, learning styles that prefer non-print formats and the effect of disease and treatment on information processing (Foltz & Sullivan, 1999).

There have been a number of reports in the literature that written information is often incomprehensible to many patients because of inadequate legibility and high reading levels (Arthur, 1995). More recent research has shown that these shortcomings still persist. A national survey in Great Britain found that many of the leaflets provided by palliative care units failed to meet basic guidelines on legibility and readability and that 64% of the leaflets could be understood by only an estimated 40% of the population (Payne, Large, Jarrett, & Turner, 2000). An unpublished study of written information available for people with TBI and their families in New Zealand found that many leaflets had inadequate legibility and a reading level above what is recommended for the general population (Moore, 2001).

The widespread nature of low literacy levels among the general population was highlighted by a survey in the United States which found that approximately one quarter of adults had only rudimentary reading skills and another quarter had limited reading skills (Weiss et al., 1998). Literacy skills that are adequate for home or work may be marginal or inadequate in a health setting. A survey of hospital patients found that 41.6% could not understand directions for taking medicine on an empty stomach, 26% did not understand information about when their next appointment was due and 59.5% did not understand a standard informed consent document which is a clear ethical concern (Williams et al., 1995).

The importance of literacy level to health was made clear by research which found that lower reading skills were associated with poorer health status and higher use and costs of health services (Weiss et al., 1998). This may be particularly problematic for older people who have a higher risk of illness and disability and may have lower literacy levels than the general population (Tooth et al., 2000; Weiss,

Reed, & Kligman, 1995). There is a growing recognition that limitations in the reading skills of patients need to be considered when communicating about health issues (Levin-Zamir & Peterburg, 2001).

The dominance of written materials in information provision may also be a disadvantage for people who learn better from non-written forms of information (Foltz & Sullivan, 1999). Many people, including some with high educational levels, do not like reading or do not retain what they read (Rankin & Stallings, 2001). Some people respond better to information provided on videotape (Holland & Shigaki, 1998). A study of people aged 60 years and over found that television was their primary source of information regardless of their literacy level (Weiss et al., 1995). In this group, 97% obtained information from television, 51% from newspapers, 23% from radio and 19% from magazines (Weiss et al., 1995). However, in another study a focus group of patients did not have a clear preference for video, audio, computer based or printed material (Coulter et al., 1999).

For information to be effective it needs to be presented in a form that is acceptable to patients (Coulter et al., 1999). There has been a consistent call in the literature for health information to be provided on videotape in order to improve the suitability of the information to people with limited reading skills and people with different learning styles and preferences (Foltz & Sullivan, 1999; Holland & Shigaki, 1998; Tooth et al., 2000; Weiss et al., 1995; Wyatt, 2000).

3.5 Information Provision by Videotape

Television has had a substantial impact on society and that impact shows little sign of diminishing (Dowrick & Associates, 1991). The popularity and pervasive use of television as well as its ability to be entertaining and informative means that it influences knowledge, attitudes and skills (Rankin & Stallings, 2001). The amount of time people spend watching television and videotapes indicates that they generally prefer viewing over reading even when they are literate (Gagliano, 1988). The use of video in education including health education is widespread. Educational videos generally aim to provide information but they may also be used to influence attitudes and promote skill development (Dowrick & Associates, 1991).

An advantage of using video to provide information is its greater ability to attract the attention of people particularly compared to audiotapes or printed material (Dowrick & Associates, 1991). A key reason for this is that video can portray the human presence, which is still a compelling stimulus in today's world (Dowrick & Associates, 1991). Having gained the attention of viewers, video has other properties that allow it to maintain their attention and interest. It can involve viewers personally by encouraging them to identify with the experiences of those on screen and to project themselves into the situations being portrayed. (Dowrick & Associates, 1991). The impact of what is being presented can also be increased through the use of various production techniques that can enhance the effect of the sound and the visual images. The ability of video to present experiences, places and situations that replicate life, facilitates learning by encouraging people to explore attitudes and understandings (Rankin & Stallings, 2001).

These properties have seen videotapes become a popular educational tool and the use of video in many different health care settings has grown in recent years (Parrish & Babbitt, 1991; Rankin & Stallings, 2001). This growth can be attributed to three factors: (a) the emergence of relatively inexpensive video equipment, (b) the need for structured and standardised approaches to patient education and (c) a greater emphasis on cost effective health care (Parrish & Babbitt, 1991). The production of a videotape is more expensive than verbal instruction or live modelling but it can be used repeatedly to convey standardised information to patients and their families in a manner that is effective and uses staff time and cost efficiently (Parrish & Babbitt, 1991). Furthermore, the production of extra copies of a videotape is relatively inexpensive (Dowrick & Associates, 1991).

Videotapes in health care services are used mostly to provide information to patients, to prepare them for medical procedures and to teach them self-care skills (Parrish & Babbitt, 1991). They can be made relevant to viewers with a particular health concern by answering commonly asked questions and by presenting realistic accounts from people with the same health condition and issues (Rankin & Stallings, 2001). Video is an ideal medium for portraying the procedures involved in medical operations and for modelling the behaviours and skills associated with self-care. Videotapes can be viewed by patients and their families as often as needed which

allows them to assimilate the information at their own pace. They can be used in group settings to convey information efficiently and to promote discussion (Parrish & Babbitt, 1991). In overall terms, the use of videotapes to provide information should reflect the role of information provision in general and that is to support the teaching of health workers rather than replace it (Rankin & Stallings, 2001).

During the 1960s there was much debate over whether the influence of television as a communication medium was greater than the influence of the content of the programmes (Dowrick & Associates, 1991). The power of television to attract viewers is clear, however, there is evidence that the influence of video on learning is irrelevant. A review of comparison studies of different instructional media concluded that in five decades of research there was consistent evidence that no particular media produced greater learning benefits and only the content influenced learning (Clark, 1983). Those studies that showed advantages of one medium over another were found to be confounded by the uncontrolled effects of instructional method and novelty (Clark, 1983).

A further review by Gagliano (1988) examined the efficacy of video in patient education compared to traditional methods of education. Although video was sometimes more effective at increasing short-term knowledge it was found that, in general, video offered no advantage over the other methods at increasing short-term and long-term knowledge or compliance with medical regimens (Gagliano, 1988). The results of a recent study of patients with a sleep disorder are consistent with this review. The patients either watched a videotape or read a brochure containing similar information about sleep apnea and the videotape group showed significantly greater short-term knowledge than the brochure group in only 3 out of the 11 areas of knowledge tested (Murphy et al., 2000).

Research also suggests that video is no more effective than print media at conveying information to people with limited reading skills. In a study involving cancer patients with limited literacy skills, the participants were randomly assigned into three groups to receive either a booklet, a videotape, or no intervention (Meade, McKinney, & Barnas, 1994). The booklet and the videotape contained similar health information that was specifically designed for low literacy levels. The study found that both the videotape and booklet intervention significantly increased patient

knowledge about cancer compared to the control group but neither intervention was more effective than the other (Mead et al., 1994). The sleep disorders study by Murphy et al. (2000) also indicated that the properties of video are not enough on their own to overcome low literacy levels. In that study, the reading level of the video script and brochure was too high for 40% of the participants and the low-level readers missed much of the content even when it was presented on video. Among the participants with a low reading level, the videotape group showed significantly greater short-term knowledge than the brochure group in only 2 out of the 11 areas of knowledge tested (Murphy et al., 2000).

Although the effectiveness of video in information provision appears to be mostly on a par with other media it may have advantages for people with memory difficulties. Video has the capacity to convey information in both visual and auditory modes and dual-modality presentation techniques can increase the effectiveness of memory when compared to presentation in a single mode (Mousavi, Low & Sweller, 1995). People with TBI commonly have memory difficulties and information provision by videotape allows for dual coding of information, which may give them a greater ability to learn and retain information than single coding (Wilson, 1992).

There is also another area of learning where the use of video may be particularly appropriate. This mode of learning relies on the ability of video to replicate human behaviours and actions. The literature review by Gagliano (1988) indicated that the greatest advantage of video over other educational methods was in modelling. Video modelling was found to be more effective than other forms of modelling at reducing anxiety, pain and arousal and increasing knowledge, co-operation and overall coping ability (Gagliano, 1988). A recent literature review further supported the benefits of using video modelling in patient education (Krouse, 2001). This review found that video modelling was effective at increasing self-care behaviours, knowledge of treatment options and the desire to be involved in decision making and can help to reduce anxiety and arousal during stressful procedures.

There is other research evidence that videotapes can be an effective educational resource in the health services. The use of videotapes in patient education has been associated with cost savings, increased patient satisfaction and reduced risk of inappropriate discharge or readmission (Rankin & Stallings, 2001). Although video

has been shown to be an effective way to convey health information and to prepare patients for treatment, its ability to influence health behaviours has been less clear (Dowrick & Associates, 1991). However, there is growing evidence that the use of an educational videotape can be an effective way to increase cancer-screening behaviour particularly when it is based on input from those it targets and it is part of a health promotion package (Davis et al., 1998; Pignone, Harris, & Kinsinger, 2000; Yancey, Tanjasiri, Klein, & Tunder, 1995).

Video has the advantage that it can present a moving image of people talking and carrying out activities. Participants in studies have endorsed this ability of video to use people with the same medical condition and issues as the viewer to describe health-related experiences and to model relevant behaviours (Murphy et al., 2000; Patyk, Gaynor, Kelly, & Ott, 1998). The attributes that make video an effective communication medium can also be a detrimental to the viewer (Dowrick & Associates, 1991). Some activities such as medical procedures are potentially disturbing when portrayed on screen and video producers need to proceed carefully with this kind of material. In patient education and in education in general, the effect of video will be the sum of the use of the medium and the value of the information it presents (Dowrick & Associates, 1991).

It has been emphasised in the literature that brochures and videotapes should not be used as isolated forms of information provision but rather as part of a multisensory approach to patient education (Hanger et al., 1998; Murphy et al., 2000; Rankin & Stallings, 2001). The properties of video suggest that it has an important and unique role in such an approach. Effective patient education requires a therapeutic relationship that provides an individualised response to health consumers' needs and the use of resources that best meet those needs (Rankin & Stallings, 2001). Information on videotape can be a valuable resource in efforts to respond individually to people's needs.

Although research into information provision by videotape has involved many different medical conditions there appears to be a lack of research involving TBI. A search through a number of electronic databases including PsycInfo, Web of Science, Medline, ERIC, CINAHL, SportDiscus and Dissertation Abstracts produced no relevant research on information provision by videotape in relation to TBI. The

closest was a survey on the effectiveness of providing information on brain injury by interactive CD-ROM (Patyk et al., 1998). People with TBI and their families have their own particular information needs and research that investigates the use of video in information provision in relation to TBI can assist health providers to meet those needs.

CHAPTER FOUR

Formulation

4.1 Introduction

This study follows on from a recent survey by Moore (2001) that investigated the nature of the information made available to people with TBI and their families by GPs and hospitals in New Zealand. None of the hospitals or GPs who responded to that survey had information available on videotape. The Head Injury Society of New Zealand and the Brain Injury Association of New Zealand were contacted as part of this study and they also reported that they had no videotapes specifically designed for information provision following TBI.

A number of authors have recommended that patient information be made available on videotape to help meet different individual needs for information (Foltz & Sullivan, 1999; Holland & Shigaki, 1998; Tooth et al., 2000; Weiss et al., 1995; Wyatt, 2000). However, a search of electronic databases available through Massey University found no research on information provision by videotape in relation to TBI.

4.2 Aims

The aim of the present study was to address both the lack of information available on videotape for people with TBI and their families in New Zealand and the lack of research into the use of video in information provision for TBI. The literature review of TBI in Chapter Two revealed that early intervention that includes information provision can reduce the level of social disability and post-concussion symptoms after mild TBI. With such a high incidence of mild TBI there are potentially clear benefits to the people injured, their families and society from research that investigates ways to improve the effectiveness of information provision for this group. This study aimed to do this by investigating the perceived utility of conveying information by videotape to people with mild TBI and their families.

The research was in the form of a pilot study in that the videotape and a brochure, which were to be used in the research, were developed as part of the study. The videotape and brochure will also be referred to as resources or information resources for ease of presentation. The investigative part of the study examined and compared the participants' responses to a survey about various aspects of information provision according to whether they received the videotape and brochure, the brochure only or neither resource.

4.3 Hypotheses

Hypotheses were developed for the study based on the theory and research findings from the literature on information provision reviewed in the previous chapter. The only research found that compared videotape to brochure in information provision was in the area of patient knowledge and it revealed that the two media have a similar effect on levels of knowledge. There was a lack of research that compared the use of these two media in relation to the aspects of information provision being investigated in the present study.

The first item in the survey investigated satisfaction with information provision. The literature review revealed that the provision of information in written form or by videotape is associated with increased patient satisfaction. It was hypothesised that there would be a difference in the level of satisfaction reported by participants depending on whether they received the videotape and brochure, the brochure only or neither resource. In particular, the literature review indicated that participants who received the information resources would report a higher level of satisfaction than participants who did not receive the resources.

The survey further investigated one of the factors that may lie behind a lack of satisfaction with information provision. People may become dissatisfied because they do not receive an appropriate amount of information. The literature review found that some health consumers have not received enough information but it is important not to overwhelm patients with too much information and finding the right balance can be difficult. It was hypothesised that the level of satisfaction with information provision would be higher among participants who reported that the amount of information they received was about right compared to participants who reported that they received an insufficient or excessive amount of information.

Information provision by written material, videotape and other media has an important role in meeting the information needs of health consumers. People who do not receive such patient information may not be getting enough information. It was hypothesised that participants who did not receive the information resources would be more likely to report that they received insufficient information compared to participants who received the brochure or the videotape and brochure.

A key objective of information provision is to improve understanding of the patient's health condition among patients and their families. The literature review revealed that information provision by brochure or videotape can improve knowledge among health consumers. It was hypothesised that there would be a difference between the participants who received the videotape and brochure, the brochure only or neither resource in the reported level of help they obtained from information provision in understanding concussion and its effects. The literature review suggested that participants who received the information resources would report a higher level of help than participants who did not receive these resources.

Research reviewed in the previous chapter indicated that some people prefer to receive information by television or videotape compared to written material and other formats while others do not have a clear preference for a particular format. Many people may prefer to receive information on both types of media. It was hypothesised that more participants would prefer to take home information on both videotape and brochure rather than on videotape or brochure alone or any other means. Finally, the study investigated whether the participants who received the information resources did refer to them and how often and whether those participants who received both the videotape and brochure referred to one more often than the other.

CHAPTER FIVE

Method

5.1 Ethical Issues

To meet ethical requirements, applications were made to the Manawatu Wanganui Ethics Committee and the Massey University Human Ethics Committee for approval of this study. The main ethical considerations and how they were dealt with are discussed below. Approval for the present study was granted by both the Ethics Committees.

5.1.1 Informed consent.

An information sheet (see Appendix A), which followed the guidelines of the National Ethics Committee, was produced to inform participants about the study. It outlined their rights in relation to participation and contained the identity and contact details of the researchers and their supervisor. The participants were advised that if they completed and returned the questionnaire then it would be assumed that they had consented to participate.

5.1.2 Confidentiality.

There were two aspects to confidentiality in this research. Firstly, there was a need to protect the confidentiality of the clients' information held by the Concussion Clinic. To meet this requirement, the researchers were not given access to the identity or contact details of the clients. Staff at the clinic who had access to this information assisted the researchers by addressing the survey letters to the clients. Secondly, there was a need to maintain the confidentiality and anonymity of the participants and their responses. To meet this requirement, each client was identified by a three digit code number which was matched with the age and gender of the client and the date at which he or she attended the clinic. The participants names did not appear on the questionnaires which were identified only by the code number.

The client details attached to each code number were useful to the researchers for several reasons. They allowed the researchers to indicate to the clinic those people who had not responded to the first survey letter and should be sent reminder letters. The attendance date was important for the current study because it revealed the type of information resource that was provided and therefore it indicated which of the three groups of participants each code number belonged to. The age and gender details were also useful for describing the demographic characteristics of all potential participants.

5.1.3 Debriefing.

In the information sheet, participants were invited to receive a summary of the findings of the studies. They were able to indicate their preference by responding to the appropriate item in the questionnaire. At the conclusion of the current study a brief summary of the results and conclusions, in language appropriate for the general population, was sent to those who requested it.

5.1.4 Use of data.

There were two different studies using data from the questionnaire and it was important that this was made clear in the information sheet. Potential participants were given the names of the two researchers and were informed that they would be using data from the survey to study different aspects of the clinic's service. They were also informed that any information they gave would only be used for the two studies and that all questionnaires would be destroyed once the studies were completed.

5.2 Participants

The participants in the study were clients of the Midcentral Health Concussion Clinic and the people who accompanied them to the clinic. All clients and their companions who attended the clinic from its inception in September 2001 until January 14, 2003 were eligible to take part in the survey. The clients were referred to the clinic for assessment after sustaining a concussion. Details about the source of referral and other demographic characteristics of the participants are presented in the results section. For the purposes of this research the participants consisted of three groups. These groups were defined according to the type of information on concussion the clients received from the clinic other than verbal education. Of those

participants who received the information resources provided by the clinic, one group received the videotape and brochure and the other group received the brochure only. The third group consisted of participants who attended the clinic before the brochure and videotape were produced and therefore they did not receive these resources.

5.3 Procedure

The procedure for this study consisted of three stages. The first two stages involved the development and delivery of the two information resources to clients of the Concussion Clinic. These two stages were followed by the third and final stage of the study in which participants were surveyed about various aspects of information provision. For the final stage, the current study was combined with another study by Leach (2002) who was conducting a client satisfaction survey of the Concussion Clinic. The questionnaire items for the current study were included in the questionnaire used by the client satisfaction survey and the procedure for contacting clients and gathering data was the same for both studies.

5.3.1 Development of the brochure.

In the first stage of the study a brochure (see Appendix B) for people with concussion and their families was produced. The brochure contained information about concussion and its consequences and some advice on how to assist the recovery process and manage the effects of concussion. It also provided information about the nature of the assessment process at the clinic. The content of the brochure was based on written information about TBI available in New Zealand for patients and their families. This included information sheets, pamphlets and booklets produced by ACC, the Brain Injury Association and the Head Injury Society as well as those gathered and studied by Moore (2001). It also included the book "Head Injury The Facts: A guide for families and care-givers" by Gronwall, Wrightson and Waddell (1990).

Guidelines on how to write material that communicates effectively to health consumers, as outlined by Murphy et al. (2000) and Wyatt (2000), were used in deciding what content would be included and how it would be presented (see Table 3). The researcher prepared a draft of the brochure based on the information resources and these guidelines.

Table 3

Guidelines Used in Writing the Brochure

Limit the amount of information presented to that which is essential

Limit the number of concepts

Use a conversational style and an active voice

Use simple language comprising short words and sentences

Present the information in a logical sequence

Use headers

Focus on behaviours or actions

Focus on positive rather than negative messages

The draft was revised several times after input and feedback from the study supervisor and staff working at the Concussion Clinic and the Massey University Psychology Clinic. Once the brochures were printed and delivered to the Concussion Clinic they became a standard part of the clinic's service and were posted out with the usual appointment details to all upcoming clients from that time onwards. This circumstance created a group of clients who received only the brochure because the videotape had not yet been produced. These clients and the people who accompanied them to the clinic became potential participants for the brochure only group.

5.3.2 Production of the videotape.

The second stage of the study involved the production of a videotape containing information about concussion and based on the brochure produced in the first stage of the study. There were several factors that influenced the making of the videotape. The videotape needed to be made relatively quickly so that there would be time to carry out research into its use. The amount of funding available to make the video was adequate but to stay within budget it was necessary to keep the filming costs to a minimum and to avoid using expensive video techniques. Consistent with that was the need to keep the running time of the videotape relatively short. Researchers have recommended that the duration of patient information videotapes should be less than 8 minutes (Murphy et al., 2000) and this is particularly relevant to people with concussion who often have difficulty concentrating and paying attention.

In summary, the goal was to make a short video within a limited budget and as quickly as possible.

The videotape was designed to contain, as close as possible, the same information about concussion and its consequences as the completed brochure. The wording of the final version of the brochure became the script for the commentary in the video. However, the version of the brochure that was printed was different from the one that was used for the video commentary (see Appendix C for video script). This meant that there were some unintended differences between the wording in the brochure and the videotape commentary although the essential information about concussion was the same. The differences were also relatively unimportant because there were two more obvious ways in which the videotape differed from the brochure.

The brochure had a section under the heading “Your visit to the Concussion Clinic” which contained information for clients about the assessment process at the clinic. This section of the brochure was not reproduced in the videotape for two main reasons. The videotape was to be handed out to clients after their assessments at the end of their visit to the clinic and therefore any information in the videotape about the assessment process would be largely redundant. If this section had been included in the videotape it would have been necessary to videotape the assessment procedures. This would have interfered with the procedures and the client’s privacy and would have added to the complexity and cost of producing the video.

The videotape also clearly differed from the brochure because it included interviews with people who described various experiences of concussion that related to the commentary. The interviews were included to take advantage of the potential of a videotape to involve the viewer through identification with the experiences of others (Dowrick & Associates, 1991). Seeing and hearing the stories of other people with the same medical condition has been rated highly by patients and family members as an aspect of information provision by videotape (Murphy et al., 2000; Patyk et al., 1998). The interviews were done by amateur actors and the experiences of concussion they described were based on a script prepared by the researcher. This approach was used to make the production process simpler and quicker. It can be difficult and time consuming to find people who can describe their experiences

effectively on video. It may also have been distressing for some people to recall their personal experiences about concussion. At the end of the videotape it was acknowledged that the interviewees were actors.

The interviews about concussion used two contrasting characters, which allowed for two different viewpoints on concussion to be presented. One character was chosen to be a young man of 19 years in order to represent the most common group who get concussion as described in the brochure and the video commentary. The other character was chosen to be a middle-aged mother in order to give a viewpoint from a different age and gender to the first character. The decision to have only two interviewees made it easier to produce the videotape and to keep the amount of information and the duration relatively short and concise.

The interview scripts (see Appendix C) were based on the same guidelines and written material that were used to develop the brochure and feedback on the scripts was obtained from the study supervisor who has considerable experience working in the area of TBI and concussion. The actors were also asked for feedback on the wording of the scripts and were encouraged to use their own words and phrasing when relating the experiences written in the scripts. This was done to help the actors feel more comfortable and natural in front of the camera and to improve the ability of the scripts to reflect the perspective of the characters in the video who were different in age or gender to the researcher.

The interview segments were interwoven throughout the videotape and for most of them the actor was shown speaking. They were designed to enhance the information contained in the commentary by giving it a personal dimension and were not intended to add important new information. There were several sections in the videotape where the actors demonstrated behaviours relevant to the script to provide a visual reinforcement of the commentary. Most of these demonstrations occurred in the two sections under the headings “What helps recovery?” and “What should I try not to do?” These demonstrations took advantage of the potential of video modelling as an effective device in patient education (Gagliano, 1988).

Where possible, the visual material in the videotape was chosen to match the message in the commentary so that the vision and sound acted to complement and reinforce each other. For example, there was vision of young men when the

commentary noted that they were the most common group to get concussion and there was vision of various sports when the commentary discussed the role of sports in concussion. Where matching visual material was not available, general pictures of people in everyday activities were used. There were regular scene changes throughout the videotape, which is valuable technique for maintaining the interest of the viewer (Murphy et al., 2000).

Graphics (computer generated images) were used in the section under the heading “What is Concussion?” to provide vision to match the commentary and to increase the visual appeal of the videotape. Although expensive graphics were beyond the budget of this project we were able to generate simple but effective graphics showing the head and brain being jolted and the axons of brain cells being damaged. Word graphics were used to illustrate certain key points in the commentary and to produce titles and headings in the videotape that matched the ones in the brochure. These techniques help to reinforce the information being heard in the commentary and to clarify the structure of the narrative and are recommended to increase the effectiveness of information provision by videotape (Murphy et al., 2000).

The other visual effects that were used to enhance the impact of the commentary included slow-motion action to illustrate slowed reactions, blurring of the picture to portray blurred vision and creating a “white out” on screen to support the point that bright light can be disturbing for people with concussion. It is important to consider the tempo at which information is presented (Murphy et al., 2000) and therefore several pauses with no speaking were inserted throughout the videotape in an attempt to allow the viewers enough time to process the information. Music was used at the start of the video to gain the interest of the viewers and during some of the pauses and at the end to help maintain their interest.

The videotape went through a similar review process as the brochure with health professionals from the Concussion Clinic and the Massey University Psychology Clinic as well as the study supervisor providing feedback on an early version of the videotape before it was finalised. Their comments were very positive with the main theme being that it looked “very professional”. The information in the video was considered to be relevant and did not need changing. This probably

reflected the fact that it was based on the brochure that had already been developed through consultation with most of the same people.

There were two main changes made as a result of the feedback process. The pauses between speaking parts were extended to slow the pace at which the information was presented. The original pace seemed appropriate but there was room to slow it without making it laboured and it seemed sensible to do so. The first music track was replaced with a quieter and more gentle music track because there were comments that it might be too strident and irritating for some people with concussion. The final duration of the videotape was 6 minutes, which met the recommendation of being less than 8 minutes (Murphy et al., 2000).

The master videotape for the study was produced on digital video and copies were made for home video recorders (VHS) and were delivered to the Concussion Clinic. A consecutive group of clients who attended the clinic from that point onwards were given the videotape until 22 videotapes had been given out. These clients also received the brochure that was being posted out to all clients as part of the clinic's service. The clients who received the videotape and the people who accompanied them to the clinic became potential participants for the videotape and brochure group.

5.3.3 Survey procedure.

In the third stage of the study the participants were surveyed about various aspects of the information they received from the Concussion Clinic. The survey contained 6 questions related to information provision that were included in a client satisfaction survey conducted by another researcher. Potential participants for the survey were recruited from the clinic's records and were contacted by post (see section 5.1.2). The clinic staff posted out the survey letter that contained a cover letter from the clinic, an information sheet (see section 5.1.1), two copies of the questionnaire, and a reply paid envelope.

The cover letter (see Appendix D) was included to inform clients that the researchers were conducting an independent survey to evaluate the service provided by the clinic and to reassure clients that the researchers did not have access to their files, names or contact details. One copy of the questionnaire was for the client to

complete and the other copy was to be completed by a person who accompanied the client to the clinic. It was estimated that it would take the participants approximately 15 minutes to answer the questionnaire. Participants were advised to return the completed questionnaires in the reply paid envelope. Approximately two weeks after the first letter was sent out a second survey letter was sent to clients who had not returned a completed questionnaire (see section 5.1.2). The second letter contained the same contents as the first letter and was sent in order to increase the return rate.

The Concussion Clinic was open one day a week and the survey covered a 16 month period of attendances at the clinic. This was done in order to include the clients who attended the clinic from its inception in September 2001 and to allow enough time to produce and deliver the brochure and videotape to enough clients to provide a satisfactory number of potential participants. The survey procedure of a first letter then a follow up letter was conducted twice over the 16 month period to reduce the delay between attendance at the clinic and the mailing out of the survey for the clients from the early part of the survey period.

5.4 Instruments

A set of 6 questions were developed specifically to gather data for this study. These questions were included in a larger client satisfaction survey carried out by another researcher (Leach, 2002) that contained two standard instruments. The main instrument in the overall survey was the Service Satisfaction Scale-30 (SSS-30), a multifactorial scale assessing several components of client satisfaction with health services (Greenfield & Attkisson, 1999). This scale was developed relatively recently and has shown adequate validity and reliability in research so far (Greenfield & Attkisson, 1999). The other instrument was the Satisfaction With Life Scale, a brief scale that assesses satisfaction with life as a whole and also has shown adequate psychometric properties (Pavot & Diener, 1993).

There were two characteristics of the overall survey that made it appropriate to include the 6 questions for the current study. Firstly, one goal of the current study was to investigate satisfaction with information provision and that fitted in with the focus of the overall survey on client satisfaction. Secondly, the 6 items for the current study could be suitably placed after the 30th item of the SSS-30 (Attkisson & Greenfield, 1996). The development of the 6 questions was guided by three criteria

that helped to determine the number of items and what the questions should aim to discover. The first criterion was to develop questions that were consistent with the hypotheses outlined in the previous chapter. The second criterion was that the questions should be compatible with the client satisfaction questionnaire that this study was associated with. The third criterion was to restrict the number of questions chosen so that the length of the overall survey did not discourage potential participants from completing it.

The first question in the current study investigated the participants' satisfaction with the information they were given by the clinic on concussion. There were no items in the SSS-30 dealing with this topic but the SSS-30 has an optional 31st item (Greenfield & Attkisson, 1999) and this item was replaced by a question on information provision that matched the wording of the other items in the SSS-30 and used the same response format. Therefore the first item of the current study was item 31 in the overall survey and it had an increasing 5-point scale ranging from *terrible* to *delighted* (see Appendix E for survey questionnaire).

The other questions in the study were not about client satisfaction and their wording and response format were different from the SSS-30 therefore it was necessary to make this obvious to participants. This was done by clearly separating them from the SSS-30 at the top of a new page and by introducing them with a new sentence that explained the change in focus of the next questions (see Appendix E). Although there was a change in focus away from client satisfaction the other questions for the current study did flow on from item 31 because they were also about information the clients were given on concussion and they continued the numbering sequence from 32 to 36.

The second question in the study (item 32) asked participants whether the amount of information they received was *far too much*, *too much*, *about right*, *too little*, or *far too little*. The middle response option (about right) was taken to mean that an appropriate amount of information was received and the options on either side indicated that the amount of information was excessive or insufficient. The third question (item 33) asked participants to estimate how well the information they received helped them to understand concussion and its effects. There was an

increasing 5-point scale for this item with the response options ranging from *not at all* to *a great deal*.

The fourth question (item 34) asked participants to indicate whether they preferred to take home information on both videotape and brochure, or videotape alone or brochure alone, or some other format. The final two questions asked those participants who received the brochure (items 35) to indicate how many times they had read it and those who received the videotape (item 36) to indicate how many times they had watched it.

There were other aspects of information provision discussed in the literature review that were not investigated in this study mainly because they were outside the scope of the current study. The participants were not asked whether they understood the information they received because the question was similar to item 33 and this could have confused the participants and raised doubts about the validity and reliability of their responses. Furthermore, the brochure and videotape in this study were developed using guidelines on how to write material that communicates effectively to health consumers and most clients and their families would have had little difficulty understanding the information. The overall survey questionnaire also included several items to gather demographic information. The data from these items were used by both studies to describe the demographic characteristics of the sample.

CHAPTER SIX

Results

6.1 Demographics

Seventy nine clients attended the Concussion Clinic during the period of the survey and all were sent questionnaires. This meant that a group of up to 79 family members or friends who accompanied the clients to the clinic were also sent questionnaires. Six of the letters were returned unopened because the clients no longer resided at that address. Twenty two completed questionnaires were returned of which 20 were from clients and two from family members. The response rate was 25% (20 out of 79) for clients and less than 3% (2 out of 79) for family or friends. The number of responses from family members was too low to be provide meaningful results and their data were therefore omitted from the study results and discussion. The two family members were mothers of teenage clients.

The demographic characteristics of the participants indicated that they were a diverse group of people on each variable. They came from all age groups except that there was no one aged 75 years or over (see Figure 1). The most common age groups were 35 to 44 years and 45 to 54 years with half of the participants in these age bands. The most common age group among all clients who were eligible to participate was younger at 15 to 24 years, which is the age group with the highest incidence of TBI commonly reported in epidemiological studies (Naugle, 1990). Figure 1 indicates that the participants were older as a group than the clients who were eligible for the study.

The majority of the participants were male (60%, $n = 12$) and this is consistent with the results of epidemiological studies, which regularly find that more males than females sustain a TBI (Naugle, 1990). The proportion of males among all clients who were sent questionnaires was similar at 62%, which indicates that the gender mix of the participants was representative of all clients who were eligible for the survey.

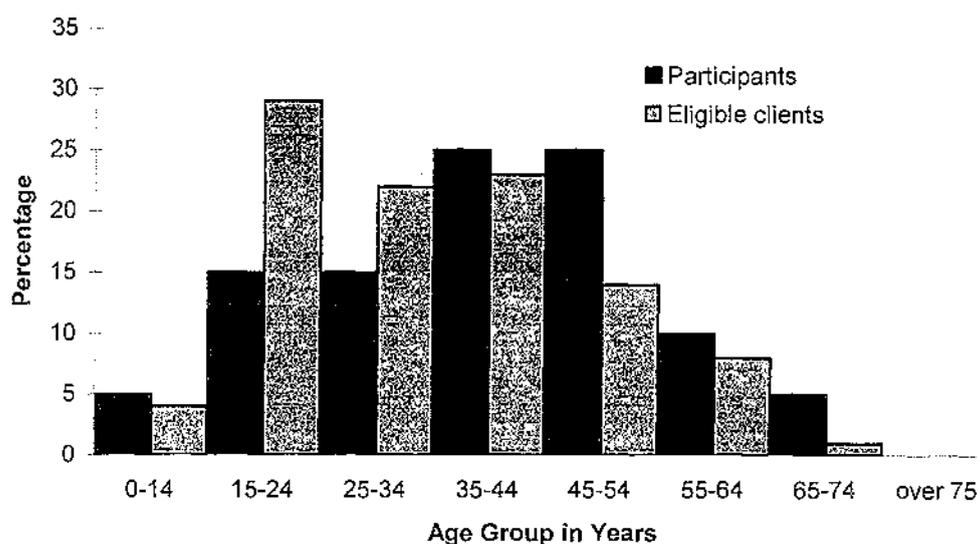


Figure 1. Percentage of participants and all clients eligible to participate in each age group.

The other demographic characteristics of the clients who participated in the study are presented in Table 4. The leading cause of concussion among the participants was traffic accidents. Other common causes of concussion such as falls, sports injuries and work accidents were also represented but no participants sustained their concussion from an assault, which is a common cause of concussion in some regions and countries (Jennett, 1996). The most common source of referral for participants was from the hospital in which the Concussion Clinic was situated but some were also referred by ACC or their GP. The referral source for 1 client was missing.

The majority identified their ethnic origin as New Zealander / Pakeha and some of those who selected European may also be New Zealanders who did not identify with the term Pakeha. The most common educational level completed by the participants was 5th form. None had completed their education at the 7th form but four had attended a tertiary institution perhaps reflecting a trend that most people who complete the 7th form go on to tertiary study. Data were missing from 2 clients for highest educational level and from 1 client for ethnicity. The majority were in some form of employment or study with the highest number being in full-time employment.

Table 4

Demographic Characteristics of Participants

	Frequency	Percentage
<i>Cause of concussion</i>		
Traffic accident	8	40
Fall	5	25
Work injury	4	20
Sports injury	3	15
<i>Source of referral</i>		
Hospital	8	40
ACC	6	30
GP	5	25
<i>Ethnicity</i>		
NZ/Pakeha	12	60
European	5	25
Maori	1	5
<i>Highest Educational level</i>		
Some high school	2	10
Completed 5th form	7	35
Completed 6th form	3	15
Completed 7th form	0	0
Attended tertiary institution	6	30
<i>Employment status</i>		
Employed full-time	7	35
Employed part-time	4	20
Unemployed	3	15
Full-time student	3	15
Part-time student	2	10
Sickness beneficiary	1	5

The 20 participants in the study included 7 who received the videotape and brochure (VB group), 6 who received the brochure only (B group), and 7 who did not receive these resources (O group) because they were not available in the first few months that the Concussion Clinic was in operation. The demographic characteristics of the participants were highly variable across these three groups, however this variability is understandable given the low numbers of participants in each group.

The six items in the questionnaire (items 31 to 36) related to the current study produced nominal and ordinal data from independent samples in each of the three groups of participants. For this reason non-parametric tests for unrelated data were used to analyse the data and to produce the inferential statistics presented below. The

results were analysed using the SPSS statistical package and the tests were conducted at an alpha level of .05.

6.2 Satisfaction with Information Provision

Data from this item produced a negatively skewed distribution (see Figure 2) towards high satisfaction ($M = 4.20$, $SD = 0.95$) with half of all the participants reporting that they were *delighted*. The high level of satisfaction was predominantly accounted for by the participants in the VB and B groups. All but one member from each of these groups reported that they were *mostly satisfied* or *delighted*. The effect of type of information resources received on level of satisfaction was examined using the Kruskal-Wallis one-way analysis of variance and it revealed that there were no significant differences between the three groups ($p > .1$) although there was a trend for the VB group ($M = 4.43$, $SD = 0.79$) and the B group ($M = 4.50$, $SD = 0.84$) to be more satisfied than the O group ($M = 3.71$, $SD = 1.11$).

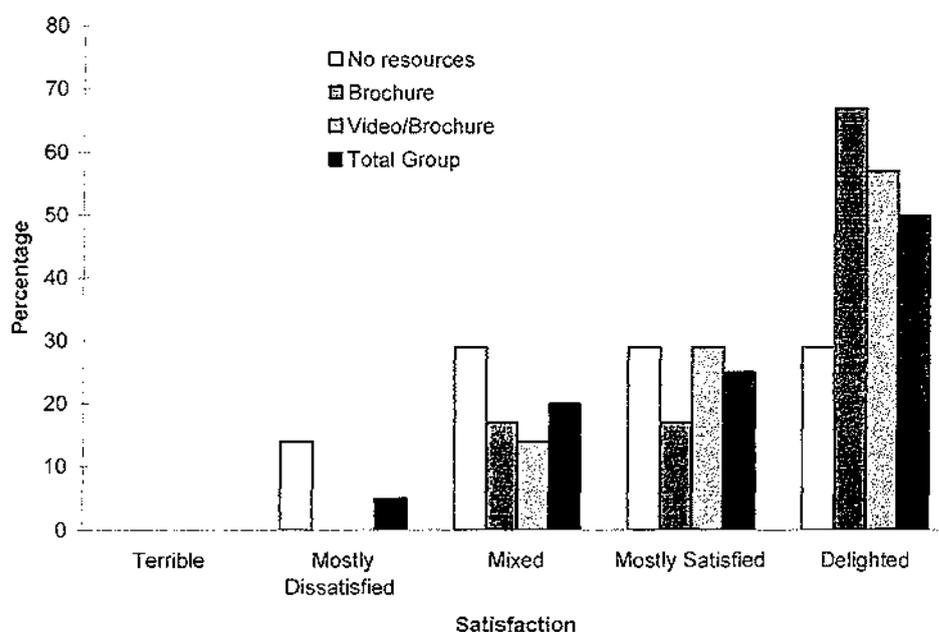


Figure 2. Level of satisfaction with information provision reported by all participants and participants in the VB, B, and O groups.

The data for the VB and B groups were collapsed to form one group who received one or both resources. Further analysis comparing the satisfaction level of the combined resources group (R group) to the O group using a one-tailed Mann-

Whitney (U) test found that there was no significant difference between the two groups ($p > .1$): R group ($M = 4.46$, $SD = 0.78$) and O group ($M = 3.71$, $SD = 1.11$).

6.3 Amount of Information Received

The majority of participants reported that the amount of information they received on concussion was *about right* (60%, $n = 12$). Of the other 8 participants, 7 reported that they received *too little* information and 1 reported receiving *far too much* information. Figure 3 indicates that there was a tendency for a higher proportion of the VB group (57%) and the B group (83%) to report that the amount of information they received was about right compared to the O group (43%). From another perspective, 57% of the O group (4 from 7) reported that they received too little information compared to 23% (3 from 13) out of the combined VB and B groups. This difference was not significant ($p > .1$), however, when the expected frequencies of several cells fall below 5 in a total sample of 20, as is the case here, the utility of testing for significance with the chi-square test is questionable (Coolican, 1994).

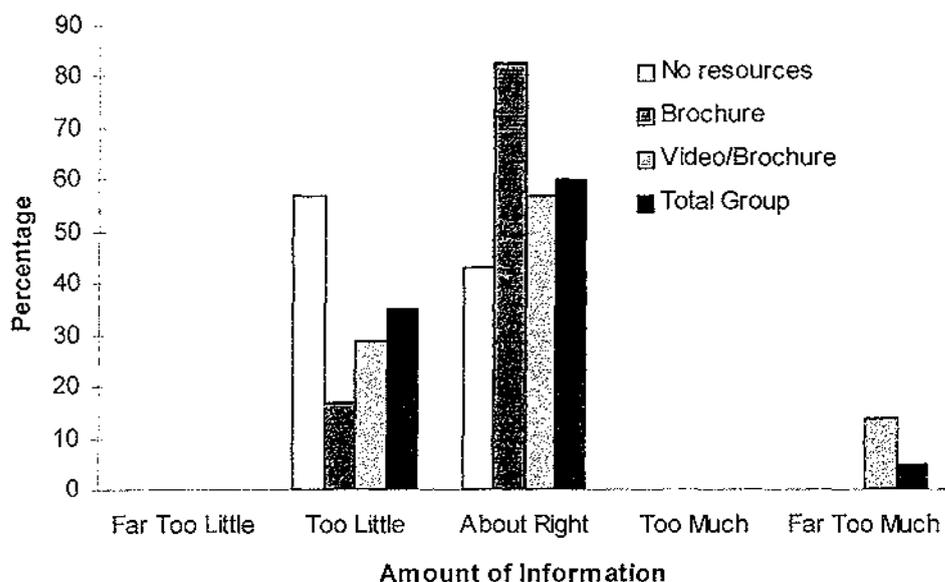


Figure 3. Amount of information received on concussion as reported by all participants and participants in the VB, B, and O groups.

The data were analysed to investigate the level of satisfaction with information provision among participants who reported that the amount of information they received was about right compared to clients who reported receiving an insufficient or excessive amount of information. This analysis, using a one-tailed Mann-Whitney (U) test, found that satisfaction level of the 12 clients who selected *about right* ($M = 4.83$, $SD = 0.39$) was significantly higher than the satisfaction level of the 8 clients who selected either *too little* or *far too much* ($M = 3.25$, $SD = 0.71$), $z = -3.76$, $p < .0005$. The alpha level indicates that this finding was highly significant.

6.4 Understanding of Concussion

The participants were asked to judge how well information provision helped them to understand concussion and its effects. The data in Figure 4 indicates that the level of help reported by the total group was at the high end of the scale ($M = 3.75$, $SD = 1.02$). The majority of participants reported that information provision helped them to understand concussion and its effects either *quite a bit* (40%) or *a great deal* (25%). Eleven out of the 13 participants who recorded these two highest levels of reported help were in the VB and B groups.

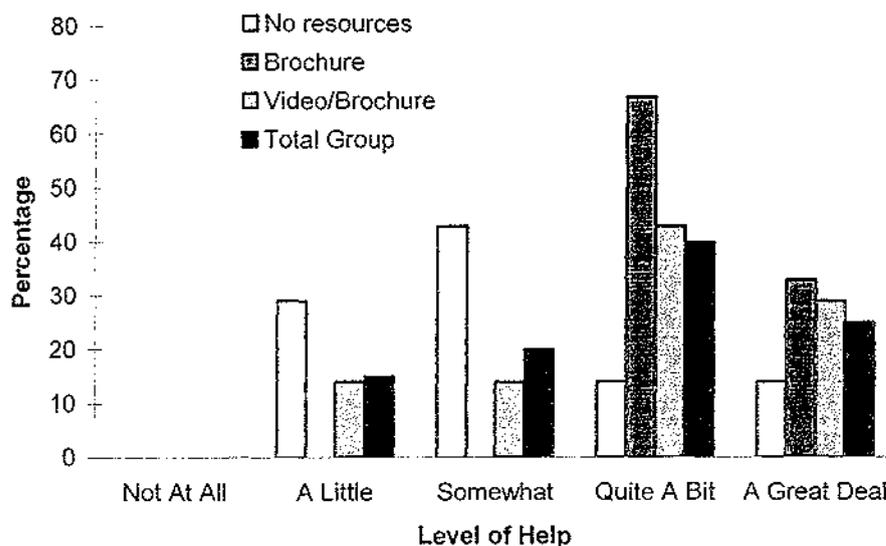


Figure 4. Level of help received from information provision in understanding concussion and its effects as reported by all participants and participants in the VB, B, and O groups.

The effect of type of information resources received on the level of perceived helpfulness was examined using the Kruskal-Wallis one-way analysis of variance. This analysis revealed that there were no significant differences between the three groups ($p > .1$) although there was a trend for the B group ($M = 4.33, SD = 0.52$) to report a higher level of help than the VB group ($M = 3.86, SD = 1.07$) and for both of these resources groups to report a higher level of help than the O group ($M = 3.14, SD = 1.07$).

The data for the VB and B groups were again collapsed to form one group who received one or both resources. Further analysis comparing the reported level of help of the combined resources group (R group) to the O group using a one-tailed Mann-Whitney (U) test found no significant difference between the two groups although the difference was close to significance ($p = .068$): R group ($M = 4.08, SD = 0.86$) and O group ($M = 3.14, SD = 1.07$).

6.5 Preference for Type of Information Media

Participants were given four options from which to indicate their preference for the type of media in which they would prefer to receive information. The majority indicated that they preferred to take home information on both videotape and brochure (55%, $n = 11$). Of the 9 other participants, 6 preferred information on brochure, 2 preferred videotape and 1 gave an invalid response that was excluded from further analysis. The preference of participants for receiving information on both videotape and brochure compared to the other options was significant, $\chi^2(2, N = 19) = 6.42, p < .05$. The preferred type of media within the three groups varied. Most of the VB group (71%) and the O group (57%) preferred to receive information on both videotape and brochure whereas half of the B group (50%) preferred to receive information by brochure only.

6.6 Number of Times Information was Referred To

All of the participants who received the resources had referred to them at least once. Half of the participants who received the brochure (VB and B groups) had read it three or more times and nearly half who received the videotape (VB group) had watched it three or more times. The VB group tended to refer to their resources more often than the B group. The brochure was read more than once by 83% of the VB

group compared to 50% of the B group and 71% the VB group referred to the videotape more than once. Of those participants received both resources (VB group) there was little difference between how often they watched the videotape and how often read the brochure.

CHAPTER SEVEN

Discussion

7.1 Introduction

The current study investigated the perceived utility of information provision by videotape and brochure to people with concussion and their families. Since there were insufficient data from family members for it to be included in the results, only the perceptions of people with concussion were considered. The investigative part of the study was centred on a comparison of the participants' responses to a survey about various aspects of information provision depending on whether they received the videotape and brochure, the brochure only or neither resource. The results of the study are discussed below in terms of the five aspects of information provision investigated. The headings follow those used in the previous chapter.

7.2 Satisfaction with Information Provision

The results of the survey did not support the hypothesis that there would be a difference in the level of satisfaction with information provision reported by participants depending on whether they received the videotape and brochure, the brochure only or neither resource. This finding is not consistent with a number of reports in the literature that information provision by videotape or brochure can contribute to increased patient satisfaction (Arthur, 1995; Kenny et al., 1998; Rankin & Stallings, 2001). Instead, the results of the current study imply that these information resources do not make clients of a concussion clinic more satisfied with information provision.

However, there are other possible explanations for the finding. The researcher was not able to completely control the kind of information obtained by the participants and therefore the findings of the study may have been confounded by the availability of other information materials. In particular, the clinic had available information materials on brain injury in general produced by ACC and The Brain Injury Association. These materials were not specifically provided to clients but the

responses of some participants, particularly those who did not receive the study resources, may have been influenced by access to these materials. Some participants' responses may also have been influenced by information gathered from other sources such as their GP, the internet or the library even though it was not provided by the clinic.

There was a trend for the participants who received the information resources (VB & B groups) to report a higher level of satisfaction than those who did not (O group) but the availability of other information materials may have been enough to prevent the satisfaction level of the O group from being significantly lower than the other groups. This possibility is consistent with the finding that, overall, most participants reported a high level of satisfaction with information provision.

Another possible explanation is that the verbal information that participants received in consultation with clinic staff may have satisfied their information needs to the extent that the information resources did not significantly increase their satisfaction. However, this explanation is countered to some extent by the findings discussed in the next section, which suggest that verbal information alone may not be adequate for most clients' needs. There was little difference found between the level of satisfaction of participants who received the videotape and brochure and those who received the brochure only. Without further research, this result implies that information provision by videotape for each client of a concussion clinic is not justified particularly because of the extra cost when compared to a brochure.

7.3 Amount of Information Received

The results of the study strongly supported the hypothesis that participants who reported that the amount of information they received was about right would have a higher level of satisfaction with information provision than participants who reported that they received an insufficient or excessive amount of information. Only one participant reported that the information received was excessive and therefore the reduced level of satisfaction was almost entirely due to a lack of information. There was no research directly related to this hypothesis found during the literature review, however, most of the patients in one study reported that they had wanted more information about their condition and treatments than they had received (Coulter et

al., 1999). The finding of the current study indicates the importance of providing enough information to meet the needs of clients of concussion clinics.

Information resources are considered to be a key tool for satisfying the information needs of health consumers for a number of reasons. Inadequacies in verbal communication by health professionals can lead to patient dissatisfaction with information provision (Van der Molen, 1999). Some health consumers may get less information than they need due to reduced contact time with health professionals (Holland & Shigaki, 1998). Also, many people forget what their health professionals tell them and therefore information resources can help them to retain information (Kenny et al., 1998). Furthermore, information-seeking behaviour is an important coping strategy for many patients (Van der Molen, 1999) and there have been reports that requests for information from patients are increasing (Krouse, 2001; Meredith et al., 1995).

The results of the current study appeared to be consistent with these reports because 57% of participants who did not receive the information resources compared to only 23% of those who did receive the resources reported that they received too little information. However, the utility of testing this difference for significance was questionable because of the low data numbers. Therefore, there was not enough evidence to support or reject the hypothesis that participants who did not receive the resources would be more likely to report that they received an insufficient amount of information compared to those who did receive the resources. Although the findings of this part of the study are unclear, the consistency of other reports in the literature suggests that information resources are an important tool to meet the information needs of clients of concussion clinics.

It has been pointed out that it is important not to overwhelm patients with too much information and that finding the right balance can be difficult (Coulter et al., 1999). No research on the effect of providing too much information to health consumers was found during the literature review. The amount of information that patients are required to read has increased (Dixon & Park, 1990) but there was not a large amount of reading involved in the information resources provided in this study and only one participant, a boy aged 14 years or younger who received the videotape and brochure, reported that he had received an excessive amount of information. This

implies that the information contained in a brochure and a six-minute videotape is not excessive for the majority of concussion clinic clients.

7.4 Understanding of Concussion

The results did not support the hypothesis that there would be a difference between the participants who received the videotape and brochure, the brochure only or neither resource in the reported level of help they obtained from information provision in understanding concussion and its effects. There were no studies found during the literature review that investigated this aspect of information provision, however, this finding is not compatible with research reviews that have reported that information provision by written material or videotape can increase patient knowledge (Arthur, 1995; Gagliano, 1988; Kenny et al., 1998). Instead, the results of the current study imply that information provision by brochure or by videotape and brochure does not provide increased help to clients of a concussion clinic in understanding concussion.

However, there are other possible explanations for the finding similar to those discussed above (see section 7.2). There was a trend for the participants who received the information resources (VB and B groups) to report a higher level of help than those who did not (O group) but the availability of other sources of information may have been enough to prevent the level of help reported by the O group from being significantly lower than the other groups. This possibility is consistent with the finding that, overall, most participants reported that they received a high level of help from information provision in understanding concussion. There was also a high level of satisfaction reported by most participants and these two general findings indicate that the participants in the study were inclined to be positive about information provision from the Concussion Clinic.

Eighty five percent of participants who received the brochure reported that information provision helped them to understand concussion either quite a bit or a great deal. This result is consistent with another recent study, which found that 77% of carers of people with TBI reported that an information booklet they received was very helpful and only one carer reported that it was not helpful (Morris, 2001). Although similar, Morris' study involved carers rather than people with TBI, it did

not measure whether the information booklet was helpful for understanding TBI and it did not make a comparison with carers who did not receive a booklet.

There was little difference between the participants who received the videotape and brochure and those who received the brochure only in the reported level of help they obtained from information provision in understanding concussion. This result is comparable with many studies which have found that there is little difference in the level of knowledge attained after information provision by videotape compared to brochure (Gagliano, 1988; Mead et al., 1994; Murphy et al., 2000). Again, this implies that the extra cost of providing a videotape to each client of a concussion clinic compared to a brochure does not appear to be justified.

7.5 Preference for Type of Information Media

The results of the study supported the hypothesis that more participants would prefer to take home information on both videotape and brochure rather than on videotape or brochure alone or any other means. There was only one study located during the literature review that examined the preferences of health consumers in relation to information media. In that study it was reported that a focus group of patients did not show a clear preference for video, audio, computer-based or printed materials (Coulter et al., 1999).

The disparity between the findings of the current study and the previous study may well be explained by differences between them. In the current study the participants could indicate a preference for receiving information on two forms of media (videotape and brochure) whereas the other study appeared to offer patients a choice of one out of four types of media. Therefore the patients in the other study may have shown a preference for both video and printed materials if they had been given that option.

The other difference between the two studies is that in the current study the majority of participants reported that the amount of information they received was about right whereas most of the patients in the other study had wanted more information about their condition and treatments than they had received (Coulter et al., 1999). The patients in the Coulter et al. study indicated that they were more concerned with the content of information and were appreciative of any media that

provided useful information. This implies that they had other priorities, in terms of information provision, than choosing a type of media.

Another study with a group of older people (60 years and older) found that 97% obtained information from television, 51% from newspapers, 23% from radio and 19% from magazines (Weiss et al., 1995). This study was different from the current study in that it involved an older age group seeking general information that was vicariously obtained rather than provided as in the current study. However, its findings are consistent with the current study in that most of the people were choosing to get information from both video and print media.

The finding from this section of the study suggests that making information available on both videotape and brochure will help to meet the needs of many concussion clinic clients who prefer to get information on both types of media. This is consistent with recommendations in the literature that videotapes and brochures should not be used as isolated forms of information provision but that both should be part of a multisensory approach to health education (Hanger et al., 1998; Murphy et al., 2000; Rankin & Stallings, 2001).

7.6 Number of Times Information was Referred To

The results of the study revealed that all of the participants who received information resources had referred to them at least once and nearly half had referred to them three or more times. While there were no studies found in the literature review which investigated how often health consumers referred to information resources this finding is compatible with reports that there is an increasing demand for health information from patients (Krouse, 2001; Meredith et al., 1995) and that many patients seek information as a strategy to cope with the stress surrounding their health difficulties (Van der Molen, 1999). As a group, those participants who received both the videotape and brochure reported little difference between the number of times they watched the videotape compared to reading the brochure. This finding comes from a small sample of only six participants and therefore it is difficult to draw any conclusions. This is unfortunate because there is a lack of research on the rate at which health consumers access different forms of patient information.

In the study discussed above with older people, video was referred to more often than print media (Weiss et al., 1995), however, that group were seeking information for themselves rather than having it provided as in the current study. It has been noted that the amount of time people spend watching television and videotapes indicates that they prefer viewing over reading (Gagliano, 1988). There have also been reports in the literature that some people do not like reading (Rankin & Stallings, 2001) or learn better from non-written forms of information (Foltz & Sullivan, 1999) or respond better to information provided on videotape (Holland & Shigaki, 1998). The results of the study are not consistent with these observations but instead indicate that most clients of concussion clinics are comfortable with both reading and viewing information about concussion.

The findings from the five aspects of information provision investigated do not support the provision of a videotape to each client of a concussion clinic but they do indicate that the clients prefer to have access to information on videotape and will use it. The best way to provide information by videotape may be to make it available for viewing at concussion clinics and to provide extra copies for those who wish to borrow it.

7.7 Limitations

An important limitation of the present study was the low response rate (25%) which undermined the validity of its findings. This is often a drawback of postal surveys of client satisfaction, which generally produce a response rate of less than 45% even with a follow-up (Greenfield & Attkisson, 1999). The response rate for the study was affected by the length of time between the clients' attendances at the clinic and the mailing out of questionnaires, which varied between one week to as high as thirteen months. Most of the completed questionnaires (70%) were returned by clients who had attended the clinic within three months of receiving the questionnaire. The response rate from this group was 52% compared to a 12% response rate from clients who received the questionnaire more than three months after they had attended the clinic.

The low response rate may have produced a bias in the study sample due to non-response and mean that it is not representative of clients of the Concussion Clinic. In particular, it has been found in other postal surveys with the SSS-30 that

there can be a tendency for those who did not respond to be the least satisfied of the clients (Greenfield & Attkisson, 1999). This is consistent with the responses of the participants in the current study who were mostly positive about information provision by the Concussion Clinic.

Higher response rates to client satisfaction surveys can be achieved if both staff and the researcher approach potential participants on site (Greenfield & Attkisson, 1999). This method was not applicable for the current study, which had to be retrospective and it was not permitted by the ethics committees who had approved the study. Another way to raise response rates is to conduct a telephone survey but this approach was also ruled out because the ethical requirements meant that the researchers were not permitted direct access to the clients and it would have been impractical for clinic staff to contact all the potential participants to gain their consent for the researchers to phone them.

Another reason for the low response rate may be that many clients were not motivated to complete the questionnaire because the service did not have an important impact on them. Most of the clinic's clients were seen only once whereas many client satisfaction surveys involve inpatient services or community or outpatient services in which people are seen regularly (Greenfield & Attkisson, 1999) and these services are likely to have a greater impact on their lives. Furthermore, very few of the clinic's clients in the 15 to 24 years age group responded (13%) and these teenagers and young adults may have felt less responsible for completing the questionnaire. It also needs to be recognised that some potential participants may have been put off by the size of the questionnaire, which contained six pages and 56 questions.

The low number of participants in each of the three experimental groups meant that there may not have been enough statistical power to detect differences that actually existed between the groups (type II error). This was particularly the case because the type of data collected for the study required non-parametric tests of significance, which have less power than parametric tests (Coolican, 1994). During the process of sending out the questionnaires to potential participants it became apparent that many of the people who were referred to the Concussion Clinic did not attend their appointments. Accurate data on the number of non-attenders has not been

compiled by the clinic but an estimate based on the number of potential participants in the current study suggested that approximately one third of the people did not attend their appointments. It is not known why people did not attend the clinic but most people who sustain a minor concussion recover rapidly (Gronwall & Wrightson, 1974) and many may not seek further assessment.

There are also a considerable number of people who sustain a mild TBI who do not seek any medical assistance (Sosin et al., 1996) and would therefore not be referred to a concussion clinic. This implies that the participants in the study were not representative of all people who sustain a concussion, particularly those who do not seek initial medical help or further assessment. Furthermore, epidemiological studies indicate that there are regional and national differences in the characteristics of people with TBI (Jennett, 1996) and this suggests that the findings of the study may not be applicable to clients who attend concussion clinics outside of the Palmerston North region. The participants were also older on average than what is commonly found among people with TBI and were not representative of Maori or other Non-European groups.

The study especially failed to obtain sufficient responses from family members or others who accompanied the clients to the clinic and therefore no findings could be presented from their perspective. A possible reason for this is that the survey letter was addressed to the clients and therefore the people who accompanied them to the clinic may not have realised that the researchers wanted their views as much as the clients or they may not have seen the invitation to them in the information sheet. The lack of findings from the perspective of family members is unfortunate because it is clear in the literature that information is one the most important needs of family members of people with TBI (McPherson et al., 2000; Serio et al., 1997; Sinnakaruppan & Williams, 2001).

The questions that were used to gather data were specifically developed for the study. Although the items appeared to have face validity to the researcher and the study supervisor they did not undergo formal pilot testing and the overall validity and reliability of the items is unknown. The data gathered came from a self-report measure and there are some inherent limitations in this type of measure. They are subject to response biases and misleading evaluations either deliberately or

subconsciously (Coolican, 1994). Also, the effects of the concussion such as the irritability, tiredness, anxiety or depression may have affected the way some clients responded.

7.8 Conclusions and Recommendations

The current study produced two information resources, a videotape and a brochure, for clients of a concussion clinic and investigated the perceived utility of these two resources. The results of the study did not confirm any advantages for the use of videotapes as compared to brochures for people with concussion in relation to the following aspects of information provision: (a) satisfaction with information provision, (b) perceived amount of information received, and (c) perceived helpfulness in understanding concussion. The study also found that clients who received the information resources did not respond more favourably about information provision than clients who did not receive the resources. This finding should be questioned because of limitations in the methodology used and because it is not compatible with a number of studies in other areas which indicate that information resources can increase the effectiveness of information provision for health consumers.

In other results, it was found that obtaining an appropriate amount of information increased client satisfaction with information provision and that clients who did not receive the information resources may not have received enough information. The study also found that clients preferred to receive information on both videotape and brochure and they tended to use these information resources often and a similar number of times. Although the study did not confirm any advantages for the use of videotapes as compared to brochures, its findings do support the use of videotapes in information provision for people with concussion when they are used alongside written resources rather than replacing them.

The process of carrying out this research project has pointed to some directions for future research in this area. The effectiveness of information provision can be enhanced by taking into account the views of the health consumers who will receive the information. Future studies could investigate the views of people with concussion and their families about the effectiveness of the videotape and the brochure produced by this study and could seek suggestions on how to improve these resources. This

research could then provide guidelines for information providers on how to produce such resources for New Zealand situations.

This approach could also take a more specific focus on sports clubs, particularly rugby clubs, which are popular in New Zealand and involve a sport in which concussion is an important safety issue. The content of information resources in this area could be developed to provide safe guidelines for returning to sports after a concussion. Another group whose views could be specifically researched is Maori. Studies with Maori could perhaps work through iwi groups or Maori health providers and could provide guidelines on producing information resources on concussion relevant to Maori.

Information provision by videotape may be particularly appropriate for people with low literacy levels. This aspect of information provision was not addressed in the study and future research could investigate this area particularly among older people who may have a higher incidence of low literacy skills than the general population. Only one person aged 65 years or over attended the Concussion Clinic during the period of the study and this implies that older people should be recruited from services that specifically target this age group.

The current study was limited by a low response rate and a low number of participants and there are changes that could be made to improve the effectiveness of this type of research. The study could be repeated with adjustments to allow for the use of a prospective design that would recruit potential participants at the clinic. The number of potential participants could be increased by situating the study at a one or more of the concussion clinics in the major cities.

Traumatic brain injury is a major health problem in New Zealand and it results in a large number of concussions. Many of these mild injuries lead to long-term difficulties but research has indicated that early intervention can be effective at reducing these difficulties and it underlines the value of information provision in these interventions. Further research that seeks to improve the effectiveness of information provision has an important role to play in efforts to reduce the impact of concussion on the people injured, their families and health services.

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APPENDIX A

Information Sheet

Client satisfaction at the Midcentral Health/Massey University Concussion Clinic

Hi, our names are Roxanne Leach and Grahame Scoullar. We are graduate students at Massey University studying client satisfaction at the Midcentral Health/Massey University Concussion Clinic. As a previous client of the clinic you are invited to take part in this research. If a family member or friend went with you to the clinic they are also invited to take part. The aim of this study is to find out what clients and others think about the service provided by the clinic.

Roxanne's study will look at the overall service at the clinic and Grahame's study will look at the information provided by the clinic. You will be asked to answer some questions about how satisfied or dissatisfied you were with the services provided by the Concussion Clinic. Answering the questions should take about 15 minutes. Your responses can be sent back to us in the self-addressed envelope provided. You may get a reminder about the questionnaire after two weeks.

It is voluntary to take part in the research and you can choose not to answer any questions. If you complete the questionnaire and send it back then it will be assumed that you are consenting to take part. All the information that you give will be confidential and will only be used for our studies. The questionnaire will be labelled with a code number instead of your name. There will be no information that could identify you in any reports about the studies. At the end of the studies all questionnaires will be destroyed. Your answers will not affect the past or any future contact you may have with the clinic.

If you would like to receive a summary of the results, please tick the feedback item at the end of the questionnaire. Your participation would be greatly appreciated. The supervisor for this research is Professor Janet Leatham.

If you would like any further information or have any questions about the studies please do not hesitate to contact Roxanne Leach, Grahame Scoullar or Professor Janet Leatham on the following number: 06 3505799 extn 6864.

This project has been reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 02/119 and the Manawatu Whanganui Ethics Committee, Protocol 29/02. If you have any concerns about the conduct of this research, please contact Dr Pushpa Wood, Chair, Massey University Regional Human Ethics Committee: Wellington, telephone 04 801 2794 ext 6723, email P.Wood@massey.ac.nz.

What Is Concussion?

Concussion is a mild injury to the brain.

It can be caused by a blow to your head or when your head is suddenly jolted.

Your brain gets twisted and its brain cells are injured.

This can knock you out or make you giddy and confused for a while.

Who gets Concussion?

People of all ages get concussion.

The most common group is males aged 15 to 24 years old.

They often get concussion from traffic accidents, assaults or when playing sports.

Children and older people often get concussion from falls.

What are the effects?

There are many effects of concussion and each person is affected differently.

Some of the common effects are tiredness, headaches and difficulty sleeping.

You may be clumsy, feel dizzy and have blurred vision.

Bright light and loud noise is a problem for many people.

Some other effects

Your brain may feel sluggish.

Your reactions and thinking will be slow.

It will be hard to concentrate, pay attention and remember things

Changes in your mood

Your mood may be up and down.

You might be irritable and bad tempered at times and over react to small things.

All of these changes may make you feel anxious and depressed.

The effects of concussion are unpleasant but most people recover and get back to normal.

When will I get better?

Many people get over their effects in a few weeks.

However even a minor injury can have longer lasting effects.

This is called Post-Concussive Syndrome.

If you still have the effects of concussion after 4 weeks you should see your doctor.

Most people who need further help recover in 3 to 6 months.

About 15% take longer to get back to normal.

*Your visit to the Concussion Clinic**What is a Neuropsychological Assessment?*

A neuropsychological assessment is a way to find out how well your brain is working.

It is done by a neuropsychologist who is trained in how the brain works and how it affects your behaviour, thinking and personality/emotions.

There are tests in skills like concentration, memory, language and solving problems. You will be answering questions, writing things down, working with shapes/objects and drawing pictures.

The tests can find out your good skills and the things you have problems with.

What is a Physical Assessment?

A physical assessment is another way to see which parts of your brain are working well and which are not.

The examination looks at how different parts of your body are working like your head, eyes, ears, neck, arms, legs and muscles.

It will check your reflexes and the way you stand and move.

It will also check your senses for things like smell, touch, heat, and pain.

The clinic staff use both of these assessments to help your recovery.

What helps recovery?

Rest and regular sleep are important.

Go back to work, study and other activities gradually.

Write things down to help your memory.

What not to do?

Do not drive a car until your reactions have returned to normal.

Take care with alcohol and drugs. They will have a greater effect than normal.

Avoid doing things where you could get a blow your head again. Even a minor injury can be serious while your brain is still recovering.

This is one reason why sports people who have had concussion should wait at least three weeks before playing again.

Don't get too tired as this can make the other effects worse.

Family and Partners

Family and partners of people with concussion are also affected by the injury.

They may need to look after you while you recover.

Your emotional changes can be very hard for them to adjust to.

Here is a list of organizations that are available to support you and them.

The Concussion Clinic - 350 8033

ACC - 0800 101 996

The Brain Injury Association - 354 3540

Prepared by
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MidCentral Health/Massey University
Concussion Clinic

about

Concussion

APPENDIX C

VIDEO SCRIPT for “about Concussion”

SCRIPT/AUDIO

VISION

This video will answer some of your questions about concussion.

Title: about Concussion

Concussion is a mild injury to the brain. It can be caused by a blow to your head or when your head is suddenly jolted. Your brain gets twisted and its brain cells are injured.

Title: What is Concussion?

Animated Graphics: View of head and brain.

Head and brain move.

Network of brain cells twisting.

This can knock you out or make you giddy and confused for a while.

Adam is 19, he got concussion in a traffic accident.

Actor 1 interview

“I don’t remember much, my head was thrown around and I was unconscious for about 10 minutes.”

Jane got concussion when she fell at home. “I tripped over some of my daughter’s stuff and hit my head on the wall. I was dazed and giddy but I didn’t pass out.”

Actor 2 enters kitchen

Actor 2 interview

People of all ages get concussion. The most common group is males aged 15 to 24 years old. They often get concussion from traffic accidents, assaults or playing sports. Children and older people often get concussion from falls.

Title: Who gets Concussion?

People in city streets

Young males in street

Traffic and rugby

Children and older people in street

There are many effects of concussion and each person is affected differently. Common effects are tiredness, headaches and difficulty sleeping.

Title: What are the effects?

People in street

Word graphics: tiredness, headaches, difficulty sleeping

<p>“I got really tired after the concussion, even watching TV gave me a headache.”</p>	<p>Actor 1 interview</p>
<p>“I didn’t have enough energy to cope with the family. My mother came around each day and my husband and my children both, all helped out.”</p>	<p>Actor 2 interview</p>
<p>You may also be clumsy, feel dizzy and have blurred vision. Bright light and loud noise can be hard to cope with.</p>	<p>Actor 2 drops pot lid, actor 1 reading magazine, blurred image effect and ‘white out’ effect.</p>
<p>“I couldn’t listen to music for quite a while, had to wear sunglasses more.”</p>	<p>Actor 1 interview</p>
<p>“I couldn’t bear the noise the children made, it was hard for them to be themselves.”</p>	<p>Actor 2 interview</p>
<p>Your brain may feel sluggish. Your reactions and thinking could be slow. It might be hard to concentrate, pay attention and remember things.</p>	<p><i>Title:</i> Effects on brain power <i>Slow motion shots:</i> Actor 1 making coffee, actor 2 peeling a carrot <i>Word graphics:</i> concentrate, pay attention, remember</p>
<p>“They often had to repeat what they said to me, I just seemed to lose it in the middle of a sentence, later on I would probably forget it anyway.”</p>	<p>Actor 2 interview</p>
<p>“I couldn’t follow what my friends were saying especially when more than one of them were talking.”</p>	<p>Actor 1 interview</p>
<p>Your mood may be up and down. You might be irritable and bad tempered at times and over-react to small things.</p>	<p><i>Title:</i> Changes in your mood <i>Word graphics:</i> irritable, bad tempered, over-react</p>
<p>“A lot of things seemed to annoy me, I got into a few arguments with my flatmates.”</p>	<p>Actor 1 interview</p>
<p>“Sometimes I would be quite cheerful and then I would get upset over some small thing. It was hard for the children and my husband to get used to.”</p>	<p>Actor 2 interview</p>
<p>“That made me worry that things wouldn’t get better, that things wouldn’t get back to normal.”</p>	

<p>All of these changes may make you feel anxious and depressed. The effects of concussion are unpleasant but most people recover well.</p>	<p>People in street</p>
<p>Many people get over the effects of their concussion within a few weeks. However even a minor injury can have longer lasting effects. These effects are together called Post-Concussion Syndrome.</p>	<p><i>Title:</i> When will I get better? People in street <i>Word graphics:</i> Post-Concussion Syndrome</p>
<p>Most people who need further help recover in 3 to 6 months. About 15% take longer than that. “After a month I was coping pretty well in the mornings and my mother only came in the afternoon. But it was still 3 months before I felt I was back to normal.”</p>	<p>People in street Actor 2 interview</p>
<p>“About 2 months after the accident I could go back to uni and study part time. I could concentrate okay in the morning but in the afternoon I had to take a break. If I tried to do too much I’d get a headache. 6 months later I was studying full time and I was back to normal.”</p>	<p>Actor 1 interview Actor 1 at computer</p>
<p>Your return to work, study and other activities should happen gradually. Rest and regular sleep are important.</p>	<p><i>Title:</i> What helps recovery? Actor 1 at a computer Actor 1 in bed</p>
<p>“So that’s Saturday is it, okay just a minute” Try to write things down to help yourself remember things. “I had to write things down a lot more than before but at least I remembered most things.”</p>	<p>Actor 2 on the phone Actor 2 writing on a white board. Actor 2 interview</p>
<p>Tell someone about any difficulties you are having and seek help for them.</p>	<p>Actor 1 phoning for medical help</p>

Do not drive a car until your reactions have returned to normal.

Take care with alcohol and drugs. They can have a greater effect than is usual for you.

“One night I went out. After one drink my mates had to bring me home, I could hardly stand up.”

Avoid doing things where you could get another blow to your head. Even a minor injury can be serious while your brain is still recovering.

“The children were really good about keeping things tidy after my fall. We didn’t want to risk another accident like that.”

Sports people who have had concussion should wait at least three weeks before playing again.

Try not to get too tired as this can make the other effects of concussion worse.

“Sometimes the house wasn’t as clean as it could be. I soon learnt not to overdo it or I wouldn’t get through the day.”

Family and partners of people with concussion are also affected by the injury. They may need to look after you while you recover. Your emotional changes can be hard for them to adjust to.

If you have any other questions or would like more information you can contact these organisations.

Title: What should I try not to do?
Actor 1 hands over car keys

Actor 1 declines a drink

Actor 1 interview

Actor 2 slips on a rug

Actor 2 interview

Horse riding, netball

Actor 2 reads cook book

Actor 2 interview

Title: Family and Partners
Families and partners in street

Title: For more information and support:

Word graphics:

The Concussion Clinic 350 8570

ACC 0800 101 996

The Brain Injury Association 354 3540

APPENDIX D

(On Concussion Clinic Letterhead)

Dear

The Midcentral Health Concussion Clinic is working with two researchers from Massey University who are studying the service provided by the clinic. The researchers are independent from the clinic. They have not been allowed to see your files and do not know your name or contact details. The studies will examine our service and help us to improve it. We have included the information sheet and questionnaire for the studies in this letter. If you decide to take part, please send your replies to the researchers in the envelope provided.

APPENDIX E

SERVICES EVALUATION

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Please read the following statements carefully. Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your overall experience based on all visits or contacts that you have had with the Midcentral Health/Massey University Concussion Clinic. By 'practitioner' we mean the one or more doctors, psychologists, etc. who have worked with you.

What is your overall feeling about the...

1. Kinds of services offered

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

2. Opportunity to choose which practitioner you see

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

3. Effect of services in helping you deal with your problems

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

4. Office personnel (receptionist) on the telephone or in person

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

5. Office procedures (scheduling, forms, tests, etc.)

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

What is your overall feeling about the...

6. Professional knowledge and competence of the main practitioner(s)

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

7. Location and accessibility of the Concussion Clinic (distance, parking, etc.)

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

8. Appearance and physical layout of the Concussion Clinic (e.g. waiting area)

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

9. Ability of your practitioner(s) to listen to and understand your problems

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

10. Personal manner of the main practitioner(s) seen

TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED

11. Waiting time between referral to the Concussion Clinic and the appointment (date and time) given

DELIGHTED MOSTLY SATISFIED MIXED MOSTLY DISSATISFIED TERRIBLE

12. Waiting time when you come to be seen or keep an appointment made

TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED

What is your overall feeling about the...

13. Ability of your practitioner(s) to listen to and understand your problems

DELIGHTED MOSTLY SATISFIED MIXED MOSTLY DISSATISFIED TERRIBLE

14. Cost of services to me

TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED

15. Effect of services in maintaining well-being and preventing relapse

DELIGHTED MOSTLY SATISFIED MIXED MOSTLY DISSATISFIED TERRIBLE

16. Confidentiality and respect for your rights as an individual

TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED

17. Amount of help you have received

DELIGHTED MOSTLY SATISFIED MIXED MOSTLY DISSATISFIED TERRIBLE

18. Availability of information on how to get the most out of services

TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED

19. Prescription (or non-prescription) of medications

DELIGHTED MOSTLY SATISFIED MIXED MOSTLY DISSATISFIED TERRIBLE

20. Explanations of specific procedures and approaches used

TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED

What is your overall feeling about the...

21. Effect of services in helping relieve symptoms or reduce problems

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

22. Response to crises or urgent needs during office hours

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

23. Arrangements made for after hours emergencies or urgent help

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

24. Thoroughness of the main practitioner(s) you have seen

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

25. Appropriate use of referrals to other practitioners or services when needed

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

26. Collaboration between service providers (if more than one)

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

What is your overall feeling about the...

27. Publicity or information about programs and services offered

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

28. Handling and accuracy of your records (as best as you can tell)

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

29. Contribution of services to achievement of your life goals

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

30. In an overall general sense, how satisfied are you with the services you have received

TERRIBLE *MOSTLY DISSATISFIED* *MIXED* *MOSTLY SATISFIED* *DELIGHTED*

31. Information you were given about concussion

DELIGHTED *MOSTLY SATISFIED* *MIXED* *MOSTLY DISSATISFIED* *TERRIBLE*

The next questions are also about information you were given on concussion...

32. The *amount* of information I was given about concussion was

FAR TOO MUCH TOO MUCH ABOUT RIGHT TOO LITTLE FAR TOO LITTLE

33. How well did the information given to you help you to understand concussion and its effects

NOT AT ALL A LITTLE SOMEWHAT QUITE A BIT A GREAT DEAL

34. How would you prefer to get information to take home

VIDEOTAPE BROCHURE VIDEOTAPE & BROCHURE OTHER _____

35. Did you get the yellow brochure called "about Concussion" YES NO

If yes, how many times have you read it

NONE 1 2 3 OR MORE

36. Did you get the videotape called "about Concussion" YES NO

If yes, how many times have you watched it

NONE 1 2 3 OR MORE

It is important to know something about the participants, so we request this extra information. Only grouped data will be used, and you will never be identified. However if you prefer not to answer any or all of the questions, you may freely do so.

37. Are you the: Client Family/friend

38. Gender: Female Male

39. Age (years):

0 – 14	<input type="checkbox"/>	15 – 24	<input type="checkbox"/>
25 – 34	<input type="checkbox"/>	35 – 44	<input type="checkbox"/>
45 – 54	<input type="checkbox"/>	55 – 64	<input type="checkbox"/>
65 – 74	<input type="checkbox"/>	75 & over	<input type="checkbox"/>

40. Yearly Family Income:

Under \$10,000	<input type="checkbox"/>	\$10,000 - \$20,000	<input type="checkbox"/>
\$20,001 - \$40,000	<input type="checkbox"/>	\$40,001 - \$60,000	<input type="checkbox"/>
\$60,001 - \$80,000	<input type="checkbox"/>	Over \$80,000	<input type="checkbox"/>

41. Current Employment:

Employed full time	<input type="checkbox"/>	Employed part-time	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>	Full-time student	<input type="checkbox"/>
Part-time student	<input type="checkbox"/>	Retired	<input type="checkbox"/>
Other (Please specify) _____			

42. Occupation (Please specify)

43. Education

- | | | | |
|-------------------------------|--------------------------|--------------------|--------------------------|
| Some high school | <input type="checkbox"/> | Completed 5th form | <input type="checkbox"/> |
| Completed 6th form | <input type="checkbox"/> | Completed 7th form | <input type="checkbox"/> |
| Attended tertiary institution | <input type="checkbox"/> | | |

44. What is your ethnic origin

- | | | | |
|------------------------|--------------------------|----------|--------------------------|
| NZ/Pakeha | <input type="checkbox"/> | Maori | <input type="checkbox"/> |
| Polynesian | <input type="checkbox"/> | European | <input type="checkbox"/> |
| Other (please specify) | _____ | | |

45. Reason for being referred to Concussion Clinic

- | | | | |
|------------------------|--------------------------|---------|--------------------------|
| Car Accident | <input type="checkbox"/> | Fall | <input type="checkbox"/> |
| Sports related injury | <input type="checkbox"/> | Assault | <input type="checkbox"/> |
| Other (please specify) | _____ | | |

46. What distance did you have to travel to get to the Concussion Clinic (Km's)

47. Referral to the Concussion Clinic was through

- | | | | |
|------------------------|--------------------------|---------------|--------------------------|
| ACC | <input type="checkbox"/> | My G.P. | <input type="checkbox"/> |
| Case manager | <input type="checkbox"/> | A neurologist | <input type="checkbox"/> |
| Other (please specify) | _____ | | |

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding. The 7-point scale is as follows:

- 1 = strongly disagree
 2 = disagree
 3 = slightly disagree
 4 = neither agree nor disagree
 5 = slightly agree
 6 = agree
 7 = strongly agree

- ___ 1. In most ways my life is close to my ideal.
- ___ 2. The conditions of my life are excellent.
- ___ 3. I am satisfied with my life.
- ___ 4. So far I have gotten the important things I want in life.
- ___ 5. If I could live my life over, I would change almost nothing.

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THANK YOU VERY MUCH FOR YOUR HELP WITH THIS SURVEY, WE WOULD APPRECIATE ANY ADDITIONAL COMMENTS ABOUT THIS SERVICE YOU WOULD CARE TO ADD. YOU MAY WRITE THEM BELOW.

The thing I have liked best about my experience here is:

What I liked least was:

If I could change one thing about this service it would be:

Would you like the Concussion Clinic to send you a summary of the results

Yes

No