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Family Preparedness for  
Life with a Traumatically Brain Injured Relative

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## ABSTRACT

The numbers of people surviving traumatic brain injury are increasing, as medical technology and crisis management systems improve. The demand for rehabilitation and support services outstrips supply and typically it is the families of individuals with brain injury who step in to meet the shortfall in services. Yet families are rarely prepared for the changes traumatic brain injury brings. It was a premise of this study that well prepared families would be more likely to understand what was required to effectively facilitate their injured relative's recovery, and be more capable of doing so, than families that were not well prepared.

Using an evolving methodology, this three-phase mixed method study set out to investigate family preparation for life with a brain injured relative, focusing on the period where the injured relative was an inpatient at a rehabilitation facility in the Manawatu, New Zealand. Semi structured interviews and a self-administered mail questionnaire were employed to examine the roles performed by family members following their relative's brain injury, and their perceptions of the preparation they received for these roles and for the effects of role performance on their own lives, while their relative was an inpatient at the Rehabilitation Centre.

The study found that family members often played a critical part in their relative's recovery from injury, assuming one or more of the roles of caregiver, case manager and therapist. Consistent with the literature, many family members considered they had not been adequately prepared for these roles during the period of inpatient treatment and suggested many changes were required to the way in which the process of family preparation was approached.

From the experiences reported by family members, an evidence-based model of family preparation was developed to guide family preparation initiatives during the period of inpatient rehabilitation. The model is based on the premise that each family has unique preparation needs, reflecting the different capabilities of their brain injured relative, the family's social capital, and the range of professional and lay services available to the injured relative and the family at any given time. The changes to family preparation proposed in the study include enhanced collaboration between families, practitioners

and agencies, greater inclusion of families in the inpatient phase by practitioners, and the adoption of a more planned approach to family preparation. These changes are largely achievable within existing resource constraints.

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To describe PhD research as a ‘challenging journey’ is to somewhat understate the case. In virtually every respect, the demands associated with conducting this research exceeded my expectations. So too, however, did the rewards. The process of conducting this research has brought me in contact with some most remarkable people, people whose contributions have helped to shape not only the work presented here but also my thinking generally. To these people, too numerous to mention individually, I am most indebted.

- ☛ To the families who shared their stories with me so that I might better understand and convey that understanding to those with the capacity to instigate change, in the hope that the stories of families (who in the future will follow in your footsteps) might be different - I hope I have accomplished what you wished;
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## **CHAPTER 1**

### **INTRODUCTION**

Advances in technology and acute care practices mean survival rates following traumatic brain injury (TBI) are increasing to such an extent that the term 'epidemic' is frequently used to describe the phenomenon (e.g. Gronwall, Wrightson & Waddell, 1990; National Institute of Handicapped Research, 1986; Powell, 1994; Sullivan, 1997; Wesolowski & Zencius, 1994). Our ability to save lives, however, far exceeds our ability to restore function and it is a sad but undeniable reality that, for many people who sustain brain injury, life will never be the same again.

This truism may be equally applied to the families of brain injured individuals. From the moment of injury, they are plunged into an environment which is usually unfamiliar and requires them to cope with, and adapt to, a plethora of experiences for which their lives previously may have done little to equip them. In the majority of cases, family members play the largest role in the injured relative's long term care and rehabilitation, continuing their efforts far beyond the point at which professional involvement has ceased (Brooks, 1991b; Jacobs, 1991; Oddy, Yeomans, Smith & Johnson, 1996). Viewed in this context, TBI becomes not so much a medical issue as a social and familial one (Waaland, 1998).

This study documents the experiences of family members where a close relative has sustained a brain injury. The focus of the study is family preparation. Descriptions of family members' experiences of life with a brain injured relative are used, therefore, to provide a context for understanding family members' need for, and experiences of, preparation.

A distinction is made in the study between the period of inpatient treatment, where responsibility for the brain injured individual lies primarily with medical/rehabilitation professionals, and the post discharge period, where responsibility typically lies with the family. After discharge, family members assume a variety of roles in response to the relative's care and rehabilitation needs and in the broader context of general family

functioning. It is the study's general aim to explore the period of inpatient rehabilitation, as viewed retrospectively by family members who have assumed responsibility for the care of their injured relative. Experiences recounted illuminate the process by which family members believe they were prepared for post discharge life.

The notion of families being ill-equipped to meet the challenges of traumatic brain injury is neither new nor startling. The literature is replete with references to unprepared, poorly prepared, inadequately prepared and ill-equipped families. The focus of rehabilitation is widening, however, emphasising the importance of helping brain injured individuals find a meaningful place in society rather than solely ameliorating deficits. This brings into focus a greater need to identify barriers to successful community re-integration and to pursue initiatives which help foster a successful transition from inpatient to community living. Ensuring that people involved in the everyday life of brain injured individuals possess the knowledge and skills required to facilitate those individuals' recovery and ongoing development is central to the achievement of this goal (Ylvisaker & Feeney, 1998) and, according to the literature, a key responsibility of rehabilitation practitioners. Jacobs (1989b), for example, describes the ability of the brain injury survivor and their family to "carry the torch", once formal treatment ends, as being an important measure of the overall effectiveness of rehabilitation practitioners' efforts (p. 314).

Four primary aims were established for this study. Firstly, in order to provide a context for understanding the significance of family preparation, the study aimed to explore: the impacts of brain injury on family members; the roles played by family members in the recovery process; and the responses of family members to the brain injury, its impacts on family members and the roles they performed. Second, the study sought to identify the steps family members believe were taken by the various professionals involved in their relative's rehabilitation to prepare them for life with a brain injured relative, focusing particularly on preparation for the roles performed by family members and the effects performing these roles might have on them as family members. Third, family members' feelings about the preparation process and the various efforts made were to be investigated. Finally, their views were sought as to how the preparation process might be improved for



other families, where they felt such improvements were required. The goal was that, by addressing these aims, a coherent and comprehensive model of family preparation for continuing rehabilitation and care of a relative post TBI would be developed.

The study was based around a particular rehabilitation centre in the lower North Island of New Zealand, attached to a public base hospital. Participating family members were recruited via a pool of 115 eligible individuals; the pool comprising individuals who had received services from the Rehabilitation Centre on an inpatient basis in the past decade after sustaining a traumatic brain injury. Three family members were interviewed, to aid in the development of a questionnaire subsequently administered to the larger group. Post-questionnaire followup interviews were also conducted to explain issues addressed in, or arising from, the questionnaire.

Participants in the study were quite open and direct in the criticisms made of staff and of services provided, and these criticisms have been reported in the following chapters as they were reported to me, with neither embellishment nor 'watering down'. Overall, participants described a facility that, at times, struggled to meet the needs of its clients and their families, and the study's general finding that families felt inadequately prepared and supported for life with the brain injured relative has important implications both for reintegration of the injured individual into society and for the wellbeing of the family. At the same time, participants were equally generous with their praise and quick to point out the strengths of the staff and facility, as they saw them. References were made to the wonderful efforts made in particular areas, with some questionnaires containing requests to pass on their thanks and gratitude to rehabilitation staff, including specific staff members.

In conducting such a study, it is necessary to consider both the right of participants to have their experiences heard and valued, and the right of those working in the field - a field, L. Miller (1991) suggests, should be avoided by anyone requiring regular doses of success and gratitude - to have their efforts similarly acknowledged. I have endeavoured to be fair to both parties in this study, reporting both perceived strengths and deficiencies within the Rehabilitation Centre and in the general care continuum, as they were reported to me. It is

important to remember this study presents the views of family members and that no attempts have been made to verify their accounts with practitioners, practitioners who may well hold considerably different views on the matters examined. Further, the picture depicted relates to the time period covering 1988-1997; no attempts have been made to determine the continued applicability of participants' comments in the context of the current continuum of care and practices.

## A Personal Introduction

Traumatic brain injury is a harsh reality of contemporary western life and a society commonly characterised by high motor vehicle use, high speed, and high stress, together with increasingly sophisticated emergency care. Growing numbers of people are affected by brain injury, whether it be through personal injury or through the injury of someone known to them. I am no exception to this situation, having experienced brain injury as a friend, a step parent, a health professional, and now, as a researcher.

My introduction to the area of brain injury was probably fairly similar to that of many others, as a concerned but highly uninformed friend of someone who was in a car accident. Like many people who sustain brain injury, my friend received basic medical attention following the accident and was subsequently discharged without any advice or forewarning of possible problems she might encounter. For more than a year, she struggled with the effects of an undiagnosed brain injury, as, to a lesser extent, did those around her. The defining incident was the conversation when she rang to tell me she had learned she was brain damaged; she was very excited and pleased about the news. While I responded at the time with the enthusiasm she felt the announcement deserved, I also felt at a total loss as to understand why anyone could possibly be pleased with such a diagnosis. It was not until I embarked on post graduate study a few years later and studied the phenomenon of undiagnosed minor brain injury that I came to understand her relief at this pronouncement.

After leaving University for the first time, I worked as a coordinator for people with psychiatric and intellectual disabilities living in the community. As is so often the case, a

few of my clients had brain injuries. However, their unique circumstances and needs went largely unrecognised, not only by myself, who still knew virtually nothing of brain injury at this point, but also by other staff and management, whose understanding of the condition unfortunately matched my own. Frustrated by my complete lack of success with these clients, I embarked on a learning process, aided by the generous and tolerant assistance of those professionals I could locate who possessed knowledge of brain injury, a learning process which eventually led me to undertake the doctoral research reported here.

A particular case while working as a community coordinator stands out. One of my clients was a middle-aged man who had sustained a severe brain injury almost two decades previously. Heavily focused on his family, and with a strong sense of his responsibility to them as the oldest son/brother, the man was enormously distressed by his family's lack of current involvement in his life. At his request, I made contact with family members, separately, as in his case notes it was emphasised that information regarding the whereabouts of particular family members was not to be made available to him or to other family members. Eventually, a visit between my client and his mother was arranged. Almost as soon as she arrived, the mother started crying and found it difficult to make eye contact with her son. In a series of conversations with her, it became clear that, while acutely aware her son had changed significantly since his accident, she understood virtually nothing of the mechanics of brain injury nor precisely how the injury had caused the changes she could observe in her son. She agreed to meet with a psychologist with some expertise in brain injury, who explained the nature of her son's injury and the effects on his behaviour. Together they engaged in some basic counselling to address her feelings about the experiences she had had.

Watching two decades of guilt lift from her shoulders was a wonderful experience, one which left me, however, somewhat bewildered. How was it possible for anyone caring for a severely brain injured relative to go for so long - almost two decades in this case - without understanding the phenomenon which had led to the situation encountered? What had happened at the time her son was injured? Hadn't anyone taught this mother what she

needed to know? Presumably some professionals had been involved with the family before it broke apart from the stress - what had they done to help the family?

My perspectives on brain injury broadened and became more personal when I became involved with someone whose son had sustained a brain injury a few years previously. Our efforts to facilitate professional involvement to help him with difficulties he was encountering in the classroom were again an eye-opening experience. Issues frequently identified in the literature were highlighted: the lack of suitably-trained practitioners; the lack of public (and teacher) awareness and tolerance for brain injury; the phenomenon of funding agencies-acting-as-gatekeepers, to name a few. During the course of the study, as I was exposed to the difficulties encountered by participants, I found myself drawing parallels between their experiences and my own, filling in gaps in my understanding of certain areas and issues through their insights.

My experiences of brain injury influenced the approach I took to the study as well as my interactions with participants. The choice of topic, for example, stemmed from work experience, specifically, my curiosity as to how a parent could know so little about brain injury (although so much about its impacts) years after the initial accident. A strong belief that families have a right to be prepared for life post brain injury characterised my thinking, both at the beginning of the research and now, at its conclusion, stemming from the suffering I had observed amongst families struggling to cope with insufficient resources. An ability to empathise with participants was another outcome of my experiences - a quality I believe helped me to ask more pertinent questions and ultimately made the interviews a more empowering process for participants. This close involvement clearly raised issues of researcher bias (see chapter 13); however, it is my belief that, overall, my previous experiences of brain injury made me a more effective researcher and ultimately helped to produce a more useful dissertation on family preparation than would otherwise have been the case.

## Language Used in the Study

I have tried to avoid the temptation of using excessive jargon in the present study, reflecting a personal belief that research is of much greater use when it can be understood by those without an expert's knowledge of the subject as well as by those who do possess such an understanding. Where it has been unavoidable, definitions have been provided alongside the term within the body of the text to assist those unfamiliar with the area. For reference, the following terms and abbreviations are commonly used:

ACC	The Accident Compensation Corporation, a crown-owned entity and currently the sole provider of accident insurance in NZ. Its purpose is to facilitate injury prevention activities, case management and rehabilitation services, and manage relationships with health providers. While the organisation has had various names since its formation, on all occasions the acronym ACC has been retained.
NZ	New Zealand.
Premorbid	Refers to the period before the onset of brain injury.
Postmorbid	Refers to the period following the onset of brain injury.
TBI	Traumatic brain injury. The preferred term used in the present study, used interchangeably with 'brain injury', describing sudden damage to the brain from an external force.

Throughout the thesis, "relative" is used in reference to the individual who sustained a traumatic brain injury, while "family member" is used to describe other members of that individual's family. A description of the term "family" is provided in chapter 3.

I have intentionally not included a glossary of terms for Maori terms in the thesis. The few terms which are used are in common usage in New Zealand, as is evidenced by their inclusion in the New Zealand Oxford Dictionary (see Deverson, 1998). Any reader unfamiliar with a Maori term encountered is therefore referred to the NZ Oxford dictionary, or alternately, to the Reed Dictionary of Modern Maori (Ryan, 1995).

I have avoided the use of the term 'victim' in reference to individuals with brain injury and have similarly tried to avoid labelling individuals on the basis of disability. Economy of expression and neutral language do not always easily combine, however, and where conflicts arose, 'readability' was emphasised. For this reason, the terms "brain injured relative" and "injured relative" are used in conjunction with "relative" to describe the individual who sustained traumatic brain injury, even though "individual with brain injury" is the preferred term (see American Psychological Association, 1994).

### Significance of the Study

The study's significance is multiple:

- for the family members themselves;
- for clinicians and organisations working with family members, both those specialising in the area of brain injury and the many 'generalists' who are increasingly being called upon to provide assistance as part of their work in other areas;
- for its contributions to the understanding of the role of family post traumatic brain injury [TBI] and of the preparation families feel they require for the successful performing of those roles;
- to the debate about what constitutes an appropriate level of family responsibility and under what conditions;
- to better practice, where better practice is required, and to more confident practice, where good practice already occurs.

In Hubert's (1995) research into life after head injury, she describes how her study, which involved indepth interviews with 20 brain injured youths and their families, adds "a vital

perspective to the existing data - that of the people themselves" (p. 106). The present study takes a similar approach, exploring participants' views of their experiences of TBI and the adequacy of their preparation process for those experiences. There is no doubt that others involved in the rehabilitation process would have given vastly different accounts of the preparation process from those provided by participating family members. However, the aim of the study was never to determine exactly what happened during the period of inpatient treatment, only what family members perceive to have happened. This perspective is certainly relevant: even if another study were to find that family members had been provided with more information than they reported receiving, if those same family members had no recollection of receiving the information and felt inadequately informed, then practically, from the families' perspective, it makes little difference whether or not that information was actually provided. In such a scenario, there is a need for modifications to the education process used.

The opportunity for family members to 'tell their side of the story' is another feature of the research, the value of which should not be underestimated. Participants often expressed a belief that others, including the professionals involved in the brain injury field, neither understood nor cared about their plight or their needs. The opportunity to tell an interested outsider was happily, and sometimes gratefully, accepted by participants, some of whom appeared to find the process of participation quite therapeutic and/or empowering. One father, for example, commented on how being interviewed and talking about the family's experiences with the whole family present had been helpful for the family. In another example, a spouse, at the conclusion of the questionnaire, wrote, *"This was a very good paper. It made me wonder how the hell did I do it, without anyone helping or preparing me for the future"*.

The value of research, according to Kressel (1990), is often measured against prior research, without adequate consideration of its social relevance. The social relevance of the present study, and more specifically, its timeliness, may be considered one of its strengths. As survival rates following TBI increase and costs associated with rehabilitation and care escalate, it becomes tempting, and indeed it has become increasingly common, to

view the family as an 'efficient' provider of long term care and support for brain injured individuals. While fierce debate continues as to the appropriateness of such a move, it is important to consider issues surrounding the provision of care and support by families and to identify what exactly is required by families if they are to be able to carry out the roles they are being designated. Investigation into the preparation needs of family members and examination of the ways in which these needs are and are not met, even within the restricted context of a single rehabilitation facility as was the case in the present study, is a useful contribution to this body of knowledge.

By making the area of family preparation the primary focus, the study differs from other research, where the topic of family preparation tends to be covered indirectly or secondary to something else. Indeed, the literature review revealed that while much literature has been premised on the notion of inadequate preparation, the area of family preparation has itself not been thoroughly explored. The insights the study provides, therefore, should go some way to addressing gaps within the existing literature.

### Structure of the Thesis

The next two chapters in the thesis discuss relevant literature, first in relation to TBI rehabilitation and brain injured individuals (chapter 2), and then on the family in brain injury rehabilitation (chapter 3). The first of these bodies of literature demonstrates that the outcome achieved by an individual and the type of life ultimately led following TBI is not simply a matter of biology but rather a product of many different factors which combine to influence recovery in a manner which is, as yet, incompletely understood. It appears from the existing literature that family represent one of the key determinants, possibly a critical determinant, of outcome.

The second of these bodies of literature explores various aspects of the family in brain injury rehabilitation, revealing that family members play many different roles in their relative's life following TBI which, in conjunction with the event of the TBI itself, have a multitude of effects on their own lives. While numerous interventions have been



developed for use in the brain injury realm, family members continue to feel inadequately prepared for life with a brain injured relative, a scenario which has many far-reaching and negative ramifications on the health and wellbeing of individual family members as well as on the family unit as a whole.

Chapter 4 comprises an overview of the study's methodology, providing an outline of the process by which the topic of family preparation was investigated and a rationale for the approach taken. The research setting is described in chapter 5, as are the research participants themselves, thus describing the context for the study.

Chapters 6 through to 12 report in detail on participants' experiences of the brain injury of their relative and their preparation for the roles performed as part of their relative's recovery process. Each chapter focuses on a particular theme, presenting and then discussing relevant findings. Chapters 6 and 7 describe the general experiences of family members, first in relation to the preparation process (chapter 6) and second in relation to their post TBI experiences (chapter 7). Chapters 8 through to 12 provide detailed findings on specific components of the preparation process, focusing on information provision (chapters 8 and 9), skills training and development (chapter 10), family self care (chapter 11), and the discharge process (chapter 12). In each of these chapters, findings are reported on the perceived nature and adequacy of preparation received. More detailed description of each chapter's contents is now provided.

Chapter 6 sets the basis for subsequent chapters by summarising, in quantitative form, participants' feelings about the preparation process. The general picture that emerges is of families who are ill-equipped to meet the challenges associated with TBI and largely dissatisfied with efforts made. Chapter 7 describes the range of impacts of brain injury on the lives of brain injured individuals and their families, and the ways in which family members responded to the brain injury and its various impacts. The impacts on life are such that life post injury is often changed dramatically.

Chapter 8 reports findings on the information provision process during the period of inpatient rehabilitation, revealing widespread dissatisfaction with the provision of information to family members by rehabilitation practitioners, and with the communication process generally. Chapter 9 goes on to explore family-practitioner communication dissatisfaction in greater detail, examining the various factors participants feel, or the literature suggests, may have contributed to the scenario depicted in chapter 8.

Chapter 10 explores family role performance following TBI. Family members adopted quite different approaches when trying to meet their relative's post TBI care and support needs, approaches conceptualised in the study as 'care giver', 'case manager' and 'therapist', reflecting common themes derived from both the literature and participants' accounts. In some cases, family members relied on a single strategy, while in others, they described moving between strategies as circumstances dictated, performing the associated tasks with widely variable levels of effectiveness. Because family members typically lacked much of the knowledge, skills and support needed to perform these roles at the time of their relative's inpatient discharge, these competencies were instead acquired over time and through trial-and-error, if at all. Considerable anger and resentment was expressed by some of the participants who felt not only that they should have been much better prepared for what lay ahead but also that what was expected of them as family members was quite unreasonable.

Chapter 11 examines the area of family self care (of uninjured family members) and the types of assistance participants in the present study drew on to cope with the emotional burden stemming from TBI. The chapter reveals that family members frequently rejected offers of assistance following their relative's brain injury yet, perversely, there were instances when the assistance offered reflected the type of assistance and support participants described a need for. A sense of apparent regret was sometimes evident amongst participants, with many indicating that they should have made greater use of different sources of emotional assistance than they actually did.

The final chapter presenting and discussing findings, chapter 12, explores participants' experiences of discharge and the associated planning process, focusing on both weekend home visits and final inpatient discharge. Participants suggested that discharge planning meetings, the primary planning mechanism in use at the Rehabilitation Centre, are a useful but inadequate mechanism for addressing family members' planning needs, although not all participants believed they had taken part, or had the opportunity to take part, in such a meeting while their relative was an inpatient at the Rehabilitation Centre. The limitations identified in the discharge planning process, in conjunction with the broader problem of inadequate preparation for life post TBI, meant that families were often confronted with challenges on their relative's return home which they had little or no basis for understanding or managing.

In the final thesis chapter, chapter 13, an evidence-based model of family preparation is presented. Families constitute the model's primary focus, with the injured individual assuming an important but less central role. Rehabilitation services are provided within a complex social, economic and political environment, an environment which has undergone substantial change over the past few decades. Applying this model in practice, reducing the divergence between practices described in the study and those advocated by the model is, accordingly, a complex task. Some of the study's recommendations can be accomplished within existing resource constraints, while others require an allocation of resources. Given that society at large pays the cost when families are unable to support their brain injured relatives, this resource allocation represents a redistribution in cost as opposed to new costs, a shift which ACC, as the major funder of rehabilitation services, needs to facilitate. Recommendations made for future research centre around applying the model and overcoming the study's limitations, which are also discussed in the chapter.

## Conclusion

The study aimed to examine the area of family preparation for life with a brain injured relative, within the context of a single rehabilitation facility. While a number of participants considered they had benefited by participating in the study and having the opportunity simply to talk about their experiences, others felt they derived no direct benefit.

However, they agreed to participate in the hope that findings would lead to an improved experience for families who followed in their footsteps. As one mother wrote:

*I feel this questionnaire has come 6 years too late for my son but it is a positive step in the right direction for other head injury victims and for future training of people in this area so familys [sic] and victims do not have to go through the mental trauma that we went through and are still going through.*

It is my hope, as a researcher and as someone personally involved in the area, that the findings and recommendations of the study will influence policy and practices in the rehabilitation of brain injured persons particularly insofar as they involve family members.

## **CHAPTER 2**

### **SETTING THE CONTEXT: AN OVERVIEW OF TRAUMATIC BRAIN INJURY**

Of every 100,000 people, each year up to 30 die from brain injuries, victims of the road toll, sporting and industry-related injuries, accidental falls, and violence (Gronwall et al., 1990; Kraus & McArthur, 1999; Winslade, 1998). However horrendous these deaths may be, they comprise only part of a much larger picture. The hidden toll of brain injury - the effects on those individuals who survive injury with a disability, and on their families, friends, colleagues and so forth - is at least as great.

The focus of the present study is the family in brain injury rehabilitation, primarily the preparation family members require and receive for life with a brain injured relative. Other related topics are also explored, albeit in a more peripheral manner, to shed light on the subject of family preparation, such as the nature of roles performed by family members post TBI, the effects of such role performance on them, and the types of assistance family members believe they require to maintain these efforts over time.

In this chapter, contextual information is provided to illustrate the significance of the study generally and to explain key concepts and issues. The epidemiology of brain injury is examined, in particular identifying those segments of the population most at-risk for sustaining traumatic brain injury. Severity-based classifications are then described, incorporating a discussion of the features and outcomes that characterise different injury severity levels. Common sequelae and associated outcomes are also identified, following which the process of brain injury rehabilitation is reviewed in respect to the contexts of service delivery, cost and efficacy. Having read this chapter, a reader unfamiliar with the subject of TBI should understand both the subsequent literature-based chapter on families and preparation, and the study itself.

## Epidemiology of Brain Injury

The majority of individuals who sustain traumatic brain injury are male, in their late teens and early twenties, with a normal life expectancy and, most likely, sustained their injuries in a motor vehicle accident.

### Incidence and prevalence

Huge variation exists in the published incidence of brain injury. Willer, Abosch and Dahmer's (1990) review of epidemiological studies, for example, revealed rates ranging from 180/100,000 to 3,486/100,000. Generally, however, rates reported fall within the 180-300/100,000 range (e.g. Finlayson & Garner, 1994; Frankowski, 1986; Kraus, 93; Kraus, Black, Hessel, Ley, Rokaw & Sullivan et al., 1984; Naugle, 1990; Torner, Choi & Barnes, 1999). Such large variation in reported rates primarily reflects variations in the criteria used to determine inclusion (see below for a discussion on classifying brain injury).

Conducting research into prevalence has presented particular difficulties and consequently little reliable information is currently available (Kraus & McArthur, 1999; Naugle, 1990; Torner, et al., 1999; Willer, Abosch et al., 1990). The nature of brain injury itself is at least partly to blame; large numbers of individuals either receive treatment outside of the hospital setting or do not receive medical treatment at all post injury, leading to an overall under-reporting of cases, while the enormous variation in the level of resultant disability between brain injured individuals and in a single individual over time, makes the establishment of criteria for 'brain injured individuals' for the purpose of prevalence studies a complex and confusing task. In one of the more widely cited studies, Bryden (1989) suggests 55,000 people in the United Kingdom experience 'considerable disability' as a result of head injury.

The limited data available suggests the situation for New Zealand is similar to that depicted overseas. Gronwall et al. (1990) suggest approximately 200 people are admitted to hospital each week following head injury, and for each of these individuals, an additional two to three people will receive treatment without being admitted to hospital. The incidence rate

calculated for the Central Region of New Zealand, (the present study's geographic focus) was 25/10,000, thus falling within the 180-300/100,000 identified internationally (Central Regional Health Authority, 1996a). In an investigation into mild head injury in NZ, Wrightson and Gronwall (1998) estimated the annual incidence of mild head injury to be 2,920/100,000 for those under 15 years and 1,769/100,000 for those over 15 years (note: figures are cases per 100,000 of age specific population, not entire population). No prevalence figures were identified.

### Risk factors associated with brain injury

Sachs (1991) comments that one of the most difficult things for practitioners working in the brain injury field to come to terms with is the realisation that happy, well-adjusted, productive and promising individuals can be cut down by the trauma for no apparent reason: "Being a 'good person' does not necessarily minimise one's chance of suffering a traumatic brain injury" (p. 2). While everyone is potentially a candidate for brain injury, statistics indicate that some sectors of the population have a greater likelihood of injury than others.

Age is a critical factor, with those between the ages of 15 and 24 at greatest risk of sustaining brain injury (Kraus et al., 1984; Kraus & McArthur, 1999; Lezak, 1995; Naugle, 1990; Willer, Abosch, et al., 1990). Males are more likely to acquire brain injury than females, with acquisition ratios reported in the literature commonly ranging from approximately 2:1 to 4:1 depending on the age group reported on (for reviews see Naugle, 1990; Willer, Abosch, et al., 1990). Powell (1994) suggests males in the highest-risk age group of 15-24 years may actually be up to five times more likely to sustain a brain injury than their female counterparts.

Other risk factors identified include certain types of physically challenging or risky occupations, lower socio-economic status, and pre-existing personality and life adjustment problems, such as a disrupted family life, learning difficulties, treatment for emotional maladjustment, and/or a history of alcohol/drug abuse (Klonoff, Costa & Snow, 1986; Kraus & McArthur, 1999; Kreutzer, Witol & Marwitz, 1997; Lezak, 1995; W. G. Miller,

1986; Rimel, Jane & Bond, 1990; Sachs, 1991; Torner et al., 1999). People who have already sustained a brain injury are also at greater risk of incurring subsequent brain injuries (W. G. Miller, 1986), with Gaultieri and Cox (1991) suggesting that a single brain injury doubles the risk of a future injury, while two such injuries raise the risk eightfold. In New Zealand, there is also evidence brain injury may be a particular issue for Maori, with reports documenting higher rates of injury for this population compared with non-Maori (see Central Regional Health Authority, 1996b; Head Injury Working Group [HIWG], 1994; Te Puni Kokiri, 1995, 1998b; Yeates, 1997).

### Classifying Brain Injury

A cursory examination of the literature reveals an array of terms and classifications which may confuse even the most seasoned of veterans in the field, let alone the uninitiated. Numerous examples can be found where the terms 'brain damage', 'head injury', 'closed head injury', 'brain injury', 'traumatic brain injury', and 'acquired brain injury' have been used apparently interchangeably and also, in other cases, to describe quite specific conditions. In the present study, the preferred terms will be 'brain injury' and 'traumatic brain injury'. The terms will be used synonymously, encompassing injuries to the brain as a result of trauma (i.e. neither degenerative nor congenital) injuries that may produce an altered state of consciousness and may result in a decrease in cognitive, behavioural, emotional or physical functioning (see Badock, 1988; Brantner, 1992; D'Amato & Rothlisberg, 1997; Rose & Johnson, 1996; J. S. Taylor, 1996).

### Measurement of severity

In practice, four basic clinical categories are commonly used to describe the severity of damage sustained: mild, moderate, severe, and (persistent/permanent) vegetative state (VS) (Cope, 1994). Classifications are usually assigned on the basis of coma depth and duration (e.g. Glasgow Coma Scale) or length of post traumatic amnesia period (e.g. Post Traumatic Amnesia [PTA], Galveston Orientation and Amnesia Test, Westmead PTA Scale) (Begali, 1992; Bigler, 1990; Cope, 1994; Crovitz, 1987; Evans, 1994; Jones, 1992; Kolb &



Whishaw, 1990; Levin, 1990; MacNiven, 1994; L. M. Smith & Godfrey, 1995; Wade, 1992; Walsh, 1991; B. A. Wilson, Evans, Emslie et al., 1999).

Where PTA is used as a measure of severity, as was the case in the present study, a PTA period of less than five minutes represents a very mild injury, 5-60 minutes a mild injury, 1-24 hours a moderate injury, 1-7 days a severe injury, 1-4 weeks a very severe injury, and more than 4 weeks an extremely severe injury (W. W. McKinlay & Watkiss, 1999). It is necessary to note, however, that injury severity does not, as W. W. McKinlay and Watkiss (1999) state, “tell the whole story of TBI” (p. 75). Other factors are also important in determining outcome, such as pre-injury factors, the nature and location of cerebral damage, the adequacy/availability of initial injury management and ongoing care, and the presence of social supports.

Mild. Historically, the medical profession has been fairly unsympathetic to the plight of people with mild or minor injuries. Because the traumas which produce mild brain injury often appear minor and the resultant deficits are more subtle, concerns expressed by affected individuals and their families have largely been dismissed by professionals as exaggerated or fictitious or, in some cases, as unscrupulous attempts to obtain undeserved financial compensation. The terms ‘malingering’ and ‘compensation neurosis’ have regularly been applied to this group, and under-diagnosing and misdiagnosing has been common (Bernstein, 1999; Clements, 1997; Conboy, Barth & Boll, 1986; Fabiano & Daugherty, 1998; Hinnant, 1999; Schapiro, Sataloff & Mandel, 1993; A. Smith, 1994). The lack of attention traditionally paid to mild injuries is clearly evident in the inconsistent behaviour of researchers towards the inclusion of the mild category in epidemiological studies.

More recent research into the area has revealed mild TBI to be a far more serious and common condition than previously believed, with an estimated 80% of all brain injuries acquired falling into this category (Tellier, Della Malva, Cwinn, Grahovacs, Morrish & Brennan-Barnes, 1999). Common sequelae include memory, attention and concentration difficulties, reduced speed of information processing, sleep disturbances, lethargy,

irritability, depression, and headaches (Bernstein, 1999; Clements, 1997; Hinnant, 1999; Geffen & McFarland, 1996; Schapiro & Sacchetti, 1993; Tellier et al., 1999).

While short term outcome is generally quite good for this group, assuming appropriate treatment is given, the cumulative effect of deficits can have considerable social and economic consequences for both injured individuals and their families (Shackford & Wald, 1999). Schapiro et al. (1993) argue that a linear relationship between the severity of injury and the severity of ensuing symptoms should not be assumed, suggesting the problems experienced by people with mild injuries are often indistinguishable from those found in people with more severe injuries and that, in some cases, people with mild injuries may actually have a greater level of distress because of their greater awareness of symptoms and higher personal expectations.

Moderate. According to Cope (1994), moderate injury is the least clearly differentiated category in terms of distinct clinical characteristics, which has contributed to a general paucity of literature about this population. It is believed moderate injuries represent 8-10% of all injuries sustained (Lezak, 1995), commonly resulting in ongoing difficulties in the areas of cognition, behaviour, emotional functioning, and various daily living activities (Hellowell, Taylor & Pentland, 1999; Hinnant, 1999; Lezak, 1995; New Zealand Head Injury Society [NZHIS], 1993).

As was the case with mild injuries, the severity of ongoing deficits following moderate injury varies. The work of Rimel, Giordani, Barth and Jane (1982), for example, suggested that moderate injuries resulted in morbidity and mortality levels between mild and severe, while S. I. Anderson, Taylor, Jones, and Miller (1994) found no significant differences in global outcome and neuropsychological impairment levels amongst the moderately and severely injured groups examined. In Hellowell et al.'s (1999) recent work, between 40% and 50% of the moderately injured participants had moderate or severe disabilities two years after onset.

Severe. The proportion of people who have survived severe brain injury has historically been small in comparison with other levels of brain injury. Advances in medicine and technology mean this number has substantially increased over the past decade, however, so that now more people are surviving serious injury than ever before and surviving with more severe residual deficits (Clark, 1997; Jennett, 1996; Lezak, 1995; Plylar, 1989; Voogt, 1994; Wehman, Kreutzer, Wood, Morton & Sherron, 1988).

People with severe injuries present a significant challenge to society because of the extensive, and expensive, rehabilitation and care input required (Lezak, 1995). Ongoing assistance with some or all activities of daily living may be required, ranging from supervision to total care, with those individuals capable of returning to some form of employment generally doing so only after a number of years and in a reduced capacity (Lezak, 1995; Sloan, Balicki & Winker, 1996). As is the case with other severity levels, however, considerable variation is evident in the type of outcomes associated with this category. Further, there is evidence that positive outcomes possible following severe brain injury have the potential to be greater than previously believed or achieved, with a number of studies producing positive results by providing greater levels of rehabilitation and/or over longer periods of time (e.g. Burke, Wesolowski & Guth, 1988; Tuel, Presty, Meythaler, Heinemanns & Katz, 1992).

Vegetative State. Following brain injury, a small percentage of people pass from coma into a vegetative state [VS], the essence of which, according to Jennett (1996), is “wakefulness without awareness” (p. 6). In a VS, the individual is typically able to breathe spontaneously, shows reflex responses in their limbs, has periods of spontaneous eye-opening, manifests sleep-wake cycles, possibly swallows food when placed in the mouth, but is unable to speak, follow commands or indicate an ability to understand, and is completely dependent on others for their survival (Jennett & Teasdale, 1981; W. G. Miller, 1986; NZHIS, 1993, Shubin, 1990; Zasler, 1999).

In their 1981 work, Jennett and Teasdale suggested that a vegetative state could be recognised with confidence at one month post injury and that the possibility of an

independent future could be virtually excluded for those who remained in a VS three months post injury. Since that time, this statement has been frequently misinterpreted to mean no recovery will occur once a VS has continued beyond three months (Jennett, 1996). Jennett (1996) addresses this misperception, stating that consciousness may be regained and improvement may occur beyond this period, although the individual is likely to remain dependent.

## Effects of Brain Injury

### Psychological changes: Personality and mood

Disturbances of personality and mood are considered the most common sequelae of brain injury, cause the greatest distress to both the injured individual and to family, and potentially constitute the greatest barrier to successful community reintegration (Bond & Brooks, 1976; Jennett & Teasdale, 1981; Kosciulek, 1994b; W. W. McKinlay & Watkiss, 1996; Rosenthal & Bond, 1990; Willer & Linn, 1993). These disturbances may arise from organic damage, i.e. a direct consequence of brain injury, or in response to the brain injury itself, i.e. a secondary or indirect consequence (for a discussion of emotional responses, see Bergland & Thomas, 1991; Jackson & Gouvier, 1992; Lezak, 1988; Nochi, 1998; Tyerman & Humphrey, 1984).

At the mild end of the spectrum, subtle changes in interpersonal competency may occur. The person may appear less capable when interacting with others, demonstrate a tendency to use inappropriate language or gestures, talk excessively, sometimes with little apparent regard for relevance, fail to use environmental cues to guide their interactions, or fail to initiate or attend to a conversation (Armstrong, 1991; Gronwall et al., 1990; Parker, 1990; Prigatano, 1987a, 1992; L. M. Smith & Godfrey, 1995).

There may be more obvious changes in motivation and emotional control. Rapid mood changes, inappropriate social responses such as uncontrolled and inappropriate laughter and general 'child-like' behaviour, irritability, agitation, belligerence, anger, impatience, recklessness, suspiciousness, depression, and loss of drive, initiative and interest in the

environment, have all been reported in the literature (M. Cooper & Glover, 1996; Lezak, 1995; Prigatano, 1992; L. M. Smith & Godfrey, 1995; R. L. Wood, 1990).

At the most severe end of the spectrum are behavioural disorders (L. M. Smith & Godfrey, 1995; R. L. Wood, 1988). In one of the more commonly used approaches to behavioural disorder classification, behaviours are allocated using 'positive', 'negative' and 'syndromal' classes (see Eames, Haffey & Cope, 1990). Positive behaviours include aggression, impulsivity, disinhibition (difficulty controlling impulses), perseveration (prolonged repetition of words or actions), and inappropriate or uncontrolled sexual behaviour, while negative behaviours, associated with an absence of behaviour, include a lack of insight, drive, and motivation. Behavioural disturbances associated with psychiatric syndromes have also been identified (i.e. syndromal class) including depression, paranoia, obsessive-compulsive disorder, emotional lability (rapid mood changes) and hysteria (see Davis & Goldstein, 1994; Eames, 1990; Eames et al., 1990; Gloag, 1985b; Grant & Alves, 1987; Griffith, Cole & Cole, 1990; Lloyd, 1996; Prigatano, 1992; R. L. Wood, 1984; Zasler & Kreutzer, 1991).

### Cognitive changes

Cognitive disorders are extremely common following brain injury, particularly in the case of more severe injuries, where D. N. Brooks (1990) describes them as the rule rather than the exception. While considerable variation exists in the way they are classified, most classifications encompass disorders of attention and concentration, initiation and planning, judgement and perception, learning and memory, speed of information processing, and communication (Benedict, 1989; D. N. Brooks, 1990; Gloag, 1985a; Gronwall et al., 1990; Lezak, 1995; Parker, 1990; Prigatano & Fordyce, 1987; R. L. Wood & Fussey, 1990; Ylvisaker, Szekeres & Haarbauer-Krupa, 1998).

Owing to the complex relationship between the thought processes and other areas of functioning, cognitive deficits are believed to have a far-reaching and pervasive effect on post injury outcome. Research has suggested, for example, that cognitive impairment may be the core deficit underlying poor vocational performance, disturbed behaviour,

communication disorders and lack of awareness of disability (see L. M. Smith & Godfrey, 1995).

### Neurophysical changes

Disturbances in physical functioning are the most conspicuous form of deficit following brain injury and have historically received considerable attention as a result (Richardson, 1990; L. M. Smith & Godfrey, 1995). It now appears, however, that the emphasis on physical functioning may have been misplaced, with a sizable body of research suggesting that disturbances in physical functioning constitute the least significant of the various problems faced in the long term, either by the injured individuals themselves or by their families (D. N. Brooks, 1984; Cervelli, 1990; W. G. Miller, 1986; Oddy & Humphrey, 1980). In the short term, however, changes in physical functioning may be a source of considerable distress for both the injured individual and their family (Sachs, 1991).

Both motor and sensory systems may be affected post TBI, affecting areas such as movement and posture (Bryan, 1995; P. W. Duncan, 1990; Griffith & Mayers, 1990; Olver, Stillman & Disler, 1996; M. L. Russell, Krouse, Lane, Leger & Robson, 1998), and vision, hearing, smell and taste (Begali, 1992; Bryan, 1995; Chorazy, Crumrine, Hanchett, Russell & Smith, 1998). Language ability may also be disturbed (Adamovich, 1990; Ewing-Cobbs, Levin & Fletcher, 1998; Groher, 1990; Marquardt, Stoll & Sussman, 1990; Parker, 1990; Rollin, 1987). Sleep disorders and fatigue have been well documented (Gronwall, et al., 1990; Hillier, Sharpe & Metzger, 1996; O'Shanick, 1998; Watkins, 1997), as has the possibility of post traumatic epilepsy (Chorazy et al., 1998; Jennett & Teasdale, 1981; Kumar, 1988; Panting & Merry, 1972). Owing to the inter-related nature of functioning, disturbances in other areas (e.g. cognition) can also have a considerable impact on physical ability (M. L. Russell et al., 1998).

### Social changes

Complete recovery following TBI is rare, particularly when a major injury was sustained, and even when a 'good recovery' has been made in medical terms, injured individuals are likely to be left with residual deficits in a range of different functional areas (L. M. Smith

& Godfrey, 1995). The cumulative effects of these deficits may place considerable restrictions on the nature and quality of work, leisure, and family life, in some cases for the remainder of the injured individual's life. Given that the majority of people who sustain brain injury are under the age of 25 and have a normal life expectancy rate, this post-injury life may be up to 50 years or more (Tyerman, 1997).

Friendships are a common casualty following brain injury, with reductions in social networks a well documented phenomenon. It is widely reported that reduced social networks stem from the nature of the injured individual's deficits and corresponding personality changes, with the injured individual often unable to contribute to relationships in the same manner as previously and friends finding the contact less satisfying (Bellon, 1997; Hubert, 1995; Jackson & Gouvier, 1992; Jacobs, 1988; Kozloff, 1987; NZHIS, 1993; Oddy & Humphrey, 1980; Thomsen, 1974; Willer, Allen, Durnhan, & Ferry, 1990; Zencius & Wesolowski, 1999).

Recent work by Whalley Hammell (1994) provides an interesting adjunct to this thinking, however. In a comparison of psychosocial outcomes achieved by brain injured and spinal cord injured males and their respective female spouses, the author found no significant differences in the levels of social integration availability and adequacy reported by any of the groups examined. In each case, low levels of social integration and high levels of depression were noted. These findings led Whalley Hammell to conclude that factors other than the actual brain damage sustained may contribute to the social isolation traditionally associated with brain injury. It is possible, for example, that emotional responses to changes stemming from significant injury influence social functioning to a greater degree than previously anticipated.

Participation in leisure activities may decrease or cease, either because some of the activities previously are enjoyed no longer practical or because of a lack of recreation partners (Hubert, 1995; NZHIS, 1993; Tyerman, 1997). Mobility and accessibility restrictions, as well as diminished financial status, may also play a role. Reluctance to identify with other people who have disabilities has been noted in the literature (Hubert,

1995; Jacobs, 1989a; Nochi, 1998), with very few individuals with brain injury participating in recreational groups for disabled persons (Mazaux & Richer, 1998). Funding limitations restrict the number of recreational and social programmes available specifically for people with brain injury, while those available are rarely able to attract or cater for the diverse needs and abilities of this population. In combination with the desire of many brain injured individuals to participate exclusively in “‘normal’ activities with ‘normal’ people” (Tyerman, 1997, p. 33), the responsibility for meeting the social and recreational needs of people with brain injuries frequently falls on family.

It is difficult to identify who will be able to return to work following TBI and under what conditions. It is also difficult to state, with any certainty, the overall percentage of people who do return to work post injury; as L. M. Smith and Godfrey (1995) state, there are “dramatically different” rates of return to employment reported in the literature (p. 8). In one example, Mazaux and Richer (1998) suggest that, on average, 60-70% of people with TBI will be working two years after injury: an average of 75%-90% in the case of mild injury, 60-70% following moderate, and 30-35% following severe (for more on this issue see Bergland & Thomas, 1991; Cook, 1990; Fraser, Dikmen, McLean, Miller & Temkin, 1988; NZHIS, 1993; Oddy et al., 1978b; Rao, Rosenthal, Cronin-Stubbs, Lambert, Barnes & Swanson, 1990; Wehman et al., 1988).

Of those who do return to the workforce, many find themselves unable to work at the same level as previously. According to Fabiano and Daugherty (1998), for example, in the case of mildly injured individuals, approximately one third will work at a lower level of productivity than before the injury, resulting in frequent job changes and a decreased level of work-related responsibility. The picture is even less encouraging for the more severely injured, for whom alternative (i.e. non-competitive) vocational placement options are often ultimately required (see Brantner, 1992; Fawber & Wachter, 1987; Jacobs, 1989a; Wachter, Fawber & Scott, 1987).



## Brain Injury Rehabilitation

### Process and services

The rehabilitation process following brain injury represents a continuum of care, ranging from acute services to those which enable the injured individual to live in the community over the longer term. The historical dominance of the medical model in the health and rehabilitation field has meant the desired outcome of this process has traditionally emphasised physical functioning and the alleviation of impairment. Growing recognition that ‘a good outcome’ by these standards has often existed alongside “social or emotional misery and distress”, however, has prompted new thinking about the desired outcomes of rehabilitation (McKenna & Haste, 1999, p. 162). Increasingly, emphasis is shifting towards community reintegration and the (re)establishment of meaningful lives within those communities (Mazaux & Richer, 1998; Newsome & Kendall, 1996; Mayer, 1989), with concepts such as empowerment and quality of life playing a prominent role (Banja, 1990; Bolton & Brookings, 1996; Marsh, 1994; Waaland, 1998; Zimmerman & Warschausky, 1998).

In the case of mild injuries, some individuals receive medical treatment at the time of the accident and are typically discharged immediately or after a brief hospital stay, while others receive no medical treatment at all. Historically, most mildly injured individuals have received no post-acute followup or rehabilitation input, although this situation is changing somewhat due to increased awareness of the condition and its potential ramifications (Bernstein, 1999; Clements, 1997; Fabiano & Daugherty, 1998; Gronwall et al., 1990; Hinnant, 1999; Liberto, Tomlin, Lutz, Nash & Schapiro, 1993; Novack, Roth & Boll, 1988; Shackford & Wald, 1999; Tellier et al., 1999).

Where the injury is more severe, acute services are aimed at ensuring the injured individual’s survival. Once medically stable, the individual is then transferred to another setting where further recovery can take place. Ideally, this would involve a facility with staff knowledgeable about TBI and able to provide intensive rehabilitation across a wide range of functional areas (Cervelli, 1990; Grinspun, 1987; Gronwall et al., 1990; Levin,

Benton, Muizelar, & Eisenberg, 1996; Mazaux & Richer, 1998; J. D. Miller, Pentland & Berrol, 1990; Rosenthal & Lichtenberg, 1998; Sachs, 1991; Zasler, 1999).

The enormous variability in type and severity of sequelae associated with brain injury means a diverse range of service options are required to meet the needs of this population beyond the duration of inpatient hospital treatment. In a discussion on the need for a comprehensive system of care, Tyerman (1997) comments that no single agency can possibly develop such an “all-embracing service” (p. 43). In addition to continued functional-based rehabilitation, multiple living situations providing differing levels of care and support are required enabling individuals to move between settings as their needs and abilities change (Higham, 1998; Higham & Phelps, 1996; Oddy et al., 1996; Voogt, 1994). Vocational rehabilitation and social/recreational-oriented options are similarly critical (Cervelli, 1990; Cook, 1990; Hubert, 1995; NZHIS, 1993; L. M. Smith & Godfrey, 1995), while some form of case management service is essential to ensure injured individuals receive the assistance they require/are entitled to, in a coordinated and timely manner (Cervelli, 1990; W. W. McKinlay & Watkiss, 1996; Powell, 1994; Resnick, 1993; J. Wood, 1995).

While the need for services such as those described above is widely accepted, it is equally widely accepted that people with brain injuries have almost never had the complete access to services needed and, in many cases, still do not. There is general consensus that the standard of acute care is adequate and appropriately accessible; it is in the post acute phases that differences in treatment become more evident (Powell, 1994; Tyerman, 1997; Winslade, 1998). In regard to the United Kingdom, for example, Hubert (1995) stated there are a number of factors which determine the assistance provided post discharge, ranging from the nature and context of problems experienced by the brain injured individual and their family, to sheer luck. Of particular concern was Whalley Hammell’s (1994) study which found that the most common number of weeks of rehabilitation received by the severely brain injured males in her UK-based study was zero.

### Efficacy of rehabilitation services

The past two decades have witnessed prolific growth in the number and type of TBI rehabilitation services offered. In the United States, for example, the number of neurological rehabilitation programmes available increased from approximately 45 in 1980 to more than 700 in 1991 (Evans & Ruff, 1992). As of 1992, however, fewer than half of the head injury programmes available had been accredited by the American Commission on Accreditation of Rehabilitation Facilities, leaving approximately 58% unaccredited (Klonoff, Shepherd & Lamb, 1994). Evaluation and efficacy studies have, accordingly, become increasingly essential, not only for the traditional purpose of aiding understanding rehabilitation interventions (e.g. Bond & Brooks, 1976) but also to justify services and to ensure continued funding (W. W. McKinlay & Watkiss, 1996; Oddy et al., 1996).

The ultimate design for strong clinical evidence of efficacy is the double-blind, randomly assigned, matched prospective study. However, various methodological, social, financial, and ethical considerations mean such studies are virtually impossible in the area of brain injury rehabilitation (D. N. Brooks, 1991a; Cope, 1995; W. W. McKinlay & Watkiss, 1996; Oddy et al., 1996).

Where this methodology is used as the standard for efficacy measurement, it may then be argued that there is no 'proof' that brain injury rehabilitation actually works because no studies of this nature currently exist (Cope, 1995). Pertinent information has been obtained, however, by conducting general outcome studies. Aronow (1987), for example, found people who received rehabilitation achieved better outcomes than those who had not, even though those who received rehabilitation had been more severely injured, and that, assuming the outcomes achieved did not decline, the cost of the rehabilitation treatment could be recouped in savings within three years.

Cope, Cole, Hall and Barkin (1991a, 1991b) found brain injured individuals demonstrated considerable gains in independent living and vocational ability following participation in post acute residential programmes, as did M. V. Johnson and Lewis (1991) and M. V. Johnson (1991) following participation in community reentry programmes. Enhanced

status has also been demonstrated in various areas by Burke et al. (1988) and Prigatano, Fordyce, Zeiner, Roueche, Pepping, and Wood (1984, 1987), while McManus (1981) and Papastrat (1992) provide support for rehabilitation from financial provider perspectives. Numerous specific outcome studies have also been conducted examining individual programmes and interventions, providing varying degrees of support for different approaches used (for a review, see L. M. Smith & Godfrey, 1995).

### Cost

Much of the information on nation-wide TBI-related costs has emerged from the United States, which partly reflects the litigious and insurance-based nature of the health/rehabilitation/disability sector and the dominance of private facilities. As with other aspects of brain injury, considerable variation is evident in the situations depicted by various authors. In the U.S., Klonnoff et al. (1994) suggest, US\$4 billion is spent on health care and rehabilitation services for people with head injury each year, while C. A. Brooks, Lindstrom, McCray and Whiteneck (1995) note the total cost of new cases of hospitalised TBI in one year has been estimated to exceed US\$8 billion annually.

Estimates of the economic cost of brain injury in the U.S. include an annual productivity loss of US\$20.6 billion (Klonnoff et al., 1994), arising from reduced work capacity or total disability, and a total annual economic cost of US\$25 billion per year (Fabiano & Daugherty, 1998). The lifetime economic cost of all persons who sustained injury in the U.S. in 1985 has been reported at US\$129.4 billion, US\$37.8 billion (29%) of which related to the death and/or hospitalisation of the 327,907 people who sustained head injuries in that year (see Max, MacKenzie & Rice, 1991). Expanding on this work, Klonnoff et al. (1994) estimated that by 1988, the figure of US\$37.8 billion had increased to an estimated US\$44 billion, and assuming the rate of increase remained constant, the total lifetime cost of TBI injury would be approximately US\$51 billion in 1991 and in excess of US\$59 billion in 1994.

Limited information is available on the NZ situation, with published figures generally encompassing a restricted range of cost areas. One of the more widely cited figures placed

the total cost of public health care for head injury in NZ at NZ\$25 million (at 1993) (HIWG, 1994). In a 1996 study based at Waikato Hospital, the total annual cost of ICU care to the hospital following severe head injury was calculated at NZ\$1,174,478, and NZ\$879,014 for non-ICU hospital stays, while the national annual cost of ICU care was estimated to be \$10.9 million and the national annual cost of overall hospital stay (including ICU) to be \$19 million. These figures exclude non-severe brain injury-related hospital admissions, which are estimated to represent 80% of all TBI admissions (Havill, Sleigh, Kersel & Marsh, 1998). Comparison of ACC claim figures also provide a useful, if incomplete, guide to cost. Between 1 July 1996 and 30 June 1997, ACC paid NZ\$2,231,000 in entitlements for concussion/brain injury claims registered in this period and a further NZ\$6,641,000 in entitlements for claims registered in a previous financial year (ACC, 1997). A similar figure (NZ\$2,625,000) was reported for claims registered in the period 1 July 1999 to 30 June 2000, while the ongoing claims cost for the period had risen to NZ\$12,418,000 (ACC, 2000a).

Figures detailing TBI-related costs at an individual level are similarly variable. The figure most commonly cited in the U.S. media regarding the cost of lifetime care is US\$4 million-\$5 million per person (C. A. Brooks et al., 1995); however, alternative figures of US\$3 million-\$20 million and upwards have also been cited (Bush, 1990; Voogt, 1994). In McMordie and Barker's (1988) study, doctor/hospital costs incurred per participant since TBI onset ranged from US\$100-\$1 million, drugs/medical costs ranged from \$100-\$120,000, legal expenses from \$100-\$750,000, structural modifications in the home from \$100-\$30,000, and specialised therapy from \$500-\$90,000. Cost of rehabilitation programmes reported include US\$350-\$1500+ per day for post acute programme (Voogt, 1994), US\$106,000 per average stay in a community re-entry programme (M. V. Johnston, 1991) and US\$90,000 to \$165,000 per person for acute medical (see Bush, 1994; Gamboa, 1994; Havill et al., 1998; Max et al., 1991).

#### The New Zealand situation

Since its inception, New Zealand's system of accident management has been the subject of much debate both in NZ and internationally. Under the scheme, based on the

recommendations of a Royal Commission of Inquiry in 1966 and subsequently enacted through legislation in 1972, any New Zealander injured through accident in NZ or overseas and any other person injured through accident while in NZ is covered by a 24 hour, no-fault insurance scheme. The Accident Compensation Commission [ACC], the organisation formed to carry out legislative requirements of the Act, was assigned responsibility for accident prevention, rehabilitation and compensation. The tradeoff for this “certainty and adequacy of entitlement” was that New Zealanders lost the right to seek legal redress for compensation through the Court system (G. Duncan, 1995, p. 245), a system widely considered in NZ at the time to be inefficient and inconsistent in its treatment of people injured through accident.

A multitude of alterations have since been made to the scheme by successive governments although the fundamental principles of the scheme itself - 24 hour, no fault coverage for both work and non work injuries - have remained essentially unchanged. One of the most controversial changes to occur involved the abolishment of lump sum compensation through the 1992 Accident Rehabilitation and Compensation Insurance Act, to be replaced by a weekly independence allowance. Further intentions of this legislation were to increase the rehabilitation focus of ACC’s operations, clarifying rehabilitation entitlement and ensuring consistency/equity of treatment between clients; previously, ACC staff had a high degree of discretionary power which led to considerable inconsistency in the assistance provided to clients.

Criticism has been directed at various aspects of the scheme by many different parties. For example: an inappropriate focus on financial payments over rehabilitation; inadequate financial payments and loss of compensation to those affected by accident; the overall cost of the scheme and the distribution of that cost across different funding sources; the anomaly between those affected by injury as opposed to illness (the comparable scheme for people incapacitated through illness initially envisaged was never implemented because of cost); and the failure of the scheme to meet the needs of Maori. Increasingly, the legitimacy of the tradeoff between ACC coverage and legal redress is being challenged and public pressure is pushing for a resumption of the right to sue. In its defence, Gaskins

(1999) states ACC “still provides greater coverage for more accident victims at lower cost than other system in the world” (p. 13). (See ACC, 1999; H. Armstrong, 1999; Birchfield, 1991; G. Duncan, 1993, 1995; G. Duncan & Nimmo, 1993; Insurance Council of New Zealand & others, 1999; Lee, 1994; Minister of Labour, 1991; T. J. Moore, 1995; New Zealand Employers Federation, 1995; New Zealand Manufacturer, 1995; Te Puni Kokiri, 1995, 1998a, 1998c; R. Wilson, 1996, 1999; Woodhouse, 1999).

The accidental nature of the condition means ACC is a dominant force in traumatic brain injury rehabilitation in NZ. With the exception of a brief period from July 1999 to March 2000, where accident insurance for work place accidents was provided by private insurers, ACC has been the sole provider of accident insurance and is therefore the primary source of funding for traumatically brain injured individuals and their families (ACC, 2000e; Insurance Council of NZ, ACC & Department of Labour, 1999). With the exception of its case management service, introduced in 1994, ACC does not provide rehabilitation services itself. Its funding function, however, makes the organisation extremely influential in service development.

New Zealand suffers limitations in service provision similar to those described by many other western nations. The absence of specialised rehabilitation centres has meant that most intensive (post acute) rehabilitation has been carried out within a general hospital setting, often without appropriately trained or knowledgeable staff (NZHIS, 1993). Demand for transitional living and community/residential care facilities grossly outstrips supply, with a seemingly large proportion of brain injured individuals residing in settings inconsistent with their own and/or their families’ wishes. The Executive Director of Auckland’s Brain Injury Association, for example, has publicly stated there is an urgent need to “go through rest homes and psychiatric facilities to find brain injured people ‘shoved’ there by no choice” (Young, 1997, p. 8).

There is also a lack of suitable, community-based support for brain injured individuals and their families in NZ, evidenced by the NZHIS (1993) report which found service users considered services to be inadequate across virtually all areas investigated. Inadequacies in

community-based support services were highlighted by the high-profile murder of a professional respite caregiver by a severely brain injured young man in 1995. Subsequently, an Occupational Safety and Health (OSH) Investigation concluded that the victim, employed as a professional caregiver by a caregiving agency for three years, lacked training and knowledge of brain injury and had 'personal problems' which made her unsuitable for providing overnight care (F. Ross, 1996).

This case also drew public attention to deficiencies in the case management system used by ACC. Key features of the system, introduced to alleviate the "fragmentation, duplication and lack of coordination which had previously characterised ACC's service delivery" (ACC, 1994a, p. 16), were to include early intervention, integrated service planning and delivery, proactive monitoring of service effectiveness, quality and cost, continuous monitoring of claimants' case management plans, and a clearer customer focus (ACC 1994a, 1994b; I. Campbell, 1996; Te Puni Kokiri, 1995). The OSH report revealed that ACC's high staff turnover, in conjunction with poor coordination and communication, had significantly contributed to the situation which led to the caregiver's death.

Widespread inconsistencies in the type and level of assistance provided to people with brain injuries and their families in NZ have been similarly noted in NZ-based literature. An investigative journalist compared the assistance received by two brain injured individuals and their families, highlighting enormous discrepancies in what was received by the two parties and the fact that one of the families received considerably less than what they were entitled to (see the cases of Sir Tim Wallis and Marcus Clark-Taylor, Brett, 1996). The then-president of the local Head Injury Society stated this situation was not at all unusual and that, all too often, "the amount of assistance a brain-injured person will get from ACC will be determined not by their legal entitlements but by the forcefulness and confidence of whoever is acting on their behalf" (Brett, 1996, p. 59). The author of the article further warned readers: "Don't imagine that the Clark-Taylor story is unusual.... The ingredients of the story are repeated throughout the country: delay; fragmentation of services; lack of co-ordination; poor consultation and more delay" (Brett, 1996, p. 59).



Efforts have been made to improve the NZ situation. At the instigation of Regional Health Authorities, a high-level working group was established in 1994 to address concerns raised in the NZHIS (1993) study; the first substantive research project conducted into head injury in NZ. The group identified three major barriers to the provision of a head injury service in NZ including the limited availability of expertise, the limited public and professional understanding of the needs of people with head injuries, and the lack of comprehensive home support services (NZHIWG, 1994). Recommendations made by the group for improving service delivery emphasised assessment, quality assurance and evaluation, screening and early referral, service coordination, comprehensive management, and the education, training and development of service providers. National guidelines were also developed in 1998 by an ACC- and the National Health Committee-appointed panel, outlining essential features of a TBI rehabilitation service, for use as a basis for funders and providers contracting for brain injury services. The guidelines are intended to contribute to further understanding and development of TBI rehabilitation services, lead to improved decision making, service quality and outcomes, and ensure the most effective use of available resources (see ACC & National Health Committee, 1998).

## Conclusion

Statistically, brain injury most frequently strikes a person in the prime of their life - somewhere between 15 and 25 years of age. During this period, people are typically at various stages of establishing the social, vocational and economic patterns which will characterise their life. Brain injury, when it occurs, interrupts this process in a profound and frequently irreversible way (Rosenthal, 1999).

The extraordinary array of physical and mental sequelae resulting from TBI poses enormous difficulties for the treatment and ongoing management of brain injured individuals. No two brain injuries will produce exactly the same sequelae; thus the development of individualised treatment programmes for those who sustain such injury is necessary.

There is a growing body of research to suggest that rehabilitation and skilled patient management can produce worthwhile gains, not only from the perspective of injured individuals, their families and medical/health professionals, but also from that of funding providers (e.g. McManus, 1981; Oddy et al., 1996; Papastrat, 1992). The development of specialist services, however, has been “patchy and in some places slow” (W. W. McKinlay & Watkiss, 1996, p. 119), with numerous instances reported in the literature of people receiving little or no assistance beyond the acute medical phase (e.g. Hubert, 1995; NZHIS, 1993; Tyerman, 1996; Whalley Hammell, 1994). The potential ramifications of this scenario for families of brain injured individuals are many: physical, emotional, and financial distress and burden; isolation and alienation; burnout; family dysfunction and breakdown. These issues are explored with others in the following chapter.

### **CHAPTER 3**

#### **FAMILIES AND TBI: A REVIEW OF LITERATURE**

Traumatic brain injury alters lives, and often change is profound and irrevocable. In many cases, this is as true for families of the brain injured individuals as it is for the individuals themselves, with changes in functioning and aspects of daily living described as affecting family members almost as frequently and profoundly as for the brain injured individuals. Prior to the last few decades, however, literature on the effects on brain injury on family members was virtually nonexistent. While there was a general awareness amongst clinicians of the pervasive impact of brain injury, it was not until researchers such as Panting and Merry (1972), Rosenbaum and Najenson (1976), Oddy, Humphrey and Uttley (1978a) and Lezak (1978) began publishing fairly detailed accounts of family members' experiences that significant attention was drawn to their plight (D. N. Brooks, 1991b).

Since then, a plethora of research has been conducted on families within the context of TBI, revealing the significant role families play in the rehabilitation, care and support of brain injured individuals, not only in the early stages following the accident but over the long term. Such research has also established, however, that the resulting demands placed on family members post TBI are often far broader in scope and longer in duration than families ever anticipated or desired, with family members' strength and abilities tested, in some cases, to the limits of their endurance or beyond.

This chapter reviews literature concerned with the family. It begins with an examination of the role of families in the rehabilitation and long term support of people with brain injury, and the ways in which families can influence the recovery process, following which the issues of family burden and morbidity are examined. The relevance of major theories are then discussed: first, family adaptation theory, as it applies to brain injury, and then, theoretical and practical aspects of family intervention. The chapter concludes with a discussion of literature relevant to the area of family preparation, the focus of the present study, identifying and critiquing key themes and supporting evidence.

## Defining 'Family'

Prior to any examination of family-related literature, it is first necessary to examine what is meant by the term 'family'. Publications in the area of brain injury commonly use a systems approach when addressing this issue, where 'family' represents a system "in which all individuals are involved, working towards both individual and mutually accepted group goals" (D. N. Brooks, 1991b, p. 156). The advent of brain injury disrupts the system's equilibrium, (although in reality, not all families are necessarily 'in balance' prior to this anyway), the impact of the disruption being felt throughout the entire family system. The system must adapt if it is to remain intact and continue to meet the needs of its members (Cottone, Handelsman & Walters, 1986; Jacobs, 1989b; Maitz, 1991; Mathis, 1984).

Any description of family also needs to extend beyond the traditional model of the nuclear family (i.e. biological parents and children); there is an abundance of evidence that such a view runs contrary to the reality of many people's lives (e.g. D. N. Brooks, 1991b; Gittins, 1985; Inglis & Rogan, 1994; Ministry of Health, 1998; Morgan, 1995; Te Pumanawa Hauora, 1996; Williams & McKay, 1991). Barry and Clark (1992), for example, noted that only 41% of brain injured children who had attended their rehabilitation facility over a five year period had both biological parents living together. In New Zealand, four out of every five New Zealanders currently live as part of a family: 44.9% are families with children which are headed by two parents, 17.7% are families with children headed by one parent, and 37.3% are couple-only - i.e. do not have children or have children who no longer live with them. The proportion of two-parent families relative to other family types is decreasing, the result of continuing substantial increases in the number of one-parent families, with Maori and Pacific Islanders represented in one-parent family statistics in far greater proportions than for the general population (Statistics New Zealand, 1998a).

## The Role of Families in Brain Injury Rehabilitation

According to Papastrat (1992), before the origination of the shock trauma unit (STU), one in two people who sustained TBI would die as a result of the injuries, whereas today, the

portion of people who survive after receiving treatment in the STU is as high as 90%. Although Papastrat makes no reference to injury severity levels when making this point, it would seem his comments are most applicable to the more severely brain injured population - those most likely to require STU services. In combination with the less severely brain injured, this has translated into a growing and cumulative population of people, with normal life expectancy, requiring rehabilitation services at all levels of the care continuum.

The huge costs associated with brain injury have placed enormous pressure on the State and individuals alike, raising complex and emotive issues about social justice and the allocation of scarce resources within the brain injured population and between this and other needy populations (see Banja, 1999; DeJong & Batavia, 1989; Fearnside, 1996).

The response of virtually all developed countries to the growing strain being placed on resources has been to implement policies of community care, with a focus on families as the mainstay of care provision (Higham, 1998; Means & Smith, 1994; Morris, 1993; Nolan, Grant & Keady, 1996). The assumption underlying this trend, according to Callahan (1988), is that families will, "with some modest degree of social support, be able practically to manage such care, and have the moral, psychologic, and spiritual strength to do so" (p. 323). Callahan describes the renewed emphasis on family support as both 'ironic' and 'appealing':

Part of the ideology behind medical and technological progress is that of freeing human life from the inexorability of bodily decay and disability and, at the same time, from the uninvited and smothering social burdens they impose on our individual and communal life. It is then ironic that that progress should lead us back to embracing just those same burdens. (1988, p. 323)

The emphasis on families as the mainstay of care is well documented in the brain injury literature. Upwards of 80% of brain injured individuals return to the family home upon discharge (Liss & Willer, 1990), frequently on a long term or permanent basis. In the absence of adequate community-based services and/or resources to access those services

which do exist, the responsibility for the injured individual's care typically falls on family members. Research has repeatedly demonstrated that families constitute the major source of support, socialisation and assistance to people with TBI across all major life areas (e.g. Jacobs, 1988).

### The Influence of Family on Recovery

Families have consistently been identified as a significant, if not critical, variable affecting the outcomes achieved by brain injured individuals (Farmer, 1997; Farmer & Stucky-Ropp, 1996; Grinspun, 1987; Livingston, 1985; L. Miller, 1991; NZHIS, 1993; Powell, 1994; Rosenthal & Young, 1988). Johnson and McCown (1997) refine this idea somewhat, suggesting the brain injured population can be divided into three groups, with the outcomes of only one group being dependent on family. The first and second groups identified represent two extremes: a small group whom, the authors suggest, will experience a natural recovery regardless of family and other social variables, and a slightly larger group whose injuries are so severe that family responses and stressors will have little impact on their outcome. The third group, comprising up to an estimated 80% of the population, represents those whose outcome is largely dependent on what happens to them in their recovery process. It is for this group, J. Johnson and McCown suggest, that families play a critical role in the recovery process.

Amongst the positive influences of families reported in the literature are families' ability to: provide professionals with useful information on the injured individual's pre- and post-morbid condition; provide practical and emotional support and motivation to the injured individual; contribute to the goal setting process; assist with discharge planning; and help the injured individual generalise relearned skills from clinical settings to the person's natural environment (Berger & Regalski, 1990; Bogan, 1997; Durgin, 1989; Farmer, Clippard & Luehr-Wiemann et al., 1997; Livingston, 1990; W. W. McKinlay & Hickox, 1988; McNeny & Dise, 1990; Quine, Pierce & Lyle, 1987, 1988; Ylvisaker & Feeney, 1998a).

Over the longer term, families may be the strongest and most motivated of advocates for brain injured individuals, be more likely to continue long term treatment when others have given up or service entitlements have run out, and are often the only ones able to ensure continuity of care throughout the various phases and transitions associated with recovery. Of particular significance, given the increasingly cost-conscious climate of the health sector, is the possibility that the enhanced quantity, quality, and duration of rehabilitation associated with long term involvement of well-prepared families may be achieved at little or no ongoing expense to individual medical/rehabilitation facilities (Durgin, 1989; Freeman, 1997; Jacobs, 1991; Jennett, 1990; Prickel & McLean, 1989; Ylvisaker & Feeney, 1998a).

It has also been documented, however, that families can behave in ways which negatively impact on the rehabilitation process and outcome of a brain injured individual. This behaviour may occur during the early stages of the rehabilitation process and/or over the long term, as evidenced by those individuals who make good progress in treatment but regress after return home (Burke et al. 1988; Greer, Knack & Roberts, 1992; Powell, 1994).

The types of negative influences family members can have on the injured individual are both numerous and diverse. Those who are unwilling to accept the nature or extent of TBI deficits may discourage the injured individual from participating in rehabilitation interventions, or may engage in a process of 'shopping around' different rehabilitation facilities for miracle cures when dissatisfied with the progress made in a particular programme (Hall, 1989; Romano, 1974). They may discourage the injured individual's attempts to accept the brain injury, may encourage them to undertake vocational or social activities to which they are unsuited and will probably fail (W. W. McKinlay & Hickox, 1988; Silver, Price & Barrett, 1991; L. M. Smith & Godfrey, 1995), may blatantly deny that their relative has changed (Romano, 1974), report progress where there is none (D. N. Brooks, 1991b), become reluctant to share information with practitioners they view as being overly pessimistic, and refuse to learn strategies necessary for the injured relative's post discharge care (J. Johnson & Higgins, 1987). They may also become overprotective of their injured relative, long beyond the time where such regulation of the individual may

be considered necessary, fostering passivity and dependence (Grinspun, 1987; Hubert, 1995; Willer, Linn & Allen, 1994).

## Burden

Over the past few decades, family burden following brain injury has been the subject of extensive, and intense, scrutiny, resulting in the establishment of a substantial body of literature on the topic (e.g. D. N. Brooks, Campsie, Symington, Beattie & MacKinlay, 1986, 1987; Jacobs, 1988; Lezak, 1978; Livingston, 1987; Livingston et al., 1985a, 1985b; McMordie & Barker, 1988; NZHIS, 1993; Oddy et al., 1978a; Panting & Merry, 1972; Peters, Stambrook, Moore & Esses, 1990; Romano, 1974; Rosenbaum & Najenson, 1976; Zeigler, 1987). Numerous reviews of the burden literature have also been published (e.g. D. N. Brooks, 1984, 1991b; Florian, Katz & Lahav, 1991; Kreutzer, Marwitz & Kepler, 1992; Liss & Willer, 1990; Livingston & Brooks, 1988; Perlesz, Kinsella & Crowe, 1999).

Traditionally, burden has been conceptualised in terms of 'objective' burden, involving family members' perceptions of the injured individual's impairments and of the caregiving demands, and 'subjective burden', the amount of stress experienced by family members, stemming from TBI-related changes (D. N. Brooks, 1984; Livingston & Brooks, 1988; Sander & Kreutzer, 1999). The authors cited above identify as frequent burdens associated with brain injury: psychological distress (anxiety, depression and stress); high levels of psychosomatic disorders; reduced social functioning and increased isolation; abnormal role change; financial burden; and increased consumption of psychotropic medication and alcohol.

Considerable effort has also been devoted to the identification of accurate and reliable predictors of family morbidity. Such predictors have been considered critical because of their ability to aid in the early identification of (and ideally the provision of appropriate assistance to) potentially at-risk families. Much of the research conducted in this area has focused on the nature of relationship between family member and injured individual, the severity of injury, and the nature of sequelae (e.g. D. N. Brooks et al., 1986, 1987; Gervasio



& Kreutzer, 1997; Kreutzer, Gervasio & Camplair, 1994; Livingston et al., 1985a, 1985b; Oddy et al., 1978a; Peters et al., 1990; Rivara, Fay, Jaffe, Polissar, Shurtleff & Martin 1992).

## Family Adaptation

Traditionally, family adjustment to major brain injury has been depicted using modified developmental stage model theories of death/loss/grief, reflecting the belief that loss experienced post TBI is comparable to that following the death of a loved one (see work on 'partial death': Muir & Haffey, 1984; Muir, Rosenthal & Diehl, 1990). According to such theory, the primary task facing family members is to grieve, and ultimately to accept, the loss of their relative's premorbid self (Hackler & Tobis, 1983; Klonoff & Prigatano, 1987; Rosenthal, 1989), which may be accomplished by successively progressing through a number of fairly distinct stages (Gronwall et al., 1990; Hornby, 1992; J. Johnson & McCown, 1997; Rollin, 1987).

While some variation is evident in the specific stages described in the literature, most traditional models of adaptation have included: an initial shock response (Martin, 1988, 1990; Mauss-Clum & Ryan, 1981), emotional relief, denial and unrealistic expectations (Gronwall et al., 1990; Lezak, 1986; Ridley, 1989; Romano, 1974; Rosenthal, 1989), acknowledgment of permanent deficits and emotional turmoil (e.g. anger, resentment, blame, despair, frustration, guilt, depression) (Conoley & Sheridan, 1997; Gronwall et al., 1990; Klonoff & Prigatano, 1987; Lezak, 1986; Rogers & Kreutzer, 1984), bargaining (Hall, 1989; Lezak, 1978), mourning or 'working through' (Blazyk & Canavan, 1986; Guth, 1996; Hall, 1989; Lezak, 1986; Martin, 1988), and acceptance and restructuring of family (Martin, 1990; Rape, Bush & Slavin, 1992; Rogers & Kreutzer, 1984; Rosenthal, 1989).

More recently, however, a significant philosophical shift has occurred in the way families and their experiences post TBI are perceived, stemming from a recognition of the variability in outcome evident amongst families post TBI. Traditional developmental

models of family adjustment have failed to account for this diversity of outcome, where some families successfully adapt to the challenges while others become overwhelmed and immobilised (Rape et al., 1992; Waaland, 1998). Indeed, it is well established that families are not universally burdened post TBI and positive outcomes can occur (Adams, 1996; Perlesz et al., 1999).

Subsequently, attention has moved away from areas such as family burden and the negative consequences of TBI, a focus Perlesz, Kinsella and Crowe (1996) suggest was initially necessary in order to draw attention to the very real suffering experienced by families post TBI, towards a focus on low stress families and the factors which encourage successful adaptation and coping. A number of models have now been proposed in the literature to describe the adaptation process, frequently tying in family systems work with various crisis and coping theories (e.g. the family adaptation to TBI framework: Perlesz et al., 1996; the integrated developmental stage model and Minuchin's family systems theory: Rape et al., 1992; the resiliency model of family stress, adjustment and adaptation: Kosciulek, 1994a, 1994b; Kosciulek, McCubbin & McCubbin, 1993; the modified ABCX family crisis model: Maitz, 1991; Martin, 1990). J. Johnson and McCown (1997) adopted a somewhat different approach, using mathematical complexity and chaos theory to describe family functioning post TBI.

### Family Interventions

A central objective of professional practice in the disability area is to empower families and help them achieve mastery and control over the circumstances of their lives (Marsh, 1994). To this end, numerous forms of family intervention have been applied to the area of brain injury rehabilitation over the past two decades, in recognition that the capacity of family members to assist in the long term care and support of their brain injured relative is considerably reduced when insufficient attention is paid to families' own needs. Rosenthal and Young (1988) reinforce this view, stating that a failure to provide appropriate family interventions will limit the potential success of any rehabilitation programme. The ultimate goal, according to L. M. Smith and Godfrey (1995), is for the family, "in the face of all

challenges, to accept the realities of traumatic brain injury, remain responsive to the TBI family member, and keep the aspirations they hold for their own lives” (p. 127).

The need for intervention, and the type of intervention required, varies both between and within families, and over time. At one end of the spectrum are those who already possess many of the skills required to cope with and manage the effects of trauma, who primarily require basic education about TBI and appropriate referrals to community-based services for use as required. At the other end are those families described by Rosenthal and Geckler (1986) as ‘high-risk’ who, without appropriate intervention, are most likely to become disrupted by brain injury and least likely to be able to assist in the injured relative’s recovery process. Characteristics associated with high-risk families include a history of dysfunction or maladaptive interaction patterns, prolonged denial regarding the relative’s postmorbidity condition, and the presence of severe, chronic cognitive and/or behavioural deficits in the injured relative (Rosenthal & Geckler, 1986).

Other variables are identified in the literature which are believed to influence the types of services available to, and appropriate for, brain injured individuals and their families including: socioeconomic status; ethnic background; cultural attitudes; and geographic location (Prickel & McLean, 1989; Waaland, 1998). Waaland suggests that sociocultural characteristics account for some brain injured individuals being less likely to gain access to the services required, leaving families, whose access to assistance may be similarly limited by sociocultural factors, to cope without adequate outside assistance. It may be argued such families should also be considered high-risk and made the focus of intervention simply because of the greater probability of alienation and the associated difficulties.

Rosenthal and Geckler (1986) state that families rarely will directly request assistance from staff within the rehabilitation setting, and suggest it is thus appropriate for practitioners to assume responsibility for identifying families’ need for assistance post TBI. Comprehensive assessment of the family therefore needs to precede the development of any programme designed to assist a family to cope with, and manage, the effects of TBI. Numerous examples of assessment schedules are described within the literature (e.g.

Depompei & Zarski, 1991; Guth, 1996; Sander & Kreutzer, 1999; L. M. Smith & Godfrey, 1995; Waaland, 1998).

The actual intervention techniques used within the brain injury area are commonly divided into two broad types: those led by rehabilitation professionals, such as family education, counselling and therapy; and those led by non-professionals (e.g. peers/family members), such as family-to-family programmes, self-help groups, outreach and advocacy, and community networking (Conoley & Sheridan, 1997; Grahame, 1991; Rosenthal, 1989; Rosenthal & Young, 1988; Sachs, 1991; Williams, 1991b). A hybridisation of these categories is also occurring, where both professionals and specially trained non-professionals provide different components of a single intervention.

#### Family education

Data indicating that families require information post TBI have, according to Muir et al. (1990), been responded to with so much enthusiasm by clinicians that family education programmes now constitute the most prevalent form of family intervention used in brain injury rehabilitation. Numerous examples of family education programmes are described within the literature (e.g. Acorn, 1993; Conoley & Sheridan, 1997; Grinspun, 1987; Muir et al., 1990; L. M. Smith & Godfrey, 1995). According to Rosenthal and Hutchins (1991), family education is essentially a process by which information about the nature of TBI and TBI rehabilitation is conveyed so that families can apply it to help optimise outcome. It is relevant at all phases of the rehabilitation process, with families requiring a limited amount of select information during the initial crisis stage, more comprehensive information for planning purposes as the medical crisis recedes and, in the latter stages (associated with disengagement from active professional intervention), access to community and professional information resources (D. N. Brooks, 1991b; Muir et al., 1990; Rosenthal & Hutchins, 1991).

#### Family counselling

Family counselling may be similarly beneficial at different periods throughout the recovery process, as family members attempt to adapt to, and cope with, the TBI and its

consequences (Conoley & Sheridan, 1997; Muir et al., 1990; Rosenthal, 1989; Rosenthal & Geckler, 1986; Rosenthal & Young, 1988). In the early stages, counselling may be useful in challenging denial and unrealistic expectations. Later, counselling may help families deal with their feelings surrounding discharge, to anticipate future problems and be better prepared physically and psychologically for assuming the 'burden of care'. Over the long term, counselling may be useful on an 'as required' basis, as different issues arise (Muir et al., 1990; Rosenthal & Geckler, 1986). Counselling may be conducted with the whole family, with a sub-group, such as parents or siblings, or an individual family member.

### Family therapy

Family therapy emphasises the family system as a whole and is of particular use with families who have a premorbid history of dysfunction and/or exhibit catastrophic reactions, maladaptive communication, and dysfunctional interaction patterns within the family system postmorbidly (Guth, 1996; Muir et al., 1990; Rosenthal & Geckler, 1986). Therapy may be applicable at different stages of the recovery process: in the early stages with families struggling to cope with coma or inpatient rehabilitation or with the possibility that their relative may be too severely injured to return home at all; and after the injured relative returns home, if the demands associated with daily living begin to overwhelm family members. Family therapy may continue to produce beneficial results over the long term, assisting with adjustment, obtaining 'closure' and managing burnout (Rosenthal & Young, 1988; Zarski & Depompei, 1991).

### Family support

Over the past two decades, prolific growth has occurred in the size and influence of the self-help movement in TBI rehabilitation, as evidenced by the increased size and influence of organisations such as the National Head Injury Foundation, Headway, the Head Injury Society and the Brain Injury Association (Sachs, 1991; Tyerman, 1997). Affiliated branches of such groups are similarly established in NZ. Underlying the self-help movement is a recognition that families are often more able to obtain useful and ongoing assistance coping with TBI from within their own communities than from professional services (W. W. McKinlay & Hickox, 1988; Rosenthal, 1989; Rosenthal & Geckler, 1986).

Williams (1991b) emphasises this theme in her work on family support, suggesting that in most cases, families turn to professionals only where the necessary assistance is not available from their present social networks.

Various programmes have been developed, or borrowed from other areas, for use with families with brain injured relatives. Such programmes typically attempt to enhance families' capacity to meet challenges by increasing their social support within the community (Williams, 1991b). Common initiatives include support and self-help groups, principally for education, support and advocacy purposes, and various outreach and community networking programmes (C. H. Campbell, 1988; Muir et al., 1990; Rosenthal, 1989; Rosenthal & Geckler, 1986; Rosenthal & Young, 1988; Sachs, 1991).

### Family Preparation

The need to prepare families for the future is a central theme in much of the recent work on families and TBI (e.g. Freeman, 1997; Grahame, 1991; Hubert, 1995; Jacobs, 1991; Klonoff & Prigatano, 1987; Sachs, 1991; Sanguinetti & Catanzaro, 1987). Despite the emphasis accorded to this area, however, there remains an apparent dearth of research on family preparation. In a comprehensive review of literature, none of the articles identified provided a definition of the concept, nor was the term, when used, anchored operationally. Instead, the term 'preparation' was used as if completely understood by all concerned.

Further, no studies were identified which specifically investigated or measured the state of preparedness of families post TBI. Numerous references were made to the generally poor state of preparedness amongst family members, typically through descriptions of unprepared, poorly prepared, ill-prepared, or ill-equipped families, families who did not expect the difficulties encountered, families who believed practitioners had failed to adequately educate them, and so forth (e.g. Farmer & Stucky-Ropp, 1996; Hackler & Tobis, 1983; Jacobs, 1991, Kneipp, 1991; Oddy et al., 1978a; Peters et al., 1990; Ridley, 1989; Uomoto & Brockway, 1992; Whitehouse & Carey, 1991; Willer & Linn, 1993).

Rather than reflecting specific, on-topic findings, however, it appeared these assertions of poor preparedness were based on a synthesis of related studies' findings, such as those investigating aspects of family need, information and/or service provision, family involvement in the rehabilitation process, and so forth (e.g. Hubert, 1995; Kreutzer, Serio & Bergquist, 1994; Merritt & Evans, 1990; Panting & Merry, 1972; Resnick, 1993; Stebbins, 1997; Stebbins & Leung, 1998; Thomsen, 1974). Of those studies reviewed, McMordie, Rogers and Barker's (1991) work on family satisfaction with service provision appeared the most closely linked to preparation, and was repeatedly cited by other authors requiring empirical support for their own assertions of poor family preparation (e.g. W. W. McKinlay & Watkiss, 1996; L. M. Smith & Godfrey, 1995). As stated, however, the focus of McMordie et al.'s study was on family satisfaction with service provision rather than on preparation itself, and its contributions to the understanding of family preparation are limited by this.

Considerably more information was identified which instructed readers on how to work with families post TBI. Descriptions of programmes and, to a lesser extent, accounts of their use and/or efficacy, were abundant in the literature, drawing on the various family intervention techniques discussed previously. The usefulness of this material, however, although clearly relevant to preparation, was somewhat limited. The programmes described often comprised a single intervention strategy or approach (e.g. Acorn, 1993; J. Anderson & Parente, 1985; Grinspun, 1987; J. Johnson & Higgins, 1987; Klonnoff & Prigatano, 1987; Quine et al., 1987, 1988; Rao, Sultan, Young & Harvey, 1986; Rogers & Kreutzer, 1984; Sanguinetti & Catanzaro, 1987; Uomoto & Broackway, 1992). Consequently, they provide a somewhat piecemeal view of family preparation, which in practice would encompass a much broader range of areas and issues, such as knowledge of TBI (education), practical patient management skills (skills training), and coping/self care skills (counselling, therapy and support).

Further, many of the interventions described covered a time period either longer than, or different from, that associated with the preparation period. From the families' perspective, the recovery process may be divided into two fairly distinct time periods: inpatient

treatment, where responsibility for the injured individual's care lies primarily with medical/health professionals, (the focus of the present study), and post discharge where, in the majority of cases, responsibility for the injured individual's care lies primarily with the family. Family interventions which target the inpatient phases of recovery may be considered part of the preparation process; however, those which exclusively target the post discharge phase may be more appropriately considered part of the process of ongoing assistance, thus distinct from preparation.

This distinction is consistent with the literature, where the term 'preparation' tends to be used in the context of inpatient treatment (e.g. Hubert, 1995; McMordie et al., 1991; North, Meeusen & Hollinsworth, 1991; Peters et al., 1990; Rao et al., 1986; Ridley, 1989). Frequently, the family intervention-related articles reviewed did not make this distinction, however, with relevant interventions spanning time periods or occurring after discharge (e.g. Acorn, 1993; J. Anderson & Parente, 1985; Man, 1999; Sherr & Langenbahn, 1992; L. M. Smith & Godfrey, 1995; Uomoto & Broackway, 1992). Consequently, it is necessary for the reader interested in family preparation to extract relevant activities and techniques from the broader descriptions of family intervention initiatives reported in the literature.

Another limitation of the preparation-related literature reviewed involved the scarcity of direct comment from family members. The literature reviewed was, in most cases, firmly grounded in research and/or clinical practice and clearly drew on family members' reports of their experiences. In the presenting of material, however, these accounts were often presented as common themes and couched in technical or clinical terms, with the voice of family members lost to the reader. Hubert's (1995) study into life after head injury was a notable exception to this trend, incorporating considerable material directly from interviews into the text and, in the process, providing the reader with valuable insights into the lives and views of family members.



## Conclusion

The outcome achieved by a brain injured individual is not “the inevitable unfolding of biological consequences”, but rather an ongoing process influenced by the decisions of those involved with the individual (Ylvisaker, 1998, p. 7). Families, typically constituting the major source of support and assistance to brain injured individuals, comprise key participants in this process. The extent to which families’ influence on the injured individual’s recovery will be positive, however, varies extensively, largely depending on their ability to adapt to the brain injury and the changes arising from it.

Given the current absence of a cure for brain damage, arguably one of the greatest contributions which can be made in brain injury rehabilitation is to help families adjust, both emotionally and practically, to the person with TBI and the associated changes (Oddy et al., 1996). It is also a contribution, Oddy et al. suggest, which is currently undervalued because it lacks “the clinical prestige” associated with attempts to influence brain function and does not meet the patients’, families’ and health funders’ desire for a cure (p. 89). The authors argue, however, that attempts to ensure satisfactory quality of life should “be afforded greater importance both clinically and for research” (p. 89).

Efforts to prepare families for life with a brain injured relative may be considered part of such an attempt to facilitate adaptation and ensure satisfactory quality of life. The need for adequate preparation becomes paramount when it is recognised that the post discharge experiences for many people will be characterised by inadequate access to necessary supports. In some cases, this will occur within the context of a service vacuum. In others, however, it will occur even in the context of adequate service availability, because family members are unaware of the existence of services or are unable to take the steps necessary to secure access.

The literature reviewed has revealed a considerable amount of material on the topics of family burden, adaptation, and intervention. While some useful information relevant to the topic of family preparation was identified, in terms of fully explaining the area and

associated issues, the picture is incomplete. Despite the frequency with which the word 'preparation' was used, no definitions of the concept were provided, nor was the term operationalised. A clear theme of inadequate preparation emerged with little apparent reference to research, while that research which was identified frequently covered the topic of preparation in a manner secondary to other areas or issues. Of particular concern was the lack of direct comment by family member participants, a consequence of the dominance of the researcher/clinician perspective. It was difficult, for example, to gauge families' feelings about the different types of initiatives undertaken or the extent to which families believed the initiatives actually helped them.

Given Oddy et al.'s (1996) call for research into initiatives facilitating satisfactory quality of life, a more comprehensive investigation of family members' perspectives of the preparation area appears timely. In light of the limitations of existing literature identified, such research should approach the area of family preparation broadly, exploring family members' experiences following their relative's brain injury (both initial and over the long term) to provide a context for understanding what it is families need to be prepared for. Family members' feelings about the preparation process they experienced need to be explored in detail, examining issues of content, method, and style, as well as their behaviour and responses to preparation efforts.

In the context of such research, family members could make suggestions as to how the preparation of families could be improved; the process of research thus becomes empowering and a potential catalyst for change, rather than merely data gathering and an opportunity for complaint. With the voices of the participants remaining prominent at all points in the research process, from the initial identification of areas to be explored through to inclusion of participants' comments in the final reporting, the theme of family preparation is effectively communicated from the perspective of specialists to that of the objects of preparation, by family members themselves.

## **CHAPTER 4**

### **METHODOLOGY**

The existing literature reviewed has highlighted the complex and sensitive nature of issues surrounding the preparation of families for the ongoing care and support of their brain injured relatives. The process by which the topic of family preparation was investigated is now described, beginning with an outline of the study's significance and aims, followed by an overview of the research design in reference to both procedure and underlying rationale. The research setting and participants are introduced only briefly, (a more detailed description is provided in the following chapter), and the steps involved in the initiation of the study outlined. The study utilised a multi-method, multi-phase design; this design allowed the research to evolve in response to key issues that emerged as the study progressed. The process of collecting the different types of data and the associated analysis are then described, with the chapter concluding with a discussion of limitations relating to the study's design.

#### **Significance of Study and Aims**

In summary, the limitations of existing research on family preparation within the area of TBI are that, in spite of the frequency with which 'preparation' is used in the literature, the term has not been clearly defined nor has it been anchored operationally. There is a clear theme that family preparation is inadequate, though with little apparent reference to research, while the relevant research identified tends to cover the topic of preparation as secondary to other areas and issues. Considerable attention is directed towards interventions which may be used when working with families which, however, often do not differentiate between preparation and ongoing support. These distinctions are important: preparation is principally needed when the injured relative is receiving inpatient treatment, where responsibility for the brain injured individuals lies primarily with professionals, while intervention needs shift to support post discharge, where responsibility lies primarily with family members. The literature is further limited by the scarcity of direct comment from family members, ultimately, the 'true experts' in the area.

As identified in the previous chapter, a broad approach needs to be taken to the study of family preparation, encompassing family members' post discharge experiences, in order to demonstrate what it is families need to be prepared for. If models of family preparation are to be accessible, appropriate and useful, family members' feelings about such preparation as it was experienced need to be explored in detail, as do their emotional and behavioural responses towards preparation efforts. The research process itself needs to provide adequate opportunity for family members to offer views on what preparation has been received and the process of preparation, and what they say they needed, with participants' voices remaining prominent throughout the research process.

In view of the situation described above, the study set out to answer the following complex of inter-related questions:

1. Questions relating to the impact of the brain injury:

What roles did family members play in their injured relative's recovery process? What were the impacts on the brain injured relative and on their family members? What were family members' responses to the brain injury?

2. Questions relating to the process and adequacy of family preparation:

What steps did family members believe were taken by the various rehabilitation professionals to prepare them: (a) for their role in the relative's ongoing rehabilitation and care; and (b) for the effects providing such care might have on them as family members? How did family members feel about these steps?

3. Questions relating to family members' views on how family preparation might be improved:

How do family members feel the preparation process might be improved?

It was intended that, by answering the above questions, a coherent and comprehensive model of family preparation for continuing rehabilitation and care of a relative post TBI would be developed. The validity of this model would be achieved through the use of the

inductive approach, whereby the experiences and views of the families themselves informed conceptualisation and development of the model.

## Research Design

The present study employed an evolving approach to the research design, comprising a three-stage data collection process. The principal data collection instrument was a self administered questionnaire (see Appendix B1). The questionnaire was developed following a review of literature, interviews with Rehabilitation Centre staff, and interviews with family members drawn from the final sample identified. These interviews comprised the first phase of the study, facilitating the identification of local issues and confirming that issues identified were relevant and should be included. In the second phase, after pre-testing, the questionnaire was mailed to potential participants so that the issues which emerged in the qualitative unstructured interviews during the first phase could be confirmed as relevant to the wider group with greater confidence. Further questions arose from the questionnaire; a number of respondents had made margin comments, and others gave apparently contradictory responses. These issues warranted further study and so a third phase was conducted, entailing a further series of unstructured interviews seeking to explore those emergent issues.

The combining of different research methods in a single study is a practice which stems from principles of triangulation, a surveying and navigating technique where multiple reference points are used to obtain a more accurate estimate of an object's position (Jick, 1979). Four types of triangulation are commonly described in the literature: the use of multiple methods (both 'between' and 'within' methods); multiple data sources (across time, space and/or person); multiple theories; and multiple investigators (Berg, 1998; Carnwell, 1997; Denzin, 1978; Janesick, 1994; Knafl & Breitmayer, 1991; Patton, 1990).

Historically, the combining of methodologies in a single study has been employed as a tool to counter threats to validity (Berg, 1998; Brewer & Hunter, 1989; Jick, 1979; Minichiello, Aroni, Timewell & Alexander, 1995). As Patton (1990) notes, studies which use only one

method are more vulnerable to errors linked to that particular method than those using multiple methods where the different types of data provide validity checks. Triangulation may also be used, however, as a means of obtaining a more complete, holistic and contextual portrayal of the phenomenon under investigation (Jick, 1979). When using triangulation for this purpose, according to Knafl and Breitmayer (1991), the researcher does not necessarily expect the various data sources to confirm each other but, rather, to add additional pieces to the puzzle. Although the combination of quantitative and qualitative methods can produce divergent results, thus presenting considerable interpretative challenges, working through the conflicts can lead to a substantially enriched explanation of the research problem (Jick, 1979; Patton, 1987).

Considerable support exists for the use of mixed method research in the literature although, as Knafl and Breitmayer (1991) suggest, many researchers display a tendency to treat triangulation generally as “an inherent good” without ever actually justifying the approach taken or explaining its contributions to the findings subsequently produced (p. 237). The authors argue strongly that the decision to employ a triangulated approach must be firmly grounded in the context of the study’s overall purpose and “in an explicit recognition of the goals to be achieved through triangulation”, namely confirmation or completeness (p. 227).

The combining of qualitative and quantitative methods in the present study was aimed primarily at achieving completeness. As is commonly noted in the literature, qualitative research is particularly suited to studies where the intention is to uncover patterns in order to understand interactions, processes, beliefs or values (Marshall & Rossman, 1989; Miller & Crabtree, 1992). Quantitative research has the advantage of easily incorporating large sample sizes and producing generalisable findings; however, its methods rarely address adequately the meaning of the behaviour to the individual nor the context which gives meaning to the act, and its practice of isolating variables to single dimensions belies the complex and diverse nature of the human behaviour and the social science domain (de Vaus, 1995; Minichiello et al., 1995; Patton, 1990; Swanson & Chenitz, 1982). Using qualitative and quantitative methods of data collection used together, a far greater understanding of the area of family preparation could potentially be obtained. In addition

to the aim of completeness, confirmation of findings was also achievable through the present study's methodology and, to a lesser extent, this was similarly a purpose of the methodology selected.

The use of qualitative techniques during the early stage of the study was a reflection of the essential role qualitative techniques play in questionnaire and scale development (Bowling, 1997; Knafl & Breitmayer, 1991). The collecting of quantitative data via the questionnaire provided a breadth of information on family members' experiences of the preparation process, particularly in regard to the degree to which different phenomenon were experienced or perceived. Followup interviews enabled further exploration, and a subsequently greater understanding, of participant responses to questionnaire measures.

#### Methodological rigour

Ensuring the quality of a study is a task fundamental to any research effort. The way in which this might successfully be achieved for different methods of inquiry, however, has been the source of considerable debate. Research based on the positivist paradigm, utilising scientific methods of inquiry, has well-established and widely accepted criteria based on the concept of rigour. Rigour is achieved through the minimalisation or neutralisation of threats to the study's reliability and validity and through the maintenance of researcher objectivity (Bouma & Atkinson, 1995; Bowling, 1997; Brewer & Hunter, 1989; Dane, 1990; Guba & Lincoln, 1994; B. Taylor, 1998).

In the case of qualitative methods of inquiry, the process has been less clear. Arguments have been made for the application of existing quantitative criteria to the evaluation of qualitative research, with the understanding that broader definitions must be given to the concepts of reliability and validity, or in a context of appropriate allowances for the unique features of the qualitative methodology used (Hagner & Helm, 1994; Minichiello et al., 1995; Sanders & Liptrot, 1994). Other theorists have argued the concepts of reliability and validity are relevant only to the realm of quantitative research and that more general concepts of 'credibility' and 'trustworthiness' should be applied instead (e.g. Leininger, 1994; Lincoln & Guba, 1985; Sandelowski, 1986). Sandelowski (1986), for example,

applies Guba and Lincoln's (1981) framework of evaluation criteria to the area of nursing research, advocating a focus on 'credibility' to establish truth value rather than internal validity, 'fittingness' rather than external validity to confirm applicability, auditability rather than reliability for consistency, and confirmability rather than objectivity for neutrality. Leininger (1994) provides an alternative, but similar, framework incorporating: credibility; confirmability; meaning-in-context; recurrent patterns; saturation; and transferability.

In the present study, multiple initiatives were conducted to achieve rigour. Information has been provided about the researcher, as recommended by Patton (1990), to enable the reader to recognise the possible influence of background factors on the study's design and direction. Information has also been provided about the study itself, enabling others to follow and understand the study's progression, to judge the quality of resultant findings, and to repeat the study if desired. Interviewees were offered the opportunity to examine the transcript of their personal interview, primarily in order to ensure they were satisfied with the views they had expressed, (although only one participant took up this offer), and as part of the questionnaire pretesting phase, the involved participants and a practitioner from the Rehabilitation Centre were asked to comment on the extent to which they believed the questionnaire covered what they considered to be the key issues. Triangulation of data collection methods was used, with seemingly contradictory or atypical findings reported along with possible explanations identified through further exploration. The questionnaire phase also enabled initial interview findings to be generalised to a larger group of family members.

#### Rationale for questionnaire

A self-administered mail questionnaire was selected as the principle research instrument for both practical and ethical reasons. It was known that potential participants were dispersed not only in the Manawatu region but also throughout New Zealand and a postal questionnaire would facilitate the participation of as many as could be contacted and gave their consent. The relative speed with which the process could be conducted, as well as the low associated costs, further supported the choice of method.



The recruitment process similarly supported the use of a self-administered questionnaire (described later in the chapter), a process that better protected confidentiality and the right not to participate when making contact with family members through their brain injured relative. Further, mailing out self-administered questionnaires ensured that family members were able to complete the questionnaire at a time of their choosing, at their own pace, and in privacy; these were critical considerations given the highly personal and often emotionally-charged nature of the issues being discussed. Mailed questionnaires are also considered less vulnerable to the effects of interviewer bias and social desirability bias (Bowling, 1997), the latter a particular issue in the present study where the topics under investigation were sensitive, and there was the potential for family members, however unwarranted, to perceive potential risks to participation.

#### Desired response rate

Low response rates are commonly associated with the use of self-administered questionnaires, which creates difficulties when carrying out statistical analysis and contributes to sample bias (Brewer & Hunter, 1989; de Vaus, 1995). Various authors have suggested a response rate of between 30% and 50% may be considered satisfactory (e.g. D. R. Cooper & Emory, 1995; Fowler, 1993; Zikmund, 1994); however, it is not unheard of for studies to obtain rates as low as 15%.

Maximising response rates is central to the avoidance of such statistical and bias-related problems. In the present study, [as recommended in the literature (e.g. Dane, 1990; Dillman, 2000; Roberts, 1998b; Zikmund, 1994)] pre-testing of the questionnaire was used to identify potentially problematic aspects of the questionnaire which may discourage participants from completing the questionnaire. Several areas of concern identified during the pre-testing phase centered around questionnaire length and clarity of instructions, and are discussed below.

A number of other techniques can be used by researchers in an effort to increase response rates, including a clear explanation of the importance of the study and the potential benefits of participation, assurances of confidentiality, and the inclusion of a stamped return

envelope (Dillman, 2000; Bowling, 1997; de Vaus, 1995; Roberts, 1998c). Each of these techniques were used in the present study. The opportunity to receive a summary of the results, presented as a benefit of participation, was taken up by 70 percent of participants (see Appendix A7).

A due date of three weeks post mail-out was also set for the returning of questionnaires to encourage participants to complete and return the questionnaire, although there is evidence to suggest this technique simply accelerates the rate of return rather than increases the response rate itself (D. R. Cooper & Emory, 1995). In addition, follow-up letters were sent to those participants who had not yet returned a questionnaire one week prior to the due date, reminding them of the purpose of the study and the timeframe set, at which stage they were also offered the opportunity to receive a replacement questionnaire in the event the original had been misplaced. The follow-up letter also explained that they would not receive further information relating to the study beyond that point, in order to minimise the possibility of any participants feeling pressured (see Appendix A5).

The questionnaire ultimately developed was quite long. Literature on research methods is somewhat divided on the influence of questionnaire length on response rates. While many argue longer questionnaires produce lower response rates (e.g. Bouma & Atkinson, 1995; Dillman, 2000; Roberts, 1998c), examples are also available where long questionnaires have yielded high response rates (see D. R. Cooper & Emory, 1995) and where no differences have been found in the response rates to variably long questionnaires (e.g. Cartright, 1988 cited in Bowling, 1997). According to de Vaus (1995), the optimal length for a questionnaire is dependent on the topic under investigation and the nature of the sample, with the acceptable length increasing in relation to the perceived relevance of the topic and the extent to which the sample is specialised (i.e. general population vs. a specific segment/group). It was hoped that the subject under investigation would be of sufficient interest and importance to participants to elicit involvement and this did appear to be the case, with participants often providing considerably more comment than the basic format required. Questions of possible sample bias were raised by the heightened interest of participants, however - an issue addressed later in the chapter.

The final number of participants can also be maximised through the initial selection of a large sample size. Bouma (1996) suggests that a minimum of 30 participants is required in order to provide a pool large enough to carry out basic statistical analyses. The present study was complicated, however, by the ethical principles requiring that the questionnaires be mailed to the brain injured individual, to be forwarded by that individual to the family member they considered their primary support person. Further, geographic mobility made it likely that at least some of the addresses of the brain injured individuals would have changed since the time they attended the Rehabilitation Centre. To achieve a minimum return of 30 completed questionnaires, based on the 30-50% responses rate commonly described and allowing for the convoluted distribution process, a final sample size of 115 individuals was selected. This encompassed all individuals who had been inpatients at the Rehabilitation Centre following traumatic brain injury within the past decade (1988-1997).

### Research Setting

The study population was recruited through a Rehabilitation Centre attached to a public base hospital in the lower North Island of New Zealand, operated by MidCentral Health Ltd, which is responsible for providing health services in the Manawatu, Palmerston North, Horowhenua and Tararua districts. Further information relating to the Centre and its practices and policies is provided in chapter 5.

Several factors contributed to the selection of the Rehabilitation Centre as the setting for the present study. The Centre is one of a very small number of facilities in New Zealand providing intensive, multidisciplinary TBI rehabilitation on an inpatient basis, during the acute rehabilitation phase. Because of the study's focus on family members' experiences both immediately preceding and following the brain injured relatives' return home, it was necessary to select a site where this transition occurred. Other brain injury-related facilities tend to provide rehabilitation and community-support services at later stages of the recovery process, once the injured relative has already returned home, or where the continuing care option was deemed necessary and the relative may not have returned home at all following intensive inpatient rehabilitation. Furthermore, a senior staff member at the

Centre expressed an interest in the research and was willing to provide necessary support, including facilitating access to participants.

## Participants

Participants in the study were family members of individuals who had sustained a traumatic brain injury, individuals who had attended the Rehabilitation Centre on an inpatient basis, and who had been discharged from the Rehabilitation Centre a minimum of six months and a maximum of ten years prior to the study.

### Rationale for selection criteria

The selection of individuals who had sustained a traumatic brain injury and who had attended the Rehabilitation Centre on an inpatient basis reflects aspects of the study's focus previously discussed. The requirement that participants' brain injured relatives had been discharged from the Rehabilitation Centre a minimum of six months prior to the study was set for two reasons. Firstly, the immediate post discharge period is known to be difficult for many families and the researcher wished to avoid adding to their distress and burden. Further, a 'honeymoon phase' has been described (Lezak, 1978) when family members are relieved their relative has survived but have not yet come to appreciate the full impact and long term implications of brain injury. The researcher considered it possible that such families may be less able to provide insight into the topic being investigated than those with longer experience although, clearly, the six month cut-off date provided no guarantee that this would be so. The other cut-off period of ten years was set because it allowed sufficient numbers to enable a reasonable sample size, while being not too long to reasonably expect family members to recall their experiences.

### Recruitment process

Using guidelines developed by the researcher, a staff member at the Rehabilitation Centre identified the individuals from the Centre's database who had sustained TBI and attended the Rehabilitation Centre as an inpatient, whose family members thus potentially met the

study's criteria ( $N = 115$ ). All family members who participated in the study were identified through this list of 115 brain injured individuals.

Packages prepared by the researcher were posted by a representative of the Rehabilitation Centre to the brain injured individuals previously identified, who were asked to forward the information sent to them to the family member whom they considered to be their primary support person. The package for the first and third phases of the study included an information sheet explaining the study, a consent form, and a prepaid return envelope (see Appendices A1, A2, A3). The second phase package contained an information sheet, a request for a summary of findings, a questionnaire, and a prepaid return envelope (see Appendices A4, A6, B1).

The packages themselves were sent by an intermediary person designated by the Rehabilitation Centre in order to maintain confidentiality of hospital records. For ethical reasons, the researcher did not have direct access to the facility's database, thus needing to rely on staff at the Centre who had right of access. Nor was it ethically possible to contact family members of the TBI individuals directly while bypassing the brain injured relative, with the researcher, instead, needing to rely on the brain injured individual to pass on information to his or her family.

This rather cumbersome, but necessary, process increased the likelihood that family members might not actually receive information about the study. While the process had the advantage of preventing family members from participating in the study without the knowledge of their brain injured relative, it also meant that some family members who might have wished to comment on their experiences may not have had the opportunity to do so. The researcher was also unable to determine the currency of addresses or follow up on postings returned marked 'not at this address'.

#### Response rate

Of the 115 questionnaires mailed out, 33 were returned completed and a further 39 were returned marked 'no forwarding address'. Excluding the known unreachable participants, the final rate of response was 41%. It is highly probable that a further portion of

questionnaires were sent to out-of-date addresses but were not returned to the researcher, or received by the brain injured individual but not forwarded to a family member, thereby further reducing the total number of questionnaires which actually reached the intended destination. It cannot therefore be assumed that the non-responses necessarily imply a refusal or lack of interest on the part of family members.

## Initiating the Study

### Ethical issues and approval

Ethical issues at different stages of the research process centered around themes of harm, consent, privacy, and confidentiality, as is the case with research involving human subjects generally (Bouma & Atkinson, 1995; Dane, 1990; Hek, Judd & Moule, 1996; Punch, 1994; Roberts, 1998a). Family members were informed they had the right to ask questions, to decline to participate, and the right to withdraw at any stage from the study. To ensure family members and their relatives understood that participation, or non participation, in the study would not affect service provision, the relationship between the study, the researcher and the Rehabilitation Centre was clearly described in information sheets.

Confidentiality was a key issue, both in terms of medical records held at the Rehabilitation Centre and of participants' identities and responses, and was assured through the process described previously. The researcher learned only the identities of those participants who agreed to participate in an interview. Likewise, staff at the Rehabilitation Centre did not know the identities of participating family members as the questionnaires were sent directly to the researcher. The process for maintaining confidentiality was outlined in the information sheets distributed to participants.

In one particular case, the maintenance of confidentiality was complicated by the participant's unusual circumstances. Having both a brain injured son and husband, this woman had insights of considerable value to the study; however, detailing this in the study made her identifiable. The researcher discussed the dilemma with the participant, whose

wish was to include the material, knowing she was identifiable, as she felt it was important the insights she had gained through the two different experiences be acknowledged.

The possible adverse effects on intra-family relationships arising from participation in the study was also of some concern in planning the research. It was possible that family members could participate in the study against the wishes of their brain injured relative, which could potentially have quite negative and far-reaching ramifications for the family. Ultimately, however, the researcher was satisfied that this was unlikely to be a major problem, firstly, because the study focused on family members rather than on the brain injured individual, and secondly, because those brain injured individuals who strongly opposed their family's participation could choose not to pass on the study material. As a precaution, however, participants were provided with the name of a research supervisor and a senior staff member at the Rehabilitation Centre, as well the researcher, to contact in the event difficulties arose.

The sensitive nature of the topic under investigation was of considerable concern to the researcher. It was anticipated that participants would find some or many of the issues covered in the study painful and/or disturbing. Prior to the commencement of interviews, strategies were identified which could be used to support participants where distress was observed, including taking a break from the interview, changing the subject to one participants found less distressing, and self disclosure by the researcher. In addition, available formal services were identified by the researcher in the event participants required support following the interview, including counselling services, Headway and, again, a senior staff member at the Rehabilitation Centre.

Consent was obtained from participants for each of the research phases. Prior to the conducting of each interview, participants were asked to sign a specific consent form which again outlined their rights in the study and required them to indicate whether or not they gave permission for the interview to be audio taped. Consent for participation in the questionnaire phase of the research was approached a little differently, with the information sheet informing family members that the returning of a completed questionnaire would be

taken as an indication of the family member's consent to participate in the study under the conditions outlined.

Ethical approval for the study was obtained from both the Massey University Ethics Committee [MUEC] and the Manawatu-Wanganui Ethics Committee [MVEC].

### Management approval

Approval to conduct the research was obtained from the Chief Executive Officer of MidCentral Health and the Group Manager of Services for the Elderly, Rehabilitation and Disability (responsible for the Rehabilitation Centre). Management approval entailed the identification and justification of hospital resources involved in the study, such as staff time.

### Informing Rehabilitation Centre staff

A meeting was held at the Rehabilitation Centre where the researcher outlined the proposed study to Centre staff. This provided staff with the opportunity to ask questions and raise any concerns, and enabled the researcher to clarify misconceptions and address concerns raised. The main concern identified by staff appeared to stem from a fear that the study would attempt to evaluate Centre and staff performance. The purpose of the study was further clarified to the satisfaction of staff, with attention given to the subjective nature of family members' accounts and the effects time could have on family members' recollections of events and, subsequently, the limitations which could be placed on the study's findings. Following the meeting, the wording of the aims of the study was revised to emphasise that the focus of the study was to identify family members' feelings about various topics, including staff efforts, rather than being an actual evaluation of staff efforts.

### Conducting the Study

The steps involved in the development of the principal data collection instrument are now described, followed by a discussion of the questionnaire administration phase and the followup interviews conducted after questionnaires had been returned and analysed.



### Development of principal instrument

A three-phase process was used in the development of the principal data collection instrument, comprising, firstly, a literature review, secondly, indepth interviews, and thirdly, a pre-testing of the questionnaire once developed.

The initial interview phase of the study aimed to obtain information on the experiences of family members following traumatic brain injury for use in the development of the questionnaire, specifically in relation to the context in which their relative's rehabilitation occurred, building on the general information obtained from the literature review. Using the process described above, information sheets and consent forms were sent to ten families, via the brain injured relative, inviting them to participate in an interview. Initially, three family members responded agreeing to be interviewed, while another two family members who subsequently consented but were not required at that point were reserved for possible participation in the pre-testing phase. Interviews were conducted in venues decided by participants, venues which included the researcher's office and participants' homes. All interviews were recorded on audio-tape, with each participant's permission, and field notes taken.

A semi-structured, in-depth interview was carried out with one family member from each of the three families. This method was used to obtain information because it not only enabled a broad range of areas to be covered in a relatively short space of time but also provided sufficient flexibility for both the researcher and interviewees to raise and explore topics which had not been previously identified in the literature or considered by the researcher. Participants were encouraged to discuss their experiences of being formally prepared by rehabilitation professionals for their brain-injured relative's discharge during the time their relative was in the Rehabilitation Centre. Typically, this broadly encompassed the identification of steps taken by rehabilitation professionals to prepare families/their family and some discussion of the quality, quantity and effectiveness of those steps, discussion of participants' general satisfaction with the preparation process, and an exploration of the ways in which participants felt the preparation process for families might be improved. Basic demographic information was also obtained from each participant.

The interviews themselves were fairly informal, in light of literature suggesting participants may feel more at ease and consequently more comfortable about sharing information when a less formal, conversational approach to interviewing is used (e.g. Fontana & Frey, 1994; Mishler, 1986; Oakley, 1981; Paget, 1983; Patton, 1990). Clarification and verification of comments was obtained by the researcher where needed, as recommended by Minichiello et al. (1995), and questions asked to encourage participants to either discuss a particular topic in greater depth or to cover a new topic. Generally the researcher allowed the interview to flow on with minimal interruptions, finding that the answers participants gave continually prompted further conversation and that participants tended to provide ideas that were new to the researcher when they were given the latitude to do so.

Following the initial interviews, the questionnaire was developed, focusing on a variety of aspects of family members' experiences of traumatic brain injury and the preparation process. In order to minimise the number of non-usable responses provided, predominantly restricted-answer questions were included, using three-, four- and five-dimensional scales as well as 'yes/no' options. A few open-ended questions were also utilised where considered appropriate, and two of the questions used were taken from a questionnaire designed for the NZHIS (1993) study on head injury in New Zealand (See Appendix B, section 'TBI Impact', Part A, Q1 and Part B, Q1). Injury severity was assessed using the Post Traumatic Amnesia measure (see chapter 2 for a description).

Following the interviews and the development of the draft questionnaire, scholars with expertise in questionnaire design were asked to critically review the instrument, following which changes were made both to the format of the questionnaire and to the way questions were phrased. A copy of this amended draft questionnaire was also sent to the Rehabilitation Centre's representative for review. Three consenting members each from three different families were then approached to participate in the pre-testing of the questionnaire: two were individuals who had consented but were not required to participate in the interview phase, and the third was another member of a family who had been interviewed. Both research professionals and intended respondents have been identified as suitable pre-test participants in the literature (Dane, 1990; Zikmund, 1994).

Pre-testing the questionnaire used the same process as was intended for the final questionnaire. Packages posted to the participants included a questionnaire, an information sheet and instructions. Participants in pre-testing were contacted on two occasions: first to seek their involvement in the pre-test, and second, to discuss their reactions to the questionnaire approximately ten days after it was sent out.

The first two pre-test participants completed and returned the questionnaire with few misunderstandings. Followup telephone conversations revealed they had experienced little difficulty with the wording or structure of the questionnaire and were satisfied with the content covered and the length. However, one of these two participants had not completed the section relating to satisfaction with preparation because she felt it did not apply to her, having identified earlier in the questionnaire that she did not receive any preparation-related services. Comments at the start of the section that had contributed to her confusion were subsequently removed.

More difficulties were encountered with the third participant, and a followup telephone conversation revealed that the participant was, in fact, the individual who had sustained the TBI. While aware the questionnaire focused on family members, the individual had not realised that she could not answer on her family's behalf. Both the information sheet and the instructions were subsequently amended to make the procedure clearer.

The overall length of the questionnaire, while considered acceptable to the pre-test participants, was felt to be too long by the researcher and supervisors. Accordingly, the questionnaire was further refined and reduced.

#### Administration of final questionnaire

The questionnaire, in its final form, was administered to participants through the process outlined. Two of the family members initially interviewed were included in the sample, as were two of the family members who participated in the pre-testing of the questionnaire. The third family member, who had participated in both the interview and the pre-test study, did not participate in this phase.

### Followup interviews

Some participating families indicated a desire to discuss their responses to the questionnaire in greater detail, through margin notes in the questionnaire. Moreover, during analysis of the questionnaires, several areas were identified which required further investigation. Semi-structured interviews provided a suitable mechanism for fulfilling both of these needs and, consequently, four additional interviews were conducted. Two of these interviews were with individual family members and two were with entire families (without the brain injured relative present). All the followup interviews were conducted in homes of the families being interviewed, at their request.

### Analysis of Data

The main purpose of preliminary interviews was to identify key themes and concepts associated with the area of family preparation, in order to develop a questionnaire which further examined the area but in a more standardised manner and on a larger scale. The purpose of the second series of interviews with family members was to follow up on, and explore in greater detail, participants' responses to the questionnaire, with a view to gaining a more comprehensive understanding of the topic generally.

In both interview phases, an inductive approach was taken to the analysis of data, with patterns, themes and categories emerging from the data rather than being imposed on it (Bowling, 1997; Carnwell, 1997; Creswell, 1994; Minichiello et al., 1995). Interviews were transcribed in full, generally soon after each was conducted and prior to subsequent interviews. The analytic process itself was non-numeric, with attention directed at exploring the meaning of emergent concepts and themes rather than at determining frequencies of particular elements. A computer was used to assist in the data analysis process, although the process itself drew on a manual cut-and-paste approach rather than involving a specialised analysis software package. The themes subsequently identified were subjected to an ongoing process of revision as new information was obtained, and adjusted and refined in discussion with the research panel.

Questionnaire responses were coded by the researcher and subsequently entered into an SPSS database. SPSS was used to perform a variety of statistical analyses, including the calculation of means, standard deviations, and frequency distributions for different items, as well as various tests of statistical significance such as t-tests, chi-square tests, Pearson correlations, Anovas. Ultimately, only some of these analyses were included in the final report. In the following chapters, figures are reported in relation to the number of valid responses unless otherwise stated.

### Limitations of Study

While the study emphasised the family in their wider social context, the majority of primary data collected was from individual family members often speaking on behalf of their family. Consequently, it may be more appropriate to view the 'voice' of family members presented here as being of individual family members rather than that of 'families' in the broader systems sense. This does not necessarily represent a weakness of the study or diminish the usefulness of the accounts provided. It is important, however, to view the study's findings within the constraints this imposes.

The retrospective nature of the design utilised has considerable implications for the interpretation and use of findings in the present study. Recall difficulties, associated with both selectivity of recall and actual memory, and the tendency for participants to reinterpret their distant past experiences in light of their more recent ones, are well documented in the literature (e.g. Bowling, 1997; de Vaus, 1995) and quite likely affected the accounts provided by participants in the present study.

The researcher's desire for participants to be able to critique the preparation process in light of their post discharge experiences, however, necessitated the use of a retrospective approach. The relatively small number of potential participants available, given the size of the Rehabilitation Centre's client base, further supported its use; in order to obtain a sufficient sample size, it was necessary to search back into hospital records for a

considerable period of time. To obtain a similar sample size using a prospective approach would have required the researcher to devote many more years to the study.

None of the alternative designs considered by the researcher appeared satisfactory. Examining the preparation process on site - as it unfolded for different families - would have entailed some disruption to family members during what is typically an uncertainty and distressing time for them, and the researcher had no desire to add to their burden by seeking their involvement in yet another task. Further, ethical issues would have arisen in regard to the vulnerability of family members at this time and the extent to which consent was freely given, with the risk of family members agreeing to participate in the hope of positively influencing service provision. Maintaining confidentiality of participants from Rehabilitation Centre staff would also have presented difficulties. Prospective longitudinal studies, while meeting the need for a hindsight perspective, would still have required some examination at the time of inpatient treatment, with the associated ethical and time concerns.

## Conclusion

A mixed method approach was employed in the present study, drawing on both qualitative and quantitative research techniques to comprehensively explore the area of family preparation in the context of brain injury. The design itself was evolving, identifying and further investigating issues as they arose. The setting of the study was an inpatient rehabilitation facility attached to a major public base hospital in New Zealand's lower North Island, with study participants comprising family members of brain injured individuals who had received inpatient-based services from the Centre. The study, and its resultant findings, are subject to a variety of design- and general research-related limitations; the steps taken to counter or diminish the effects of these have been described above. Both the research setting and participants are reported on in greater depth in the following chapter.

## **CHAPTER 5**

### **THE CONTEXT OF THE STUDY AND PARTICIPANTS**

The setting of the research, and the people who participated in it, are discussed in this chapter, contextualising the present study. The Rehabilitation Centre, around which the study was based, is described with reference to its purpose, its funding, and the clients who are referred to and from it. The Centre's operating practices are also overviewed, focusing on the underlying theoretical basis for practices adopted and the nature and cause of changes to the services provided to family members over time. The participants themselves are described, encompassing both the family members who participated in the study and those brain injured relatives represented by the various family member participants.

#### **The Rehabilitation Centre**

The Rehabilitation Centre provides assessment, treatment and rehabilitation for people recovering from injuries or illnesses, for both inpatients and outpatients. During the period covered by the study, service contracts with the Health Funding Authority provided the main source of revenue for the Rehabilitation Centre, via MidCentral Health. Further revenue was obtained from the Accident Rehabilitation and Compensation Insurance Corporation and other health insurers (MidCentral Health, 1998).

Referrals to the Centre are received from a variety of sources including other wards within the same hospital, other hospitals, and from within the community. In the case of TBI, brain injured individuals may be referred from other facilities and then discharged, or in some instances, they may leave the Centre to attend another rehabilitation facility and then return for further rehabilitation.

The Centre utilises a multidisciplinary approach to rehabilitation, incorporating a range of medical and rehabilitation professionals including doctors, nurses, psychologists, physiotherapists, speech, occupational and recreational therapists, as well as social

workers, workshop instructors and administrators. The makeup of the rehabilitation team will vary for each rehabilitation client, depending on the types of skills required. One member of the team will be appointed to act as the client's key worker for the duration of the rehabilitation process. Usually this will be the staff member who is expected to have the most involvement with the client, although other factors such as who has the most available time will also affect the decision.

Introduced primarily as a cost-saving measure in the late eighties, it is hospital policy to close the Centre between Friday 3pm and Monday 7:30am. The consequence of this practice has been that care of brain injured inpatients commonly becomes the responsibility of their families for the weekend period, with the injured individuals usually returning to the family home, or in cases where this is not possible, transferred to other hospital wards. Occasionally, when neither option is available, they are billeted with willing persons within the community or placed in a motel.

Traditionally the Centre has utilised a 'social discharge' policy, where the injured individual is discharged when rehabilitation staff, together with the family, believes the necessary community supports have been established and the family is coping adequately. This policy has enabled staff to exercise discretion in the discharge process, with individuals occasionally remaining in the Rehabilitation Centre beyond the minimum time needed for inpatient rehabilitation because the necessary community supports have not been in place. The increasingly cost-conscious and regulated health environment within which the Centre operates has, over the past few years, discouraged the use of such an approach, with staff having less opportunity to exercise such discretion. However, virtually all of the injured individuals represented in the present study attended the Centre while this social discharge policy was in place.

Formal procedures are in place to obtain feedback from patients, their family members, and 'significant others' such as guardians, holders of power of attorney, and so forth. Regular patient forum meetings are run by hospital social workers, where people can comment on aspects of the rehabilitation process and service provision, which is then fed back to Centre



staff by the forum facilitators. Questionnaires are also displayed in the foyer of the Centre, covering various aspects of service provision, which can be completed and returned via a mail box in the Centre. This feedback is used to gauge customer satisfaction with service provision and guide future service delivery.

Although the primary provider of rehabilitation services to brain injured individuals are the Rehabilitation Centre and staff, other professionals and agencies outside the Rehabilitation Centre are also commonly involved. External agencies most commonly involved with the injured individuals and/or their families during the time period covered by the study included Accident Compensation Corporation and Headway (which became known as the Brain Injury Association during the final stages of the study). Those practitioners who provided assistance prior to the injured individual arriving in the Rehabilitation Centre, for example, emergency medical/surgical staff, and ICU staff, are not included in the study.

#### Theoretical frameworks for rehabilitation

Practitioners' views towards family members, as well as the approaches taken to family intervention at the Rehabilitation Centre, were examined as part of a series of interviews with Rehabilitation Centre staff, (representing three disciplines in total), conducted prior to the commencement of family interviews. In each interview, the staff member acknowledged both the potential contribution of family members in TBI rehabilitation and the need for practitioners to work with families to ensure their contribution to the rehabilitation process was positive and consistent with general rehabilitation efforts.

When asked, however, none of the staff members interviewed were able to identify the theoretical base which guided either their specific discipline's efforts to involve family members and to prepare them for post discharge life, or the efforts of the rehabilitation team overall. After further discussion, each interviewee described what they considered to be the general approach to family intervention taken by practitioners within their discipline at the Rehabilitation Centre. According to the physiotherapist interviewed, for example, the physiotherapy section focused primarily on informational and skills-training approaches, reflecting the need to educate family members about physical sequelae and the

recovery process and to train family members to assist the injured individual with ongoing maintenance therapies. The nursing section focused more on informational and supportive approaches aimed at helping families understand the brain injury and enhancing their emotional capacity to cope.

The psychological section drew on both informational and supportive approaches, aimed at helping family members understand, and come to terms with, the psychological changes in the injured individual. In some instances, however, elements of skills training approaches were incorporated, aimed at providing family members with specific skills to help manage the injured individual. The clinical judgment of the psychologist concerned was used to determine whether particular family members should participate in skills training activities or whether the focus should be on helping families access professional support services. Ultimately, the psychologist was the only practitioner interviewed who described the need to vary the approach taken to meeting the preparation needs of each family.

The difficulties demonstrated by practitioners in articulating the family intervention models which inform their individual practices without prompting are not unusual. Practitioners interviewed suggested that the practices of health professionals tend to be guided by their professional training, where theoretical frameworks are implicit. Consequently, it was only when practitioners were presented with a choice of models reflecting the core philosophy and practices of their disciplines that they were able to select those which most closely reflect their style of working (see Zipple & Spaniol, 1987).

While each interviewee was ultimately able to identify the model of practice in use within their particular discipline, this was not so for the Rehabilitation Centre as a whole, where there appeared to be an absence of a single, articulated, coherent model of practice. This apparent absence has a number of implications in terms of the services provided, and raises a number of issues about the preparation of family members.

The use of multiple and differing approaches by Centre staff has the potential to be confusing to families, as will be evident in subsequent chapters. For example, some

disciplines will encourage family members to take an active role in the rehabilitation process, teaching them how to provide hands-on assistance to their relative, while others will encourage the same family members to adopt a more passive role, leaving their relative's treatment and care to specialists and professional caregivers. The result of such a conflicting approach is to inhibit family members establishing a clear and consistent role in the relative's recovery, and to compound the confusion resulting from being placed in an unfamiliar and, frequently, overwhelming situation.

The inconsistent use of approaches to family intervention may also cause families to question the competency and usefulness of individual practitioners, with those who employ approaches most closely meeting the preferences of particular families being considered more knowledgeable and understanding than those whose approaches do not. Families may perceive staff as having differing levels of commitment to the injured relative's recovery and to family members' wellbeing, again based on the approach used by individual practitioners. The rehabilitation team as a whole may also appear disorganised and lacking a clear purpose or direction when various, contradictory approaches are utilised.

#### Changes to family intervention over time

During the interviews, staff members identified a number of factors that developed during the past decade which they felt had influenced the type and nature of services offered to families by the Rehabilitation Centre. One of the most significant involved the increasingly regulated and financially-conscious environment within which the Centre operates.

Although staff acknowledged the strain on families and families' corresponding need for support, they felt services focusing on aspects of family adjustment and long term coping were becoming increasingly difficult to justify. The specific service evaluation criteria set by funding providers were perceived as having resulted in a reduction in the amount and type of assistance and preparation-related services they were able to offer to family members. One staff member stated that they were not funded to work with families, only

with the brain injured individual, and as a consequence, *“We do a bare minimum with the family. We do what we can with the family given the constraints of the contracts... but the focus is almost totally on the client.”* The exception to the above is family interventions perceived to directly reduce either the amount of professional input required or the duration input is required for, such as the training of family members by the physiotherapy team to carry out an injured individual’s physical maintenance programme - considered more likely to meet service criteria.

As a result, a number of the services previously offered to family members are no longer provided, including a Centre-based family education and support group (‘Headlink’) and educational sessions conducted outside the Rehabilitation Centre, where members of a given individual’s social support system are educated regarding the TBI (e.g. education sessions by a psychologist in a brain injured child’s class, prior to the child’s return to school). Psychological counselling of family members, traditionally provided by Centre psychologists, is provided on a less frequent basis than previously, again as a consequence of resource constraints.

Many of the study participants, family members of the brain injured individuals, have been affected by these changes, particularly those whose relatives attended the Rehabilitation Centre more recently. It is difficult to be certain of the extent to which different families were affected by the changes, however, because of the gradual nature of the reduction in services offered.

Staff interviewed expressed considerable frustration with the lack of opportunities available to them to work with family members and help them adjust to, and cope with, their new roles. Staff also indicated that, had there been sufficient funding, they would have liked the services previously available to family members to have continued.

At the same time as the services offered by the Rehabilitation Centre have diminished, ACC has effectively ceased funding private counselling for family members – in practice, if not in policy. While the Centre’s social workers are still able to provide some individual

counselling and family therapy, the standard of counselling is uncertain, reflecting extensive variation in the counselling component of social work training in New Zealand. Even this service by social workers has decreased, again as a result of resource constraints, with further reductions anticipated.

A support and advocacy group was established in Palmerston North for people affected by brain injury as part of the national 'Headway' organisation. The organisation has evolved considerably since its inception, experiencing periods of growth and periods of decline in membership, in staffing levels and in the range of services the organisation was able to provide. Consequently, the nature and type of assistance available to participants through Headway following their relative's TBI has varied considerably.

Other changes have also occurred. An ACC Case Manager is now based at the hospital in an effort to increase communication and accessibility, and reduce the likelihood of individuals 'falling through the cracks' and not receiving attention, while an additional psychologist was appointed by the hospital approximately five years ago, increasing the total resource time available in the psychology discipline.

Another change Rehabilitation Centre staff have observed in the last decade, which they attributed in part to the changing financial climate within the health sector and the move towards increased accountability, involves an increase in the expectations of rehabilitation service users. Staff interviewed felt family members who did take a proactive, or at least participatory, role in their relative's rehabilitation, tended to be more demanding in terms of wanting information and expecting rehabilitation practitioners to be able to provide it. One staff member commented that family members would no longer accept rehabilitation team members being unable to answer questions in their area of expertise, which they generally would have in the past.

## Study Participants

The questionnaire participant group ( $N = 33$ ) was analysed on the basis of a number of different criteria, relating either to the participants or to their injured relatives and their injured relatives' brain injuries, criteria the literature suggested may influence aspects of family experience and outcome. These included the family member's: gender; relationship to the brain injured relative; ethnicity; age; occupational background; and prior knowledge of brain injury, as well as: the year the brain injured relative attended the Rehabilitation Centre; the duration of time spent by the relative as an inpatient; and the severity of injury sustained. It was originally anticipated that further analysis would be conducted examining the influence of these variables on participants' responses to various different questions and issues. A decision was made not to proceed with this, however, after early analysis revealed the sample size was too small for meaningful analysis to be conducted.

### Characteristics of participants

Of the 33 family members who participated in the study, 28 (88%) were female and only four were male (13%). One participant provided virtually no descriptive data in any area; consequently, many of the subsequent descriptions of participants represent 32 rather than 33 participants. The 32 remaining participants comprised 18 mothers (55%), 10 female spouses (wives or defacto partners) (30%), one father (3%), two brothers (6%), and a husband (3%). At the time of the study, the mean age of participants ( $N = 33$ ) was 46 years (reported to the nearest year,  $SD = 12.5$ ), with a range of 23-75 years. Three participants did not provide age-related information. Almost all participants identified as Pakeha (85%), with a further two (6%) identifying as Maori and two (6%) as New Zealanders.

Of the 32 participants who responded, twenty (61%) reported knowing nothing about TBI prior to their relative's accident, seven (21%) reported knowing a little, four (12%) reported knowing some, while one (3%) knew a great deal. Taking a dichotomous approach, seven (21%) participants reported a professional background in health while twenty (61%) did not. The remaining six (18%) did not provide the necessary information.

The characteristics of caregiving family members reported above are consistent with general literature on family members who assume the role of primary support person to a brain injured relative. The predominance of female caregivers was anticipated, with the high proportion of mothers and female spouses. The reported ages spanned a wide range of years, highlighting the way in which brain injury affects family members at many different life stages. Very few family members in the primary caregiving role had a knowledge of TBI prior to their relative's injury, consistent with the low levels of awareness of TBI amongst the general public. Even those with a medical background tended to possess little prior knowledge of TBI, demonstrating that the existence of positive relationships between the two variables should not be assumed.

#### Characteristics of brain injured relatives represented in the study

Of the 33 brain injured individuals represented in the study, 30 (91%) were male and three (9%) were female. The mean age at time of TBI onset was 28 years (ranging from 14-64 years,  $SD = 11.8$ ), with a mean of 4.1 years ( $SD = 2.4$ ) since onset. All injured relatives represented in the study attended the Rehabilitation Centre as an inpatient between 1988 and 1997, for a mean of 11.1 weeks (ranging from 1-63 weeks,  $SD = 14.7$ ). On the basis of PTA scores, derived by the researcher from coma-related information provided by participants, three (9%) relatives had a mild injury, one (3%) had a moderate injury, and 23 (70%) had a severe injury, with coma-related information not provided or unknown for the remaining six (18%) relatives.

As was the case with family members, the brain injured relatives in the study appeared representative of those acquiring brain injury generally. The vast majority were male, as was expected from the higher acquisition ratios reported in the literature in comparison to females. The mean age for injury onset lay outside the range considered representative of the most at-risk for brain injury; however, this was a reflection of three more extreme figures which raised the mean age, with the median age calculated ( $Mdn = 25$  years) consistent with general epidemiological literature. That a large proportion had a severe injury reflects the study's inpatient context, with individuals with seemingly lesser injuries more likely to return home at the conclusion of acute medical treatment and therefore be

excluded from consideration in the present study. The average length of inpatient stay was variable, as is consistent with the diverse recovery courses and rehabilitation needs evident amongst the TBI population generally.

## Conclusion

The use of a multidisciplinary approach to service provision may be considered a defining characteristic of the Rehabilitation Centre's operations, as may its restricted operating hours, and its focus on individuals' recovery from both injury and illness which necessitates that staff possess or develop skills and expertise across a broad range of areas. The use of models of practice which are implicit and informed by discipline-specific training, and which result in a variability in practices across the Centre, are also key features, albeit ones which does not appear to be unique to the facility. Its brain injured clients, of which a portion elected to have an involvement in the study through their families, appear fairly representative of the TBI population generally, as do the family members who participated in the study as primary support people to the brain injured individuals represented.

Like other health and disability-related organisations, the nature of operations at the Rehabilitation Centre is strongly influenced by the wider political, economic and social contexts in which the Centre functions. Considerable changes have occurred over time in response to developments in the wider environment, affecting both the type of services provided by Centre staff and the way in which those services are provided. While indepth examination of such developments lies outside the scope of the present study, as does further examination of their effects on the day-to-day practices of Rehabilitation Centre staff, their effects on operations and the constraints they place on practitioners working within this environment should be acknowledged.

Efforts to obtain feedback from users of Rehabilitation Centre services are ongoing, with staff drawing on a number of different approaches to collect such information. Potentially, the usefulness of many of these initiatives may be limited, however, with clients of such



services usually varying considerably in their ability to provide such information and also in their willingness and confidence to do so. Fear of negative repercussions often features highly in the conducting of evaluatory-based research, particularly where the method employed does not provide anonymity for participants, and it is unlikely that Rehabilitation Centre clients will have been immune from such concerns. Indeed, family members in the present study commonly indicated they had agreed to participate because of the opportunity it provided them to comment on their experiences in a confidential manner, thus lessening the perceived potential risks involved. Consequently, it is possible, if not probable, that some of the present study's findings may differ from those obtained through previous Rehabilitation Centre efforts, as well as surprise those who have based their perceptions of the Centre and its services on such evaluations.

## CHAPTER 6

### AN OVERVIEW OF FINDINGS ABOUT FAMILY PREPARATION

The context of the study and a description of participants, that is, participating family members who were the primary support people of brain injured relatives, has been outlined in the previous chapter. The following six chapters report in detail on participants' experiences of brain injury and their preparation for the roles they performed as part of their relative's recovery process. The present chapter sets the basis for subsequent chapters by summarising, in quantitative form, participants' feelings about the preparation process, in particular, participants' responses to questions regarding levels of difficulty expected and experienced, levels of preparedness, and overall satisfaction with the preparation process.

#### Levels of Difficulty

Families expected to encounter difficulties in the time following their relative's final discharge from the Rehabilitation Centre, a period encompassing the discharge itself, the period of community reintegration, and life generally over the longer term. When asked to recall their feelings at the time of their relative's final discharge from the Rehabilitation Centre, 94% of participants (30) reported having anticipated that life with their relative would be somewhat difficult or difficult (see Table 6.1). When asked to indicate now how difficult these times had actually been, 80% of participants (24) rated the discharge period as having been somewhat difficult or difficult and 88% (28) rated the longer term as having been somewhat difficult or difficult.

When the combined figures are examined (i.e. the *difficult/somewhat difficult* and the *easy/somewhat easy* groups), it appears fewer participants found discharge or the longer term as hard as they had initially anticipated. When individual response categories are examined, however, a different trend emerges. Half of the participant group gave the extreme *difficult* rating to describe their expectations of life with a brain injured relative, and while fewer participants gave this same rating to describe their actual experiences of discharge, more used this rating to describe life over the long term.

**Table 6.1. Levels of difficulty reported by family members**

<b>Family members' expectations vs experiences</b>	<b>Difficult</b>	<b>Somewhat difficult</b>	<b>Somewhat easy</b>	<b>Easy</b>
<b>At discharge, how difficult did you expect life with a brain injured relative would be?</b>	50% (16)	44% (14)	6% (2)	(-)
<b>In hindsight, how difficult was the discharge period?</b>	43% (13)	37% (11)	10% (3)	10% (3)
<b>In hindsight, how difficult was life beyond the discharge period?</b>	59% (19)	28% (9)	9% (3)	3% (1)

*Note.* Figures in brackets represent number of respondents. (-) represents zero respondents.

No existing studies were found which quantified difficulty in the way the present study did, making comparisons with the literature hard. The level of anticipated difficulty reported was high, suggesting participants had some understanding of the challenges which potentially lay ahead. The drop in the number of participants who rated the discharge period difficult from those who reported anticipating this extreme level of difficulty, however, suggests that the frequently-cited 'discharge crisis' (where families become overwhelmed by the magnitude of impacts and changes involved, see Blazyk & Canavan, 1986; Carlton & Stephenson, 1990; M. A. Foster & Carlson-Green, 1993; Hubert, 1995; Muir et al., 1990; Zeigler, 1987) did not eventuate for a number of these participants, and that a portion of the participants may have been unduly apprehensive about discharge.

In part, this may reflect the experiences of those family members whose relatives achieved an unexpectedly good recovery, with anticipated problems failing to eventuate or occurring on a much less dramatic basis. It may also reflect such a negative outlook that the reality came as a pleasant surprise for family members. Indeed, practitioners are often accused by families of being too pessimistic in their outlook, leading them to expect difficulties which do not eventuate (Hall, 1989). This criticism was echoed by several participants in the

present study with regard to Rehabilitation Centre practitioners, although one of the participants put the onus on herself, having “*read too much and over-reacted.*”

Life over the longer term clearly presented greater difficulty to participants than the discharge period itself, as illustrated by the increase in the number who rated it as difficult and the overall decrease in the number of participants who rated it as easy or somewhat easy, as well as being more difficult for many participants than was anticipated prior to discharge. This finding is consistent with the literature, which emphasises that families’ appreciation of TBI and its impacts typically develops over time, an awareness reflected in growing rather than diminishing levels of family burden. It is also supported by a further finding that, for 52% of participants, the traumatic brain injury’s impact on their life was greater than what they had been led to believe, with only 6% indicating the impact had been less.

#### Levels of Preparedness

Preparation for life beyond the period of inpatient services was a topic of critical importance for participants - partly a reflection of the study’s focus but also an endorsement of the research topic selected. When asked to recall how they had felt at the time of their relative’s final discharge from inpatient treatment at the Rehabilitation Centre, over half of the participants (59%) selected the categories *unprepared* or *somewhat unprepared* to describe their state of readiness for post discharge life (see Table 6.2). When asked to rate their level of preparedness again, this time taking into account the knowledge and experience they had gained since their relative’s injury, the percentage of participants who rated themselves as having been unprepared or somewhat unprepared for post discharge life increased to 69%.

The only study identified which investigated family preparation in a similar way to the present study was that of McMordie et al. (1991) on consumer satisfaction with TBI services, where family members were asked to rate (on a seven-point scale) how well medical and rehabilitation staff had prepared them for caring for their brain injured relative

post discharge. Fewer than half (41.1%) indicated they had been adequately prepared, and only 28.0% rated their preparation highly. It is difficult to compare findings from McMordie et al.'s study with those of the present study because of the differences in scales used and the considerably different sample sizes involved. Of importance, however, is the theme of inadequate preparation amongst family members which emerges in both studies.

**Table 6.2. Levels of preparedness reported by family members**

Family members' feelings of preparedness	Unprepared	Somewhat unprepared	Somewhat prepared	Prepared
At discharge, how prepared did you feel for your relative's discharge and life after discharge?	26% (8)	33% (10)	38% (12)	3% (1)
In hindsight, how prepared for your relative's discharge and life after discharge were you?	44% (14)	25% (8)	25% (8)	6% (2)

#### Levels of Satisfaction

The measurement of participant satisfaction was approached in the same way as for preparedness levels, with ratings given both at time of discharge and in hindsight. When recalling their feelings at the time of their relative's inpatient discharge, just over half of the participants (53%) indicated they had been either dissatisfied or somewhat dissatisfied with efforts made to prepare them for life with a brain injured relative (see Table 6.3). When taking into account their experiences since this time, the level of dissatisfaction expressed by participants increased, with 65% indicating they now felt dissatisfied or somewhat dissatisfied with preparation efforts.

Very little work has been published on family satisfaction with services following TBI (Smith & Godfrey, 1995), with the small amount currently available focusing on practitioner-family communication and information provision (e.g. Oddy et al., 1978a; Panting & Merry, 1972; Thomsen, 1974). The work of McMordie et al. (1991) is described

by L. M. Smith and Godfrey (1995) as a rare exception. Unfortunately, the study conducted by McMordie et al. provides little information which can be directly compared with findings obtained on satisfaction in the present study - while participants are consistently critical of the services received, McMordie et al. used individual scales to measure different aspects of service provision and did not include a global satisfaction measure.

**Table 6.3. Levels of satisfaction with the preparation process reported by family members**

Family members' feelings of satisfaction	Dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Satisfied
At discharge, how satisfied were you with the preparation process?	31% (10)	22% (7)	31% (10)	16% (5)
In hindsight, how satisfied are you with the preparation process?	34% (11)	31% (10)	19% (6)	16% (5)

L. M. Smith and Godfrey (1995) investigated satisfaction amongst family members as part of the evaluation of an innovative pilot family education and support programme, designed to overcome limitations associated with traditional preparation programmes. The relatives' injuries spanned the range of severity from mild to severe, consistent with those in the present study. Family members in L. M. Smith and Godfrey's research reported high satisfaction with the programme developed, reporting a mean of approximately 6.5 on a seven-point scale where 'one' represented *not at all satisfied* and 'seven' represented *very much satisfied*. The low levels of satisfaction with preparation in the present study in comparison with those of L. M. Smith and Godfrey's may reflect the acknowledged limitations of the traditional approach used at the Rehabilitation Centre.

Furthermore, the satisfaction figures reported in Table 6.3 are, in general, consistent with the overall pattern of responses reported earlier in the chapter, where family members

anticipated and experienced difficulty and felt inadequately prepared for life with a brain injured relative. The proportion of participants who felt at least somewhat satisfied with the efforts made (47%) (reported at time of discharge) was higher than expected, particularly given that most participants expected to experience considerable difficulty and over half felt inadequately prepared. The decrease in satisfaction levels reported in hindsight mirrored trends reported previously in the chapter, reflecting the greater awareness of intervention limitations gained by family members over time.

## Conclusion

The picture emerging from the findings reported in this chapter is primarily one of families ill prepared to meet the challenges associated with traumatic brain injury. While some family members found life with a brain injured relative easier than they had initially expected, a number found it more difficult. Efforts made to prepare families for life with a brain injured relative were often considered inadequate by family members, a perception clearly enhanced over time and supported by the preparation-related dissatisfaction also reported. A wide variety of factors contribute to this overall picture of dissatisfaction, the identification and exploration of which comprise much of the focus of the present study and are reported on in subsequent chapters.

## **CHAPTER 7**

### **THE FAMILY FOLLOWING TBI**

The notion of brain injury as a social and family-related phenomenon rather than a solely medical one was established through the early work of researchers such as Thomsen (1974), Rosenbaum and Najenson (1976), Oddy et al. (1978a) and Lezak (1978), which highlighted the multiple and varied impacts of TBI on family members, and has been subsequently reinforced by researchers and clinicians asserting that family members are often equally, if not more, affected, by brain injury than the injured individual (D. N. Brooks, 1991b).

Examinations of family functioning post TBI have traditionally focused on impact/burden and emotional responses/adaptation, and this framework is followed in the present chapter which examines the ways in which families were affected by their relative's TBI, and their responses to the TBI and its effects. A small amount of background information is also provided before these two sections, overviewing the impact of TBI on the lives of brain injured relatives represented in the study (as perceived by their family members), as a way of contextualising findings on the lives of family members.

#### **The Impact of Traumatic Brain Injury**

The current section describes the impact of TBI on the lives of brain injured relatives and their family members, although it is the latter of these two groups which is the primary focus of the study and consequently receives the most attention here. Summaries are provided overviewing the magnitude of impacts for both groups, and more detailed discussion provided in relation to the impacts on family members. Areas encompassed in this discussion include: family members' independence; their participation in vocational and avocational activities; financial status; relationships with the brain injured relative, with other family members, and with friends; the attribution of blame; the isolation of family members; the effects of violence and abuse; physical and mental health; the suspension of lives; and the few positive impacts identified.



### Impact on the brain injured relatives

The lives of those individuals who sustained brain injury were, according to their participating family members, affected in a multitude of ways and to varying degrees. Participants' perceptions of the levels of difficulty their injured relatives experienced in various aspects of their lives as a result of the TBI are detailed in Table 7.1. This reveals an average of 56% of the brain injured relatives have experienced moderate or severe difficulty in the areas of functioning listed. Cognition (79%), vocational participation (74%), emotions (64%) and behaviour (64%) were the aspects of the injured individuals' functioning rated as being the most commonly and severely affected.

**Table 7.1. The impact of traumatic brain injury on the lives of the individuals with brain injury**

Aspects of the individual's functioning	No difficulty <sup>a</sup>	Mild difficulty <sup>b</sup>	Moderate difficulty <sup>c</sup>	Severe difficulty <sup>d</sup>
<b>Physical functioning</b>	28% (9)	16% (5)	38% (12)	19% (6)
<b>Hearing</b>	52% (16)	10% (3)	13% (4)	26% (8)
<b>Vision</b>	47% (15)	25% (8)	9% (3)	19% (6)
<b>Speech</b>	30% (10)	30% (10)	21% (7)	18% (6)
<b>Cognitive functioning</b>	6% (2)	15% (5)	36% (12)	42% (14)
<b>Emotional functioning</b>	9% (3)	27% (9)	18% (6)	46% (15)
<b>Behavioural functioning</b>	12% (4)	24% (8)	18% (6)	46% (15)
<b>Social functioning</b>	21% (7)	18% (6)	18% (6)	42% (14)
<b>Vocational functioning</b>	13% (4)	13% (4)	26% (8)	48% (15)
<b>Independent living</b>	27% (9)	21% (7)	15% (5)	36% (12)

*Note.* Table format taken from questionnaire used in NZHIS (1993), Head injury the silent epidemic study. Adapted with permission.

<sup>a</sup>Problem not present. <sup>b</sup>Problem present but has minimal impact on daily living. <sup>c</sup>Problem present with a noticeable impact on daily living. <sup>d</sup>Problem present and has major impact on daily living.

### Impact on family members

The brain injuries acquired by the individuals represented in this study had a major impact on the lives of their family members. Overall, the majority of family members (72%) felt their lives had been greatly affected as a result of their relative's brain injury, with only 6% (2) indicating their lives had not been affected at all (see Table 7.2).

**Table 7.2. The impact of traumatic brain injury on the lives of family members**

Areas investigated	Not affected at all	Somewhat affected	Affected a great deal
<b>Overall effect on life of participants</b>	6% (2)	22% (7)	72% (23)
<b>Participation in employment</b>	23% (7)	37% (11)	40% (12)
<b>Attendance at school or training programmes</b>	56% (9)	6% (1)	38% (6)
<b>Participation in social or leisure activities</b>	24% (7)	24% (7)	52% (15)
<b>Household or domestic routines</b>	22% (7)	28% (9)	50% (16)
<b>Relationships with other family members</b>	23% (7)	32% (10)	45% (14)
<b>Relationships with friends</b>	23% (7)	40% (12)	37% (11)
<b>Ability to leave relative without supervision</b>	20% (5)	24% (6)	56% (14)
<b>Ability to have holidays</b>	33% (10)	17% (5)	50% (15)

*Note.* Table format taken from questionnaire used in NZHIS (1993), Head injury the silent epidemic study. Adapted with permission.

The impact of brain injury on family members' lives was further explored in interviews, the major themes from which are reported here in conjunction with questionnaire findings.

Loss of independence. Loss of freedom amongst those caring for a brain injured individual is a commonly noted phenomenon in the literature, generally occurring because of the restrictions placed on family members' time as a result of the extra responsibilities assumed (D. N. Brooks, 1991b; Jacobs, 1988; NZHIS, 1993; Tyerman, 1997). These include taking on tasks previously performed by the injured individual, as well as assuming new responsibilities stemming from the injured individual's care and rehabilitation needs.

In the present study, the ability of family members to leave their brain injured relatives without supervision was the area of family members' lives most affected as a result of the TBI, with 80% indicating their ability to leave their brain injured relative unsupervised had been somewhat or greatly affected following the TBI (see Table 7.2). This inability to leave the relatives unsupervised contributed to a substantial loss of freedom amongst remaining family members, eliminating or substantially reducing the opportunities available to them to participate in various aspects of their own lives.

The unwillingness of family members to leave their brain injured relatives without supervision often stemmed from concerns held for the safety of the brain injured relatives who, left alone, may either intentionally or unintentionally harm themselves. Family members appeared to have good cause for this concern. Suicidal ideation, actual and repeated suicide attempts, depression, anger, impaired judgment, memory deficits, and access to firearms were a few of the aspects of the brain injured relatives' lives identified by family members that they needed to take into account when deciding on the level of independence they believed their relatives could be given.

The ability of the injured relatives to perform activities or tasks at a standard considered acceptable by family members was another influential factor identified. Many of the family members whose relatives had significant cognitive deficits found that, when left alone, their relatives would either fail to complete tasks or carry them out in a way that

created additional problems for other family members. Numerous examples of this nature were given, such as the brain injured individual who collects and then forgets where he has placed the family mail, or who goes out to buy items from the local shop, and returns home without the items, having forgotten what items he was to buy, or even that he was supposed to have attended the shop at all. The frustration family members felt in these instances often led family members to prefer to complete tasks themselves, without the injured individual's involvement, or to perform tasks alongside the individual to ensure it was done correctly.

Participation in vocational activities. Family members' participation in vocational activity is frequently affected following the onset of brain injury in a relative (Kreutzer et al., 1992; NZHIS, 1993; Sander & Kreutzer, 1999). In some instances, it may be necessary for a family member of the injured relative to leave work, or reduce the number of hours worked, in order to care for the relative, as was the case for half of the 36.6% of families in Jacobs' (1988) study whose injured relatives required continuous supervision. Conversely, it may be necessary for a family member who previously did not work outside the home to obtain paid employment in order to help meet the cost of rehabilitation and care expenses, as was the case for 23.8% of spouses and 16% of parents in McMordie and Barker's American-based (1988) study. Tyerman (1997) notes that, even in instances where family members are able to maintain previous employment, they are often too preoccupied or drained to apply themselves effectively to their paid work.

In the present study, 77% of participants indicated that their ability to participate in employment-related activities had been somewhat or greatly affected as a result of their relative's TBI, while 44% indicated their ability to participate in education-related activities had been somewhat or greatly affected (see Table 7.2). Participants were not asked to indicate the way in which participation was affected; consequently it is unclear whether family members had needed to leave their previous employment or obtain additional employment. The high proportion of participants who indicated their relative required full time supervision, however, suggests many of the participants may have

needed to leave work or at least reduce the number of hours worked in order to provide the supervision required.

Participation in avocational activities. Participation in avocational activities is commonly affected following brain injury (Farmer & Stucky-Ropp, 1996; Florian et al., 1991; Lezak, 1978), with negative flow-on effects to other aspects of family members' lives, such as diminished mental and physical health and relationships with friends and family. Tyerman (1997) suggests that for many families with dependent relatives, their social and leisure lives falter because statutory services tend to be insufficient to provide adequate home care and few families can afford to employ professional carers.

In the present study, 76% of participants rated their ability to participate in social or leisure activities as being somewhat or greatly affected (see Table 7.2). Insufficient spare time was a major issue for many of the participants, as was a general lack of energy and motivation stemming from being overworked.

Holidays were also problematic, both when the injured relative was included and when they were not, with 67% of participants indicating their ability to have holidays had been somewhat or greatly affected (see Table 7.2). One mother stated, *"You can't plan a holiday [without your brain injured relative]. You can't plan to go away for a weekend. It's impossible. Because if you do go, you're not having a holiday. You're busy thinking about what's happening at home."* During the years that had passed since the TBI, this mother and her partner had attempted to have one holiday without their son; however, the trip was terminated prematurely because they had both been so concerned about his wellbeing they found it easier to return home (only to find that their concerns were well-founded - he had disappeared).

Financial status. Diminished financial status of family members has been emphasised as a common outcome of TBI in the literature, in part, a reflection of the dominance of American-based research and characteristics of the American rehabilitation/welfare system. Jacobs (1988), for example, found that 28% of families questioned had used all or most of

their financial resources on TBI-related expenses, while a further 34% reported moderate or mild financial drain. In McMordie and Barker's (1988) study, 47.5% of spouses and 28.4% of parents reported needing to borrow money as a result of the accident, 26.3% of spouses and 10.4% of parents had lost significant possessions, such as a house, while 9.1% of spouses and 4.2% of parents had needed to declare bankruptcy.

While the financial consequences of TBI may not be as severe in countries where the State plays a larger role in rehabilitation and welfare services, such as the U.K and NZ, the literature suggests changes in the financial status of families remains a common outcome of TBI (e.g. Higham & Phelps, 1996; Hubert, 1995; NZHIS, 1993). The NZHIS (1993) study, for example, found similar patterns to the American studies of McMordie and Barker (1988) and Jacobs (1988), with 43% of families indicating they had experienced a decrease in income and standard of living following their relative's TBI.

While no attempts were made to quantify the financial impact of brain injury in the present study, it was apparent that the brain injury had negatively impacted on the financial status of a number of the families. Even though all of the injured relatives represented in the study were covered by ACC, by virtue of the nature of injury sustained, families frequently described needing to meet the cost of various treatments and services themselves. In some cases, the expenses stemmed from what may be described in the current context of TBI rehabilitation as 'extras', such as travelling to different cities in NZ to gauge the suitability of various treatment centres for the injured relative. In other instances, however, the treatment for which funding was sought (and denied by ACC) had been recommended by specialists, such as ongoing physiotherapy and gym membership. Those who were able to pay for the services privately generally did so, while those who were not able to went without. The need for family members to return to work before they wished to do so was also mentioned by a number of participants, a move usually motivated by financial need.

Relationships with the brain injured relative. The onset of TBI dramatically affected the type of relationships family members had with their brain injured relatives. An experience common to many of the participants, regardless of familial relationship, involved that of

‘estrangement’, although this label was derived from the literature and not from the family members themselves.

According to J. Johnson and McCown (1997), family members possess expectations of their relative following brain injury, based on premorbid knowledge, which typically go unmet because of the changes which have occurred in their relative. Because families often fail to comprehend the nature or permanence of these changes, they come to view their relative as a stranger, becoming alienated or estranged as a consequence. The injured relative becomes similarly alienated from the family as a consequence of the family’s perceived failure to understand the injured individual or to treat them in a manner acceptable to the individual.

The extent to which estrangement was evident amongst different family members varied considerably. In some cases, there was a vaguely articulated sense that things were different and the injured relative was not as familiar to family members as prior to the accident. A number of participants commented, for example, that they ‘didn’t really know’ their relative anymore. In a few cases, the estrangement was almost complete, with family members becoming emotionally disengaged from the injured relative and/or physically withdrawing their involvement in the individual’s life as much as possible (see ‘avoidance’ later in the chapter).

While the ‘estrangement’ phenomenon appeared common to the participant group as a whole, some of the changes in relationships appeared to be specific to individual participant subgroups. Parents, particularly mothers, of brain injured children, spoke often of their desire to nurture and care for their child following the brain injury, regardless of the age of their child. Parallels were frequently drawn between the brain injured relative as a young child, and their recovery from the TBI. In cases where residual deficits were more severe, parents described needing to assist and teach their child a wide range of daily living skills, as they had done when the child was small. Conceptualising the relationship in this way, apparently regardless of the age of the injured individual, appeared to help family members establish a way of interacting and rationalising the types of activities performed.

The responses of the injured relatives to this approach varied, according to the descriptions provided by their family members. In the case of younger individuals, the parent-child relationship was consistent with pre-existing family relationships and was met with general acceptance. In contrast, older individuals often resented the restrictions this type of relationship placed on their independence and sought to maintain their adult status by resisting any efforts by parents to exercise such control. Hubert (1995) describes this same response in her study, stating that the protectiveness displayed by parents of adult brain injured children is often carried out

in the face of angry resistance, and unreasonable demands.... partly because parents, in their efforts to protect, may treat their twenty year olds as though they are children again, and from the son or daughter's point of view this is unacceptable. (p. 106)

The parent-child approach adopted by parents in the present study held less relevance for other types of family members. Those spouses who did comment indicated they had found it extremely difficult to cope with their partner's dependency and need for assistance, a difficulty Zeigler (1987) suggests is compounded by the absence of support previously provided to the spouse by the partner during challenging times. One female participant, whose son and husband had both sustained brain injuries, suggested it had been much easier to come to terms with the change in the nature of the relationship between herself and her son, than between herself and her husband. Because she had never needed to perform such a role in relation to her spouse, (nor had she ever anticipated it might be necessary), she found she had no experience on which to base or model their new relationship.

This pattern of behaviour has been described frequently in the literature (e.g. Florian et al., 1991; Liss & Willer, 1990). D. N. Brooks (1991b), for example, comments how "wives take on roles for which they never bargained" and mothers "begin again roles they had long ago relinquished" (p. 178), while Kreutzer, Gervasio et al. (1994) and Gervasio and Kreutzer (1997) suggest it is more difficult and stressful to 'parent' a brain injured spouse than a brain injured child.



According to Perlesz et al. (1999), the effects TBI has on the lives of remaining siblings, as well as on siblings' resultant needs, are often neglected by parents and professionals alike. TBI frequently results in a sharp reduction in parental attention to the remaining (non-injured) children and an increase in the remaining children's responsibilities, as well as producing feelings of shame and guilt in the children (Lezak, 1988). In Hubert's (1995) study, all of the siblings reported experiencing changes in their relationship with their injured sibling after the brain injury. Changes in authority were noted, with the non injured siblings either choosing, or being forced, to take responsibility for aspects of their injured relative's care while, in other cases, siblings withdrew from their relative. In both instances, siblings expressed anger at the problems and negative impacts they perceived the injured individual had caused the family.

Few siblings participated, or were represented, in the present study. The lives of those who did, however, as well as the relationships those individuals had with their injured relatives, had been dramatically altered. Varying degrees of estrangement were evident between siblings, particularly where the non-injured siblings held the injured individual accountable for the brain injury's impact on their own lives and/or the impact on the family as a whole.

Friendships between siblings were often transformed following the TBI into less equal or less mutually rewarding relationship. Role reversals occurred, where the older, injured individual looked to the younger (non-injured) individual for guidance and direction. One mother described this occurring between her two children, adding that her younger son came to greatly resent the changed relationship, finding, to all intents and purposes, he had an unwanted younger brother:

*Jason looked up to this brother of his. They'd just got very close [before the accident]. Jason was 14, Tony was 17, coming up 18, and both sports mad. You know. Interested in girls. They'd just started talking, forming this friendship, this relationship. And then suddenly, when Tony came home [from the Rehabilitation Centre], Jason was the role model. Everything Jason did, Tony copied. So if Jason went to read the newspaper, then Tony would go and pick up a newspaper. If Jason wanted to watch TV, Tony would watch TV. He just followed Jason round like a*

*dog! And just did everything that Jason did. You know, Tony just patterned off him.*

*N.B.* Pseudonyms used.

Relationships with other family members. The traumatic brain injury's onset also impacted considerably on the relationships between the remaining (non injured) family members, with 77% of participants indicating their relationships with other family members had been somewhat or greatly affected as a result of their relative's TBI (see Table 7.2).

The spousal relationships of parents with brain injured children were placed under a great deal of pressure, as was expected from the literature (e.g. Farmer & Stucky-Ropp, 1996; Hubert, 1995; Sachs, 1991). Turnbull and Turnbull (1991) suggest that, while this pressure often pulls relationships apart, it can also bring some couples closer together, partly depending on the state of the relationship pre-TBI. For the most part, couples in this study appeared to have experienced considerable strain following the TBI, and while none of the couples interviewed had separated as a result of the TBI (one was separated prior to the TBI), several reported the stability of their marriages had been seriously threatened. For most of the couples, the problems in the marriages became evident quite soon after the injury's onset, although one spouse commented that it was only now, several years after the TBI, that the toll the stress had taken on her marriage was becoming apparent.

There is great variability in the manner wider families participate in and influence the injured relative's rehabilitation. In their work on family systems, Kay and Cavallo (1994) note that many families do not have close ties with their extended families, as a consequence of the mobility which characterises society today, and thus do not obtain the benefits which may stem from such extended family involvement. Those families in the present study who did have close ties with their extended families described deriving a wide range of benefits from their involvement, most of which related to the greater overall amount of emotional and practical support received. One family, for example, described drawing on extended family to ensure at least one person was with the brain injured

individual 18 hours a day during the early stages of recovery, which reduced the risk of 'burn out' amongst members of the immediate family.

Because, in western society, the majority of extended family members tend to live apart from immediate family, the extended family members often do not develop the same level of understanding of the brain injury and its implications as do those living with the injured individual on a day-to-day basis. As a result, they may be less sympathetic towards the injured individual and members of the immediate family, and ultimately add to the difficulties encountered and the distress experienced (Kay & Cavallo, 1994). This was clearly the case for one of the couples interviewed, whose whanau took the view that the brain injured child was "difficult" and "bad":

*It was when [my son] started getting into trouble really, in 1994, I think it was. The family really took a back track. You know. Because his name would appear in the paper and in the court cases and so on... My mum [said] to me 'He's bad!' You know, 'He needs to be put away!' And I said to her 'He's not bad...' She said 'He is not the [boy] you brought up!'*

Considerable pressure was applied by whanau to have the brain injured individual placed in permanent care. As a result of the fighting that ensued, the immediate family severed virtually all ties with their whanau, finding it easier to rely solely on their immediate family members for support.

Relationships with friends. TBI and the resultant changes in the lives of family members can impact considerably on the nature and quality of relationships those family members have with friends (Brown & McCormack, 1988; Conoley & Sheridan, 1997; Miller, 1991; Rogers & Kreutzer, 1984; Zeigler, 1987). This was certainly the case in the present study, where 77% of participants indicated their relationships with friends had been somewhat or greatly affected as a result of the TBI (see Table 7.2).

Some family members identified close friends who had provided support, and remained an essential source of strength to them throughout the entire 'TBI experience'. One mother made the following comment about her friends:

*We must have driven our friends up the wall. Usually I cover things up, but with [my son's brain injury] I just talked, and I reckon I just drove them all nuts, but that was my out. And they were just so good. They just listened, and spoke to me about it and said 'How's [your son]?' and away I'd go. But obviously they knew I needed to do it. And they were very supportive.*

Others stated that their friends possessed little tolerance for their relative's behaviour and seemed unable to appreciate what they were experiencing. One mother stated,

*Everyone says 'Oh, is he back to normal yet?' I [say] 'He never will be'. I just drive it straight back now. 'He never will be. He can't possibly be with the amount of brain damage that he's got'. ...[But] that's not to say he's not going to have a happy, independent life. It's going to be very different to what it could have been, but he's not going to be the same, he never will be.*

This perceived lack of empathy amongst friends was noted by a number of the family members interviewed. Another mother made the following comment about her friends:

*A large majority of them had no idea. And some of them still have no idea whatsoever. 'Make him do things'. 'Do this, do that'. They're full of bright ideas. But they're not there to help you put those ideas into place, and be there to support you when they fall apart either.*

When asked how she felt towards these friends, she replied,

*With a couple of the friends I did [feel angry towards them]. Yeah. Yeah. One friend in particular. I'd been friends for a long, long time. I very seldom ever see her now, because she can't cope with the fact, with what's happened in our lives. But she's got no understanding. She said 'Oh I couldn't cope with it if it happened to me'. You don't get given any choice. It happens. You've got to live with it.*

**Blame.** Family members in the present study often described being blamed for their relative's problematic behaviour and the outcomes of that behaviour, not only by other family members, friends, and the general public but also, in some cases, by medical and rehabilitation practitioners. While family members generally recognised that a lack of

understanding of brain injury underlay much of this tendency to hold families accountable for their relative's behaviour, it was something many family members found hurtful, distressing, and grossly unfair, particularly given that most felt they were doing their absolute best under very difficult circumstances.

One such father explained how his family had become victims because they had always been blamed for what their son had done, with his wife adding: *"Everybody thinks you're neglecting [the brain injured person]. That you don't care. So I think that you try that much harder."* The father responded to the allegations of blame in the following way:

*I never get ashamed about what [my son] gets into, and whether he ends up in Court or Jail. I don't care a damn about that 'cos all our family ever wanted was for our son to live and walk and talk and we're happy with that. So we're not going to play God and start judging him because we feel it's not our fault, [our son] taking some of these winding paths. We feel it's because a lot of families never had that back up support. They were never educated, and they never had the counselling.*

The problems families faced in this area were compounded by the need to balance their responsibility to the injured relative with the injured relative's right to independence and self autonomy - a complicated mix even without the added dimension of the relative's diminished capacity. Families often found themselves in the unenviable position of being expected to control their relative's behaviour when they not only lacked the skills to do so but also the legal right to do so. Efforts to gain control over aspects of their relative's lives were frequently unsuccessful, as was the case for the couple who found themselves in the unenviable position described below:

*Now [ACC] paid [my son] out. And I said to them 'Is there some way that you can put that money somewhere until [he] goes through that period where he can learn to [budget]', you know? And they said 'I'm sorry, he's 18 years old. He's his own boss. He's an adult. The cheque belongs to him. We'll bank it ... to his bank and that's it.' Well! They did! One week! Seventeen thousand, eight hundred and ninety two dollars! In two weeks he was selling the gear he brought. He brought*

*himself an amp for two thousand, and sold it for a hundred. Blah, blah. He just wasted the money. It just blew up in not even 2 weeks... When it was all gone, [my son] came back and he said to us 'It's all your fault! It's all your fault that it's gone!'.*

**Isolation.** The literature is replete with examples of the social isolation and stigma experienced by family members over the longer term (e.g. Adams, 1996; D. N. Brooks, 1991b; Florian et al., 1991; Kozloff, 1987; Rogers & Kreutzer, 1984; Rowlands, 1996), which occurs because family members often have little opportunity or energy to devote to the maintenance of social networks and because people outside the immediate family can find contact with the brain injured individual and the family too demanding.

In a discussion about spouses of brain injured individuals, Florian et al. (1991) identify lack of social support as one of the most difficult problems faced. They also suggest that brain injury is unique in relation to other types of injuries as, while ordinarily family members' social contact improves once the injured individual's physical condition stabilises and the impact of damage is comprehended, in the case of brain injury, a gradual process of social withdrawal occurs at this point.

In the present study, participants reported mixed experiences in regard to their social networks and interactions. For some, extreme isolation was apparent. One father wrote "*no back up help. Left to cope on my own. Friends and family soon disappeared.*", while another spouse wrote "*[my husband and I have] lived up [North] for seven years and have had no help... I wish someone would have helped, because even now it still gets hard...*".

In other instances, however, participants referred to supportive families, friends and in some cases, colleagues, suggesting a more extensive social network. It is difficult to determine the actual extent of the social networks, however, as no attempts were made at measurement. It is possible, for example, that families may have received a great deal of support from a few individuals, whom they referred to glowingly, but lost contact with a

great many more, thus experiencing an increase in the quality of relationships but an overall reduction in the number.

Violence and abuse - actual and potential. While authors such as Freeman (1997) may describe acts of aggression by brain injured individuals as “an eloquent cry for help..., ...a plea from the person asking for recognition of their deep need for help, tolerance and understanding” (p. 11), for the most part, family members count their injured relative’s behavioural disturbances amongst the most difficult of all TBI sequelae to cope with (D. N. Brooks & McKinlay, 1983; Florian et al., 1991; Kreutzer et al., 1992; Lezak, 1978; Oddy et al., 1978a; Powell, 1994; Thomsen, 1984; Uomoto & Brockway, 1992; R. L. Wood, 1984). In a five year follow-up study, D. N. Brooks et al. (1986) found that levels of violence against family members by their brain injured relatives had risen dramatically since the first study was conducted one year post injury, with family members feeling anxious and fearful and making ongoing attempts to avoid provoking aggressive outbursts.

Family members were frequently the primary target for their relative’s frustration and anger in the present study and as such were subjected to considerable physical, verbal and emotional abuse. Numerous examples were given of such incidents which left family members feeling agitated, upset and fearful. One such example is provided below:

*It’s just so hard to deal with it when he goes out the door and leaves it open and you call out and say ‘Could you come back and close it’ and he says ‘Sorry mum’, and he closes it nicely and off he goes. The next time he goes out and you say ‘Hey, you’ve left the door open’ and he comes back and gives you verbal abuse like you have never heard, slams the door until the glass breaks, storms off, and you don’t see him for the next two days. And you wonder ‘what the hell did I do different?’*

As with violent behaviour generally, family members often found the possibility of violence as frightening as the actual incidents. One mother described how she had cut out, saved, and continuously re-read a newspaper article about a professional caregiver who had been murdered by a brain injured man who had lost his control. This mother had cried as

she described feeling “*pretty unnerved*” when her son would lose control, adding also that her son had sufficient insight into his behaviours as to apologise afterwards.

Physical and mental health. An extensive number of reports on the psychological and physical wellbeing of family members cite a wide range of negative impacts, such as high levels of distress, anxiety, anger, depression and dissatisfaction with family relationships (e.g. D. N. Brooks et al., 1987; Lezak, 1978; Livingston, 1987; Livingston et al., 1985a, 1985b; Muir et al., 1990; Oddy et al., 1978a; Panting & Merry, 1972; Romano, 1974; Rosenbaum & Najenson, 1976). Of particular concern have been the possibilities that the impact of TBI on families may increase over time rather than decrease (Florian et al., 1991; Muir et al., 1990) and that the true extent of distress following brain injury may actually be greater than that found in studies on the topic because of the tendency of some families to display a “command performance syndrome”, where they mask the extent of their emotional distress in front of others (Farmer & Stucky-Ropp, 1996, p. 277).

The impact of psychological distress on physical health has also been demonstrated, with various studies highlighting the vulnerability of family members to stress-related illnesses such as asthma, migraines and ulcers. The use of alcohol and drugs as coping mechanisms has also been repeatedly observed (Conoley & Sheridan, 1997; Kosciulek, 1994b; Kreutzer et al., 1992; Mauss-Clum & Ryan, 1981; Oddy et al., 1978a; Panting & Merry, 1972).

Although no attempts were made to measure the state of participants’ physical and mental health in the present study, it was obvious from observation and from participants’ own descriptions that the relative’s brain injury had severely impacted on both at different times. Physical health problems attributed by participants to the TBI included migraines, back pain, high blood pressure and fatigue, while mental health problems included high stress levels, anxiety, and a loss of control and confidence. Family members took various steps in an effort to cope with these problems including seeking therapeutic attention, either medical or psychiatric, instigating their own stress management regimes involving regular leisure and social activities, and consuming larger-than-usual amounts of alcohol and cigarettes.



While the majority of participants reported adverse effects on their wellbeing, there were a few notable cases where participants indicated their health status had remained relatively unchanged or been only slightly or temporarily affected. One mother interviewed, who appeared particularly able and relaxed, stated simply that in the time following her son's accident, she had had far greater concerns and problems involving her husband's back than her son's brain injury.

The tendency for well functioning families or family members to be overlooked in examinations of TBI-related burden has been a dominant theme in recent TBI literature (e.g. Perlesz et al., 1996, 1999), where the traditional, pathological approach to the examination of families has been strongly criticised. Perlesz et al. (1999) cite Adams' (1996) publication which argues families of brain injured individuals are not universally distressed and can have quite good outcomes. Perlesz et al. suggest the emphasis placed on negative impacts has been necessary as a way of attracting the attention of researchers, rehabilitation specialists, insurance companies, policy makers and so forth to the genuine plight of families, but that it has also hindered exploration of coping-related variables by overlooking or downplaying low-stress families. While no attempts are made to explore this area in the present study, such 'low-stress' families were represented, if only in seemingly small numbers.

Suspended lives. It was common for families to suspend normal routines post injury in order to devote time and energy to the brain injured relative. Leaves of absence, often unpaid, were taken from work, housework was left undone, bills went unpaid, and the needs of remaining family members were put aside in order to allow the maximum attention to be devoted to the brain injured relative. This was particularly common in instances where the survival of the injured individual had been in doubt. Advice which focused on the well-being of remaining family members - to take time-out, to leave aspects of the injured individual's care to the professionals - was often ignored by family members who generally felt it important to be present at the hospital. This pattern of responses during the acute stage has been repeatedly described within the literature (e.g. M. A. Foster & Carlson-Green, 1993; Grahame, 1991; Hubert, 1995).

As time passed, this approach often became increasingly difficult to sustain: money was frequently running low, bills could no longer be left unpaid and decisions had to be made whether or not to return to work. Fatigue, along with the need to attend to areas of daily living which had previously been ignored, forced many of the families to resume at least some aspects of their normal lives. However, ongoing uncertainty regarding the future frequently prevented family members from fully resuming their normal lives and led them to continue the day-to-day approach to living they had adopted since the time of the accident.

A number of the families interviewed felt they had continued to use a day-to-day approach to coping long after the brain injured relative had returned home. Unrelenting stress and anxiety, the huge demands placed on their time, social isolation, as well as the unpredictability of their brain injured relative's behaviour, led these family members to conclude that living life one day at a time was the only way they could possibly survive life with a brain injured relative. One mother referred to being in "*constant crisis mode*", while another stated "*that's all our life has been for the last seven years or so. 'Let's get through today'. 'One day at a time'. Because tomorrow will take care of itself.'*"

The 'one-day-at-a-time' philosophy has been described as a 'way of life' for people with brain injuries and their families (Rogers & Kreutzer, 1984), a strategy Sander and Kreutzer (1999) suggest helps family members deal with their anxiety regarding the future. Sander and Kreutzer also suggest, however, that the strategy is likely to have significant negative long term impacts if used on an ongoing basis.

None of the families interviewed appeared to have made a conscious decision to adopt the approach. In the early stages, its use typically evolved as a response to a situation which was highly unpredictable and consequently difficult to plan for. Similarly, its continued use appeared logical to family members who learned, through experience, how easily any plans made could be disrupted. Yet, those few families interviewed who did successfully regain control over their lives demonstrated that it was first necessary to adopt a long term view, to make plans and then ensure they were not disrupted, i.e. exert control in order to

regain control. Families overwhelmed by anxiety, and the stress of reacting to unanticipated events and situations, were unable to take the long term view required, thus remaining trapped and living from day to day, in some cases several years after the injury.

Positive impacts. As has been discussed previously, the findings that families are not universally distressed following brain injury, nor are the changes experienced necessarily negative, are frequently overlooked in the literature on family outcome following TBI. Adams' (1996) much cited work on family outcome is one of the few publications examining the topic in any detail. Adams stresses that families who achieve a positive outcome, such as enhanced appreciation of the value of life, spiritual growth and increased compassion, do not necessarily suffer any less than other families; rather, they are able to find meaning and positivity in the trauma of brain injury.

Of the families interviewed in the present study, only one independently identified positive as well as negative consequences of their relative's TBI. This couple felt the experience of TBI had taught them to be more humble, patient, and tolerant of others, and had brought a new closeness between members of the immediate family: *"It sure as hell brought us close together. When we realized what we had out there [i.e. no support], we realized we had to band together. You know... for comfort. Mainly for comfort, but for strength as well."*

Positive changes were also observed by this couple in regard to their relationship. The male spouse commented that, prior to the brain injury's onset, they had not realised how much they loved each other, suggesting that as a result of their experiences they had learned to communicate more freely and effectively with each other and were now more comfortable about displaying affection. He also commented: *"I think that's what's kept us together... has been our ability to talk to each other. But we haven't had that inside of us all the time, you know? We've learned. We've learned how to do it."*

## Family Adaptation to Traumatic Brain Injury

A number of different approaches have been used to depict the process of family adaptation to TBI onset including: traditional developmental stage models; modified linear models, such as those incorporating concepts of oscillating theory, chronic sorrow, and episodic loss reactions; combination approaches, for example, the integrated developmental stage model combined with Minuchin's family systems theory; and chaos and complexity theory (see chapter 3). The following section discusses commonly-identified responses to the TBI without following a particular model of the family adaptation process. The responses have been grouped and ordered to reflect the majority of participants' accounts and, where appropriate, the point at which a particular response was experienced has also been identified. This should not be assumed to imply linearity or a uniformity in the emotional adjustment process of participants.

### Shock, disbelief and bargaining

During the period immediately following the accident, feelings of shock, disbelief, and anxiety appeared the predominant emotions experienced by family members. This was particularly likely amongst those family members whose relatives had been in a critical condition and whose survival had been in doubt. One mother described her experience during this critical time:

*On the fifth day, they prepared us for his death. They said that they wouldn't... that if the brain stem kept swelling, it was out of their control really. Which was a total shock for us. We really hadn't anticipated that. It's quite a blur when you look back at it. It was just such an emotional time.*

A process of bargaining was entered into by one of the families interviewed, who reported spending considerable amounts of time during the critical stage in the hospital chapel, asking for God's intervention in the situation. They promised they would cherish their son/brother forever, if God would ensure his immediate survival.

The reactions described above are consistently reported in academic writing on emotional adjustment, generally constituting the first category of responses in adjustment models (e.g. Florian et al., 1991; Kosciulek et al., 1993; Lezak, 1986; Martin, 1988; Mauss-Clum & Ryan, 1981; Rollin, 1987; Romano, 1974; Zeigler, 1987). The widespread acceptance of this phase has arisen because it is “intuitively credible” (Rape et al., 1992, p. 4); traumatic brain injuries, by their very nature, constitute an unforeseen crisis and thus tend to provoke an intense and immediate response. Rape et al. (1992) identify a dearth of research investigating this topic, however.

### Relief and hope

It is similarly likely that family members’ feelings of shock and disbelief at the unexpected event will turn, at least in the short term, to relief and joy at the news their relative’s survival has been assured (Rape et al., 1992). This was certainly the case with participants interviewed in the present study. One mother described the joy she felt at her son’s survival and subsequent stabilisation, believing her son and the family had been through the worst and concluding (incorrectly) that “*nothing would ever be as painful*” again.

For most family and friends, as well as for the brain injured individuals themselves, the transfer from an intensive care or special care unit to a general ward and then, once sufficiently stable, to the Rehabilitation Centre, represented a significant milestone in the recovery process. It acknowledged the progress which had already been made and was also seen as an opportunity for injured individuals to gain access to a range of specialist practitioners whom, family members presumed, would help the injured relative achieve a greater and more comprehensive recovery than that which was possible in a general hospital ward. Participants reported feeling fairly hopeful at this point, trusting that Rehabilitation Centre staff would take whatever action was necessary to aid in the recovery of their relative.

### Denial and unrealistic expectations

Traditionally, denial has been conceived as “a defense mechanism to deal with an unacceptable reality, in which that reality is replaced with the hoped for, or fantasised

reality” (D. N. Brooks, 1991b, p. 167). This view is largely due to Romano’s (1974) much-cited early work on the topic - work which, interestingly, appears to have been met with almost unquestioning acceptance by clinicians and academics alike - which continues to form the basis for much of the writing on denial which has followed (D. N. Brooks, 1991b). In the developmental stage models, the ‘denial phase’ comes soon after the shock and varyingly concurrent with, or after, emotional relief (for a review see Rape et al., 1992).

In spite of the difficulties inherent in examining such a phenomenon retrospectively and through the use of participant self reports, some interesting findings were obtained on the topic. Of those family members interviewed, most stated that they had possessed few specific expectations regarding prognosis at the time their relative was transferred to the Rehabilitation Centre, adopting a ‘wait-and-see’ approach instead, although hopes that a ‘return to normal’ might be possibly were also often voiced. The casualness or vagueness of expectations described by these participants appears somewhat at odds with other responses provided regarding the progress made by the various injured individuals. Very few believed they had experienced denial or possessed unrealistic expectations for their relative’s recovery at this time, even with the benefit of hindsight, yet the high levels of anger and dissatisfaction directed towards Rehabilitation Centre staff with regard to the progress made by some of the injured individuals implies at least some of the participants had expectations which remained unmet.

Interestingly, while few participants reported experiencing denial, they were readily able to identify the phenomenon in others. One of the few participants who did acknowledge having experienced denial following her son’s accident, suggested denial was an extremely common phenomenon:

*You go through so much denial! ‘My son’s going to be different than that!’ ... You see it all around you! ‘He’s not going to end up like that!’ ‘He’s not going to be like that!’ You know? ‘He’s going to be different’.*

Another mother described a similar response, although she did not identify it as denial: “For me... it was because I think I just wanted everything to carry on. I wouldn’t believe...

*I couldn't believe... I couldn't make myself believe that my son could be any different to what he was before this accident."*

This denial continued even after she and her son were directly challenged by her partner, the youth's father:

*[My son] had said 'When I get out of here, I want to do this, and that and so on', and [my partner] said [to him] 'Don't plan ahead of each day', because, he said 'it will take you a long time before you're right again.' And then he said 'Life will never be the same for you and it'll never be the same for us.' And I didn't think to even ask him or question him... 'Cos I just looked at him and I said 'No. No, he'll get better'. He's gonna get better and then we'll be all right again'.*

### Grief

Rather than being a single event which, once 'completed' or 'worked through', enabled family members to accept the changes stemming from the injured relative's TBI, the grieving process described by participants in the present study tended to involve reactions of varying intensity to a wide range of different events and circumstances over a long period of time. The process appeared to most closely resemble that of 'chronic sorrow', where family members never fully reconcile themselves to the loss and feelings of sadness are revisited at significant times and transitional points (Hainsworth, Eakes & Burkner, 1994; Hornby, 1992; Williams, 1991a).

Initially, grief tended to focus on the brain injured relative, particularly in relation to the loss of skills and behavioural changes evident. Family members frequently reported how devastating they found it to watch their relative struggle to carry out tasks they had previously performed with great ease and little thought. One mother cried while describing how she had become conscious of the similarities between her son and a severely handicapped child, an image she found horrifying.

As time progressed, and family members became more conscious of the degree and permanence of deficits in the relative, they also grieved over the loss of their relative's potential. Numerous references were made to the achievements their relatives could have

made, were it not for the TBI: *"He could have been an All Black, you know", "He would have got his School [Certificate], would have probably ended up being a vet or a scientist"*. Many of the family members interviewed still felt this loss intensely, even several years after the injury had occurred.

Grief was also experienced in relation to the losses family members experienced in aspects of their own lives as a result of the TBI. Various unwelcome changes occurred in the social, emotional, physical, and economic status of individual family members, and the family unit as a whole. Families grieved for what they had lost, both in terms of what they had previously had, and what they could have had in the future, had the brain injury not occurred. Again, this appeared to take a chronic form, coming and going in response to various events and experiences.

#### Anger and resentment

Anger as an emotional response has been frequently reported in the literature (e.g. A. Armstrong, 1991; Gans, 1983; Grahame, 1991; Klonoff & Prigatano, 1987; Lezak, 1978, 1986; Sander & Kreutzer, 1999; Stern, Sazbon, Becker, & Costeff, 1988). In the present study, it was directed at a variety of targets including the injured individual, other family members, medical and rehabilitation-related practitioners, and the situation generally.

Anger was expressed towards the injured individual for a variety of reasons, including the individual's moral culpability for the accident which resulted in the TBI and their role in the ensuing problems. Some family members considered their relative's difficult or inappropriate manner was an intentional ploy to gain attention or exert control over others, thus exacerbating the anger they felt,

The need for families to understand the relationship between TBI sequelae and behaviour is frequently stressed within the literature, the rationale being that family members with this knowledge will respond more sympathetically, and ultimately more appropriately, to the injured individual, producing more positive outcomes for both the injured individual and



family members than might otherwise be achieved (Florian et al., 1991; Klonoff & Prigatano, 1987; Plylar, 1989; Rollin, 1987; Uomoto & Brockway, 1992).

Being informed of this relationship was not always enough to prevent family members feeling this way, however. Several of the family members interviewed related instances where either they, or another family member, had held the injured relative responsible for particular behaviours even after specialists had explained the underlying reasons. One mother noted,

*It's not reassuring when [you're told] 'It's because he feels so safe with you in your home that you're the one that gets most of the abuse and the anger and those sorts of things, it's because he feels relaxed that you cop it all'!*

These responses indicate the limitations of a purely information-driven approach to family intervention and highlight a need for a multi-faceted approach where family members also receive assistance to deal with the emotional and practical implications of personality change and behavioural disturbances.

Anger was also expressed towards other family members, both immediate and extended, often stemming from disagreements as to the best way to manage the injured individual and their rehabilitation process. Common causes of disagreement included differing views regarding expectations, consequences for inappropriate behaviour, treatment options to pursue, and the amount of input various family members gave to the injured individual and to other family members. Some of these issues were fairly easily resolved as family members become more knowledgeable about brain injury while others became more serious and threatened to result in permanent divisions within families.

Anger was directed towards the medical/rehabilitation practitioners by a large proportion of participants in this study, both throughout the recovery process and retrospectively. The reasons for this are numerous and varied and form the focus of much of this study (see chapters 5-12 which convey a sense of this anger and provide a more comprehensive understanding of this phenomenon).

A more diffuse anger was also expressed by family members, directed at the situation they found themselves in as a result of their relative's TBI. 'Why did it have to happen to us?' was a question asked by many of the family members as they sought to gain meaning in the terrible experience of brain injury. Stewart (1989 cited in Williams, 1991b) labels this phenomenon 'attribution', involving families' search for meaning in the context of a threatening event and their attempts to master the situation.

### Guilt and the desire to protect

Feelings of guilt were expressed by a few of the family members interviewed, both in relation to the accident that had led to the TBI and to the roles family members played in their relatives' rehabilitation. Guilt regarding the brain injured relatives appeared to stem largely from a fear that the TBI had occurred because they, the family, had failed to adequately protect their relative from harm. One mother described her feelings of guilt:

*I don't know if any other families feel like that, but when it happens to you, suddenly, you think that you haven't protected [your children] enough. And that you could have done something more. Maybe 'If I had of been there at that time, well it wouldn't have happened...' you know... even though it's happened.*

This contributed to the desire often expressed by family members (not only by those who reported feeling guilty) to protect their relative from any further harm. Participants' accounts reveal that enormous amounts of time and energy were expended by family members 'protecting' their relatives, with much of the effort directed towards buffering the injured relatives from the reactions of other people towards them and, at times, from the consequences of the relatives' own actions.

Feelings of guilt about the accident which led to the TBI also produced a sense of fear amongst some parents for the safety of their remaining (non-injured) children, again resulting in a desire to protect them from any additional harm. The mother quoted above acknowledged that her and her partner's sense of guilt about their son's TBI had caused them to become extremely protective of their remaining children and that they had considerably restricted the lifestyle their remaining children had been allowed to lead:

*Even now, my younger one, she turns 16 this year... She's never been to a social. She's never been to town by herself, she's never been anywhere, because I won't let her go. And that's how it's affected us. Me especially, and him [partner]... because every time my daughter goes out the door, it's 'Where are you going? No, you can't go unless I'm with you'. Because you get to the point where you think 'God, what if she goes out that door, goes around the corner and the next thing I know, she's in hospital?'... And that's what I feel with my girl... my younger girl... is that 'No! No! No! I'm not ever going to have someone ring me up again and say 'my daughter's in hospital'.*

Guilt amongst the non-injured family members, particularly where the guilt remains unresolved for a long period of time, can drastically affect the wellbeing of the injured relative, individual family members, and the family unit as a whole (Bergland & Thomas, 1991; D. N. Brooks, 1991b; Gronwall et al., 1990; Hubert, 1995; Lezak, 1978, 1986; Powell, 1994; Sachs, 1991; Waaland & Kreutzer, 1988; Wesolowski & Zencius, 1994; Winslade, 1998). Family members who buffer the relative from the natural consequences of their behaviours may ultimately inhibit the individual's recovery as the opportunity to learn from experience is lost, assuming the necessary cognitive abilities to do so are retained.

Over-protectiveness towards other family members can interfere with natural development, as was evident in the case of the sibling who was prevented from participating in social activities normal for her peers. As well as fostering dependency, over-protectiveness may contribute to feelings of resentment towards the controlling family members and towards the injured relative for having created the situation which ultimately led to the restrictions. This is likely to have a significant and enduring effect on the family unit as a whole, with those in control becoming exhausted from attempts to protect remaining family members and those 'being protected' rebelling and/or withdrawing from the family in an effort to obtain some independence.

### Inner conflict

Additional to the guilt experienced over the TBI itself was that felt by family members about the tasks they performed in their brain injured relatives' rehabilitation process. In order to promote recovery, many of the family members had found it necessary to perform tasks they found distressing or distasteful. Numerous examples of this were given including: the need to physically and/or pharmacologically restrain or subdue agitated relatives; forcing the relative to carry out therapeutic exercises; and sending them to various rehabilitation facilities or programmes (either as a day or live-in resident) against the injured individual's wishes.

Family members in this position described feeling torn. On the one hand, they considered their actions necessary and consistent with what the premorbid relative would have wanted to happen; they had to exercise the discipline and judgment their relative had lost as a result of the TBI. At the same time, however, they agonised over the choices to be made and experienced enormous guilt when the relative became distressed with the consequences of a decision. One mother described how devastating she found it when her son, on his return to the Rehabilitation Centre each Monday morning, would stand pressed against the door of the Centre waving her back, begging not to be left there. Another mother described her pain when her son would shout at her, at times on a daily basis, *"Then why the hell didn't you leave me in that hospital bed to die?! I didn't ask to live! If I knew I was going to live like this, I wouldn't have even bothered!"*

Banja (1999) acknowledged this conflict in an examination of the ethical dimensions of traumatic brain injury, stating that brain injury requires family members to make difficult value judgements regarding aspects of the injured individual's treatment. According to Banja, at the root of the conflict experienced by family members is the need to balance what they believe were the injured relative's beliefs and values towards life prior to the injury, with their own personal beliefs and values, and with their post injury needs.

The frequency with which family members experienced emotional trauma as a result of the roles performed further highlights the need for adequate preparation and ongoing support.

Where this is not provided and the conflict becomes overwhelming, potentially, family members may choose to avoid those activities which lead to the distress. The injured relative may be allowed to abandon the rehabilitation programme established or to act in a manner harmful to others. This has far-reaching implications, not only for the injured individual's recovery but also for the family's wellbeing.

#### Anxiety, stress, and fears of 'going crazy'

Family members described experiencing enormous frustration, stress and anxiety throughout the recovery process, mirroring findings of other studies previously described. Numerous contributing factors were identified by participants, consistent with those reported in the literature, and are similarly described in both this and subsequent chapters. In some cases, the stress levels were sufficiently high to cause family members to question their own sanity, with references made to family members 'being at their wits end', 'going out of their tree', 'about to go berserk' and so on. One father commented how surprised he was that "...none of us have turned out to be a mental case, it was so hard!"

Some family members raised the issue of mental fitness in relation to their employment, commenting that, in hindsight, there had been periods where they were not functioning at a high enough level to safely carry out their work-related responsibilities. A number of the participants held positions of considerable responsibility where they were responsible for the safety and/or wellbeing of others, for example, those working in the medical field.

#### The tendency among mothers to 'be strong'

The mothers interviewed consistently expressed a desire to 'be strong' for the brain injured individuals and others affected by the injury, to provide the support required by others, and to generally 'hold the family together', thus revealing personal expectations of themselves which vastly exceeded what they expected from others. Meeting such high expectations proved enormously challenging, however, with the mothers indicating they were often only barely coping and being 'torn apart' by the stress, despite repeatedly assuring others that 'they were fine'. One mother explained her behaviour in the following way:

*I'm my own worst enemy. I mean, I was brought up in that system... My father used to say 'You don't complain' or 'You don't talk about stress, that's a failure'. So I've battled on with this problem that if you talk about it, or if you complain about it, or whatever, you're admitting failure. You don't admit failure. You know... 'You've got to pull your socks up'... [Yet] I have to admit, there were some times when I felt just like shutting the door... going bush... never to return again.*

The present study's findings about mothers is supported by a similar finding in Hubert's (1995) examination of families affected by brain injury. As previously noted, however, in the present study, mothers were represented in the interview sample in far greater numbers than other relationship subgroups. Consequently, trends evident amongst this subgroup are more likely to be apparent than those involving other participant subgroups represented. Potentially, this need to be strong for others may also be true of other participant groups, for example, primary caregivers generally, reflecting their enhanced awareness of the TBI's wider impacts, or of female family members generally, reflecting the greater role traditionally played in family care. It is also possible, although unlikely given the relatively low number of males who assumed the role of primary caregiver in the present study, that males might also identify a need to be strong for the whole family, reflecting their traditional role as family head. Regardless of the limitations, however, the finding is interesting in its ability to demonstrate both the scope of some primary caregivers' responsibilities, which clearly extends far beyond the care and wellbeing of the injured relative, and the vulnerability of these family members and their need for assistance.

### Avoidance

A number of the women interviewed indicated that their male spouses' contact with the injured relatives and/or their involvement in the rehabilitation process had diminished or ceased over a period of time. Consequently, these women had been left to assume much of the responsibility, if not all, for the injured individual's care and wellbeing. Sander and Kreutzer (1999) similarly describe this phenomenon, termed "avoidance", suggesting this practice of deliberate withdrawal is a coping strategy used in response to unacceptable and/or intolerable situations - for example, when family members come to appreciate the

adverse consequences of the injury, sense the injured individual's pain, and fear life will never be the same (p. 203). Behaviours commonly associated with the strategy include the avoidance of hospital visits, of caregiving responsibilities and of participation in the rehabilitation programme.

It is unclear whether any particular sub groups of family members are more likely than others to engage in avoidance behaviours. In the present study, however, there was a strong feeling amongst some of the participants that gender influenced responses to the brain injury and resultant difficulties encountered as well as the coping strategies used. One mother stated,

*In the end I think it just comes down to the nurturing instinct of females. So often. The males find it incredibly hard: the change in personality, the change in behaviour, and not terribly much understanding. They're awful generalizations to make, but, not being able to see in the future, that it's going to get better, or that sense of obligation or duty to stick by [the injured relative]... I really do feel, as far as brain injury is concerned, there's quite a distinctive difference between the way females cope with it and the way males cope with it.*

These differences were also evident in Hubert's (1995) study of families affected by an adolescent or adult child's brain injury. In most cases, mothers, who typically assumed the role of primary caregiver, remained protective of their injured child and continued to have high levels of involvement with them over the long term in spite of numerous associated personal difficulties. In contrast, while some of the fathers talked about how they loved their children and demonstrated reasonable insight into the difficulties their children faced, many of them appeared less tolerant of the individual and the resultant changes, responding to the individual with indifference or with outright hostility. While none of the fathers in Hubert's study appeared to have withdrawn completely from their children, degrees of avoidance were evident, with fathers leaving the care to their 'more capable' wives.

### Exhaustion and despair

None of the participants interviewed reported having experienced depression following their relative's TBI. Most, however, particularly in the case of primary caregivers, described feeling tired or exhausted at some point, being unable to continue, having 'hit rock bottom', wanting to 'give in', and so on. While none of the participants explicitly connected these feelings with depression, the link has been clearly described elsewhere (American Psychiatric Association, 1994). Sander and Kreutzer (1999) also suggest anger may be an alternative expression of depression, a response prevalent amongst these participants.

Participants may have been unaware of the relationship between their symptoms and depression, rather than simply unwilling to divulge their experiences of depression. If this is the case and family members do not, as a general rule, possess this knowledge, they may be similarly unable to identify the need to obtain professional intervention to deal with the depression. There is then a risk of the depression becoming a permanent/ semi-permanent feature of the affected person's mental/emotional state, with far-reaching, negative consequences.

### Acceptance and letting go

'Acceptance' represents the final stage in the adjustment process depicted by developmental stage models, at which point family members recognise the realities of brain injury, let go "dreams and possibilities of the past" (Silver et al., 1991, p. 193), roles and relationships are redefined, and "normal family functioning" is restored (Rape et al., 1992, p. 9; see also Gronwall et al., 1990; Klonoff & Prigatano, 1987; Powell, 1994). Rollin (1987) explains: "Finally, the bewildered family gradually accepts what has happened, attaining a realistic understanding of the patient's assets and liabilities. The patient is accepted and dealt with in his or her present reality" (p. 87).

More recent work on family adjustment, however, has criticised developmental stage models on a number of grounds, primarily regarding their failure to account for the variation in outcomes evident between different families and family members (see chapter



3). Rape et al. (1992), for example, conclude such models “lack a principle to explain why some families manage to adapt (i.e., reorganize the family system and redefine relationships) whereas other families vacillate among the stages or become entrenched in a stance of resistance to change” (p. 11).

This variability in outcome was apparent amongst participants in the present study, not only between different families but also within families. During one interview, the mother described how she had learned to accept the changes in her brain injured son, only to hear her daughter reply “*Lucky for you! I don’t think I ever will!*” In another interview, the mother participated while the father refused to be involved, reflecting his continued denial of certain aspects of the brain injury and his decision to withdraw from his son and the brain injury as much as possible. The mother commented,

*[My husband’s] still remembering what happened two years ago to him! You know? But he can’t see that [his son is] now at a different stage, and that his behavior’s changed. He’s still got that resentment from the things that [his son] did to him that long ago.*

The notion of acceptance as ‘a state to be achieved’ was evident in participants’ accounts of their responses to the brain injury, with the need to ‘let go’ of former hopes and expectations and grant the injured relative an appropriate degree of independence considered integral to the achievement of that acceptance. Examples were given of individual family members who were either unable, or unwilling, to attempt to ‘let go’ of their relative and/or their associated emotions and who were considered to experience enormous ongoing difficulty relating to their brain injured relative and to other family members who had progressed further along the acceptance process, as a consequence.

The difficulty inherent in ‘letting go’ of the injured individual and of their own dreams for their relative was frequently discussed by participants, with many indicating it had taken a considerable amount of time for them to recognise and accept such a move was necessary for their relative’s wellbeing as well as their own. In some cases, participants had been told by others that they needed to let go of their injured relative. A father in this position was

asked by a friend if he was going to live for one thousand years and, when he replied in the negative, was told, *“Well, you’re here watching over everyone like a big guardian. You know, we have to let these people go and find their own paths.”*

This father described eventually accepting the changes which had occurred in his own life and that of his son’s:

*I said to [my son] ‘You make your path. Always know that if things get too bad or rough for you out there, that you can always come back home. But... I can’t stop you from going wherever you want to go’. And of course when I came home, he was gone! And he hasn’t been back since. We haven’t seen him since January.*

He also described the pleasure he now felt when he saw his son, as a result of the acceptance he had obtained:

*When the old [version of my son] comes through, it’s such a wonderful blessing. But the present [version of my son] is good too. Because the old [version] actually complements the present [version]. They’re doing positive things. It might not all be legal....*

In other cases, certain events had triggered a recognition of the need to let go. The spouse of the father quoted above described having been extremely protective of her son for a long period of time following his injury, at enormous cost to her physical and mental health. During this time her entire life had revolved around her son and the various situations that arose as a result of his lifestyle:

*I was there. Around every corner. If [my son] got in trouble, if [he] needed anything, everything got dropped. And I was there for him. I was in Court with him. He might have been to Court ten times in the last... you know, but I was there. Every time. Panicking, my heart would bang, I’d get stressed out, but I was always there.*

Eventually her son was sentenced to time in prison, something she had always feared and considered *“the worst thing that could possibly happen.”* Unexpectedly, this became a turning point for her:

*When I came back from the prison, after the [first] visit, I felt a bit more at peace. You know, the way I looked at it was, 'Well, the worst that could possibly happen has happened. And the thing I dreaded most for my son was prison. And he's there. He's in prison. Nothing worse can happen to him now. To hurt me. Because he's already there and he's loving it. Who am I to worry about it when he's loving it?' And that was my way of letting him go. When he came out of prison and went to Pukeora, that was fine. When he left Pukeora and disappeared, that was fine too.*

Another participant described identifying a need for her brain injured son and the family to obtain some acceptance of the changes which had occurred and devised a ceremony intended to facilitate this transition.

*[Our son] kept referring to the things he used to do, and looking back all the time. And we said, 'Hey. We have to throw this old [person] away. You know, we've got a new [person] here, and we're going to move forward. We're not going to look backward any more'. It was done for all of us, but we still had his, umm, here we go again [\* she cries at this point], his clothes from the day of the accident, and, umm, [I] don't know why we kept them, stupid, but we said 'We're going to throw these clothes away and with it we'll throw the old [person] away.' So we had this little ceremony, and we all decided as a family that we were going to look forward.*

For some, religion helped them to cope with, make sense of, and accept, their current situation. The mother of the youth sentenced to prison, who became "quite religious" following her son's injury, described finding the idea of an afterlife comforting:

*Our life here is really, you know, it's really quite a hell hole. Look at us. We worry about bills every day. We've got rent, we've got power. We've got, you know, health [problems], doctors' bills and that. I mean, there must be something more to death than just dying and the lights go out. I'm sure that there's something else. God wouldn't put us here to live miserably like this and then die. He couldn't. You know?*

## Activism

While activism is not generally reported in the literature as part of the adjustment process, it has been included here because a number of the participants interviewed identified it as a response to the brain injury and subsequent experiences. These participants described developing a desire to help others affected by TBI, often with the aim of preventing them from experiencing what they themselves had experienced.

People who acted on this desire became involved in the field of brain injury in a wide variety of capacities. Some preferred to provide direct assistance to others affected by brain injury, for example, through a support group or on a one-to-one basis, while others became involved in the area of advocacy and lobbying, working to raise awareness of brain injury and improve services. This was done both through organisations specifically focused on brain injury, such as 'Headway', and through more generic groups, such as the Maori wardens.

Family members in this position often found the involvement demanding. They repeatedly relived their original traumas, either directly, as a result of sharing their experiences with others, or indirectly, in instances where the experiences of those they were supporting mirrored those of their own, causing earlier emotions to resurface. Variation was evident in the extent to which this was a problem for family members, however, with some clearly experiencing greater difficulty than others.

## Conclusion

The experiences of family members following traumatic brain injury in a close relative are described at length in the literature, encompassing both the effects brain injury has on family members' day-to-day lives and their responses to the brain injury and its effects. Findings of the present study reveal a range of experiences similar to those reported elsewhere. The impacts of brain injury on the lives of family members participating in the study were often severe, widespread and enduring, in many cases, extending far beyond that originally envisaged both in scope and in duration. The emotional responses of family

members to the acquisition of brain injury by their relative and to its effects were also numerous, frequently intense, and sometimes as enduring as the brain injury's impacts. In the minds of participants, the ramifications of traumatic brain injury had the potential to devastate lives and tear families apart, without, and sometimes even with, family support and professional input, and it is within this context of adversity and struggle that findings reported in subsequent chapters should be viewed.

**CHAPTER 8**  
**UNDERSTANDING TBI:**  
**THE PROVISION OF INFORMATION TO FAMILY MEMBERS**

Families' vigorous articulation and defence of their need for information following brain injury has been reported in both early literature (e.g. Mauss-Clum & Ryan, 1981; Oddy et al., 1978a; Panting & Merry, 1972; Thomsen, 1974) and in more recent literature (e.g. Kreutzer, Serio et al., 1994; McMordie et al., 1991; Sachs, 1991; Stebbins & Leung, 1998). This need has been responded to with enthusiasm by professionals and nonprofessionals alike who rationalise that well-informed families are more likely to exert a positive influence on the recovery process and on the nature of outcome achieved (Eisner & Kreutzer, 1989; Grinspun, 1987; J. Johnson & Higgins, 1987).

This chapter reports findings on the provision of information to family members. The types of information sought by families post TBI are described, drawing on participants' accounts and relevant literature. Findings are reported regarding the extent to which participants believed such information was provided to them while their relative attended the Rehabilitation Centre, and regarding participants' perceptions of the usefulness of information received. The extent to which families anticipated and experienced difficulty, felt prepared for post discharge life, and were satisfied with the preparation process (previously addressed in Chapter 6) are then re-examined, focusing specifically on the nature of relationships between these variables and participants' perceptions of the amount of information provided and of the usefulness of information provided. Discussion of participant responses, particularly in terms of participants' explanations for the low communication satisfaction reported in this chapter, is presented in the following chapter.

**Families' Information Needs**

Initial interviews indicated that the information required by family members centered around two main themes, the first pertaining to the brain injury itself, and the second to the

future. Drawing on these initial findings and relevant literature, specific classes of information were then identified and examined in the questionnaire phases of the research. Further examination of the topic was then conducted through the subsequent, follow-up interview phase.

### General information

The first class of information identified involved general information about traumatic brain injury. The need for this type of information is stressed within the literature, reflecting the belief that general information about the brain, its functioning, and the way in which it can be affected post TBI is the basis for subsequent learning about an individual's specific condition (Grinspun, 1987; Rosenthal, 1989; L. M. Smith & Godfrey, 1995). Rosenthal and Geckler (1986) suggest the provision of general information is also particularly suited to the early stages of recovery because it is less threatening to family members than specific details regarding their relative's injury and the problems which might lie ahead.

In the present study, 87% of participants indicated they had needed general information about TBI when their relative was in the Rehabilitation Centre. In spite of this high level of need, more than half (60%) of the participants reported receiving little or no general information when their relative was an inpatient at the Centre, with less than one fifth (17%) reporting that they received a great deal of general information (see Appendix C1). These findings are consistent with the NZHIS (1993) study, where only 29.5% of family members reported receiving adequate general information on head injury after their relative's injury, and Heath's (1992) study where only 41.4% of family members felt the provision of general information had been adequate.

Overall, the general information received by family members when their injured relative was in the Rehabilitation Centre was seen as being relatively useful, with slightly over half of the participants who reported receiving general information rating it as being of some use (55%) and over one third (41%) rating it as very useful (see Appendix C1).

### Diagnostic information

The second class of information identified involved diagnostic information, critical in helping family members understand the nature of their relative's specific condition. Larsen (1992) suggests that without adequate understanding of the injured individual's condition, family members often incorrectly attribute TBI-related changes (e.g. behavioural disturbances) to voluntary or characterological sources rather than to the TBI itself, resulting in a loss of patience amongst family members and a tendency to blame the injured individual for continued perceived failures.

In the present study, almost all of the participants (94%) indicated they had required diagnostic information when their relative was an inpatient at the Rehabilitation Centre. Fewer than half (42%), however, felt they had received an adequate amount (i.e. *some-a great deal*) during this period. Overall, the diagnostic information that family members received was perceived as relatively useful, with slightly over half of the participants rating the diagnostic information as being of some use (54%) and a further 38% rating it as very useful (see Appendix C1).

The sense of inadequacy conveyed in regard to the quantity of diagnostic information provided is reflected in other studies examining the provision of diagnostic information. Slightly under half (48%) of the participants in Heath's (1992) study indicated they had been adequately informed about the state of their relative's current condition. In McMordie et al.'s (1991) study, almost 60% of participants indicated they either were not informed at all, or were poorly informed, about their relative's post morbid intellectual functioning and personality.

Stebbins and Leung (1998) found that information regarding the injured individual's physical condition was required by 100% and 95.2% of the two participant groups, but received by 37.5% and 33.3% respectively. Only 25.5% of participants in the NZHIS (1993) study reported receiving adequate information on post morbid physical problems, 19.7% on behaviour problems, 19.1% on mood changes and 9.3 on sexual matters. While comparison between the NZHIS study and the present study is difficult, (because no



distinction is made in the NZHIS study between the different types of information received in each area), the low ratings obtained overall suggest satisfaction would not have been high in any of the individual classes of information.

Assessment of the brain injured individual plays a vital role in the acquisition of diagnostic information about that individual's condition. Consequently, the provision of feedback to family members on assessments conducted is a key component of the family education process and one which is strongly advocated within the literature (e.g. Larsen, 1992; Lynch, 1984; Prigatano, 1987b; Prigatano & Klonoff 1988; Rosenthal & Geckler, 1986). The provision of feedback also provides an opportunity to involve family members in the early stages of rehabilitation and may help to minimise family estrangement from both the injured relative and practitioners.

Potentially, assessments could be conducted in a range of functional areas, although there would be variability between individuals depending on the nature of deficits sustained. In the present study, however, for almost all of the areas of functioning identified, over half the participants indicated they either had not received the results of assessments carried out on their brain injured relative ( $M = 24\%$ ,  $SD = 6.7$ ) or had no knowledge of whether or not assessments had actually been carried out ( $M = 31\%$ ,  $SD = 12.5$ ) (see Appendix C2). This represented a combined average of 55% over all areas of functioning examined, with social functioning, daily living, and behavioural functioning attracting the highest ratings reported.

Of those participants who believed they were provided with results from their relative's assessments (see final two columns in Appendix C2), more family members believed they received a good explanation of the assessments (an average of 31% of participants over all areas of functioning,  $SD = 6.4$ ) than an inadequate explanation ( $M = 13\%$ ,  $SD = 4$ ). Participants were most satisfied with the feedback provided on cognition (42% of all participants believed they received the results with a good explanation), vocational functioning (36%) and physical functioning (34%). Participants were least satisfied with the feedback provided on behavioural and social functioning (in both instances only 25% of

participants believed they received the results with a good explanation) and emotional functioning (28%).

At an individual level, a number of the participants gave the same responses across the different functional areas (e.g. they were unsure whether assessments were carried out for each area listed). In the majority of cases, however, participants reported different responses for each functional area, suggesting they had contact with at least some practitioners and were not completely alienated from the rehabilitation process. The responses given within each of the different functional areas examined were also quite varied, suggesting none of the disciplines associated with each of the areas listed were viewed uniformly by participants. Participants' views regarding the provision of feedback on cognition, for example, were as mixed as those on physical functioning.

The finding that almost one third of all participants did not know if assessments had been carried out on their relative, while another quarter did not know the results, reveals a widespread lack of knowledge about assessment processes amongst study participants and highlights a possible need for alternative feedback procedures. The relatively large number of participants who believed they had received assessment results with a good explanation is a more positive finding. At least one quarter of all participants believed this to be true in the areas of cognitive, behavioural and emotional functioning, areas known to present particular difficulties to family members over the longer term, and areas which are often considered to be overlooked in favour of more visible areas of damage such as physical functioning.

### Practical information

The third class of information examined was, for the purpose of the study, titled 'practical information', encompassing information regarding the day-to-day implications and ramifications of the TBI-related deficits and disturbances. According to Prigatano and Klonoff (1988), the increase in the number of people surviving and living with neurological damage has led to a need to be able to identify and explain the impact of sequelae on practical aspects of life to those affected by the injury, namely the injured individual and

their family. From a neuropsychological perspective, for example, this might involve determining whether the individual can return to work or school, drive safely, or be left unsupervised. Lezak (1986) suggests that a clearly stated review of the implications of the injured individual's condition "can help family members understand their situation and come to terms with it sooner" (p. 248).

In the present study, 87% of participants indicated having needed practical information after their relative's TBI. Considerably more than half (63%) of the participants, however, reported having received little or no information of this nature. This figure is higher than that obtained in McMordie et al's (1991) study, where 50.6% of participants indicated they were not adequately informed about the consequences of the brain injury prior to discharge. Like the other types of information discussed, the practical information received was most frequently rated by participants as being of some use (44%), with a further 39% rating it as having been very useful (see Appendix C1).

#### Prognostic information

The need of families to understand the recovery process and possible outcomes has been stressed within the literature (C. H. Campbell, 1988; Grahame, 1991; D. Johnson & Rose, 1996; Kreutzer, Serio et al., 1994; Prigatano, 1989; Stebbins & Leung, 1998). In the present study, family members expressed a strong desire for information which could help them understand the recovery path their relative might follow and the types of outcomes which might be achievable, seemingly prompted by a desire to relieve at least some of the uncertainty which characterises the TBI experience. Overall, 97% of participants indicated they had needed prognostic information when their relative was in the Rehabilitation Centre, making it the most frequently-reported type of information required by family members.

In spite of this clear need, however, over half of the participants (55%) reported that they had received little or no prognostic-related information during this time (see Appendix C1). This figure is slightly more favourable than those obtained in McMordie et al's (1991) study, where 71.3% of participants felt they were relatively uninformed in this area, and in

Heath's (1992) study, where only 31% of participants felt they had been adequately informed regarding possible outcomes.

Participants were often extremely frustrated with the perceived absence of prognostic information. One spouse wrote about how "fed-up" she became with continually being told that her husband's recovery would take 'a long time', when no one would tell her what 'a long time' meant.

*Everyone was being so careful not to commit themselves, and would say things like 'It could take a long time' - which told me nothing. Even when I asked for ball park figures e.g. 2 weeks[?] 6 months[?] No one would tell me.*

Participants' comments reflected the difficulties inherent in providing accurate and detailed prognostic information, difficulties which are well-documented in the literature (e.g. Jacobs, 1991; McMordie et al., 1991; Rosenthal & Geckler, 1986). Deaton (1993, cited in D. Johnson & Rose, 1996), for example, suggests the 'safest statement' which can be made about brain injury is that "every brain injury is unique and outcome is uncertain" (p. 185). In spite of participants' awareness of the difficulties involved, however, they often expressed a belief that they should have been given a greater amount of outcome-related information, and more detailed information, than they actually were. One mother, for example, commented,

*I guess in some ways they are quite right when they say 'Every brain injury is unique', 'We can't predict what he's going to be like', or 'what his recovery is going to be like', but I guess we just wanted more than that. The 'Don't knows'... Everything seemed so unsure. No-one seemed sure of anything.*

One notable exception to this trend was provided by the father of an injured male who stated that he and his wife had no complaints regarding the Rehabilitation Centre and had been well informed of the possible long term effects of the TBI. Unlike many of the other relatives represented in this study, however, this individual, according to his father, achieved virtually a complete recovery and "is now leading a normal life." In light of the outcome achieved, the father considered the information they had been provided with by

As part of the study's examination of recovery-related information, participants were also asked to indicate their pre-discharge level of awareness of their relative's possible post discharge needs. In spite of the low portion of participants who believed they received prognostic-related information, a comparatively large portion indicated that they had possessed, prior to discharge, at least a partial understanding of their relative's post discharge needs.

On average, 74% ( $SD = 8.5$ ) of the brain injured relatives represented in this study required assistance with an area of functioning following discharge from the Rehabilitation Centre. The most common areas where help was required included cognition, behavioural, and vocational functioning. When only those participants whose relatives did require post discharge assistance were included in the analysis, an average of 68% ( $SD = 11.8$ ) of family members reported they had been aware this assistance might be required prior to discharge. Awareness was highest in the area of physical functioning, where 86% of affected family members knew that help would be required before their relative was discharged, and lowest in the areas of emotional, behavioural and social functioning (see Appendix C3).

Participants identified a variety of individuals or disciplines as being responsible for making them aware prior to discharge that this post discharge assistance might be required by their relative (see Appendix C3). The most commonly-identified sources included a doctor (identified by an average of 30% of affected family members), Rehabilitation Centre staff in general ( $M = 18\%$ ) and Rehabilitation Centre nurses ( $M = 13\%$ ). An average of 20% of participants reported themselves as being the source of information, many of whom noted in the questionnaire margins that it had become obvious from their observations of their relative that further rehabilitation would be required or that the reading and research they had done had led them to conclude it would probably be necessary. (Further information about post discharge needs is presented in chapter 10).

## Relationship between Information Provision and Participants' Perceptions of Difficulty, Preparedness, and Satisfaction with the Preparation Process

The extent to which families anticipated and experienced difficulty, felt prepared for post discharge life, and were satisfied with the preparation process, was investigated quantitatively in the questionnaire via several four-dimensional scales. Overall findings from these scales were reported in chapter 6. This section examines the relationship between these same perceptions of difficulty, preparedness and satisfaction, and participant perceptions of the quantity of information they received (across the general, diagnostic, practical, and prognostic information areas).

### Quantity of information received: Difficulty, preparedness and satisfaction

Clear relationships were found between the amount of information participants reported receiving and the levels of difficulty participants reported anticipating and experiencing. These relationships applied to all four information types (i.e. general, diagnostic, practical, and prognostic). In each case, the mean level of difficulty reported was higher amongst those who indicated they had received no or little information than for those who reported having received some or a great deal of information. In a few cases, the difference was slight and did not achieve statistical significance. In the majority of instances, however, the trends were statistically significant (see Appendix C4).

A similarly clear relationship was found between the amount of information participants reported receiving and the levels of preparedness reported. For each of the four types of information, participants who believed they had received an adequate (i.e. *some-a great deal*) amount of information also reported higher preparedness ratings (i.e. felt more prepared for life post TBI) than those who believed they had received an inadequate (i.e. *none-a little*) amount. These differences were statistically significant in almost every instance (see Appendix C5).

The relationship between perceived information quantity and participant satisfaction with the preparation process mirrored that described above. Participants who reported receiving

an adequate amount of information also reported higher levels of satisfaction with the preparation process than those who received little or no information. In this case, however, all differences in the mean satisfaction ratings reported by the two groups were statistically significant (see Appendix C6).

## Conclusion

Findings presented in this chapter depict a picture of seemingly inadequate information provision and low communication satisfaction amongst family members whose relatives were inpatients at the Rehabilitation Centre. Families' need for information was clearly evident, and its value to family members was established through the lower levels of difficulty and higher levels of preparedness and satisfaction reported by those who felt they had received greater amounts of information. However, the majority of participants considered the quantity of information received had been inadequate: overall, only 26% of participants reported having received their desired amount of information during the period their relative was in the Rehabilitation Centre. Inevitably, the information deficiencies highlighted in this chapter contribute to the problems faced by families post discharge.

## **CHAPTER 9**

### **COMMUNICATION BETWEEN PRACTITIONERS AND FAMILIES**

The previous chapter revealed widespread dissatisfaction with the provision of information to family members by rehabilitation practitioners, and with the communication process generally. These findings are consistent with the literature, where family dissatisfaction with information and communication processes post TBI appears the norm rather than the exception. In this chapter, the wider area of communication dissatisfaction is examined, focusing on factors which participants feel, or the literature suggests, may have contributed to the dissatisfaction reported. A thorough understanding of communication failure in the context of family preparation, and identification of key factors believed to interfere with communication, provide a necessary basis for developing strategies to address the problem.

The first part of the chapter explores the possibility that practitioners may have been willing but unable to provide the information desired by family members, due to constraints which generally fall outside practitioners' ability to control. Factors such as the current limits of knowledge of brain injury and the effect of privacy legislation are included. The chapter next examines the possibility that practitioners were able to provide the information needed by family members but unwilling to do so. Practitioners' beliefs about families' need for information (as perceived by participants) are discussed, as are their beliefs about the role of family members in the rehabilitation process and the value of their involvement (again as perceived by participants). The final section in the chapter explores the possibility that information was provided to family members but, due to their emotional state and/or the way information was delivered, they were unable to assimilate it, causing them to believe information was not provided.

#### **Practitioners were Willing but Unable to Provide Information to Family Members**

While practitioners may recognise the need of families for information, their ability to meet this need might be restricted by various constraints placed on them and the way they can practise. The majority of constraints identified were externally imposed and included: gaps



in current knowledge of brain injury and brain injury rehabilitation; privacy legislation; organisational operating policies and practices; resources available to practitioners; and practitioner competency.

### Gaps in current knowledge

Some of the frustration expressed by family members regarding practitioner-family communication stems directly from limitations in existing knowledge of brain injury. Even though our understanding of the brain and brain injury has increased dramatically over recent decades, what is currently known about the area remains limited. For example, a continuing lack of reliable prognostic indicators makes the prediction of outcome in any individual case of TBI highly uncertain (Cope, 1994; Jacobs, 1991). There is also considerable uncertainty regarding the efficacy of specific rehabilitation approaches and interventions, although some appear promising (L. M. Smith & Godfrey, 1995).

Consequently, even the most well-intentioned, informed, and caring practitioners are restricted in what they can tell families (Carlton & Stephenson, 1990; Jacobs, 1991; McMordie et al., 1991; Rollin, 1987). Even if such a practitioner provided a family with all the information that practitioner possessed, it is unlikely all of that family's questions would be answered. Further, practitioners who are honest about unknowns run the risk of being perceived as uninformed by families, while those practitioners who attempt to alleviate family uncertainty through information provision may be accused of ignorance or incompetence if the outcome ultimately differs from predictions.

Some participants understood the difficulties faced by practitioners and, as a result, were fairly tolerant of perceived communication inadequacies, although they did not necessarily comprehend the exact nature and extent of knowledge gaps. Reports were also given, however, of this rationale being unjustifiably applied by practitioners. In one such case, a couple who were told no information was available on pediatric TBI independently discovered a number of books on the topic several years later, books which had been published prior to, or around the time of, their son's injury.

### Privacy legislation

Privacy laws in NZ, as is the case in other countries with similar legislation, significantly impact on the extent and nature of communication between practitioners and family members. In NZ, the principles guiding the use of information within the health sector stem primarily from the Health Information Privacy Code (1994), developed from the Privacy Act (1993) (Burgess, 1996). Essentially, the Code prevents the disclosure of information to family members without the permission of the individual to whom the information relates. While there are exceptions, the situations in which disclosure may occur are quite restricted and generally allow only partial disclosure of information (S. Johnson, 1995). In an examination of health care and the law, S. Johnson (1995) states that even when the individual concerned is a child, there should be no difference in the application of privacy principles.

In a commentary to the Code, the Privacy Commissioner (1994) acknowledges that particular difficulties may be encountered when the individual concerned is mentally unwell, with such individuals (who may, the Commissioner acknowledges, feel quite hostile towards their family members/caregivers) often withholding consent for information disclosure. The Commissioner emphasises, however, that the law requires the wishes of the individual to be followed, even in this instance. Various publications exist providing advice on the handling of situations where such tension exists (e.g. Zipple, Langle, Spaniol & Fisher, 1990).

Several of the families participating in the present study indicated that their relative had withheld permission for information to be shared with family members, challenging their ability to assist their relative. In some cases, the injured relative's refusal to share information reflected pre-injury tensions. One such individual had a history of drug and alcohol abuse and, although his family wanted to be involved and he, the son, apparently expected their ongoing assistance, he refused permission for information to be shared with his family. Although a number of events occurred which concerned family members during his time as an inpatient, they consequently received no explanations from staff. For example, he exhibited bizarre behaviour during the early stages of recovery which

frightened his family, yet it was not for some years that they learned this had been due to a process of drug and alcohol withdrawal unintentionally instigated by his inpatient position.

This family were similarly denied information about their relative's drug abuse on another occasion, after being informed by Rehabilitation Centre staff that he would have to leave the Rehabilitation Centre if his drug use continued. Believing they would be expected to assume responsibility for their injured relative's wellbeing (which ultimately proved to be the case when their relative returned to the family home), the family considered the situation to be grossly unfair, questioning how they could be expected to assume responsibility for their relative with their hands effectively tied by lack of information.

In other cases, TBI sequelae directly led the injured relative to refuse permission for information to be divulged. One individual underwent a major personality change following his brain injury, becoming paranoiac with delusions of persecution, and refused permission for the disclosure of any information relating to his condition by the rehabilitation and psychiatric practitioners involved in his care. Left in the dark, his mother reported,

*I was left having to make my own diagnosis. That is the bit that makes me most angry. Because he was being sent home in the weekend and we had no idea what we were dealing with. We weren't told. We weren't prepared for that. We had no expectations. We just had this boy come home who wasn't our son anymore and I was the one who was having to make the assessment to try and figure out what was going on.*

When she took her seriously disturbed son to the family doctor, she was asked why her son was on so much psychiatric medication:

*And I had to say, like an idiot, 'I don't know. I have no idea why he's on all this medication.' That should never have happened! It should never, ever have happened! It was just things like that, we had to deal with at the time. Get on with it. But on reflection, I just get so angry about it. It didn't have to be like that at all!*

For families such as these, New Zealand's privacy legislation and its associated restrictions on information provision had a severe and negative impact on their experiences. Families had to cope with a myriad of situations about which they had little knowledge, could not understand or interpret and were ill-equipped to learn about, situations which included violent outbursts, drug and alcohol-related problems, and suicide attempts. In some cases, family members developed their own strategies for circumventing the restrictions imposed on information provision. The mother quoted above described resorting to 'snooping and spying' on whatever medical records she could lay her hands on in an effort to find out what was happening with her son. Others who did not acquire information often became increasingly estranged from both the injured relative and from practitioners.

Families clearly recognised the need for injured individuals to be accorded rights as adults; however, they often felt this was done at their expense - that they were disempowered by the efforts of practitioners to empower the injured individual. Families were expected to assume responsibility for their relative's wellbeing yet had no legal right to the information which would enable them to do this. Without exception, family members described the battles to obtain needed information frustrating, tiresome and undesirable because of the additional demands such battles placed upon already overly-taxed family members. There was also a sense that some of the conflict was unnecessary; a reflection of an overly-cautious application of legislation, brought about by inadequate understanding of the legislation amongst practitioners, rather than a reflection of the true requirements of the legislation. Greater understanding of the Act amongst those who applied it, along with a more sensible approach to its use, were considered critical elements of improved practitioner-family communication.

#### Organisational operating policies and practices

The ability of practitioners to provide family members with information is influenced by the organisation's policies and practices, which may or may not promote staff-family communication. In the present study, over half (57%) of the participants felt the policies and practices in place at the Rehabilitation Centre inhibited the sharing of information between family and staff.

One particularly problematic aspect of the Rehabilitation Centre's operating policies identified by participants involved the Centre's weekend closing policy. Work and family commitments meant that many participants, particularly those residing outside the city, found it difficult to attend the Centre in weekday working hours. The unavailability of staff during weekend periods, a more convenient time for some families to attend the Centre, meant families had little opportunity to obtain information either directly from practitioners or through observation and participation in their relative's rehabilitation activities.

Few participants described feeling welcome or valued members of their relative's rehabilitation team (see below for a more detailed discussion on this issue). To a degree, this sense of exclusion may reflect uncertainty on the part of practitioners about the extent to which the organisation supports family involvement in practice and uncertainty as to how best to facilitate such involvement. Shaw and McMahon (1990) suggest there is a dearth of suggestions in the literature about the specific ways in which families can be incorporated into the rehabilitation process, despite the frequency with which such initiatives are advocated, and no mention was made of organisational policy on the issue during background interviews conducted with Rehabilitation Centre staff. Practitioners may therefore find themselves in a difficult position, wanting to involve families in the rehabilitation process but unsure how to make this occur.

#### Practitioner competency

While some practitioners were singled out by participants for their apparent skills and experience, others were singled out because of their perceived lack of knowledge of brain injury and brain injury rehabilitation. Participants regarded the more experienced and knowledgeable practitioners as better able to provide the information required than those they considered lacked suitable expertise. The following comment is fairly representative of participants' views on this matter: having identified the few practitioners she considered excellent, this mother said of the remainder, *"That's the most appalling thing. You look at professionals as being able to do their jobs. I don't think they know enough about head injury. I really don't."*

The perceived lack of expertise of some practitioners particularly concerned the considerable number of participants who believed the Rehabilitation Centre was a specialist brain injury facility. (In reality, the Centre treats a wide range of conditions stemming from illness as well as injury). As a consequence of this belief, participants held expectations for Centre staff which they did not for other practitioners/agencies, although considerable competence-related criticism was also directed at other organisations such as ACC and various education services and community groups. Perceived practitioner competency within the Rehabilitation Centre was measured on a three-point scale, with 37% of participants rating Centre staff's knowledge of brain injury as *comprehensive*, 40% as *adequate* and 23% as *inadequate*. These aggregated figures mask both the depth of feelings about the 'excellent' staff and the extent of concern about those judged less competent.

Perceptions of the overall competence of practitioners were also influenced by the extent to which family members considered the information provided by individual practitioners had combined to form a coherent and consistent picture. According to interviewees, there was considerable inconsistency in the information provided by different staff within the Rehabilitation Centre and between that provided by Rehabilitation Centre staff and other agencies involved in their relative's rehabilitation. This not only heightened family members' general sense of confusion - who was providing the 'right' information? - but increased their doubts about the ability of practitioners to facilitate their relative's recovery.

Questionnaire findings suggested a somewhat different situation. When the usual approach was taken of comparing aggregated top and bottom rating responses on a four-part scale, a combined 77% of participants gave the two highest consistency ratings while 23% gave the two lowest consistency ratings, thus suggesting greater satisfaction with information consistency than that reported by interviewees. Closer examination of the findings, however, suggests this contradiction may actually stem from issues of questionnaire/scale design. The four-point scale used did not incorporate a logical, incremental rating system as was believed at the time of questionnaire administration - only one of the four response

options describes a state of consistency - and consequently, the findings cannot be aggregated in the way they have been in other areas.

A more logical division was subsequently made, allowing the *consistent* rating responses to be compared with an aggregated category of different *inconsistent* rating responses. This revealed fewer than half (47%) considered information provided by Rehabilitation Centre was consistent, more closely reflecting the situation described by interviewees. Further, no data were collected in the questionnaire examining consistency across different agencies, preventing comparison with interview findings in this area. In retrospect, a different approach should have been taken to the examination of this aspect of information provision.

### Resources

The extent to which an organisation is resourced will impact on family-staff communication, particularly through overall workloads which, in turn, influence the amount of time available to practitioners to meet and talk with family members. Treichler, Frankel, Kramarae, Zoppi and Beckman (1984), for example, found medical practitioners were often frustrated at trying to provide quality care under stringent time constraints.

There was a strong feeling amongst participants in the present study that staffing levels in the rehabilitation-related facilities and organisations were too low. Participants felt the resultant high case loads made it difficult for staff to spend as much time with families as the families would have liked and, in some cases, participants suggested, as much time as practitioners would have liked. A few of the participants suggested any attempts on their part to increase the amount of time staff spent with them would unfairly reduce the amount of time staff could spend with other families, a conflict which made them reluctant to put pressure on staff.

Some participants identified resource constraints as being partly responsible for perceived inadequacies in expertise amongst Rehabilitation Centre practitioners, both in terms of the quality of staff the Centre was able to attract and the opportunities available for the ongoing

professional development of staff. Participants with a health background, drawing on their own experiences, appeared to be particularly conscious of the issues associated with working in financially constrained environments and expressed considerable sympathy for the practitioners, whom they generally perceived as being over-worked and over-burdened. However, none believed that resource constraints completely explained or justified the generally poor service they believed they and their relatives received. One mother stated,

*I know we say that resources, we haven't got the resources, but it's more than that. It's people's gut feelings about people. And people knowing people. And forming some sort of relationship with them. And believing in their recovery. And actually helping them, and talking to the families. A lot of it is very basic stuff.*

Concluded another mother,

*I come with that clinical knowledge and I come with the knowledge of the system and I'm as much aware of the failings of the system as anybody is. And although I've done a lot of defending it in the past, I'm not so ready to defend it anymore.*

#### Practitioners were Able but Unwilling to Provide Information to Family Members

A second theme which emerged during both the interview and questionnaire phases of the research involved the idea that practitioners, despite their perceived capacity to meet most of families' informational needs, may deliberately refrain from doing so. Various theories were posed by participants as to why this might occur: a belief amongst practitioners that family involvement in the rehabilitation process is problematic and should be discouraged; a failure by practitioners to comprehend the central and long term role played by family members in recovery and a corresponding failure to recognise families' need for information; and practitioners' anxiety and confusion regarding families' desire for information.

#### Intentional exclusion of families from the rehabilitation process

According to Shaw and McMahon (1990), there is often confusion amongst professionals as to the desirability and practicality of family involvement in brain injury rehabilitation, combined with a desire for cooperative and compliant families. While most professionals



will publicly espouse the concept of “harmonious cooperation with families”, when problems occur, professionals often respond by denying existence of the problems or by labeling the families as maladjusted (Shaw & McMahon, p. 89).

Shaw and McMahon (1990) identify a school of thought which maintains family involvement in rehabilitation is problematic and potentially detrimental. They cite Morse and Morse’s (1985) study as an example of the inflammatory stances sometimes taken by practitioners, where practitioners argued against family involvement in the rehabilitation process because: families were difficult to deal with, obstructive and asked too many difficult questions; were too demanding of clinicians to do more in caring for their relative; were apparently uninterested in the patient’s treatment; were already overwhelmed emotionally by their relative’s medical crisis; lacked knowledge about medical problems and treatment in comparison with expert clinicians; and because family involvement often went against patients’ wishes (Shaw & McMahon, p. 89).

Participants in the present study considered the issue of family involvement in inpatient rehabilitation to be of utmost importance, as was reflected in the strongly-worded and passionate statements made on the topic. Participants argued vehemently that the nature and extent of their involvement in their brain injured relative’s rehabilitation process was a critical factor determining recovery and the type of life their relative would live. In most instances, although participants appeared to desperately desire to participate in the rehabilitation process, many indicated that they had not been encouraged to participate in their relative’s rehabilitation and/or that their efforts to be involved had been viewed negatively, not only by many of the Rehabilitation Centre staff but also by staff at rehabilitation facilities elsewhere and by ACC staff.

Participants described having been told by Rehabilitation Centre staff to leave rehabilitation to the experts, that what happened to the injured relative was none of their business, and not to worry because their relative was going to get better without them. One mother wrote, *“Families were not encouraged to take part and learn about TBI and life after. I feel that I was shut out.”* Another mother commented that she had felt practitioners

saw time spent by the injured individuals in the Rehabilitation Centre as being 'their time' and time individuals spent at home as being 'families' time'.

Examples were also given where Centre practitioners emphasised the central role families play in determining the type of life individuals will lead post TBI. One mother reported being told that the success of brain injured individuals was largely dependent on their families - that families were the 'key ingredient'. From her description, it appeared she had interpreted these words as meaning it would be her personal failing if her son did not achieve the level of recovery both she and her son wanted. Consequently, she had become highly motivated, even desperate, to play an active role in her son's rehabilitation process. Along with many other participants, however, she felt her efforts to participate were discouraged by Rehabilitation Centre staff, in spite of the acknowledgment given to her about the importance of families. In response to her distress, in combination with concerns about the quality of rehabilitation provided at the Centre, she and her brain injured son jointly made the decision to remove him from the Rehabilitation Centre and continue his rehabilitation from home.

Participants expressed surprise at the apparent failure of many of the practitioners either to recognise families' potential contributions to the recovery process or to facilitate families' active involvement. Several noted there was often no expectation on the part of practitioners that families would even want to be involved. Observed one mother,

*Families, at that stage, [when her son attended the Centre several years previously], were not encouraged to take very much part in the rehabilitation. [The staff] felt that [the patients] were better off [without family involvement]. As was put to me by one staff member: 'Our patients perform much better without interference from their family'. And I mean... One other mother made the [comment]... she was really upset about it and she said 'How dare they tell me my son will perform better without his mother around!' Maybe they felt families were too soft, that we tended to them... that... that... I don't know. I really don't know why [they would say that].*

Similar concerns were raised with regard to ACC, with some family members describing having been excluded from information provision and decision making processes. One mother, for example, described her horror at learning an ACC-appointed assessor had determined her son's daily living needs (and consequently entitlements) on the basis of information he had provided to the assessor, without consulting her as to the accuracy of that information.

*And I got very upset and rang [her] and said 'This is a head injured person who, if he says 'yes' to you, does not even know what he's saying! How can you do this?' So she came back, she apologised and we did it together.*

Families' right to participation in ACC matters is clearly assured in the organisation's informational material (e.g. ACC 2000b, 2000c, 2000d) although, as is the case elsewhere, this 'right' is subject to usual privacy constraints. As the above example illustrated, constant vigilance was often required by families in order to ensure this principle of involvement was adhered to in practice.

The sense of exclusion reported by family members in the present study also applied to others involved in the injured individual's life, such as extended family, friends and colleagues. Overall, 64% of participants indicated staff at the Rehabilitation Centre never or only occasionally encouraged this wider circle of people to be involved in the rehabilitation process, with only 15% indicating this involvement was frequently encouraged and 21% indicating it was always encouraged.

With the lack of encouragement given to family members, participants were often uncertain of their right to be involved and felt they needed to be assertive with practitioners in order to be included. However, they often felt vulnerable in doing so in case practitioners interpreted the questions and suggestions as challenges to their competency, and the injured relatives were denied access to services. One mother commented, "*I think they feel threatened professionally, if anyone steps in with a better idea or another suggestion that they haven't thought of. They actually take it quite personally.*"

Lack of confidence also caused family members to withhold comments and questions from staff, not only during the inpatient phase but also over the long term. Participants spoke of their fear of being seen as stupid and of believing they did not have the right to criticise 'the experts'. The mother of a brain injured son possessed considerable knowledge of TBI by the time her husband similarly sustained a brain injury, suggesting it had been much easier for her to query professionals after her husband's injury than it had been after her son's, and also easier than it would be for other families who did not possess her level of knowledge:

*I felt stronger about it [the second time round]. I felt on quite secure ground. ...I knew what I was talking about. But I can also identify with someone... It's completely new ground to them, some of them. You feel inclined to think 'I'm stupid', or 'I should know that' [or] 'What if they think I'm silly because I complained about...'. And you don't want people to think you're stupid because you don't know something or you find something irritating.*

Numerous prior studies have highlighted the tendency of health service users to avoid asking questions of practitioners or actively engaging in communication, even when information was desired. Power differentials between practitioner and client appear to underlie much of this reluctance to communicate, particularly in the case of people from lower socio-economic backgrounds (who are over-represented in brain injury acquisition statistics) and who, compared with their higher socio-economic counterparts, are less likely to ask questions and with whom health professionals appear less likely to attempt to converse (Roter & Hall, 1992; Waitzkin, 1991; West, 1984). This problematic situation, according to Roter and Hall (1992), is compounded by the tendency for medical practitioners to expect communication to be verbal and explicit and that clients requiring information will request it. The authors suggest practitioners often interpret any reticence on the part of the client as a lack of interest, the consequence of which is that unsolicited information is rarely offered.

The sense of alienation evident amongst families in the present study is highly concerning, irrespective of whether or not practitioners intended to exclude families or are even aware

that families feel this way. Of further concern is the finding that themes of estrangement and disempowerment continue to characterise some families' experiences of the recovery process far beyond the point of inpatient discharge. One mother wrote, for example, that her family *"had been left very bitter with all organisations in general"* as a consequence of their experiences. Ultimately, all parties are in a weaker result: families lose valuable opportunities to learn; practitioners do not obtain the information and insights which families can provide; and the injured individuals receive less specialised assistance than otherwise would have been the case.

### Practitioners' insight into the situation of families

In order to effectively meet the needs of family members, participants considered it essential that practitioners understand the way in which brain injury affected family members, not only in the early stages but over the long term. Those practitioners who possessed such an understanding would, participants surmised, be better able to empathise with family members and better equipped (and hopefully more willing) to meet their needs.

There was a feeling amongst participants, however, that not all practitioners encountered during the rehabilitation process possessed such an understanding. One mother stated, *"If they came and lived with a family with a head injury patient, I think they'd be really surprised [about] what we go through that they would never see."* This impression was consistent with comments of a junior Rehabilitation Centre staff member in response to the proposed study, made early on in the research process: *"They get the discharge notes, what else do they need?!"* Participants suggested that such practitioners often considered families' requests for information irritating and unnecessary and that, accordingly, they placed a low priority on working with families.

According to participants interviewed, the lack of empathy evident amongst some of the practitioners stemmed primarily from differences in perspectives, arising from differences in the way in which the two groups experienced brain injury. Most of the practitioners associated with the present study tended to have contact with the brain injured individuals within a fairly structured inpatient setting and for a limited duration. Consequently, they

rarely witnessed all of the impacts brain injury had on the lives of the injured individuals and their family members first-hand, or the long, drawn-out and typically incomplete recovery process involved. Numerous participants suggested practitioners were often unaware of just how long lives could continue to be affected by brain injury. Professional boundaries also enabled practitioners to distance themselves from their patients/clients, granting them an emotional protection that family members did not have, families who themselves experienced considerable emotional trauma.

### Practitioner confusion and anxiety about information provision

The possibility that practitioners may intentionally choose to withhold information within a medical or rehabilitation setting is cited often in literature, particularly with regard to the provision of prognostic information. Wardle, Clarke and Glenconner (1989) describe practitioners' concerns about giving families false hope or predicting scenarios which do not eventuate, predictions that may expose practitioners to legal action for alleged treatment failure (Shaw & McMahon, 1990). Rollin (1987), for example, actually advises practitioners to withhold their views on prognosis until such a time as stabilisation has occurred because of the "far-reaching implications" prognostic information can have (p. 96). Practitioners may also choose to withhold information because they feel guilty about giving unfavourable information or wish to avoid over-burdening already distressed family members (Wardle et al., 1989), although there is evidence that appropriate communication can have positive rather than negative impacts on family members (Power & Sax, 1978). Although the present study collected data primarily from families rather than from practitioners, it would appear unlikely that practitioners associated with the present study would be immune from these considerations. Certainly, participants reported low levels of information being provided.

Another factor identified in the literature involved practitioner uncertainty about family members' wishes for information. According to Rollin (1987), family members are often ambiguous in the messages they give practitioners regarding their desire for information. The greatest challenge to the information provider, Rollin suggests, is to understand how much, and what type, of information families wish for. This theme emerged in the present

study, with participants describing their 'readiness' for information, prior to which, they reported rejecting efforts made by practitioners to communicate. When they eventually reached a position where they wanted information, these family members found that the practitioners, whose efforts had already been rebuffed, seemed unwilling to try again. As one mother explained, *"You might not have been ready for [the information] yesterday, but, by golly, 'please just give me something [today]!' But [the staff] tried yesterday, you weren't responsive, so they're not going to try again."*

In a related theme, a number of participants suggested they had a responsibility to make their information needs known to practitioners, indicating they were in some way to blame for the communication problems experienced. Many comments were made where participants criticised themselves for not having asked 'the right questions'. This attitude was reflected in the comments of one mother who reported having 'given up asking' for information after her attempts to participate in her son's rehabilitation were rejected by Rehabilitation Centre staff. Participants considered the need to instigate information provision problematic, however. As one mother stated, *"I have heard it said by some of the doctors, 'Well, we only tell them what they ask us'. Now how are people supposed to know what to ask?"*.

#### Families were Willing but Unable to Assimilate Information

There was a strong possibility, according to a number of participants, that a greater amount of information may have been provided by practitioners than they were able to recall, suggesting that family members may have experienced a diminished capacity to assimilate information following their relative's brain injury. This possibility was strongly supported by the literature, as well as by participants themselves, who identified a number of factors to account for their perceived diminished information processing capacities. The factors described centre around emotional adjustment and coping issues, and information delivery issues.

### Emotional adjustment and coping issues

A range of emotions are experienced by family members in response to traumatic brain injury, the accident which causes it and the changes which follow (see chapter 3). Both separately and combined, these emotions can have an enormous, detrimental impact on a person's ability to absorb or retain information provided.

The early stages of TBI, particularly where the accident causing injury was life-threatening, are often a time of crisis for family members, characterised by periods of shock and disbelief. During this time, according to Hall (1989), it will be "all but impossible" for family members to take in information provided (p. 173; see also Elliot & Smith, 1985). Later on, if denial is evident, families may be similarly unable to assimilate information, with authors suggesting family members will be unable to 'hear' information until they are ready to cope with it (Hall, 1989; Rosenthal, 1989; Winslade, 1998). Expectations for recovery can also impact considerably on the extent to which family members will retain information. According to Rosenthal and Hutchins (1991), it is not uncommon for families to reject information provided by individual practitioners, or even entire rehabilitation teams, when that information is distressing or uninvited. Until families are ready to face the often-undesirable possibilities presented by practitioners or to make difficult decisions, they may find it extremely difficult to listen to information or take it on board.

In the present study, a reluctance amongst participants to accept information provided by practitioners was evident. Overall, 41% of participants indicated they had believed little or none of the information Rehabilitation Centre staff had provided on brain injury would apply to their relative's situation. A further 38% believed some of the information provided would apply, while only 21% had believed a great deal would apply.

In some cases, this rejection of information by family members appeared to stem from an inability to reconcile what they were told with what they could observe, as was the case with those participants who described how the speed of the injured relative's physical recovery had 'tricked' them into expecting other areas of functioning would recover equally fast, or who described how the 'invisibility' of some deficits had given them an



incomplete picture of the damage sustained. These responses have been similarly described in the literature (e.g. D. N. Brooks, 1991b; Hall, 1989; Jacobs, 1991, 1989b; Lezak, 1978, 1986; L. M. Smith & Godfrey, 1995; Winslade, 1998).

Participants also described their difficulties in reconciling what they were told by practitioners about their relative's condition and the image they held of their relative prior to the accident. A number of participants expected their relative's (premorbid) strength of character, determination and so forth, would 'get them through' the injury and enable a higher level of recovery to be attained than that achieved by people with comparable injuries. Participants sometimes expressed frustration with practitioners whom they perceived had not listened to their accounts of their relative's premorbid character or who had allegedly failed to take their relative's uniqueness into account.

Family members' general state of wellbeing, affected by the cumulative effect of the various stresses experienced, was also felt to have a detrimental effect on information processing abilities. Physical and mental exhaustion was commonly encountered by the primary caregivers after the injury, which negatively impacted on their ability to assimilate information provided. One mother stated,

*Your head is just so emotionally filled, sometimes you just can't take any more [information] onboard. You might be told two or three times. All my energy was trying to keep on an even keel, so I couldn't remember things.*

Another mother wrote, *"The accident was the worst thing that had happened to us and our emotional state was such that had we been told more (perhaps we were!), it may not have sunk in."*

#### Information delivery issues: Barriers to effective communication

Considerable criticism was directed at the way in which information had been communicated to family members post TBI, with participants in the initial interviews suggesting that perceived inadequacies in delivering information had further diminished their ability to assimilate such information as was provided. Aspects of information delivery subsequently investigated encompassed the timing of information provision, the

complexity of information provided, the medium used, the physical context within which interactions occurred, and the opportunities available for discussing information provided.

**Information timing.** The ability of family members to process and retain information varies considerably over time, partly as a result of their emotional and physical condition. Information is more likely to be assimilated when the information provided takes account of these fluctuations. Findings of the study indicate that timing was not adequately taken into account: overall, 67% of participants indicated that information provided by Rehabilitation Centre staff was either never or only sometimes provided at the most suitable time, compared with 33% who felt it was frequently or always provided at the most suitable time.

Information provision was commonly viewed by participants as a one-off event rather than an ongoing process (see chapter 12). Consequently, the untimely provision of information had a far greater impact on the ultimate retention of information by family members than would have been the case in an environment where information was provided repeatedly. As one mother explained,

*Anything we try for the first time, we only take onboard what we're ready for. The rest will pass over us. It's like reading a book again later, isn't it. You always remember different bits, or respond to different bits. But if it's continually fed to you. Even a week later can make a damn big difference! Because so much has happened in between. But if they only try once, they [may get negative] feedback [from families] and think 'Oh well' and give up. Whereas I think with brain injury, it's such a long, slow process. Like I've read Dorothy Gronwall's book [on TBI] probably four or five times because each time, I take out of it the stage [my son's] at.*

Many of the family members interviewed believed an inattention to issues of timeliness had contributed greatly to the difficulty they experienced accepting and retaining information, and queried why greater attention had not been paid to the issue. As one participant argued, practitioners must surely be aware families will go through phases such as denial

and, consequently, should have developed strategies to help families deal with the impact such responses had on information processing.

Information complexity. In 1984, West suggested the only clear threads of consensus emerging from literature on the use of technical language in the medical/health setting were that, firstly, patients did not like medical jargon and, secondly, that practitioners did not know what constituted it. While knowledge on the area has advanced considerably since this time, the current literature suggests that information complexity remains a problem in relation to health services (Long, Montemayor, Rinehart, Scarbrough, VandeWalle, & Williams, 1991; Pauwels, 1995; Redman, 1993; Roter & Hall, 1992).

A similar theme is evident in relation to brain injury rehabilitation, with researchers describing 'language barriers' between medical practitioners and family members, a tendency for practitioners to overestimate the cognitive ability of family members to understand information, and a lack of familiarity amongst family members with the background knowledge necessary to understand the information provided (D. N. Brooks, 1991b; Eisner & Kreutzer, 1989; Rosenthal & Young, 1988; Thomsen, 1974; Williams, 1991a). According to Bergland and Thomas (1991), a particularly problematic feature of 'brain injury talk' involves the inconsistency with which the numerous technical terms associated with the area are utilised, a theme similarly emphasised by Lezak (1995) in her definitive work on neuropsychological assessment:

*Much as the archaeologist finds artifacts that are both similar and different, evolving and discarded, so a reader can find, scattered through the decades, descriptions of the various neuropsychological disorders in terms (usually names of syndromes or behavioural anomalies) no longer in use and forgotten by most, terms that have evolved from one meaning to another, and terms that have retained their identity and currency pretty much as when first coined. Moreover, not all earlier terms given to the same neuropsychological phenomena over the past ten decades have been supplanted or fallen into disuse so that even the relatively recent literature may contain two or more expressions for the same or similar observations. (p. 19)*

Data on the extent to which information complexity was an issue for participants in the present study is somewhat mixed. During the interviews and in some of the questionnaires, criticisms were made regarding the technical nature of information provided. One spouse's suggestion for improving the information provision process was to *"Cut the medical jargon! How many of us are doctors?"* Other participants described technical language as having been a major problem for 'other families' they had come in contact with but not for themselves. One described her feelings of sympathy towards those family members who lacked her own medical background, noting the tendency for medical staff to assume the person they are speaking with possesses the same level of knowledge and the same familiarity with jargon as they possess themselves. This participant suggested that, in many cases, families simply pretend to understand the information provided rather than indicate their confusion or ask practitioners for clarification, a behaviour she attributed to a power imbalance between families and health/medical practitioners: *"Why didn't the person say 'Look, I don't understand this'? Because they feel intimidated by the profession. And this is a problem. A real problem."* This theme is similarly noted by Pauwels (1995) who states that, while the professional-client power differential will vary from interaction to interaction and according to the particular branch of health care, it will always be present to some degree.

The figures provided in Appendix C7, however, depict a somewhat different picture of participants' feelings about the complexity of information provided. According to these findings, the majority of participants found much of the information provided by staff at different brain injury-related organisations relatively easy to understand. Of the three organisations listed, (Headway, ACC, and the Rehabilitation Centre), information provided by Headway was identified as either easy or quite easy to understand by 90% of participants, while information provided by ACC and Rehabilitation Centre staff was rated easy or quite easy to understand by 70% of participants in both cases. Headway also received the greatest percentage of participants who rated the information they provided as being very useful; most participants rated the information provided by ACC and Rehabilitation Unit staff as being somewhat useful (see Appendix C7 part I).

Within the Rehabilitation Centre, information provided by occupational therapists and (non-nursing) medical staff was considered the easiest to understand of any of the disciplines listed, with approximately 80% of participants rating it easy or quite easy to understand. Information provided by the psychology team was also rated positively. Information provided by the social work team had the lowest percentage of participants (35%) who rated it as easy or somewhat easy to understand (see Appendix C7 part II).

Overall, it appears that complexity of information was not a widespread problem for participants in the present study, although inappropriate targeting of information did sometimes occur. While this finding suggests that the complexity issue is, to some extent, being addressed by the service providers examined, the potential for problems to arise from inappropriately targeted information remains and constant vigilance is required to ensure the positive findings reported here continue to characterise information provision amongst these groups.

Information medium. Prior to the early 1980s, most information provision occurred via word of mouth because very little written information suitable for families was available about brain injury or brain injury rehabilitation. Because of the complex nature and sheer volume of information to be conveyed, as well as the diminished ability of family members to absorb the information, this reliance on verbal information was highly problematic (Eisner & Kreutzer, 1989). More recently, there has been a recognition of the need for a more 'user-friendly' approach to information provision (Redman, 1993; L. M. Smith & Godfrey, 1995), as is reflected in Grahame's (1991) comments on family education:

*When [families] are not 'getting it', it is often because we are somehow not 'giving it' in the most understandable way. We must sometimes deliberately analyze whether words, pictures, or hands-on experience are most useful to meet the caregiver's learning needs. (p. 162)*

The extent to which this transformation is evident in the research setting is unclear. Almost all of the participants (97%) believed they had received the majority of their information verbally. Problems participants associated with this reliance on verbal information

included difficulties with recall (deriving from the lack of physical sources available to refer back to at later dates), and disagreements arising about the original intentions of practitioners (stemming from the tendency of different family members to interpret the information provided in different ways, even in instances where they had attended the same meeting and been provided with the same information).

Reflecting views in the literature (Eisner & Kreutzer, 1989), participants argued against this reliance on verbal information provision, with less than one fifth (15%) indicating this was their preferred medium. Half of the participants (49%) indicated they would have preferred to receive most of their information via a combination of different medium (e.g. verbal, written and visual information), while a further 33% indicated they would have preferred to receive the majority of their information in written form.

Rehabilitation Centre staff also supported the importance of utilising different media when educating and communicating with family members. Examples were given by staff in preliminary interviews of initiatives intended to overcome the deficiencies associated with verbal communication, such as pamphlets explaining different aspects of care and treatment and video taping physiotherapy exercises to help families and the injured individual remember components post discharge. Numerous participants expressed support for the videotaping initiative, however, it appeared improvements in followup were required because some of the participants who were told they would receive a videotape of the exercises did not receive one.

None of the participants interviewed, including some recent users of the service, reported receiving written information such as pamphlets. Yet on visits to the Rehabilitation Centre, the researcher observed several leaflets placed around the facility, most commonly on notice boards, reflecting the wider move to provide written information specifically tailored to the needs and capabilities of family members (e.g. Commonwealth Rehabilitation Service, 1993; Gronwall et al, 1990; The HDI Coping Series, 1996; Powell, 1995; Redman, 1993; Winslade, 1998). Research by Bennett (1984) explored the effectiveness of pamphlets as a discharge planning tool. Pamphlets were placed in surgical wards, without

advertisement, for people to take as required. A considerable number of pamphlets were taken, prompting regular restocking, initially suggesting the approach was useful. Follow-up investigation revealed that only four of the 29 patients in the general surgery ward and eight of the 51 patients who had been in a specialised ward had, however, actually read the pamphlet. Bennett's study suggested that simply leaving information around for people to take was insufficient to ensure that all of the intended audience actually took and/or subsequently read the material. Potentially, the same issues might be occurring regarding leaflets at the Rehabilitation Centre, necessitating a more active process of encouragement and guidance from staff to intended readers of the pamphlets. Such written material should be considered an adjunct to the education process, best accompanied by further, verbal explanation, rather than as a complete educational process in itself.

Physical context of information exchanges. The physical setting in which practitioner-family interactions take place can have an effect on the nature and type of communication which occurs. The degree of privacy available will potentially influence the willingness of parties to openly share information with each other, as will the level of competing stimuli with which the communicating parties must contend (Buckman, 1992; Gordon & Edwards, 1995; Pauwels, 1995; Ramsden, 1999; Rosenblatt, Cheatham & Watt, 1982).

Participants in the present study felt practitioners had a responsibility to try to optimise the likelihood of successful communication. Some suggested the physical environment in which discussions took place should be quiet, private and free from distraction. The study found that fewer than half of the participants (47%) felt information had been provided to them in such an environment. References were made to staff-family conversations conducted in hallways, at the injured individual's bedside, and various other locations where opportunities for distraction were high and opportunities for privacy virtually nil. Participants were not uniformly concerned about this, however. One mother commented: *"I mean, I was sharing it with the world anyway!"*

Opportunity to discuss information. Discussing information with practitioners (asking questions, clarifying issues, raising concerns and so forth) was seen by participants as an

integral part of developing the knowledge family members needed to understand and live with the effects of TBI. In a comparison between the three main organisations involved in TBI rehabilitation in the present study, Rehabilitation Centre staff were perceived as being accessible (i.e. frequently or always an opportunity for discussion) by the largest percentage of participants (48%), with Headway and ACC staff being rated as similarly accessible by 43% and 36% of participants respectively (see Appendix C7 part I). Within the Rehabilitation Centre, the nursing discipline was seen as accessible by the largest percentage of participants (50%), while social workers and psychologists were seen as being the least accessible; only 35% and 37% of participants respectively felt there was frequently or always an opportunity to communicate with them (see Appendix C7 part II).

McMordie et al. (1991) examined the area of practitioner-family contact within the context of brain injury rehabilitation, finding that nursing staff were the professional discipline seen by the largest proportion of family members. They were also rated as the most helpful of professional disciplines examined. This aspect of McMordie et al.'s findings are similar to those of the present study. McMordie et al. (1991) were surprised, however, to find that only 67% of family members reported having contact with social workers (who were considered fairly helpful to family members). The authors had expected the level of contact to be higher, reflecting the central role played by social workers in exploring community resources and placement options. In the context of the present study, social workers also play a theoretically pivotal role in the provision of information and support to family members, particularly in regard to post discharge life. However, they were rated as the least accessible of any of the disciplines investigated and the information they provided was rated as being of no use or somewhat useful - far less favourable even than that reported in McMordie et al.'s study.

A low level of neuropsychologist/psychologist-family contact was also identified in McMordie et al.'s (1991) study, attributed primarily to a scarcity of practitioners within the geographic region examined. A similarly low accessibility rating found in the present study may also reflect low staffing levels: for most of the period covered by the study, one full time psychologist was employed to fulfil all of the responsibilities associated with the



discipline, later increasing to one full time and one part time psychologist. Because other findings regarding the psychology discipline are quite favourable, (the information provided was frequently considered very useful and easy-to-understand, for example), it appears likely that the low accessibility ratings received by the psychology discipline stem from the smallness of the team, relative to the demand for their services.

## Conclusion

Dissatisfaction was a consistent theme amongst many of the present study's participants, with criticism directed at virtually all aspects of the communication and information provision process. Some of the dissatisfaction was considered by participants to be due to factors largely beyond the control of rehabilitation professionals, stemming from externally-imposed constraints such as privacy legislation and limits of current knowledge on brain injury. While participants were frustrated at the limits these factors imposed, they were fairly sympathetic towards the practitioners who had to work within the context of the constraints.

The majority of factors identified, however, were considered by participants to stem from sources within the rehabilitation professionals' realm of control. The perceived failure of practitioners to remedy the resultant communication/information deficiencies thus produced quite intense feelings of disappointment and anger amongst many of the participants, a number of whom suggested practitioners involved in their relative's rehabilitation had failed to meet basic standards of treatment and care.

Underlying many of the participants' communication-related criticisms in this category of avoidable concerns was the nature of the relationship between rehabilitation practitioners and family members and, more specifically, participants' perceptions of practitioners' beliefs regarding the appropriate role of family members in the rehabilitation process and the value of that involvement. In most cases, participants' accounts of staff-family relations strongly reflected a 'professional-as-expert' paradigm, synonymous with the medical model of practice, where professionals retain power and control over the

rehabilitation process and families are relegated to a secondary or peripheral role (Dale, 1996; Fisher, 1995; Todd, 1989; Ylvisaker & Feeney, 1998a).

Some efforts at staff-family collaboration were evident in the use of initiatives, such as planning meetings, which incorporate the injured individual and family members as members of the rehabilitation team. According to participants' accounts, however, rather than providing families with a genuine opportunity for input, such initiatives often simply provided an opportunity for staff to inform families of their treatment decisions and for families to ask questions. This scenario falls far short of the various partnership models of practice described within the literature (e.g. Dale, 1996; Gordon & Edwards, 1995; Mittler & Mittler, 1983; Silverman, 1987).

Using an expert/professional model to guide rehabilitation practices and practitioner-family interactions appears inappropriate in light of the critical role played by family members in the long term care and support of brain injured individuals, typically undertaken in a context characterised by absent or infrequent professional input. Certainly, strong links can be drawn between this paradigm's use and the communication dissatisfaction reported, where many of the complaints made by participants (e.g. inadequate consultation and opportunities for involvement/input, undervaluing of families' potential contributions by staff) may be considered features of the paradigm itself (see Dale, 1996).

Another key factor underlying the communication difficulties reported by participants involves the communication skills possessed by the various practitioners, skills considered by participants to lie within the realm of practitioners' control. Participants expressed concern that only some practitioners appeared aware of the need to consider factors such as the emotional state and general wellbeing of family members when attempting to provide information, and that practitioners frequently failed to adapt the communication/information provision process adequately to take account of such factors. A number of the problematic features of practitioner-family communication identified in the study, such as the reliance on verbal information, the inappropriateness of the timing and physical context of communication efforts, inadequacies in the opportunities available

for interacting and, to a lesser extent, the inappropriate use of professional jargon, reflect apparent deficiencies in the communication practices of practitioners.

According to Pauwels (1995), the teaching of communication practices continues to receive only minor attention in the training of health professionals, reflecting the assumption that such skills are best learned through experience. Such a process requires the presence of good instructors or role models in the working environment. There are a multitude of reasons why such models may not be available in the working environment or why they may not be recognised as such, where present. Further, to be successful, learning communication skills is at least partly dependent on the communication student receiving open and honest feedback on their strengths and weaknesses during the course of their practice.

Findings in the present study highlight the improbability of feedback being given: participants were often unwilling to do so because of the power differential between the parties and out of fear that their actions might have negative repercussions for either their brain injured relative or themselves. Frederikson (1993) acknowledges this possibility in her work on doctor-client communication, referring to the “well documented evidence” which demonstrates that health service users are reluctant to express critical comments about aspects of their care (p. 1). Frederikson suggests that many of the studies reporting high levels of client satisfaction reflect this bias, providing misleadingly positive findings as a result.

As Pauwels (1995) suggests, in light of this situation, it is hardly surprising that complaints about professionals so frequently centre on problematic communication. While family members typically have a multitude of information needs following brain injury, their ability to articulate these needs and clearly convey them to practitioners may be severely limited. On the other hand, practitioners attempting to meet families’ information needs, practitioners whose professional training may have only partly equipped them with the skills needed, may find their efforts to communicate pass unnoticed, information forgotten

or efforts rejected outright by family members desiring reassurances of normality and guarantees of full recovery.

In spite of the challenges, however, it would appear that many of the factors underlying the communication dissatisfaction reported both in this and the previous chapter are avoidable, at least from the perspective of the present study's participants.

## **CHAPTER 10**

### **FAMILY ROLE PERFORMANCE: FACILITATING THE BRAIN INJURED RELATIVE'S RECOVERY**

Literature on traumatic brain injury emphasises the diversity of the condition: its consequences are unique, the type and nature of outcomes achieved variable, and the impacts on family members diverse. The characteristic common to the condition is change, in its many different forms, and the need it invokes for adaptation. Change and the need for adaptation are arguably most evident in the area of role performance. From the time a traumatic brain injury is sustained, through to the point at which the injured individual is able to assume self-responsibility (assuming this point is ever reached), the essential tasks previously carried out by the injured individual and new tasks related to the injured individual's postmorbidity care and support requirements need to be performed on their behalf. In the vast majority of instances, responsibility for doing this falls on family members.

This chapter reports findings regarding family role performance following TBI. A framework was developed for this purpose during the study, where the roles performed are conceptualised as 'care giver', 'case manager' and 'therapist', reflecting common themes derived from both the literature and participants' accounts. Specific attention is paid to the contexts in which the caregiver, case manager and therapist approaches were employed, reflecting that participants varied in their employment of the approaches and that there were differences in the effectiveness with which the tasks were performed. The chapter concludes by discussing the acceptability of family members' involvement in their relative's recovery, and the limits to their involvement, perceived by family members.

#### **Tasks Previously Performed by the Brain Injured Relative**

Participants commonly described having assumed responsibility, post-TBI, for roles or tasks previously performed by their relative. However, considerable variation was evident between different participant subgroups in the type and number of roles assumed. Parents,

for example, performed few such tasks in comparison with spouses, who frequently needed to assume responsibility for many or all aspects of income earning, financial management, child rearing, housekeeping and general maintenance, which formerly had been carried out by the brain injured relative.

Variations in role change appear to reflect the differences in age and life stage of the injured individuals represented in the study. The injured individuals whose parents participated in the present study had a mean age of 21 years at time of injury ( $SD = 4.8$ ), ranging from 14-32 years. This age group is generally only beginning to establish a life independent of their families, and those represented in the present study had relatively few commitments either inside or outside the family essential to the family unit's overall functioning. This contrasted dramatically with those individuals whose spouses participated in the study. With a mean age of 39 years at onset ( $SD = 12.5$ ), ranging from 26-64 years, this group of injured individuals generally had much greater financial, familial, social and vocational commitments, many of which were critical to the functioning of their families.

The only sibling interviewed in the study described needing to assume responsibility for tasks previously performed by her brain injured brother. In her case, however, she was unsuccessful in her attempt, which had considerable negative and long term consequences for herself. At the time of her brother's accident, this sibling had been flatting with her brother and his girlfriend, whom she described as her two closest friends, and was in a business partnership with her brother. Following the accident, the girlfriend, unable to cope, left the relationship, leaving the sibling with neither the brother nor the close friend for support. Finding she was unable to carry out her brother's business-related tasks in addition to her own, the sibling was forced to close the business, leaving her with personal debts, unemployed and seeking employment.

The findings on role change in this study mirror those described in the literature. Following TBI, it is common for family members to assume responsibility for those tasks previously performed by the brain injured relative, additional to those performed by each

family member prior to the TBI (Florian et al, 1991; Guth, 1996; Hegeman, 1988; Jacobs, 1991; Lezak, 1988; Powell, 1994; Rogers & Kreutzer, 1984). The very small amount of literature identified that included consideration of different family subgroups supports the present study's finding that different family subgroups experience different role changes post TBI, both qualitatively and quantitatively (L. Miller, 1991; Sachs, 1991; Zeigler, 1987). Findings of the present study were further supported by literature suggesting that the age and lifestage of brain injured individuals affect the nature and number of roles family members needed to assume post TBI (Greer et al., 1992; Sachs, 1991).

### Tasks Resulting from the Brain Injured Relative's New Needs

While it is fairly common for tasks previously performed by the injured individual to be reassigned following TBI, the most dramatic and prevalent role changes experienced by family members relate to the relative's new care and support needs. Families have adopted numerous approaches in their efforts to meet the diverse needs of their relatives, reflected in the extensive array of terms used to describe family members' post TBI roles in the literature: caregiver; head injury manager; advocate; case manager; service delivery agent; therapist; lay therapist; co-therapist; non professional therapist and so forth (e.g. D. N. Brooks, 1991b; Grinspun, 1987; Jacobs, 1988b, 1991; Livingston et al., 1985b; W. W. McKinlay & Hickox, 1988; Quine et al., 1987, 1988, 1993). From participants' own reports, these roles can be grouped into three categories: 'caregiver'; 'case manager'; and 'therapist', and it is these categories which are used in the present study. In practice, however, the divisions between these categories are somewhat arbitrary, with considerable overlap evident between the tasks associated with each.

### Caregiver

Participants in this study were those identified as being the main provider of support and assistance to their brain injured relatives and thus may be considered the primary caregivers for their brain injured relatives. As reported previously, the participant group in this study was comprised predominantly of females: mothers (49%), and wives/defacto wives (33%),

with the remaining participants a combination of fathers, husbands, sons, and brothers (18%) (see chapter 5).

The high proportion of female caregivers compared with males is consistent with other studies involving caregiving, both within the brain injured sphere (e.g. Enright, 1991; Higham, 1998; McMordie et al., 1991; Quine et al., 1988) and outside (e.g. Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995; Dale, 1996; Gerstel & Gallagher, 1994; Means & Smith, 1994; Opie, 1991, 1995).

The dominance of the parent and spousal groups as caregivers is also consistent with other studies in the area of brain injury, although there appears to be little consistency between the size of these two groups relative to each other. A number of published studies, where caregiver participants had been drawn from a general pool of family members such as a rehabilitation facility or brain injury association, reported a predominance of parents/mothers compared with spouses (e.g. Jacobs, 1988; Kosciulek, 1994b; McMordie et al., 1991; Quine et al., 1993; Resnick, 1993). Other studies, however, revealed the opposite pattern (e.g. Man, 1999; Mauss-Clum & Ryan, 1981; NZHIS, 1993).

Health policy makers and funders often convey the impression of 'community care' as being caregiving performed by a network of family, friends and professionals. However, research suggests rather that caregiving often involves a single individual, frequently unsupported or minimally supported by others (see Enright, 1991; Opie, 1991). This phenomenon was apparent in the present study, with many of the participants indicating they had either been the only family member to have any involvement at all with their relative beyond the short term, or the only family member of those who continued to be around the injured individual who provided input on a regular basis. In very few instances was the burden of care reported as having been distributed throughout the family.

Tasks performed. Caregiving tasks performed by family members were generally aimed at ensuring the injured individuals' basic daily living needs were met. A few of the participants reported carrying out caregiving tasks during the early stages when the relative



was receiving treatment in general or neurologic hospital wards, and more reported doing so once the individual was transferred to the Rehabilitation Centre. During weekend leave and following inpatient discharge from the Rehabilitation Centre, many of the participants needed to perform caregiving tasks, such as bathing, toileting, dressing, feeding, ensuring medical regimes were followed and, often, providing regular or constant supervision and monitoring.

These tasks are similar to those described by family members of relatives ill or injured from other causes (e.g. stroke, spinal cord injury, transplant recipients, newborn babies with special needs: Easton, Zemen & Kwiatkowski, 1994; Baker, Kuhlmann & Magliaro, 1989; Weichler, 1990), although the need to provide monitoring appeared to be more commonly associated with conditions where the relative exhibited some form of behavioural disturbance, thus potentially posing a threat to themselves and/or to others (e.g. psychiatric disorders: Bernheim, 1989; M. Cooper, 1995; Goldwyn, 1988; Hatfield, 1990; McGill, Falloon, Boyd & Wood-Siverio, 1983, & dementias: Aneshensel et al., 1995; Kerley & Turnbull, 1988; Lancaster, 1988; Qureshi & Walker, 1989).

Rationale for performing a caregiver role. The performing of a caregiving role after discharge was, for many participants, a responsibility assumed out of a mix of love for the brain injured relative and a perceived lack of viable alternatives. This issue of service availability is addressed in more detail in the following ‘case management’ section; however, it is timely to emphasise here that many participants’ experiences of post discharge rehabilitation were characterised by inadequate (or absent) service provision, stemming primarily from a lack of appropriate service providers and/or a lack of knowledge of the existence of service providers (see also chapter 12).

The decision to perform caregiving tasks during the inpatient (acute/post acute) stage, however, stemmed from somewhat different concerns, centering around the themes of control/empowerment and perceived service deficiency. In the first instance, families sought to exercise a degree of control over the situation they found themselves in - a situation which was, in reality, far beyond their control. By participating in the care of

their injured relative, even in small ways, family members reported feeling useful and less helpless. As one mother explained,

*It makes you, as a parent, feel you are able to provide something worthwhile, because you feel so helpless otherwise. You just feel so out of control. All these things are happening around you... you react to everything. You have no control. At least if you're told 'Well, look you can exercise his arm this way, or massage his arm this way, or take him for a walk for x minutes, or help him relax and rest', you feel like you're helping, and that you can do something. Because otherwise, you feel so terribly helpless.*

This desire to participate in the inpatient care of a brain injured relative has been noted by other authors (e.g. J. Johnson & Higgins, 1987; Oddy et al., 1996). Grahame (1991) comments that families are often intimidated by their injured relative's changed appearance and the unfamiliar hospital environment and are consequently unsure how to behave. Suggesting that physical contact between family members and their injured relative helps both parties re-establish relationships and make family members feel useful, Grahame recommends that rehabilitation staff should actively encourage family members to provide some aspects of their relative's personal care.

Concerns regarding the adequacy of care within the hospital setting also underlay many of the participants' caregiving efforts in the inpatient phase, particularly with regard to perceived deficiencies in nursing staffing levels. In this instance, participants carried out caregiving tasks as a means of ensuring their relatives received what they considered to be an adequate standard of care. One mother described regularly cleaning up her son's bowel motions, washing and shaving him, among other tasks, because "*there wasn't a lot of time for the nurses to do that.*" She described the pressure on hospital and Rehabilitation Centre staff as "*horrendous*".

Again, this issue has been described in the literature, both within NZ and internationally. In their guide for families during the acute TBI recovery stage, written for NZ, for example, Gronwall et al. (1990) state "there are never enough staff to give all the treatment

which is needed, and family will have to do a great deal to back up the treatment of the professionals” (p. 29). A desire to reduce the demands placed on hospital staff, and ultimately the cost of nursing input, was one of the rationales underlying the development of a coma arousal programme in the US (see Quine et al., 1987, 1988, 1993). The programme aimed to train family members to act as lay-therapists in an acute care hospital, thus reducing the need for remunerated staff.

Participants in Hubert’s (1995) UK-based study also made frequent references to perceived deficiencies in inpatient care for brain injured individuals, which had made family members reluctant to leave their relatives without family supervision and advocacy. While Hubert acknowledged deficiencies did exist in the care provided, particularly in smaller hospitals, she also suggested that many of the participants’ concerns were a reflection of their lack of understanding of the care and recovery process following brain injury rather than being indicative of inadequate care. Hubert suggested improved communication and family education could have prevented some of the issues participants erroneously identified as problems from arising. Such lack of understanding is highly likely amongst participants in the present study, in view of the widespread communication failures reported in previous chapters.

Time spent caregiving. In an American study, Enright (1991) found that caregivers of brain damaged individuals spent an average of 88.9 hours per week providing caregiving assistance within the home. Those also employed outside the home averaged 56.6 hours of caregiving per week, compared with 109.2 hours for those without outside employment. Enright also found that caregiving wives, whose personal incomes were the lowest of all relationship groups investigated, and thus least able to afford paid assistance, received the least help from family and friends. Husbands, with higher incomes when employed, received the most help. In contrast, the primary caregivers in Kreutzer, Serio et al.’s (1994) TBI study reported spending much less time caregiving, with 40% spending between one and four hours per week, 18% between five and eight hours, 12% between nine and 16 hours, and 14% more than 16 hours per week. No information was provided on the amount of caregiving assistance provided by other sources, such as relatives or paid caregivers.

It is impossible to determine conclusively which of the above studies' findings best reflect participants' experiences in the present study, as no attempts were made to quantify the amount of time family members in the present study spent performing a caregiving role or the amount of assistance (paid or unpaid) received by family members. Kreutzer, Serio et al.'s study appears the most relevant because, through its use of a traumatic brain injured population, it most closely matches the conditions of the present study. In contrast, Enright's study encompasses brain damage stemming from degenerative impairment, where improvement in functioning is often unlikely and the input required from caregivers may increase rather than decrease over time, as well as non-degenerative damage (e.g. traumatic brain injury), where some recovery may be possible and the need for caregiving input may decrease over time. It was apparent, though, that participants devoted a considerable amount of time to the performing of caregiving tasks by participants in the present study, often with little or no assistance or support.

Participants varied considerably in their views on the amount of caregiving assistance their relative required and the duration of time for which that assistance was required. It was difficult to determine, however, the extent to which this variation was due to genuine differences in the capabilities of the injured relatives or to the characteristics of individual families/caregivers. For a variety of reasons, family members may adopt an overprotective approach to the care of their injured relative: feelings of guilt relating to the accident which led to the TBI; a desire to protect the individual from further harm and so forth (Bergland & Thomas, 1991; Gronwall et al., 1990; Hartman, 1987; W. W. McKinlay & Hickox, 1988; Powell, 1994; L. M. Smith & Godfrey, 1995; Waaland & Kreutzer, 1988). Others may intentionally foster ongoing dependence because it gives their own lives a sense of purpose and they have come to enjoy the additional responsibilities which were thrust upon them following the accident (Hubert, 1995; W. W. McKinlay & Hickox, 1988).

Ignorance of the injured individual's condition and capabilities can also lead to overprotectiveness, with family members carrying out tasks the individual is capable of performing independently or with a degree of supervision (Klonoff & Prigatano, 1987; Sachs, 1991). Such action is often rewarded as family members will generally perform the

tasks more quickly and competently than the injured individual (L. M. Smith & Godfrey, 1995; Willer et al., 1994). A number of the participants in the present study commented they had found it easier, certainly during the earlier stages of recovery, to perform the tasks themselves rather than have their relative attempt to do it at a typically slower pace and lower standard. In the long run, however, such an approach merely serves to add to family members' burden and provides the injured individual with few learning opportunities.

Research suggests families often learn only over time how much assistance to provide to their relative and how much independence to grant. In Stebbins and Leung's (1998) study, for example, 87.5% of participants whose relatives were injured less than two years previously reported needing help in deciding how much to let their relative do by themselves, (although only 50% of participants reported having obtained such assistance), while participants whose relatives were injured more than two years previously did not include such assistance among their important needs. Participants described a similar pattern in the present study, acknowledging the importance of trial-and-error in establishing appropriate levels of support and independence. One mother discussed how she had ultimately wearied of the considerable effort she initially expended caring for her son and protecting him from the consequences of his actions: *"After a while [I] thought 'Oh, blow it! You've got to take a few rockets yourself. I'm sick and tired of shielding you'."*

Participants' feelings about the caregiver role. The portion of participants who provided information on this topic indicated a general willingness to perform a restricted caregiving role, for a limited period of time. A number expressed pleasure at the opportunity caregiving provided them with to demonstrate their love for their relative. One mother, for example, commented: *"I suppose when you've been in a life and death situation, and your child lives, all you want to do is have them at home and nurture them. It's just a motherly thing, isn't it?"*. This theme, however, emerged primarily from the accounts provided by caregiving mothers - a qualitatively different subgroup to the others represented in the study - and is not necessarily representative of other participants. Many of the mothers interviewed on the topic had previous nursing or caregiving experience and all had specific experience 'mothering' their relative. Unlike spouses, they were able to revert to previous

parent-child relationships as a way of coping with, and managing, the changes which had occurred (see chapter 7).

A different picture emerged from a male participant in the study who described becoming his son's primary caregiver after other family members and friends "*disappeared*" following the accident. This participant reported considerable difficulties in performing a caregiving role but did not elaborate on why this was. Research into caregiving has demonstrated that, in many instances, males have not previously developed as many of the skills needed to carry out caregiving tasks as women and thus may find themselves poorly equipped to meet the demands associated with the caregiving role (Opie, 1991). It is possible this man's difficulties arose because he had little previous caregiving experience prior to his son's injury, had few established skills to draw on to help him perform this role, and needed to develop these skills without the support of other family members and friends.

#### Case manager

According to Rehabilitation Centre staff, each person admitted to the Centre is assigned a key worker who oversees the injured individual's rehabilitation programme and liaises between the injured individual, their family, and other members of the multidisciplinary rehabilitation team. An ACC case manager also forms part of the rehabilitation team and it is expected their ongoing involvement in the injured individual's rehabilitation will help to provide some continuity in the rehabilitation programme once the injured individual is discharged from hospital and the associated intensive rehabilitation ceases (see chapter 5). Participants commonly disputed the scenario depicted by professionals, however, with a number indicating they had found the rehabilitation process to be characterised by a fragmentation of services, an absence of coordination and direction, unclear or undetermined rehabilitation goals at both an individual discipline level and overall, and a failure by some rehabilitation staff to deliver services as planned.

Concern over aspects of their relative's care during inpatient rehabilitation led some family members to adopt a more active role in the rehabilitation process during this time than they

believed they would otherwise have taken. These participants described themselves as advocates for their relative, performing tasks such as speaking on behalf of the injured individual and ensuring their needs were acknowledged by practitioners, and endeavouring to oversee their relative's rehabilitation - ensuring rehabilitation plans were made and followed through, that services were provided on schedule, and so forth. Several family members felt that their advocacy had been essential to ensure their relative received adequate inpatient rehabilitation - otherwise their relatives would have received a lower quality and amount of treatment.

Once the injured relative returned home, even more family members assumed a case manager role. Typically, the level of recovery achieved by the brain injured individuals by the time of inpatient discharge was far from complete, with most requiring continued professional input in at least some areas. According to a number of participants, the only pre-arranged contact with rehabilitation professionals had been a single, general follow up with Rehabilitation Centre staff some time after the injured individual had returned home, giving rise to a growing sense of isolation. At this point, family members often concluded their relative's best hope for recovery lay in their own actions.

Searching around for someone to guide their relative's rehabilitation, family members often approached their ACC case worker, anticipating that the case manager would find the necessary assistance. A number found that their assigned case manager proved simply to be an 'approver of funding' for appropriate services, after family members had identified those services, rather than an active facilitator or director of their relative's rehabilitation. Others reported that their case manager lacked sufficient knowledge of brain injury to be of much use or, in the experience of some families, the case managers changed frequently, frustrating family members' efforts to develop effective working relationships. This appeared to apply to participants who received ACC services under the pre-1994 system of rehabilitation coordinators and to those who received ACC services under the post-1994 case management system.

With the Rehabilitation Centre team largely withdrawn from active involvement and the role of ACC case manager tightly circumscribed, participants needed to find other sources of professional support for their relative's rehabilitation programme. This led many to adopt the role of case manager, which typically involved identifying the injured relative's needs, locating appropriate services within the community, and facilitating service provision. Each of these areas is discussed below.

Tasks performed: Identification of the injured relative's post discharge needs. As was reported previously, an average of 74% ( $SD = 8.5$ ) of the brain injured relatives required assistance with an area of functioning following discharge, most commonly in the areas of cognition, behaviour and vocational functioning (see Appendix C3). An average of 68% ( $SD = 11.8$ ) of family members for this group of brain injured relatives reported being aware, prior to discharge, that this assistance would be required. Overall, participants appeared to have relatively few problems determining the general areas where their relatives required ongoing assistance and input.

Tasks performed: Location of service providers. With Rehabilitation Centre assistance being largely limited to the inpatient period, following discharge, families needed to access sources of assistance within the community. This process is consistent with rehabilitation theory where it is envisaged that individuals will move along a continuum of care encompassing acute medical treatment, intensive neurologic rehabilitation, community reintegration-related services, and services providing long term support for the injured individual and their family within the community (Cervelli, 1990; Gronwall et al., 1990; W. W. McKinlay & Watkiss, 1996; Oddy et al., 1996; Sachs, 1991; Tyerman, 1997). Existing research clearly demonstrates that, as a means of facilitating a smooth transition between inpatient care and community reintegration, families will require information on available services and sources of assistance within their community (C. H. Campbell, 1988; Mauss-Clum & Ryan, 1981; McMordie et al., 1991; NZHIS, 1993).

Questionnaire responses indicate few participants knew, prior to their relative's discharge, where they could obtain such assistance. Figures in Appendix C3 show that, of the average



of 68% of participants who knew their relative would need post discharge help in an area of functioning, an average of 37% (*SD* = 9.4) knew, prior to discharge, who could provide the assistance needed. Awareness was highest in the area of physical functioning, where 56% of family members whose relatives required assistance following discharge knew where that assistance could be obtained, and lowest (25%) in the area of behavioural functioning.

A separate analysis was carried out involving awareness of post discharge services among those participants whose relatives required post discharge assistance, regardless of whether or not the participants knew prior to discharge that this assistance might be necessary (see Table 10.1). This showed that an average of only 22% (*SD* = 11.9) of participants knew, prior to discharge, where to obtain necessary post discharge help. The highest rating of awareness was in the area of physical functioning (48%), and the lowest in the areas of behavioural functioning (13%), emotional functioning (14%) and social functioning (17%).

**Table 10.1. Awareness of post discharge service providers among family members whose relatives required assistance**

Area of functioning	Percentage of family members who knew where to obtain post discharge assistance
Physical functioning	48%
Cognitive functioning	22%
Emotional functioning	14%
Behavioural functioning	13%
Vocational functioning	21%
Social functioning	17%
Daily living	20%

A review of the literature on preparation and information provision following TBI suggests the lack of knowledge found in this study is not unusual. In McMordie et al.’s (1991) study, 77.7% of family members indicated they were not informed or had been inadequately informed of the resources available to them and their injured relative, prior to

their relative's discharge, while 77.6% indicated they had not been told where additional information could be obtained from. In the NZHIS (1993) study, only 19.7% of family members reported having received information on available services and community resources. Campbell's (1988) study highlighted the potential role of brain injury support groups in the provision of such information to family members: 100% of participants in her study reported needing information about available community resources, with over half (57%) indicating their support group had proven helpful in providing such information.

When post discharge services were needed, family members commonly approached the Rehabilitation Centre for assistance with the expectation that Centre staff would either provide the services sought on an out-patient basis or refer them to relevant agencies or groups within the community. With few exceptions, family members described staff as either unable or unwilling to do either. Rehabilitation Centre staff referred to this situation themselves during interviews (see chapter 5), discussing their frustration with the negative impact of funding restraints on their ability to work with injured individuals and/or their families beyond discharge.

Many families then began to search for assistance in the wider community and again encountered enormous difficulties in locating appropriate service providers within the community. Participants ascribed this to an absence of appropriate services in their area, a lack of awareness of the existence of the service at the time the service was required, and/or their unwillingness to utilise a particular service because of quality-related concerns.

*Lack of services.* Numerous families reported their desperate and often unsuccessful searches for assistance for their relative and for themselves, with some describing having travelled to other parts of NZ to obtain needed assistance. Many ultimately concluded that at least some of the services they and their relatives had required following discharge were unavailable within the local Region. Two of the mothers, (each with a health background), stated it was unreasonable to expect families to locate services within the community when *"the services aren't there to be located"*, and the number of people providing TBI-related services in the local region *"could be counted on one hand."* While some families residing

in rural areas attributed their difficulties in locating services to their geographic isolation, participants residing in the Region's city also experienced similar difficulties locating required services, highlighting the lack of available services.

Providing a comprehensive brain injury service is complicated by the diversity of potential sequelae resulting from brain injury and the consequent diverse needs of the brain injured individuals and their families. Ylvisaker and Feeney (1998a) point out that knowing someone has a history of brain injury says nothing about the person's abilities or needs. Further compounding the situation is the lack of predictability as to when particular services will be required by brain injured individuals and their families. Consequently, it is extremely difficult, even under ideal conditions, to provide a comprehensive brain injury service which will meet all of the differing needs of these two groups.

The NZ Head Injury Working Group (HIWG), established to "develop an ideal model of service delivery, irrespective of the source of purchaser or provider, for people with head injuries" (1994, p. 3), acknowledged many of these difficulties in its subsequent report (see HIWG, 1994). The working group identified three levels of service: those which should be provided at a local level (defined as available within an hour's travel from the usual place of residence for 80 per cent of the population); at a regional level (available in one or two sites within each of four population-based regions); and a national level (available in one or two sites only). Using this framework, it appears some of the absences in services noted by participants, and their need to travel to obtain assistance, may in fact reflect a rationalised service provision model.

Even allowing for this, gaps in service provision are evident at all three levels. Many of the services that participants believed were unavailable were those the Working Group identified as being ideally provided at a local level, such as appropriate accommodation options (supported living, respite care and so forth), individual and family support and development services, recreation and leisure services, advocacy services, vocational rehabilitation services, education services, and adequate information provision.

It would appear that five years on, many of the Working Group's recommendations are yet to be implemented in the local area where the study was based. Factors identified in the HIWG report (1994) as barriers to the service delivery model developed may be partly to blame, such as the continued limited availability of expertise on brain injury in NZ and the lack of professional understanding of the needs of people with head injuries. Funding constraints undoubtedly also play a major role, as they do internationally. Winslade (1998), for example, states that money is the major obstacle keeping thousands of brain trauma victims from reaching their full potential.

*Lack of knowledge of available services.* Some participants suggested that a significant number of the problems faced by families following brain injury were due to a lack of awareness of available services rather than a real absence of services. One father commented, *"Yes, there is help. There is always help. For everybody. The point is that it's hard because we've had to locate it. It's like, we've got to have a water stick to find the right person."* A similar finding was reported by L. M. Smith and Godfrey (1995), with family member participants unaware of the existence of services provided by various community agencies and hospital outpatient clinics. As part of their educational-based pilot programme for families of brain injured individuals, the authors found it was necessary to actively assist families in accessing existing community services, particularly given that families often perceived the process of obtaining assistance from agencies to be complex and adversarial.

This lack of knowledge was sometimes a two-way process, particularly when the individual/family shifted to a new area or received their acute treatment elsewhere and then returned to the Manawatu. One spouse, whose husband had received acute care in Wellington, wrote how Rehabilitation Centre staff had been unaware of her husband's existence until she contacted them. *"I was told that we got lost in the paper work. The first [the Rehabilitation Centre] knew was when I rang them 1 year after because I needed help"*.

Families typically expressed considerable anger at having to acquire information regarding available services themselves, describing the process as slow and somewhat haphazard. Often luck appeared to play a central role in the acquisition of knowledge, with some family members reporting having obtained useful information as a result of one-off chance encounters with medical or rehabilitation practitioners, meeting other people affected by brain injury or from reading articles in the media. A particularly problematic aspect of the chance characteristic of information acquisition was that information was rarely obtained in a timely manner. One example involved a family who, after three years of desperate searching for help for their severely behaviourally-disturbed son, finally learned about CYPS with the following result:

*About 3 days after [my son] turned 17, I found out about \*CYPS. So I went there. And the lady at CYPS said to me... I still remember [her] sitting there and saying to me 'It's a shame. What a shame you didn't come to see us last week.' And I said 'Why?' And she said 'Because we can't help you. He's 17'. And I said to her 'Hey! He had [his head injury] when he was 14! Where were you people between 14 and 17?' And she had no answer for me.*

*N.B.* Children and Young Persons' Service (CYPS), the primary child welfare agency at the time of the study, works with families whose children are 16 years or under.

At the time of the study, a considerable number of participants had still not obtained the information they required regarding community-based services, evidenced by the number of participants who requested information or referrals at the conclusion of the questionnaire. Some families reported having given up searching, or even hoping, for outside assistance and appeared to have reconciled themselves to a life of caring for their brain injured relative unsupported and alone. In a few interviews, family members had been shocked to hear that a particular service they had required and believed to be unavailable had, in fact, been available all the time.

One of the strongest themes to emerge from this area of the research was families' belief that they should have been given this information before their relative was discharged from the inpatient rehabilitation facility. One mother in this position stated,

*Now that we've found out about all these departments and what their jobs are, and what they should be doing, and what they're not... I look back and I... I shake my head. And I say to [my partner] 'You know, if we'd have known all this then, we, and our boy, would never have had to go through half of what we've been through.' You know?*

Lack of choice in service providers. In a number of instances, participants indicated they were reluctant to use certain services in the area because they were concerned about the quality and competence of particular medical/rehabilitation practitioners, a problematic situation given the small number of practitioners with expertise in brain injury currently practising in the area. One local private practitioner, for example, was described by a family in the study as a 'white collar criminal' because, in their opinion, he had taken money for working with their son while producing no observable results. These concerns were mirrored by participants in the NZHIS (1993) study, who criticised the general knowledge and understanding of TBI amongst practitioners working in the brain injury field. Both the NZHIS (1993) and the HIWG (1994) recommended steps to enhance the educational development and training of practitioners.

Use of generic service providers. When unable to locate the community-based specialised services required or unwilling to utilise those identified, families commonly turned to more generic service providers in an attempt to obtain assistance. In some instances, families were successful in locating one or two individuals or groups within the community who could provide some form of useful assistance, even if it was not exactly what was required. In such situations, families tended to rely heavily on individual or organisational service providers to modify and adapt their services to meet the diverse and considerable needs of the brain injured person and their family.

A number of participants in this position reported having used their General Practitioner (GP) as their key person, although the nature and degree of assistance they provided appeared to vary considerably. One mother, whose family ultimately came to depend on their GP, commented,

*The only one that understood, out of everybody we knew, was my family doctor... He was the only one I could go to! And talk! And he never charged me! I would make an appointment, go there, and tell him my feelings, and he had me on medication in the end as well, because I couldn't handle [my son] anymore. He was the only one who supported us in what we needed to do.*

This GP had himself sustained a brain injury as a young adult, but GPs without this personal insight into brain injury were also identified as useful by participants, sometimes simply because of their accessibility and a willingness to listen. These characteristics make GPs an extremely important potential resource in rural areas, where they often constitute the only local source of professional assistance available.

GPs were found to play a similarly central role in the provision of post discharge assistance in the NZHIS (1993) study. In that study, 78.3% of participants indicated their GP had provided assistance to their injured relative after their brain injury, making them the most commonly used source of professional assistance identified. In the present study, however, those participants who commented were generally quite positive about their GP. In contrast, family members in the NZHIS study were “particularly critical” of their GPs, in spite of the frequency with which the GPs were used, finding them to possess “limited understanding of the consequences of brain injury and poor knowledge of the services available to help them” (p. 30). Families in the study were subsequently described as “extremely frustrated”, having expected their GPs to be of greater assistance (p. 31).

Other generic service providers used by participants in the present study were viewed as lacking an understanding of TBI and, in many cases, were criticised for failing to develop the knowledge necessary to be able to effectively assist the injured individuals and their family members. By failing to acknowledge the underlying cause of problems for which help was being sought (i.e. the TBI), the services such practitioners provided rarely satisfied the injured individuals and their families. In most cases, the problem was not resolved. This situation was acknowledged by Jacobs (1989a), who stated that general rehabilitation, care and support agencies have never excluded people with TBI but have, instead, failed to distinguish or cater to this population's unique needs.

One such case was described by a mother whose son, under the care of a mental health team as a consequence of the psychological disturbances resulting from his brain injury, had been instructed by his key worker to join a 'Men Against Violence' group in order to improve his anger management skills. Her son had been required to enrol in the course through Police at the local District Court. He associated the requirement with criminal behaviour and was very uncomfortable doing so, and found participation in group work both unpleasant and difficult. When participation in the group failed to produce the desired behavioural changes, her son was instructed to attend a session one-on-one. He attended one meeting where, according to the son's report, the worker kept saying 'now does that make you angry?' in relation to various topics. The son had found it ridiculous and favourite jokes for him and his family revolved around the 'now does that make you angry?' theme. Problems of diminished tolerance and control were unchanged.

Another case where appropriate and timely assistance was not provided involved a community police officer, approached by a mother seeking assistance and advice regarding her brain injured adolescent son's behavioural disturbances. She related part of their conversation:

*I said, 'My boy is getting into trouble, I can feel it. What can you do for me?' And he said 'We can't do anything for him until he gets into trouble'. ...And I said 'But what will happen if he does get into trouble?' And he said 'Well he'll go to Court like everyone else.' And I said 'But I'm trying to tell you this before he gets there' and he said 'Well, we can't do anything till he gets into trouble, and if he gets into trouble, he'll be dealt with like everybody else!' And I told him he was just a damn... you know?*

This youth was, as has been discussed previously, later imprisoned for offenses committed post TBI.

An absence of TBI-specific services, and a failure of generic services to cater to the needs of brain injured individuals and their families, appeared to be a particular problem in the area of respite care. Families commonly expressed a need, and a willingness, to take breaks away from their relative. However, the lack of suitably trained or knowledgeable



respite care providers was a major deterrent for such families seeking to make use of ACC respite care funding. As stated previously, references were made to the 1995 killing of an ACC-funded professional caregiver by a brain injured male: the subsequent investigation found the caregiver was largely untrained and had a history of alcohol abuse and personal problems which the investigator suggested made her unsuited to a caregiving career (see chapter 2). One mother commented,

*They would say you could have 2 weeks reprieve, but who the hell do you get to look after him? We just knew that there was no one around, apart from family, that had a remote understanding. And even then, extended family had a lot of difficulty, as we did, as immediate family. Had a lot of difficulty. And someone who knows nothing about brain injury, you just can't hand him over. So it was all very well saying that, that you could get relief, but, but we just knew it wouldn't be safe.*

The difficulties with respite care identified by participants in this study mirrored those identified in the NZHIS (1993) study, where families were found to be reluctant to use the few facilities which did provide respite care in NZ. The respite care options for brain injured individuals identified in the study were geriatric and long stay wards which are widely considered inappropriate for this typically young population. Families in the NZHIS (1993) study described themselves as being reluctant to place their relatives in such environments, believing the needs of their injured relatives would be neither understood nor met.

A similarly unsatisfactory situation was depicted in the UK by Higham and Phelps (1996), who stated that while TBI carers needed both planned and emergency access to respite care, they currently had neither. Many carers were found to lack the knowledge to access respite care, while those who were able to access it often reported experiencing such guilt at the distress, confusion and fear that respite care provoked in their relatives, that they chose not to use it again.

Tasks performed: Facilitation of service provision. Once the appropriate service providers had been located, it was necessary for families acting in a case management capacity to

then ensure the service was provided. While for many families the biggest challenge they faced involved the locating of service providers, for others the problems which had plagued them up until this point continued as they sought to obtain access to those services.

Most problems identified by participants related to issues of funding and involved ACC, as the main funder of brain injury services in NZ. In some cases, the difficulty lay in proving to ACC that the injured relative needed and/or was entitled to receive a particular service, with ACC frequently perceived as acting in a gatekeeper capacity. An example commonly cited by participants involved ACC's refusal to fund ongoing physiotherapy or gym membership, in spite of pre-discharge recommendations that they receive ongoing physical maintenance of this nature. In such instances, families frequently ended up paying for the necessary services themselves, often at considerable ongoing financial cost to the family as a whole.

Difficulty was also encountered by families attempting to ensure ACC regulations relating to the procurement of services were met. One family member learned of the existence of a rehabilitation program outside the Manawatu area, for example, which she felt could be extremely beneficial to her brain injured son. Working in conjunction with her son's ACC case manager, she arranged for members of the program to come to the Manawatu to assess her son for possible inclusion in the program. The assessments were carried out and, to the satisfaction of both his family and the ACC case manager, the son was deemed suitable for participation in this particular program. Shortly after this, the ACC case manager learned of an ACC regulation which prevented practitioners from both carrying out assessments to determine eligibility for a service and providing the actual service, and the family was informed their son could not participate in the program. The brain injured male involved did eventually attend the rehabilitation program he was assessed for but only after considerable lobbying on the part of his family and, in this instance, his ACC case manager.

The need for families to fight in order to obtain post discharge services for their relative was a common theme in the study. Families felt very strongly that, had they not done so,

their relatives would not have received the services needed and consequently would not have achieved the same level of recovery. Other authors have noted a similar phenomenon, with Singer et al. (1994) quoting one parent:

‘It isn’t enough to just do battle for a child’s life. Then comes the battle to get rid of machines, the battle with insurance companies, the battle for services, the battle for information, the battle of holding yourself together with a spouse and other children, and there seems to be no end.’ (p. 39)

One mother reported being asked by a local rehabilitation practitioner if she had turned into “*one of those political women*” as a result of her attempts to gain help for son following his injury, commenting that while this practitioner agreed her son’s progress was largely a result of her efforts, he had been distinctly uncomfortable with her actions while he had been part of her son’s rehabilitation team. Families thus find themselves walking a tightrope between ensuring their injured relatives’ rehabilitation needs are met and not alienating, by their ‘pushiness’, the practitioners, whose input is often considered crucial by family members.

### Therapist

When families found that they were unable to secure appropriate professional assistance for their relative, many chose to provide the required therapeutic services themselves in order to facilitate their relative’s recovery. In this way, families departed from both the semi-reactive caregiving role (a ‘doing for’ the injured relative) and from the case management role (endeavouring to organise agencies and professionals). The therapist role was characterised by a more proactive and direct role, aimed at producing change and ultimately reducing the injured relative’s dependence on others.

The nature of activities performed by family members acting in a therapeutic capacity varied extensively, ranging from the most basic through to highly complex training programmes more commonly associated with specialist practitioners. The interventions developed - interventions often borne out of absolute frustration and desperation - were typically characterised by imagination and innovation. As with rehabilitation generally, the

interventions developed by family members targeted both the relearning of lost skills and/or the development of compensatory strategies for those abilities the relative could not regain, and encompassed a broad range of functions. Cognitive skills, addressing such areas as memory, attention, concentration, literacy and numeracy skills, were a common focus of attention, as were aspects of physical functioning and daily living.

Consistent with the literature, family members reported finding aspects of their injured relatives' emotional and behavioural functioning among the most problematic of all TBI sequelae and among the more enduring, particularly the specific areas of anger, depression, anxiety and socially inappropriate behaviour (D. N. Brooks & McKinlay, 1983; Jacobs, 1988; Klonoff et al., 1994; W. W. McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy et al., 1978b; Powell, 1994; Thomsen, 1974). Participants also found assistance in this area amongst the most difficult to obtain and, consequently, much therapist-type work carried out by family members targeted this area of functioning. The present study examined in detail the area of emotional and behavioural functioning, reflecting the importance of this area for both the injured individual and for family members. Two areas were focused on in particular: the ability of family members to manage their relative's emotional and behavioural disturbances (stemming directly from brain damage sustained); and the ability of family members to help their relative cope with their relative's emotional responses to the brain injury. Findings regarding each of these areas are presented below.

Managing the brain injured relative's emotional and behavioural disturbances. In the present study, participants rated emotional and behavioural functioning amongst the more common and severe functional disturbances following the TBI (see Table 7.1 & Appendix C3). They related numerous accounts of their relatives carrying out acts of physical, verbal, and/or emotional violence, targeted at family members and others, at property, and frequently at the injured individuals themselves. According to one family, their relative incurred \$14,000 worth of motor vehicle-related fines in less than a year. Other families had to cope with their brain injured relative running away from home, sleeping on the streets and on construction sites, stealing from both the family and others, making repeated suicide attempts, and gaining access to firearms.

At each of the data collection stages, a clear theme of inadequate family preparation for such personality changes emerged. Participants commonly described or demonstrated a lack of understanding of the nature of emotional and behavioural disturbances during the study. Some participants, for example, reported being aware prior to discharge that their relative could exhibit personality changes as a result of the TBI but failed to realise they would be as dramatic or enduring. Others reported believing at some point that they must be causing their injured relative's behavioural disturbances - a belief typically arising because, according to their accounts, no one had warned them these changes could occur. One mother, for example, commented,

*You feel 'Oh, obviously [my son] didn't do this in hospital. It must be something I'm doing'. And you start to feel guilty that you've caused it, so you don't ask in case someone tells you that 'Yes, it is you'.*

Florian et al. (1991) suggest the tendency for family members to attribute their relative's behavioural disturbances to their own inadequacies is fairly common when families don't understand TBI.

Difficulties encountered by family members in trying to manage their relatives' emotional and behaviour disturbances, and the effects of those disturbances on themselves and others, ultimately constituted one of the most significant problems faced by participants over the longer term. Participants consistently indicated they had lacked the skills and techniques needed to manage their relative's disturbances and to facilitate positive changes in this area of their relative's functioning, and strongly criticised practitioners whom they perceived should have made a much greater effort to prepare them for this task. Enormous frustration was evident amongst participants who often felt practitioners had instructed them as to what the injured individual should and should not do post discharge, without giving them the skills necessary to carry these instructions out. They also were frustrated at being expected to take responsibility for aspects of their injured relative's behaviour when, in reality, they had no legal or practical means of ensuring compliance.

Participants were also concerned about the use of alcohol and/or drugs by brain injured individuals. Many reported being told by Rehabilitation Centre staff that the consumption

of alcohol or drugs by the brain injured individual would be detrimental to their recovery and that family members should attempt to ensure this did not occur. None of the participants who discussed the issue of drug and alcohol use, however, indicated they had been informed by practitioners as to how this might be accomplished.

One father in this position discussed how, during his son's time in the Rehabilitation Centre, the family first learned their relative had a long-standing history of both drug and alcohol abuse. Describing how staff had advised him that his son, under no circumstances, should have any alcohol or drugs, the father, along with other members of his family, expressed his desire to ensure his son complied. Once the son returned home, however, his friends would come to the family home to take him out for the evening. The father would explain to them about his son's brain injury and how important it was for his recovery that he did not drink excessively or take drugs; however, the friends' responses were typically along the lines of *"Silly bloody old man"* and (to his son): *"We'll get you away from [here], we'll see you right."* Invariably, the father would later receive a phone call from the friends, asking him to come and collect his son who, after taking the substances, would be vomiting, urinating and fighting uncontrollably.

In addition to being exceedingly frustrated with the situation, the various members of this family were also resentful of Rehabilitation Centre staff whom, they felt, had expected them, as the individual's primary caregivers, to assume responsibility for their relative's behaviour. According to the family, their relative had taken drugs while at the Centre, with the staff's knowledge. Other than telling the individual he would have to leave if he continued to take the drugs, the family felt staff took no real action to address his ongoing abuse. The family questioned how Centre staff, unable to resolve the issue themselves, could possibly expect them to do any better by themselves.

Participants interviewed agreed it was unrealistic to expect that practitioners could prepare family members for every situation they might encounter post discharge or equip them with all the skills they might require. There was a very definite sense, however, that practitioners could (and should) do considerably more than they currently do. The mother

of the injured individual discussed above, for example, suggested that staff at the Rehabilitation Centre should make a greater effort to inform families of the likelihood of behavioural disturbances and also work with them to lay the foundations for a behavioural management programme, encouraging and enabling them to seek out additional help when required.

#### Helping the brain injured relative cope with their emotional responses to the TBI.

Participants often described various ways in which their relative had responded to the effects of the TBI on their own and on other peoples' lives. Consistent with the literature, themes of depression, guilt, worthlessness, loss of self esteem and a loss of interest in various aspects of life were commonly noted, while a number of participants also discussed how their relative had come to question the meaning of the accident and why the accident had occurred. Feelings of anger, frustration and anxiety amongst the brain injured relatives were also commonly reported by participants, the expression of which was variously directed at family members and at the injured individuals themselves (see Bergland & Thomas, 1991; Jacobs, 1989a; L. Miller, 1991; Nochi, 1998; Prigatano & Klonoff, 1988; L. M. Smith & Godfrey, 1995).

Suicide emerged as a reasonably common theme, with participants indicating their relative had either thought about, or actually made attempts to commit suicide. One mother explained that her son had tried to kill himself so many times that she now needed to collect and manage all of her son's psychiatric medicine because, left to his own devices, he would use the medication to overdose. According to this participant, a loss of confidence underlay her son's repeated suicide attempts, a loss she attributed to the "*consistently negative information*" her son had received about himself and his abilities since his accident. She discussed how her son now believed he was useless, that he 'couldn't do anything', and that he had great difficulty finding meaning in his life since being told by rehabilitation practitioners that he would never be the same again.

The sense of loss felt by the brain injured individuals was poignantly expressed in the case of one young man who had, by his parents' account, taken a somewhat 'winding path'

since the accident. Realising his parents were utterly devastated when he was sent to prison following a series of incidents, the son attempted to ease his parents' concerns about his wellbeing when they visited him in prison. According to the son, prison was "*a piece of cake*"; he explained that he had been in a form of prison ever since his accident, that nothing could be worse than that, and least in jail he could talk to people.

Like most people facing a major life change, people with brain injuries typically need assistance in coping with the changes which have occurred in their and their families' lives. A very clear theme emerged in the study, however, that participants considered professional assistance of this nature had either not been forthcoming or had been inadequate when provided. A small number of participants indicated their relative had received some basic counselling while they were an inpatient at the Rehabilitation Centre; however, this was rarely considered adequate. Families searching for suitable assistance within the community experienced considerable difficulty locating counsellors knowledgeable about brain injury - generally considered by participants to be critical for counselling to be effective.

As in other areas where services were not readily available, family members often found themselves assuming the role of service provider, in spite of a lack of training and in spite of any problems they themselves may have been having trying to understand or adjust to the brain injury. While families generally considered they had done the best they could, it appeared to the researcher that only some of these attempts were likely to have been productive and that sometimes even the assistance provided by a single person would have varied considerably in its effectiveness.

For example, one father advised his son after his accident,

*This is the first day of your whole life. It's not a frightening thing, but it's a whole new experience. Some parts of it, you're not going to understand. It's gonna be confusing for you. What I suggest you do is push them aside, and carry on with the positive things. And if confusion gets in, try and move it along. Move it along so it doesn't stop you from getting ahead.*



While this advice seemed helpful, he had also suggested to his son, who had asked why he was experiencing so many changes in his emotions and behaviour, that there were ‘two versions’ of him. According to the father, his son’s original (premorbid) self was trying to “*come back*” but the present (postmorbid) version of his self was stopping that from happening, resulting in ‘a struggle between the two selves’. While well-intentioned, the explanation appeared to the researcher to convey to the son not only that his current state was undesirable but also he could return to his former state should he be able to find the right key.

Training for the role of therapist. In view of the need for families to assume a therapist role, how do they gain the skills necessary to perform the role? Participants rated training received from rehabilitation practitioners, prior to their relative’s discharge, that had taught them how they could help their relatives with ongoing rehabilitation. The findings, reported in Appendix C8, support previous findings that participants felt inadequately prepared to assist in their relative’s life post TBI.

A relatively small proportion of participants ( $M = 15\%$ ,  $SD = 5.2$ ), indicated their relatives had not required ongoing therapy in the areas of functioning listed and thus they had not required any training for a therapist-type role in those areas. An average of  $52\%$  ( $SD = 5.2$ ) of participants indicated that they had required training that would help them assist in their relative’s ongoing rehabilitation but had received none while their relative was an inpatient. A further average of  $9\%$  ( $SD = 5.1$ ) reported receiving training they rated as being of no use, while an average of  $16\%$  ( $SD = 7.3$ ) rated the training received as being somewhat useful, and an average of  $8\%$  ( $SD = 2.6$ ) rated it as being very useful.

The figures in Appendix C8, and participant responses generally, indicate that the knowledge and skills required by family members to assist in their relative’s ongoing rehabilitation were rarely developed as part of the formal preparation process during inpatient rehabilitation. Other studies examining training relevant to the performance of a therapeutic role, including those by Kreutzer, Serio et al. (1994) and Stebbins and Leung (1998), have reported similar findings. Almost all of the participants (94%) in Kreutzer,

Serio et al.'s study, for example, rated the need to be taught how to manage their relative's behavioural disturbances as important, yet only 30% rated that need as having been met. The majority of participants in Stebbins and Leung's study, (both those whose relatives were injured less than two years, and those whose relatives were injured more than two years previously), also rated the need to be taught how to manage their relative's behavioural disturbances as important (87.5% and 85.7% respectively). Again, however, very few rated that need as having been met (25% and 4.8% respectively).

In the absence of systematic preparation and consistent access to information, a trial-and-error approach appeared to play a significant role in the development of skills and strategies necessary for the performance of a therapist role, with families trying out countless approaches with their relatives in various areas of their lives. This was particularly common in the area of behavioural management, where some of the strategies described by families, particularly those used during the early stages of recovery, appeared fairly unsophisticated. One mother stated,

*What we used to do with [our son] was grab him and hold him. And just keep saying in his ear, even though he was fired up and everything, what I used to do was stick my whole arms around him, and hold him. And I used to just say - even though he was abusing the shit out of me - I used to say 'But I love you boy, I love you, I love you'. And he used to say 'Love isn't effin good enough'. But that's all I could say.*

Over time, family members generally became more knowledgeable about their relative and about brain injury, often resulting in the implementation of increasingly sophisticated management strategies. Libraries, book stores, and the Internet were commonly used to help family members fill gaps in expertise, while many participants also reported seeking advice from the different medical and rehabilitation-related practitioners they came into contact with. Family members described becoming more aware and usually more accepting of their relative's limits, and more knowledgeable about ways to maximise achievement within given limitations. In the area of behavioural management, for example, participants described learning to identify and avoid triggers which precipitated

certain responses or outbursts and how best to respond to such outbursts when they occurred.

In the area of cognitive functioning, family members developed skills such as how to present information in a way that would optimise the brain injured relative's comprehension and retention, and how to guide their relatives through decision-making and problem solving processes. Families learned to incorporate time and fatigue management techniques into their relatives' daily lives, to structure their relative's environment in order to minimise the demands placed on their relative and to optimise their relative's ability to cope with those demands which were placed on them.

Participants with a professional background, particularly health- or education-related, appeared relatively confident in, and effective at, seeking out information needed to develop therapeutic-related strategies. A number of those with a medical background had existing sources of information they could access, such as an old friend with relevant expertise or a friendly GP, or already possessed themselves some of the skills needed. Considerable difficulty was still experienced by these family members, however - one mother with a nursing background explained that while she knew the types of programmes that needed to be put in place and was capable of implementing them for others, she had found it extremely difficult to do so for her own son.

The apparently greater ability of these individuals to obtain necessary information and input has been discussed by Waaland (1998) in her work on TBI families. Waaland suggests that even though there may be no difference in need, people from a higher socioeconomic group, typically from the dominant cultural group and more highly educated, are more successful at "negotiating service mazes" and obtaining desired results than those from lower socioeconomic groups (p. 352). Cultural minorities who are poor and undereducated are, in contrast, often subject to discrimination and poor treatment by agencies, are ultimately less likely to receive assistance than those from higher socioeconomic groups, and are more likely to become alienated from professionals.

## Overall Role Performance

Overall, participants demonstrated an enormous commitment to their brain injured relative and their relative's rehabilitation, expending considerable energy over long periods of time trying to help the relative in their recovery process. Participants engaged in a variety of tasks, adopting different strategies of care and support provision, strategies which, as has been previously discussed, were labelled 'care giver', 'case manager' and 'therapist' in the study.

Participants' use of strategies may be best characterised as dynamic, with family members tending to move between strategies depending on need and circumstance. In many cases, day-to-day caregiving tasks were carried out by family members as required, professionals were brought in to assist where possible, and family members filled in any additional gaps to the best of their ability.

Within this pattern, a tendency for participants to favour a particular strategy over others was often evident, typically reflecting participants' belief as to whether or not services were available within the community. Those who believed they were, regardless of difficulties associated with service location or access, tended to emphasise a case management approach over the personal provision of therapeutic services. One mother stood out amongst those who had adopted such an approach, devoting enormous amounts of time and energy attempting to obtain rehabilitation services for her son. Where services required had been unavailable at a local level, she arranged for her son to attend rehabilitation facilities in other regions, as well as attempting to facilitate the development of such services at a local level. She described having assigned her role as 'mother' to both her children to a close friend for a period of time in order to focus on the performance of her adopted case management role, and while it had taken her a couple of years to implement the comprehensive rehabilitation programme she believed her son required, she felt the process (and associated struggles) had been worthwhile.

Participants who believed services were not available within the community tended to favour the use of a therapist-type strategy in the provision of care and assistance to their brain injured relative over a case management approach. One father, for example, suggested his family had provided all of the rehabilitation services his son had received: “[We were] everybody-and-anybody-whose-got-anything-to-do-with-medical-rehabilitation-and-counseling... We did everything.” Such participants often devoted considerable attention to the development of their therapeutic knowledge.

Participants were also identified, however, who appeared unable or unwilling to adapt their approaches in line with the varying needs of their relative and the assistance available. This was particularly obvious with one of the families interviewed who had confined their efforts to performing basic caregiving tasks, even though they recognised their relative’s need for more comprehensive and advanced rehabilitation input and desperately wanted their son to achieve an optimal recovery. In this particular case, the family appeared to have withdrawn from active involvement in their son’s rehabilitation at an early stage, explaining that Rehabilitation Centre staff had discouraged them from attending treatment sessions. This family did not adopt the strategy of direct service provision, as some participants had done, seemingly continuing to comply over the long term with the message received from the Rehabilitation Centre - that their son’s rehabilitation was the domain of professionals and not of family members.

One of the more striking themes to emerge concerned the enormously variable levels of effectiveness with which family members performed the different roles associated with their relative’s rehabilitation. While family members typically demonstrated a strong commitment to their relative’s recovery, some family members were able to achieve considerably more than others through their efforts. The ability of family members to function in different contexts appeared to be a major factor in determining effectiveness.

Some participants were more confident in dealing with medical/health professionals and with bureaucratic organisations generally, and those with past experience seemed to fare better than others. Some family members, for example, had familiarised themselves with

various policy documents and operating procedures, particularly regarding ACC, to ensure their relative received all the assistance they were entitled to. Where services had not been provided, these family members would point out to the various practitioners their obligations and responsibilities, and the family's/injured individual's entitlements. One family described having taken photocopies of all documentation between themselves and ACC, even during the initial crisis stage, which they were later able to use to their benefit when ACC suggested the family had failed to follow the appropriate procedure in applying for assistance.

Participants took markedly different approaches when interacting with practitioners. More confident families took the position that they should receive the services needed as of right, an approach that seemed reasonably successful. In contrast, the less confident appeared to take a more submissive (and usually less successful) approach, evident to the researcher through the language used by participants to describe family-practitioner interactions. One family from a low socioeconomic background, for example, talked about their efforts to obtain assistance in terms of having 'gone begging for help' to various agencies and having cried and pleaded during meetings with practitioners. This contrasted markedly with those families who described attending meetings to inform practitioners of their expectations and requirements.

Again, these differences appear to reinforce the notion that different sociocultural groups within society may have markedly different experiences of rehabilitation/health service providers; a theme which has similarly been noted in NZ literature (e.g. Malcolm, 1996; Ministry of Health, 1995; Te Puni Kokiri, 1995). This situation is a particular concern in the context of TBI, given that brain injury occurs disproportionately amongst those from lower socioeconomic groups and those who have historically been alienated from conventional medical/health services (see chapter 2).

## Families' Feelings about the Roles Performed

The literature again is generally in agreement regarding the acceptability of families as caregivers, both from the perspective of health professionals and from the families themselves. Moral expectations as to what it is to be a 'good family member' remain strong and continue to influence individual and public thinking on the matter, as is reflected in the notions that 'families stick together through thick and thin', 'blood is thicker than water' and so forth. These cultural ideals remain strong, even though family and medical circumstances have changed over time (DeJong & Batavia, 1989).

A similar philosophy was evident amongst many of the families in the present study, who indicated they had a responsibility to provide basic care for their relative. While caregiving presented some challenges, particularly to family members who either had not performed a caregiving role before or had not been a caregiver to the individual in question, family members generally understood what was expected of them as a caregiver and felt they were able to assume the role.

The majority of participants' criticisms related to the more complex roles family members performed as case manager and/or therapist. A disparity was clearly evident between what participants considered was a reasonable contribution to their relative's recovery and what they had ultimately needed to do, with many describing feelings of surprise (and, in many cases, horror) experienced upon discovering the critical role they were to play in their relative's post discharge rehabilitation. Apparently underlying much of the surprise was a belief that responsibility for meeting the more complex rehabilitation and care needs of accident victims lay with the State, via the various publicly funded medical/rehabilitation agencies, rather than with families.

Popular opinion on the appropriate role of families in brain injury rehabilitation is somewhat divided, partly reflecting differences in views surrounding the appropriate allocation of burdens to family and society (see DeJong & Batavia, 1989). According to Jacobs (1989a, 1989b, 1991), it is realistic to expect family members to act as case

managers for their brain injured relative and, therefore, the teaching of case management skills should be included as part of the general rehabilitation process. Jacobs (1989a) argues strongly against the notion of families acting as therapeutic agents in brain injury rehabilitation, however, stating,

*Expectations that family members can assume total responsibility for long term treatment are ... ill-founded. Few families have the training to assume such a role or the time and ability to develop the required skills. Professional treatment teams represent decades of diverse education and experience, and it is not realistic to assume that many families can match or acquire this knowledge. (p. 311)*

Jacobs (1989a) further argues that where services do not exist, advocacy (involving the lobbying of relevant public and private bodies for resources) becomes the critical role of family members.

Participants' comments supported some of Jacobs' views, with participants strongly emphasising, for example, the critical role of advocacy in service development. Several participants reported having become very involved in this type of work within their area. Similarly, participants tended to agree that the role of therapist lay beyond the capabilities of most family members.

Other views expressed by participants, however, suggested that while Jacobs' position on therapeutic assistance may be philosophically sound, it fails to reflect the realities of many families' situations. Brain injured individuals and their families, both generally and within the context of the present study, do not have complete access to services required. Advocacy, while providing useful results in the longer term, does not necessarily help families to meet their relatives' and their own needs on an immediate basis. Thus, families commonly assume responsibility for performing these complex roles by default, as reflected by Jacobs' own study which found families comprised "the primary source of therapeutic treatment because of insufficient programmes" (1988, p. 429). While it may not be reasonable to ask family members to assume the responsibility of direct therapeutic service provision, families are clearly doing so.



The performing of a case management role was a similarly contentious issue, with participants' views diverging somewhat from those expressed by Jacobs. Those who commented generally indicated that, although they were willing to perform a case management role if absolutely necessary, a clear preference was demonstrated for professional case management services. The researcher recalls one frustrated participant declaring they had just wanted to be a parent!

Some expressed anger that the case manager role had effectively been forced on them without adequate warning or preparation - essentially a case of 'throwing families in the deep end' and leaving them to sink or swim. According to T. J. Moore (1995), while the NZ health and disability environment arguably contains "pockets of excellence, both in terms of people and services", there is also "an extremely confusing myriad of state and service agencies... with little coordination taking place" (p. 11). It is this complex and confusing environment that participants in the present study have needed to negotiate in order to aid their relative's recovery. From participants' accounts, it appears many had little to draw on initially beside their own initiative and previous problem-solving experience.

Taking a pragmatic view, it would seem sensible to prepare families for what they will experience, rather than for what professionals feel families should experience in an ideal world with adequate support services. Certainly those participants interviewed identified strongly with this sentiment. Many were genuinely and intensely angry about the inadequacies they perceived in the training provided for the various roles they ultimately performed, questioning why, to all intents and purposes, they had been 'abandoned' by the professionals and left to develop the necessary competencies by themselves and after their relative returned home. One mother asked,

*Why can't we, as lay people, be trained? Why can't families be given some training...? Very easy. One hour a week. Get together. 'Now when this happens... or when [the brain injured individual] does that, this is the way I want you to react. These are the words I want you to use. Be consistent.' Why can families not be given that? ... 'When this situation arises, you know, try and deal*

*with it this way'. And that's all we're asking. Just give me a sense of direction... You know, I'd go to [a particular practitioner] and say 'Christ! What do I do when [my son] does that?!!' You know?*

## Conclusion

An enormous range of tasks need to be performed following the onset of TBI, stemming both from the premorbid responsibilities of brain injured individuals and their postmorbid care and support needs. While professional input is usually forthcoming in the early stages of recovery, it has been widely established that ongoing assistance is more difficult to obtain over the longer term. In the present study, as is the case elsewhere, responsibility for ensuring the needs of brain injured individuals are met falls to family members with whom most brain injured individuals return to live following inpatient discharge.

Family members involved in the present study adopted a variety of approaches when responding to their injured relative's needs, approaches labelled 'care giver', 'case manager' and 'therapist', with the strategy selected typically reflecting both the requirements of the situation and the preferences and capabilities of the family member concerned. Considerable variation was evident in the effectiveness with which different family members performed tasks associated with the various approaches, seeming to depend, at least in part, on their previous experience and confidence in dealing with professionals and bureaucratic organisations. The overall impression gained was that the level and type of assistance ultimately received by some of the brain injured individuals was less related to their need and entitlement than to their family's ability to advocate on their behalf.

Participants had not initially expected to play such important roles in the rehabilitation of their brain injured relatives and were uniformly critical of the expectation, (as reflected through the general health/rehabilitation environment and through the behaviour of service providers), that they would and should assume responsibility of the magnitude commonly experienced. The roles of case manager and therapist were generally considered by

participants to lie more within the realm of medical/rehabilitation professionals' responsibility, while the basic caregiving role was felt by many to be a realistic contribution by families.

Ultimately, the difference between what participants felt was a reasonable contribution to their relative's recovery and general welfare and what they had been expected to contribute provoked intense emotions amongst family members. Until participating in the present study, however, many of the family members involved had had limited opportunity to express their views in an environment they considered 'safe' (i.e. free from potentially negative ramifications for their relative or for themselves). Consequently, probing participants' views on the subject often resulted in a situation paralleling the releasing of an overflowing dam - emotions poured out of participants in varying degrees of strength and control. Overall, the researcher was left with the impression that the only participants who were completely satisfied with the situation encountered post TBI were the very few whose relatives had either achieved a full recovery or a level of recovery which resulted in few ongoing obligations on their part.

## **CHAPTER 11**

### **FAMILY SELF CARE AND USE OF EMOTIONAL ASSISTANCE**

From the time a brain injury is first sustained, families of the injured individual embark on a journey where the path is as variable and uncertain as the journey itself is unexpected. Whether willing or not, to survive, families must respond to the many challenges encountered - challenges which commonly translate into troubled days, sleepless nights, and family conflict (Waaland, 1998) - by participating in an ongoing process of adaptation. Even in the best of circumstances, the experience can leave families drained of their resources. The availability and adequacy of emotional support post TBI appears to be a critical factor affecting the ability of families to cope with, and manage, the multitude of challenges experienced following TBI, accounting at least partially for the diversity in outcomes evident amongst families. As the search intensifies for new and/or more effective methods of helping families post TBI, increasing attention is being paid to this area.

This chapter reports findings of selected aspects of family self care. It follows on from previous chapters which have explored the impact of TBI on the lives of family members (see chapter 7 in particular), examining the types of assistance participants in the present study drew on to cope with the emotional burden stemming from TBI. Participants' preparedness for the emotional burden is reported, following which the characteristics of an ideal emotional support programme are described, based on participants' accounts of their support needs. Participants' use of various types of emotional assistance post TBI is also reported and the reasons underlying those patterns of usage discussed, drawing on both the literature and participants' own accounts. Throughout this discussion, comparisons are made between participants' actual emotional assistance-related behaviour and their retrospective assessments of what their behaviour should have been, when taking into account the knowledge of TBI and associated burdens they acquired over time.

## Family Preparedness for Emotional Burden

As has been asserted throughout this thesis, caring for a brain injured relative can be a demanding and relentless task that often greatly surpasses, in scope and duration, what was initially envisaged. The literature reports that families retrospectively discussing their experiences of brain injury commonly express surprise at the toll the brain injury ultimately took on their own lives, indicating they had underestimated the magnitude of emotional burden which would result. Consequently, families of brain injured individuals have been quite critical of what was done to prepare them for, and help them cope with, the emotional burden encountered post TBI (e.g. Brown & McCormack, 1988; C. H. Campbell, 1988; Mauss-Clum & Ryan, 1982; NZHIS, 1993; Resnick, 1993; Rogers & Kreutzer, 1984; Stebbins, 1997; Stebbins & Leung, 1998; Williams, 1991b).

Amongst participants in the present study, there was a sense that practitioners had failed to adequately recognise or address the emotional needs of family members post TBI. The majority of participants (81%) felt Rehabilitation Centre staff had made few or no attempts to determine their emotional needs or the extent to which they were coping, with only 19% indicating staff had made many attempts. Further, 70% of participants felt staff were never or only sometimes sensitive to those needs, with only 30% of participants rating staff as frequently or always sensitive.

Participants were more varied in their perceptions of the efforts Rehabilitation Centre staff had made to inform them of the emotional difficulties they might experience in coping with various aspects of the TBI's impact. Overall, half of the participants believed practitioners at the Rehabilitation Centre had emphasised the need for them to be emotionally prepared to cope with their own responses to their relative's TBI, or to cope with the effects of their relative's emotional responses to the TBI (see Appendix C9 & C10). A somewhat larger proportion of participants (59%) indicated staff had emphasised the need for them to be emotionally prepared to cope with the effects of their relative's TBI-related emotional and behavioural disturbances (see Appendix C11).

Consistent with other aspects of preparation investigated, participants also reported low levels of general preparedness in each of the above areas (i.e. their own responses to their relative's TBI, the effects of their relative's emotional responses to the TBI, and the effects of their relative's TBI-related emotional and behavioural disturbances). Overall, 69% of participants rated themselves as having been inadequately prepared to cope with their own responses to the brain injury (i.e. *unprepared* or *somewhat unprepared*), while 63% rated themselves inadequately prepared to cope with the effects of their relative's emotional/behavioural disturbances. A further 53% reported feeling inadequately prepared to cope with their relative's emotional responses to the TBI (see Appendices C9, C11 & C10 respectively).

Relationships were identified between the variables of participant awareness and preparedness, for each of the three areas examined above (see Appendices C9, C10 & C11). In each instance, participants who believed Centre staff had emphasised, prior to discharge, the need for them to be emotionally prepared, reported levels of preparedness significantly greater than those who believed staff had not emphasised the issue.

#### Families' Emotional Assistance Needs

##### An ideal system of support

The importance of emotional support as part of an overall programme of family assistance was consistently emphasised by participants in the present study. Those interviewed expressed fairly uniform views regarding the components they considered essential features of an ideal emotional support package, suggesting that any comprehensive programme of support must provide emotional assistance to family members at all stages of the recovery process, beginning at the acute phase and extending over the longer term. The types of assistance provided needed to take a variety of forms, encompassing the efforts of both professionals and lay-people, and, most importantly, the assistance needed to be provided to family members in their own right, as direct beneficiaries, rather than as a by-product of assistance provided to the injured relative. Further, participants suggested it would be

preferable for support providers to make the first contact, approaching family members with offers of assistance rather than waiting for families to initiate requests for help.

### Families' use of support

In spite of the consistency with which these views were expressed, interviewees' accounts, supported by questionnaire responses, depicted a pattern of behaviour vastly different to that outlined above. Interviewees described having been offered emotional assistance during the inpatient phase by specialist care providers, such as social workers or support groups such as 'Headway' (the local advocacy and support group for brain injured individuals and their families at the time of data collection), which they rejected in favour of informal support, such as that provided by immediate and extended family members and friends. Informal emotional assistance was often accepted from practitioners whom participants considered supported families incidental to their work with the injured relative, such as nursing staff and the psychology team. One family member did report meeting with a counsellor on a single occasion - part of an employee assistance scheme through her work - however, this was for the purpose of facilitating a leave of absence and she declined to use the remaining free sessions, citing exhaustion. None of the interviewees described having sought out further sources of emotional assistance for themselves at this time.

Consistent with the literature, participants often noted that life did not become easier for them over time as they had initially anticipated: in some cases, participants commented that the emotional burden they experienced following their relative's return home seemed to increase instead. Interviewees indicated that family and friends continued to provide the majority, if not all, of their support beyond the period of inpatient discharge, with the incidental support provided by rehabilitation practitioners diminishing, mirroring the overall reduction in professional involvement occurring during this time. In spite of the sometimes-escalating levels of stress and anxiety amongst family members, a reflection of both their growing awareness of the magnitude and long term nature of TBI and the burden of care now assumed, few appeared willing to take up offers of assistance previously made by groups such as 'Headway' or to seek out alternative sources themselves.

Interview themes, supported by questionnaire comments, suggest two distinct patterns of behaviour emerged amongst family members over the longer term. The first involved those family members who continued to rely on family and friends as their primary source of emotional assistance, without seeking out alternative sources of emotional assistance or taking up such offers as were made. Some of the family members who fell into this category indicated the approach had been both acceptable to the different parties involved and sufficient to meet their own support needs. In other cases, the strategy appeared problematic, with family members describing diminishing levels of family members' and friends' involvement over time and/or a need for assistance more specialised or sophisticated than that which their friends and family could provide. Both phenomenon have been similarly reported in the literature (D. N. Brooks, 1991b; Brown & McCormack, 1988; Conoley & Sheridan, 1997; Jacobs, 1989a; Liss & Willer, 1990; L. Miller, 1991; Rogers & Kreutzer, 1984; Williams, 1991b; Zeigler, 1987).

In the second pattern, family members recognised their need for support was greater than that provided by family and friends and took action to obtain additional assistance. This was usually precipitated by some sort of crisis or the reaching of a 'melt down' point, where the level of emotional burden experienced became intolerable to the family member and/or they were no longer willing or able to rely solely on the support of friends and family. Rogers and Kreutzer (1984) similarly describe this phenomenon, suggesting that a crisis often encourages families previously unwilling to engage in support-related activities to be more open to new forms of assistance. Amongst the interviewees, this trend appeared most common in those family members who had assumed the role of primary support person, with those in more peripheral roles appearing not to reach such desperate states.

Family members in this situation described needing a source of assistance with whom they could discuss their concerns and feelings without fear of causing offense or of being judged, and who could provide informed insights and advice in return - qualities not necessarily forthcoming from traditional sources of support by family and friends. A desire to avoid over-burdening existing sources of support was also a contributing factor to the seeking out of further assistance. Searches for help often began at the Rehabilitation



Centre which, for many participants, was the main, or only, brain injury-related organisation with which they had contact. Family members met with varying degrees of success, mirroring the variability experienced in the accessing of services generally. In one case, Centre staff appeared quite willing to work directly with the family member during this post discharge stage, (the family member subsequently spoke of efforts made by individual practitioners in glowing terms), while in others cases reported, staff apparently indicated they were unable to help families beyond the stage of inpatient care. The reasons underlying this seemingly inconsistent treatment of families by staff are not easily discerned.

Participants' use of emotional assistance: Why the contradiction with their self-described needs?

Overall, the above depiction of family members' use of emotional assistance appears at considerable odds with the needs described by interviewees. Participants had emphasised the need for assistance at all stages of the recovery process and for that assistance to incorporate the efforts of both professional and lay individuals/groups, yet repeatedly described having rejected offers of assistance made by both of these groups in the early stages and, in many cases, over the longer term. Participants had also expressed a desire for emotional assistance to be provided to them as rightful recipients rather than as incidental to assistance provided to the injured relative. The figures in Table 11.1 show, however, that family members received more assistance from disciplines that provided indirect assistance (e.g. psychologists and nurses) than from those providing targeted assistance (e.g. social workers, counsellors and family-based support groups). Further, in hindsight, over half of the participants did not want many of these sources of assistance to be involved. A desire for support providers to initiate contact was also expressed, yet very few participants reported having accepted offers of help that were initiated in this way. Beyond that provided by family and friends, participants appeared most inclined to accept support from sources they themselves had identified and approached.

**Table 11.1. Family members' views of emotional assistance**

Potential sources of assistance	Which of the people below helped you cope with your own or your relative's emotional/behavioural responses/changes? <sup>a</sup>	In hindsight, which of the people below would you like to have been involved in your emotional preparation? <sup>b</sup>
Rehabilitation Centre social workers	36% (12)	55% (18)
Rehabilitation Centre psychologists	73% (24)	73% (24)
Rehabilitation Centre nurses	58% (19)	52% (17)
Other families at the Rehabilitation Centre	24% (8)	27% (9)
Family support groups	12% (4)	42% (14)
Headway fieldworkers	27% (9)	58% (19)
Private counsellor	21% (7)	36% (12)
Friends	61% (20)	49% (16)
Religious	21% (7)	33% (11)

<sup>a</sup>Figures given represent affirmative responses (i.e. the source did help).

<sup>b</sup>Figures given represent affirmative responses (i.e. would like the source to have been involved).

Participants' behaviour towards potential emotional assistance providers appeared to be characterised primarily by rejection and non-involvement, with most displaying a tendency to rely on those less experienced in the area of brain injury, such as friends and family. The most notable exception to this pattern involved the small psychology team at the Rehabilitation Centre, often singled out by participants as having provided particularly informed and useful guidance.

The literature suggests this low utilisation of services, in a context of considerable need, is fairly common. For example, M. A. Foster and Carlson-Green (1993) developed a compulsory brain injury support programme for families but, despite the strong initial interest expressed, few families ultimately participated. Attendance was similarly poor at multifamily psychoeducational sessions developed for families of brain injured individuals, also initiated at the request of family members (Sherr & Langenbahn, 1992), while Rao et al. (1986) singled out non-attendance at education and counselling sessions as a key issue hindering their family preparation- and care planning-related initiatives.

It is likely that at least some part of the rejection of emotional assistance noted in the present study reflects the variation in family members' coping abilities post TBI. As has been repeatedly noted in the literature, family members are not universally distressed following brain injury, with some demonstrating considerable adaptability and resiliency (e.g. Adams, 1996; Kosciulek & Lustig, 1999; Perlesz et al., 1996, 1999; Waaland, 1998). Similarly, not all family members will experience difficulty coping (D. N. Brooks, 1991b) and not all families will require professional intervention (Sutton, 1985). This was evident in the case of one mother interviewed, who expressed considerable irritation at those practitioners she felt had failed to recognise her ability to cope:

*I'm a fairly independent person. If I need help, I'll ask for it. Like it annoyed me a little bit when one of the nursing staff said 'How are you coping?' and I said 'Fine, thank you', and she said 'But you can't be'. I said 'But I am', and she 'But you've suffered this head injury' and started to spiel on a bit, and I said 'Everything's okay'. She couldn't quite swallow that one.*

The findings also reflect particular characteristics of family members and their circumstances. Those explored here include family members' emotional state, their knowledge of the human services area, the state of practitioner-family relations, the priority families place on their own wellbeing, the relevance and quality of support available, and logistical issues.

Participants often referred to being in 'survival mode' in the time following their relative's TBI. Their personal resources, when not focused on the injured relative, were directed almost entirely at meeting the basic necessities of life - food, shelter, and so forth - with little time or energy remaining to delve into what may be considered 'quality of life' issues with either professional or lay support people. Herbert (1989) suggests this focus on the practical is both common amongst families and an attractive response option, in that it helps families avoid confronting difficult emotions and issues at a time where family stability is often fragile. The self-examination commonly associated with more formal types of emotional support (e.g. counselling or therapy) is also too threatening to some families, particularly if they have little experience of it prior to the TBI. Some may feel threatened simply by the offer of assistance, interpreting it as a criticism of their ability to cope (L. M. Smith & Godfrey, 1995). Dew, Phillips and Reiss (1989) suggest families may be unwilling to place themselves in a situation where their 'flaws' may be exposed.

In the present study, relations between family and rehabilitation staff appeared sometimes agreeable, sometimes uneasy, and occasionally hostile. Considerable defensiveness was exhibited by interviewees who, at some point during the conversations, usually stated they had done the best (for their relative and for their family) that they could under the circumstances and challenged professionals to 'do it better' - with a clear implication that the professionals would probably have struggled to even match, let alone surpass, their efforts. At the same time, lingering uncertainty amongst some interviewees as to the ultimate adequacy of their efforts could be discerned. In this climate of general wariness, it was difficult to imagine family members being willing or able to trust and relax enough to open up and share their concerns with practitioners.

The willingness of family members to avail themselves of support-related services, and their ability to do so, also appeared to be related to their level of familiarity with the health/human services area generally. A number of participants demonstrated a lack of awareness of different professional groups, confusing their roles and responsibilities, or demonstrating an almost total lack of knowledge of particular disciplines. One father, for example, when discussing the types of assistance his family had required following his

son's TBI, shouted in frustration, "*We didn't know what the hell counselling was!*" Similarly, a mother explaining her response to an earlier suggestion that she see a hospital social worker, commented, "*I didn't know what for. I didn't know what she could offer us.*"

At the conclusion of the questionnaire, one respondent expressed a desperate need to talk with someone, someone 'just for her', who could help her 'sort out' what she was feeling, and so forth, which the researcher responded to with a list detailing relevant individuals and organisations available in the Region, including a number of counsellors and psychologists. At the followup interview, she continued to express a need to talk to someone who could understand her and what she'd been through, yet when asked if she had contacted any of those listed in the earlier letter, she replied, "*What are they? Psychologists, Psych... Psychiatrists? Counsellors? I can't see how they could help.*" Further discussion revealed this woman had very little understanding of the nature or role of different professionals or the types of situations where the different professions would be most appropriately used. Both Rehabilitation Centre practitioners and the researcher had overestimated the woman's knowledge of the 'helping' area, mistakenly assuming that advising her to seek professional assistance if necessary, and in the case of the researcher, providing a list of practitioners, was sufficient to meet her needs. These responses highlight the need for practitioners to ensure family members are not only invited to access support if required, but that they are also made aware of the existence of specific services and adequately educated as to the exact nature and role of each and what help each offers.

In a NZ pilot study involving brain injured individuals and their families, L. M. Smith and Godfrey (1995) found that family members were more likely to accept help if they perceived the assistance offered was focused on the injured individual rather than on themselves. It was often only after a clinician-family member rapport had been established that family members would accept assistance targeting their own needs. Hornby (1992) suggests that families will rarely request counselling directly, asking instead for information about their disabled relative, subsequently recommending that the person who

provides the information should also possess the skills necessary to carry out supportive counselling.

Similar patterns emerged in the present study. In spite of participants' assertion that they preferred support be focused on them directly, rather than as incidental to assistance provided to the injured individual, participants were most positive about those sources of assistance which provided emotional support incidentally or informally. In a number of cases, the most significant, supportive relationships participants described having with practitioners started out as mutual attempts to help the injured relative and, as a rapport was established, the relationships transformed so that they, the family members, became the main focus of attention. Some participants suggested they may never have attended such sessions had the injured relative not been the initial focus.

To a certain extent, this focus on the injured individual probably reflects family members' commonly-held belief that it is the injured relative, and not the family, who is the 'true' victim of brain injury and who is subsequently deserving of attention. Typically, this belief is reflected in a tendency for family members to turn down assistance they perceive is not directly geared towards helping the injured individual (M. A. Foster & Carlson-Green, 1993; Sutton, 1985). Family members need to be helped to understand the link between their relative's and their own wellbeing and, once they do understand and are encouraged to make use of emotional assistance, are generally more likely to accept that which is available (Lezak, 1986; Power, 1988).

In the present study, and particularly in the short term, the clear pattern was for family members to downplay their own needs while attempting to meet all needs of their injured relative. Family members frequently sacrificed their own health and wellbeing, as well as that of the wider family, altering this pattern, if ever, only after a considerable amount of time had passed. However, the majority of participants interviewed indicated that, prior to discharge, rehabilitation staff had emphasised the importance of caregiving families taking care of themselves; this suggests that more than a recommendation to take care appears to

be required if families are to adopt a positive and sustainable approach to patient management.

Another theme to emerge in the present study affecting uptake of personal support was the perceived relevance of the types of emotional assistance offered. A mismatch was particularly apparent between services offered by hospital social workers and those required by family members, who perceived hospital social workers as offering counselling and therapeutic-type services. Often, family members had not been ready to engage in this type of direct intervention during the inpatient stages of their relative's recovery, yet ironically, this was the period when family members had greatest ease of access to social work services. By the time family members were ready for this type of involvement, sometimes months or even years post discharge, hospital operating procedures and constraints frequently prevented social workers from later accommodating family members' needs. Family members seeking out instant access in response to a crisis exacerbated the difficulties faced by social workers in meeting family members' needs.

This particular mismatch suggests that a revision of social work services and the funding for these services may be beneficial. When initially approaching family members, it may be more useful for social workers to emphasise the benefits to the injured relative, rather than offering a 'shoulder to cry on' or 'a sympathetic ear' as participants described the 'typical social worker approach', and to focus on developing a rapport with family members so they have access to someone they trust should difficulties arise at a later point. If social workers are not going to be available to family members beyond discharge, this should be clearly established early on. Further, it may be useful for social workers to adopt a more educational and planning approach, where family members are taught how to access assistance within the community in the event it is required at a later stage.

The area of peer support also appeared problematic. Its importance has increasingly been emphasised in literature (e.g. Acorn, 1993; Marsh, 1994; Sachs, 1991; Stebbins, 1997; Whitehouse & Carey, 1991) and was a common theme during the interview phase of the study, where most of the participants suggested peer support was the best type of assistance

that could possibly be provided to families post TBI. One mother likened it to musicians 'getting together to discuss what they do' - "*You help each other.*" Another mother, whose son had received acute treatment at a different hospital, described how families there had been actively encouraged by staff to remain involved with the hospital over the longer term to provide support to families of newly injured individuals. Headway had played a key coordinating role in this scheme, with representatives present at the hospital to improve accessibility. In this way, 'new families' established links beyond the hospital which sustained them through discharge and over the long term. A critical factor in the success of the scheme, according to this mother, was the proactive stance taken by staff in promoting the collaboration between families and between families and Headway.

Family collaboration appeared far less advanced in the context of the present study. As shown in Table 11.1, only 24% of participants indicated that other families at the Rehabilitation Centre had helped them cope and only 12% indicated family support groups had done the same. Fewer than half of the participants felt, in hindsight, that these sources should have been involved in their emotional preparation and support.

This apparent contradiction can be explained, at least in part, through considering the characteristics of those family members which constitute 'peers'. Those interviewed said that peer support is most useful when families at an early stage of the recovery process are matched with those at a later stage, providing an opportunity for the less experienced to learn from their more experienced peers. Similar assertions have been made in the literature (e.g. Rosenthal & Young, 1988). Some of the participants interviewed indicated they would be willing to participate in this type of scheme if it would help prevent other families going through what they had experienced.

The groups of families listed in the questionnaire, however, were likely to be at similar stages of the recovery process: other families whose relatives were attending the Rehabilitation Centre; and families participating in family support groups - because for much of the time covered by the study, the Rehabilitation Centre provided the only or main support group in the region. Interviewees suggested that, other than providing a small



degree of mutual support and comfort, there was little such families could learn from each other.

The family focus of Headway, in conjunction with the proactive stance taken by representatives in seeking out and inviting family members to participate in its activities, would be expected to result in Headway being amongst the most highly-used sources of assistance examined in the study. However, only 27% of participants indicated they had received assistance from the organisation in preparing for, and coping with, life post TBI. Participants within this category who commented were very positive about Headway, suggesting the support they had derived through their involvement had been invaluable.

Some participants cited a lack of knowledge of the organisation's existence at the time they had wanted help, implying a possible utilisation had this knowledge been possessed. Other participants, however, indicated their initial contact with the organisation had discouraged them from further involvement. These participants frequently referred to divisions in the organisation which made it 'unstable' and particular 'personalities' which, they suggested, made Headway a difficult organisation to work with. There was also a more general concern that members may be too personally affected by brain injury to be able to provide useful assistance to others. One mother stated,

*I regularly pay my \$7 or \$10 or whatever it is for me and [my son] to belong, but I've never got to the meetings. I just couldn't cope. ...There was a lot of isolationalist stuff, as there always is. Personalities within these things. Someone wants to go one way... someone [else] doesn't want it to go that way... Those were the sort of frictions I'd heard about along the grapevine. So, although I was there in spirit, I couldn't actually cope with that. I believed in what they were doing.*

Another mother gained a similar impression during her first contact with the organisation:

*When [my son] had been in rehab five or six weeks, I made contact. I was put on to this woman on the committee and... I just felt, after my first conversation with her, 'I don't want anything to do with this! I'm actually going to get more problems than I'm going to get help with.*

Many of the concerns participants associated with Headway reflect problems considered synonymous with voluntary organisations generally. Voluntary organisations are often formed on the basis of a particular set of values, and organisational conflict is a common by-product of members' attempts to translate these values into workable, practical actions. Voluntary organisations with a campaign focus, as is often the case with brain injury support and advocacy groups, appear particularly vulnerable to such tensions (Dartington, 1995; Paton, 1996). Further, people who become involved in voluntary organisations have extremely varied reasons for doing so, often seeking different things from their involvement (Poulton, 1988), and bring with them unique experiences and views (Sachs, 1991). As is the case with value issues, such diversity amongst members can contribute substantially to the types of intra-organisational tensions and conflict which participants in the present study suggested existed within Headway.

However, findings reported previously revealed a fairly high level of interest in the types of assistance Headway was established to provide and, in spite of the problems identified, a number of participants were able to benefit substantially from their involvement. This suggests considerable potential for increased family involvement should the barriers which discouraged participation amongst remaining participants be overcome.

Perceptions of competency and professionalism influenced family members' use of certain sources of emotional assistance. Participants related numerous stories which illustrated what they considered questionable treatment or inappropriate attitudes of staff towards family members and/or their injured relatives, in both interviews and questionnaires. Their comments reflected statements of authors such as Gans (1983), Groswasser (1994) and J. Johnson and Higgins (1987) that emotions such as mistrust, frustration and even hate can dominate family members' feelings towards rehabilitation staff. The literature also suggests, as did some participants, that experiences such as these will make families reluctant to engage in future interactions with practitioners, as family members will be "hesitant to set themselves up for another potentially negative experience" (Dew et al., 1989, p. 42; see also Hatfield, 1990; Power, 1988).

Logistic issues also negatively impacted on participants' utilisation of emotion-related services, as has been described in the literature (Dew, et al., 1989; Jacobs, 1989; Rao et al., 1986; Sherr & Langenbahn, 1992). Participants discussed being unable to attend support-related sessions (such as the coffee afternoons run by Headway) because they clashed with work commitments. Familial responsibilities sometimes compounded the difficulties faced, with family members finding it difficult to organise time away from the family - spouses sometimes found it difficult to locate a babysitter for their children, while one mother interviewed was also caring for her elderly and confused father who required round-the-clock care.

Another prohibitive factor identified involved the cost attached to attending the Rehabilitation Centre and participating in support-related activities. Some participants needed financial assistance to meet the costs associated with babysitters, travelling to the Rehabilitation Centre, making toll calls to staff, and so forth. As in all areas, ACC took a tightly circumscribed approach to funding, typically denying requests for assistance of this nature and thereby compounding the difficulties already facing families. The case of family counselling further illustrates this situation: only one family in the study reported having successfully obtained ACC-funded family counselling, compared with a far larger number of participants who had sought it. The lengths this family had to go to in order to obtain the approval, however, were so excessive as to lie outside the realm of most families' willpower and endurance. As has been evident elsewhere in the study, there is considerable divergence between the assistance required by families and that provided.

Once the brain injured relative returned home, the ability of family members to participate in more formal support-related activities was further inhibited by their injured relative's supervision needs. For those whose relatives required constant monitoring, the difficulties faced were even more severe. Organising a 'minder' was often difficult and in some cases resisted by the relative, and families soon learned that to do so meant they risked returning home to a distressed relative and/or caregiver with a collection of problems that took time and energy to resolve. At times, participants perceived the benefits to be obtained from attending support-related sessions were outweighed by the difficulties which arose,

discouraging them from making further attempts to seek out, or utilise, other sources of support.

## Conclusion

Any serious injury or illness is likely to precipitate a crisis situation, bringing anxiety and disruption to the lives of those involved. In the case of brain injury, however, it is not just a matter of physical injury - the brain's critical role means that, potentially, virtually every aspect of the injured individual's functioning, and consequently, virtually every domain of their life may be affected in some way (Hubert, 1995). For the injured individual's family, the changes experienced in their own lives may be equally monumental: altered family relationships; radically different roles, social activities and daily routines; possible financial difficulties; and an uncertain future.

The way in which family members perceive these life changes appears at least as critical a determinant of their ultimate effect on the family as the actual nature and degree of the changes themselves. Families who believe the challenges encountered lie within their capability and are willing and able to make the necessary adaptations, are far more likely to survive the experience of TBI with their family intact than those who are completely overwhelmed by the challenges involved. From participants' accounts and from the literature, the availability of emotional support - both of the types, and at the times, required - appears a crucial factor differentiating those families who cope from those who do not.

Overall, there was a sense amongst participants in the study that practitioners had failed to adequately recognise or address family members' emotional needs following their relative's TBI. While participants were often aware the TBI would take an emotional toll on their own lives, for many the actual magnitude and the duration of the emotional burden experienced came as an extremely unpleasant surprise. Emotional support, both from professionals and from families' existing communities, was considered critical to the

wellbeing of family members, with the type of support required varying at different stages of the rehabilitation process.

The emotional support of friends and other family appeared crucial at all stages, although the tendency to have less involvement with families and/or the injured relative over time was sometimes observed. The role of professionals and specialist lay-people, however, was less clear. While participants tended to support the concept of professional/lay involvement in the facilitation of family coping, their behaviour was often inconsistent with this belief.

A number of factors appeared to contribute to the pattern of usage of professional and specialist lay sources depicted by participants. In part, it reflected characteristics of the participants themselves. Participation in more formal support-related interventions places both practical and emotional demands on family members, an unappealing prospect to those already feeling overburdened and overwhelmed. Familiarity with the general 'helping' area was also an issue, with some participants finding it difficult to take 'the first step' because of confusion over the roles and responsibilities of different professional/lay groups. Characteristics relating to the service providers or to the nature of services offered also appeared to play an important role in determining service uptake. Issues of competency and professionalism were often raised in regard to individual practitioners or organisations, with family members reluctant to avail themselves of assistance where the abilities of the service provider were in question. The nature of relations between family members and service providers had a similar effect, with family members more willing to accept assistance from those they were familiar and comfortable with - thus highlighting the importance of establishing a good rapport with family members early on in the rehabilitation process. There was also a question of service relevance where, in a few cases, the type of assistance offered by a professional group appeared incongruent with the needs and wishes of family members.

Participants also varied in patterns of uptake, reflecting differences in the coping abilities of family members. As the literature repeatedly emphasises, what is unbearable for one

person may be little more than an inconvenience to another. Thus, the commonalities in family members' preferences and utilisation patterns also need to be viewed in a wider context of individual preference and need. Any interventions or overall programmes of assistance devised for a family need to be firmly grounded in the realities of that family's unique situation, drawing on knowledge obtained from comprehensive assessment of each family of an injured individual as well as on theory. Failure to recognise families' uniqueness, as well as their commonalities, is likely to result in the provision of interventions unnecessarily restricted in their usefulness and relevance.

## **CHAPTER 12**

### **DISCHARGE FROM THE REHABILITATION CENTRE**

In most cases, the outcome for a brain injured individual is unknown at the time of final inpatient discharge (Grinspun, 1987). Readyng families for an uncertain future, a future without the intensive professional input associated with inpatient treatment, is the essence of family preparation and an integral component of the rehabilitation process. Discharge planning, essentially the act of matching the needs of the patient/client with available resources in the community, has become an integral tool in this process (Dash, Zarle, O'Donnell, & Vince-Whitmar, 1996; Ministry of Health, 1993). In the current hospital environment, however, where cost containment and lowered patient lengths of stay are emphasised, services like discharge planning are often among the first to disappear (Feather, 1993). Levesque (1988) stresses it is therefore imperative that practitioners working within this environment not lose sight of their duties and responsibilities to the patient with brain injury and, it should be added, to their families.

This chapter examines the discharge and, for almost all of the families in the study, the subsequent return home, of participants' brain injured relatives. The planning process itself is examined, focusing on the actual planning mechanisms in use at the Rehabilitation Centre and family members' feelings about the planning process generally. Participants' experiences of the discharge process are then explored, in relation to both weekend home visits and final discharge, and the strengths and limitations of the Rehabilitation Centre's discharge practices discussed. The chapter concludes with a brief examination of post discharge followup of the injured individual and family by professionals in the context of discharge and community reintegration, topics important in a consideration of the rehabilitation process.

#### **The Discharge Planning Process**

The primary mechanism for conducting discharge planning at the Rehabilitation Centre comprises meetings of the rehabilitation team, which ideally involves both the injured

relative and their family, as well as relevant practitioners. These meetings are also used as a forum for more general rehabilitation planning, providing team members with an opportunity to share information and address various issues and concerns. According to Rehabilitation Centre procedures, at least one staff-initiated meeting should be held for all inpatients and their families/significant others.

Over half of the participants (59%) reported having attended a discharge planning meeting while their relative was an inpatient at the Rehabilitation Centre. Interview themes suggested many of these meetings had been initiated at the request of family members; however, this was not borne out by questionnaire findings, with 81% of participants indicating meetings had been initiated by a Rehabilitation Centre staff member.

The concept of planning meetings received strong support from both the Rehabilitation Centre staff interviewed and participants. Amongst the Rehabilitation Centre staff interviewed, there was an awareness of the limitations of the process utilised; that a single meeting, or even a series of meetings, was unlikely to address all of a particular family's preparation needs. This awareness was mediated by a recognition, however, of the constraints facing practitioners in terms of the time available for working with families and the range of services which could be provided. Consequently, planning meetings were considered an important, if somewhat imperfect, mechanism for addressing the needs of family members in a manner supported both by hospital management and by rehabilitation theory.

Participants expressed gratitude that the opportunity to meet formally with practitioners had been available to them following their relative's brain injury, with 84% of participants who had attended a meeting rating it as either *somewhat useful* or *extremely useful* and only 16% giving a *no use* or *minimal use* rating. The meetings were not regarded as an adequate way of addressing the diverse needs and concerns of injured individuals and their families post TBI, however, with numerous criticisms made regarding aspects of the planning meetings and the processes surrounding the meetings. Explored further in the interviews, these criticisms centred around issues of timing, the emotionally demanding nature of



meetings, perceived power differentials between families and practitioners, the inclusion of injured individuals in meetings, logistical difficulties, and the use of meeting minutes to record proceedings.

Participants were critical of the timing of planning initiatives, suggesting rehabilitation staff initiated discharge planning efforts too late in the rehabilitation process and, consequently, too close to the point at which the injured relative was to return home. As a result, family members had insufficient opportunity to process information provided by staff or to explore the implications of any options presented to them. A number of participants, for example, indicated they would have liked to have explored alternative discharge sites but, because of time constraints, had needed to make an almost instant decision about this important aspect of their own and their relative's future.

One mother, with an extensive medical background, was particularly dissatisfied at the standard of discharge planning she had observed following her son's TBI, arguing that practitioners often overlooked the importance of beginning discharge planning efforts early on in the rehabilitation process:

*Not when you start to say: 'This guy's making good progress, he should be home early next week'. That's too late [to begin discharge planning]! Far too late! It's got to be a gradual process so that [families] can take the information, they can go home overnight, think about it overnight, create their questions, come back with their questions. If you want to impart information, you give it from day one and slowly impart it. It's too late when they've got the person home and they've got all these questions they haven't got the answers for! It's got to be done a lot earlier!*

This mother's sentiments echo those expressed in the literature, where the importance of early attention to discharge planning is emphasised (e.g. Dash, et al., 1996; Durgin, 1989; S. D. Foster, 1988; Levesque, 1988; Ministry of Health, 1993; North et al., 1991). The tendency for practitioners to leave the commencement of planning initiatives until discharge is near appears to be a fairly common practice, however, with authors such as Greer et al. (1992) suggesting families are often bombarded with information just as their

relative leaves an inpatient facility - information they are consequently ill-equipped to absorb, let alone process. Beginning earlier enables information to be provided and options explored through a series of meetings rather than on a one-off basis.

Concerns were also expressed by participants in regard to the emotional demands meetings placed on them. Participants acknowledged that a certain proportion of these demands was largely unavoidable - a reflection of the traumatic nature of the situation as a whole - with family members' emotional responses to the TBI almost inevitably carried over into meetings. Concern was expressed, however, that practitioners did not appear to be uniformly aware of, or sensitive to, the emotional impact meetings had on family members. An example commonly cited involved the distress attached to discussing what were often highly sensitive and upsetting topics, distress further compounded by the presence of practitioners who were unknown or only vaguely known to family members and who were sometimes perceived to be present in intimidatingly large numbers.

The perceived power differential between staff and families added to the distress felt by some family members (see chapter 9). Family members, particularly those inexperienced in medical settings or in dealing with large organisations, described feeling intimidated by the perceived differences in status. One such father stated that his lasting impression of the Rehabilitation Centre was of *"a group of people in white coats"*, people whom, he suggested, spoke *"past us, across us, [and] over us."* He described his family's experiences of planning meetings as involving the family *"[sitting there] like bloody idiots thinking 'Well, what the hell is this?'"* In such cases, participants tended to withhold comments and questions.

A belief was expressed that planning meetings were used simply to inform families of decisions already made by staff, rather than to provide families with an opportunity to have genuine input into their relative's rehabilitation. Thus, the very process designed to enhance families' sense of involvement and competency left them feeling disempowered and estranged from their relative's recovery. Families responded in a variety of ways: by adopting a passive role in the rehabilitation process; by avoiding discussion of potentially

controversial issues as much as possible; and by indicating their support for plans or decisions made when they actually opposed them, with the intention of developing and implementing their own 'more suitable' plans post discharge.

The Rehabilitation Centre's policy of including the brain injured individual in planning meetings wherever possible was also criticised by some participants, who found their relative's presence inhibited their own dialogue with staff. While those interviewed tended to endorse their relative's right to have input into the decision-making process, a commonly-held belief that it was important not to upset the injured individual caused family members to withhold comments and questions which they feared might provoke a negative or angry response from their relative. Consequently, a considerable number of their concerns went unspoken.

None of the participants interviewed indicated they had attended a meeting of the rehabilitation team without their relative being present, although many indicated that such an opportunity would have been welcomed. One family expressed a certainty that Rehabilitation Centre staff would not have agreed to such a meeting, based on their experiences of having been refused information on their son's condition on privacy grounds. References were made to conversations between family members and rehabilitation staff without the injured relative being present but these were often spontaneous rather than planned occurrences and typically involved a single practitioner rather than the team.

As was the case with the utilisation of emotional support, a variety of logistical factors made the reliance on discharge planning initiatives based at the Rehabilitation Centre problematic. Some families were unable to attend meetings at the Rehabilitation Centre, either during working hours or at all, and the alternatives to face-to-face communication were rarely considered adequate. Families who telephoned often found that staff were unavailable to talk, either because staff were busy or off-duty, or that staff were unable to divulge information for reasons relating to privacy legislation. None of the participants indicated that staff had offered to meet with them away from the Rehabilitation Centre.

Proceedings of planning meetings were recorded in formal minutes, copies of which were, according to a rehabilitation staff member interviewed, forwarded to each team member. The minutes were considered by staff to be an important tool for ensuring decisions made were followed through and a key reference point for team members at later points. Of those family members who attended a planning meeting, however, only 44% indicated they had also received a copy of the associated minutes.

Participants tended to be less supportive of the use of minutes than staff, with one mother stating,

*Often [minutes are] full of jargon. Often very ambiguous. Written because, when you write minutes, in particular, you write them in minute fashion. They're generally shortened, so they can often be misinterpreted. If you're party to the meeting, you can know the background to what was said. Someone else picking it up will say 'Doesn't even make sense. What do they mean?' And if you're a relative who's under stress and is emotionally involved, often [you'll] read into it more than what's said. Even if [you've] been party to the meeting, when [you] see it in print, [you'll] read it and say 'I didn't agree to this' or 'I didn't do this', or 'I didn't do that'. 'I didn't hear them say that'. ...There needs to be follow-up to ensure... it's like teaching kids at school... it's that reiteration and confirmation that the information has been received... has been interpreted correctly.*

This dissatisfaction was reflected in questionnaire findings. Of the small group of participants who reported having received a copy of the minutes, 25% rated them as being of minimal use and 75% rated them as being somewhat useful. None rated them as being extremely useful. The general message from participants was that minutes were 'better than nothing' but inadequate as a complete solution to their needs.

This lack of support for minutes was evident in their subsequent treatment by participants post discharge. Amongst those interviewed, only one of the family members who had received minutes reported having referred back to them after their relative returned home. This mother described doing so on only one occasion, out of interest, to compare the

assistance she was told would be provided post discharge with the actual experience. In general, the interviewees perceived them to be of little practical use to either the injured relative or their family.

## The Discharge Process

### Weekend discharge

A rationale. The practice of discharging brain injured individuals to their family home for short visits prior to final discharge is consistently advocated in the literature (e.g. Diehl, 1983; Grinspun, 1987; Guth, 1996; J. Johnson & Higgins, 1987; Rao et al., 1986). As well as providing the injured individual with an opportunity to generalise what has been learned in inpatient treatment to their natural environment, families gain an insight into what their lives and their relatives' lives may be like after final discharge. Deficits which may not be so readily apparent in the highly-structured inpatient setting may become more obvious in a home environment, thus helping families to appreciate the magnitude of damage which has been sustained and to counter denial, where present. Home visits also reveal potentially problematic areas and, because the injured individual is still technically an inpatient, family members (at least theoretically) have access to professionals who can then assist them in developing and implementing counter-strategies prior to final discharge. Thus, home visits are potentially a key component of the preparation process.

Within the Rehabilitation Centre, home visits serve a somewhat different purpose to that which is described above. Operating practices at the Centre require that the Centre is closed from late Friday afternoon to Monday morning and that all inpatients be accommodated in alternative settings over weekend periods (see chapter 5). Consequently, returning inpatients to their family homes during weekends is for the convenience of the facility and is not introduced when each individual and their family are ready, nor as a part of a process of planned discharge. In spite of this key difference, compulsory weekend releases can still potentially aid in the recovery process in the same way that planned home visits for therapeutic rather than cost-saving reasons can do. For this reason, the

components of planned pre-discharge visits are relevant within the Rehabilitation Centre setting (Freeman, 1997; Grinspun, 1987; Guth, 1996; Rao et al., 1986).

Family members' experiences of weekend discharge. The Centre's practice of weekend home visits was generally perceived by family members to be financially motivated and not a specific and purposeful component of an overall rehabilitation plan. This perception was reflected in the sense of inevitability displayed by participants, who often felt obliged to take the injured relative home, irrespective of whether or not they actually wanted to or felt ready to. One mother commented,

*For the weekend, they said 'He can go home or he can go back to the [Geriatric] Ward'. Well! Do you send your child to a geriatric ward where there's absolutely no stimulation and nothing to do or do you let him come home?*

There was no evidence of the planning for pre-discharge visits advocated in the literature. The descriptions provided by participants during interviews suggested, at that early stage, visits were simply 'muddled through' and survived as best as possible, in clear contrast to Grinspun's (1987) recommendation that goals be formulated prior to the first temporary discharge to help families understand the visit's purpose and guide the activities which occur. Grinspun further recommended that family members receive instruction on common TBI sequelae and their outcomes and on basic patient management techniques prior to the first home visit. Again, there was no evidence that this occurred, with participants struggling to understand and cope with their relative's behaviour. Participants appeared to have particular difficulty distinguishing between behaviour which stemmed directly from the brain damage sustained (i.e. organic), behaviour that was an emotional response to the brain injury itself and, in some cases, behaviour that was 'normal' for their relative. This confusion had a negative flow-on effect on patient management strategies utilised, with family members unsure which behaviours to tolerate ('because their relative couldn't help it') and which to challenge ('because their relative could').

Participants also indicated they had been given little guidance in the area of patient care. One mother, for example, was aware her adolescent son wanted privacy while showering

but was unsure if he could be safely left unsupervised in a glass shower cubicle in view of his coordination disturbances. A similar theme emerged in Stebbins and Leung's (1998) research, with 88% of family members whose relatives were brain injured less than two years previously indicating they had required assistance in deciding how much to let their relative do independently, with only half reporting this need had been met.

The injured relative's return home is typically a time of learning, often characterised by a 'trial-and-error' approach to problem solving (Blazyk & Canavan, 1986). This was evident in the present study, with families needing to judge for themselves the potential seriousness of different situations and incidents and determine how best to respond to them. Family members described needing to give their relative the freedom to attempt a particular activity before being able to determine the extent to which it was actually safe for them to do so - a stressful and frightening experience for many participants, particularly as they often appeared unsure if this was an appropriate response on their part. For this reason, Blazyk and Canavan emphasise the importance of ongoing professional monitoring through this difficult and stressful phase.

The lack of assessment of the home environment prior to the initial discharge further contributed to the difficulties families experienced in identifying potential risks and possible approaches to management. Home visit programmes described within the literature consistently advocate that assessments of the home environment be conducted and necessary modifications made before the injured relative's return home for a temporary visit (e.g. Gronwall, et al., 1990; Guth, 1996; Rao et al., 1986). In spite of the injured individuals represented in the study experiencing high levels of ongoing difficulty with physical functioning (see chapter 7), very few participants indicated their home had been assessed by a professional to determine whether their relative could manage. The few instances where assessments had been conducted were just prior to final discharge rather than prior to weekend releases.

At the same time, enormous improvement in physical functioning is common post TBI and modifications to the house (often complicated and costly) may later prove unnecessary. In

the current health environment, alterations which may only be necessary for a short period of time may be difficult to justify. This can place families in an extremely difficult position, however, as they are expected to allow their relative to return home for weekends but are unable to ensure their relative's mobility and safety needs will be met. The situation illustrates one of the disadvantages of very early pre-discharge release.

Medication comprised a particularly problematic aspect of patient care for some participants. In spite of the literature's emphasis on educating family members about medical conditions and the proper use of medication prior to the first home visit (e.g. Grinspun, 1987; Rao et al., 1986), participants interviewed commonly considered they had been inadequately informed of their relative's medical needs, although participants did vary in their medical knowledge and the amount of information they required. One mother described how her son had been placed on a new drug regime on a Friday, just prior to his being sent home for the weekend. Over the weekend, he began to dribble, slur his speech, and went on to lose his coordination and balance and became increasingly drowsy. The highly alarmed family contacted the hospital and were told they had to keep their son at home for the remainder of the weekend and were left to monitor his condition themselves. The mother added that the dose was later reduced to one tenth of the initial dosage.

### Final discharge

Families' perceptions of discharge. The literature suggests family members vary extensively in their views towards final discharge. Some interpret discharge as a sign that things are 'back on track' or even that a full recovery is imminent, while others are distinctly pessimistic, interpreting discharge as a sign of failure, that a plateau in progress has been reached or that practitioners have given up on their relative. Views between these two extremes are also evident (Blazyk & Canavan, 1986; Brown & McCormick, 1988; M. A. Foster & Carlson-Green, 1993; Hubert, 1995; Kneipp, 1991; Lezak, 1986; Muir et al., 1990; Rosenthal, 1989; Stambrook, Moore, Gill & Peters, 1994; Zeigler, 1987)

Participants in the present study displayed a range of reactions to their relative's impending discharge as varied as those described above. Some indicated they had expected life would



return to pre-injury normal, while others anticipated that changes to their previous lives might occur. In both cases, however, it was common for participants to look forward to their relative's return home. One mother commented, for example,

*All we wanted to do [was] to get [our son] home and nurture him. You've got him. He lives, you know, there's hope. Try and get him back into the family situation as quick as possible, I think. That's all I wanted.... Get him home. Love him and make him feel wanted.*

A number of participants believed the Rehabilitation Centre had failed to meet their relative's rehabilitation needs and, while they may have had mixed feelings regarding their relative's return home, encouraged their relative's discharge because it meant they could remove their relative from that environment. In one such case, the mother simply told the rehabilitation team,

*'I'm taking him home'. [My son] wanted to leave, [I] thought it would be good. I could see he was frustrated. I could see that he would probably work harder and better if he wasn't there. It was a bit of a risk because I didn't know how safe he was, and [the Rehabilitation Centre staff] had quite definitely said they didn't think he was safe, but I was prepared to take that risk.*

Another father described making the decision to bring his son home and “*endure the trials that were coming*”, after concluding the practitioners involved in his son's rehabilitation were incapable of providing any useful assistance either to his son or his family.

Some suggested staff had given up on their relative, usually because of a perceived inability to cope with, or make progress on, problematic aspects of the individual's functioning. In this context, discharge was seen as an expression of professionals' lack of ability and commitment to the injured relative's recovery. One family suggested staff had failed to make any progress with regard to their son's ongoing abuse of drugs and alcohol and, rather than make a greater effort or involve appropriately skilled practitioners, simply discharged him so he was no longer ‘their problem’. The father in this family stated,

*At the end of the day, [the Rehabilitation Centre staff] were happy as hell to see the back of [my son]. You know, the sooner they can get rid of them, the better they like*

*it. And they, you know, don't make any secret of that. They don't actually say it, but it's pretty obvious.*

A punitive theme also emerged during the interviews, with a number of family members suggesting there had been an element of punishment in the decision of rehabilitation staff to discharge their relative - a consequence of their relative's behaviour and/or their own. Some questioned whether their relative was at fault for having a non-compliant attitude towards staff or towards different rehabilitation initiatives, or whether they themselves were to blame for having challenged or questioned staff, in both cases revealing a belief that their relative may have received a greater amount of treatment or for a longer duration had they/their relative been 'more liked' by Centre staff. Certainly there was a clear perception amongst participants that staff had resented their presence at the Rehabilitation Centre - at least one family member in each of the interviews spontaneously used the term "nuisance" to describe the way they believed staff perceived them. Blazyk and Canavan (1986) similarly identify a tendency for families to ascribe discharge to a possible alienation of practitioners, adding it is particularly apparent in situations where the level of recovery achieved at discharge is less than that anticipated by the family and especially amongst those who anticipated a cure. In this event, there may be a sense that the hospital has failed in its perceived duty to 'fix' the patient.

The variations in responses of family members to the injury, and in the extent to which family members have adapted to the TBI at time of inpatient discharge, mean there will always be a portion of family members who expect their relative to leave inpatient rehabilitation 'cured' or, at least, expect their relative to achieve an unrealistically high level of recovery. In this event, the absence of such an outcome will often be interpreted as a failure on the part of the professionals involved. Many of the participants interviewed still believed, and were very angry, that the level of recovery achieved at discharge could have been much higher had staff been willing, for whatever reason, to make a greater effort.

Such a situation seemed to indicate a lack of understanding amongst participants about the nature of recovery from TBI and the associated continuum of care. This lack of understanding was also evident in the general lack of awareness displayed by some participants of the Rehabilitation Centre's place in the continuum of care. Complaints were made about the decrease in intensity of services provided in acute care settings and in the Rehabilitation Centre - in some cases, strongly-worded criticism, as was the case with a mother who described the move from acute care at one hospital to the Rehabilitation Centre as being *"like going from a five-star hotel to a backpackers!"* This highlights a need to ensure families comprehend both the nature of the recovery process and the concept of a care continuum, and that they understand the relationship between the two. Families should not be surprised that their relatives are discharged from inpatient rehabilitation before a 'complete' recovery is achieved. A complicating factor, however, was that for a seemingly large proportion of participants, inpatient discharge was the end of their relative's formal rehabilitation input. Other community-based services did not 'pick up' where the Rehabilitation Centre left off and it is subsequently difficult to talk about a continuum of care in this context.

It is not particularly surprising, therefore, that so many participants directed their frustration and anger at Rehabilitation Centre staff: given that in so many cases the Rehabilitation Centre was the only brain injury-related organisation family members had been in contact with, what other targets did they have? From the perspective of families, if Rehabilitation Centre staff had allowed their injured relatives to remain an inpatient for longer, which some family members wanted at the time and considerably more felt in hindsight would have been appropriate, their injured relatives would not have returned home as disabled as they had. It would seem almost inevitable in this context that families would search for possible explanations as to why staff chose to discharge them at the time they did: funding; lack of concern; incompetence; a dislike of the patient or family, and so forth.

Discharge site. Immediately following inpatient discharge from the Rehabilitation Centre, 88% of the injured relatives represented in the study went to live with family members, a

proportion consistent with other figures reported in the literature (Kraus et al., 1984; Livingston, 1985; Muir et al., 1990; NZHIS, 1993). Another two individuals, both of whom had injuries their families rated as severe, went flatting in Palmerston North, while a third ran away from the Rehabilitation Centre and stayed in a backpackers hostel. Only one participant indicated their relative was discharged directly to another, longer term, rehabilitation facility (Pukeora). Overall, 97% of participants indicated their relative had lived with them at some point since leaving the Rehabilitation Centre, and 53% indicated their relative was still living with them at the time of the study.

In many cases, there appeared to have been little consultation between staff and family members as to the range of living options available post discharge. Participants often reported they themselves had simply assumed their relative would return home with them post discharge and that this assumption had gone unchallenged by practitioners, reflecting the general absence of discussion of options described earlier in regard to discharge planning meetings. While initially many participants were happy for their relative to return home, some were not. Lack of awareness of alternatives meant these family members allowed their relative to return home only because they did not realise there could be other options.

Two of the families interviewed reported having been informed of an alternative discharge site by Rehabilitation Centre staff; in one case, Pukeora, the now-closed slow stream rehabilitation facility in Waipukurau, and in the other, the Drug and Alcohol rehabilitation facility at Queen Mary's Hospital in Hamner Springs. In both instances, however, the families were unhappy with the way in which the options had been presented to them by Centre staff and with the lack of opportunity available to them to fully explore the merits of each option, thus preventing them from making an informed decision. One mother described her experience,

*After [my son] had been in rehab for nearly a year, they started suggesting he go to Pukeora. It was almost like 'That's the only choice you've got' and 'We think it's best for you'. I felt, I would have liked for it to be a more consultative thing. 'If he comes home, this is the pattern that might happen. If he goes to Pukeora, this is*

*what might happen'. Any other options that there might have been. And then for us to be given all that information and for us to be able to decide rather than being told: 'And even if you don't like it... that's what you should do' sort of stuff... I don't know. We've, we've all got quite strong feelings about how that was dealt with but I don't know that we could put our finger on what it was that we really didn't like. We just felt uncomfortable with the way it was handled. And the way we were handled.*

The benefit of hindsight led many of the study's participants to regret encouraging, or allowing, their relative to return to the family home after leaving the Rehabilitation Centre. Even amongst those participants who had chosen to remove their relative from the Rehabilitation Centre earlier than recommended by Centre staff or who had supported their relative's decision to leave, there was a very strong belief that the family home had not been an appropriate discharge site for their injured relative at that point.

The proposed discharge sites subsequently described by participants are similar to those described in various publications which examine elements of an ideal brain injury service and reflect the diverse and complex needs of this population (e.g. Higham & Phelps, 1996, 1998; Oddy et al., 1996; J. Wood, 1995; NZHIS, 1993; Cole, Cope & Cervelli, 1985). Some were highly regulated facilities which provided constant supervision and considerable structure, sometimes physically removed from the influences of the individuals' previous lives, while others involved more flexible environments, such as group or one-person flats with support people. While some participants considered such facilities or services to be temporary measures, in between inpatient discharge and the injured individual's ultimate return home, others viewed them as more permanent arrangements, reflecting the high level of ongoing care required by the individual, the desire of family members to get on with their own lives or, particularly in the case of brain injured youths, the usual progression to independent living.

Community reintegration. Limitations of the discharge planning process became most apparent to participants when they attempted to facilitate their brain injured relatives'

reintegration into the community. Participants were generally uncertain as to what they could, or should, reasonably expect from their relative on the return home or the extent to which their relative could be expected to resume participation in activities within and outside the home. While participants were often able to identify general goals or preferred outcomes for their relative, for example, 'having a job they enjoyed', or 'fitting back into the family', few appeared to know how these outcomes might be achieved.

At a practical level, many families were left wondering what their relative should be doing each day. It rapidly became obvious to some participants that their relatives were unable or unwilling to develop their own plans. Examples were given of individuals who, left alone, would sleep for large parts of the day, watch endless television, or wander without an apparent aim. One mother described how her son would sleep most of the day and, upon rising, go to the local pub until closing time or until he ran out of money. Similar scenarios are reported in the literature with depressing frequency.

Families responded to the difficulties encountered in a variety of ways. One of the families interviewed, at least in the short term, adopted a highly reactive stance, simply following any instructions they were given by outside sources. The parents described being informed by their son's school that their son must resume his schooling immediately following inpatient discharge and, while they preferred to delay his return to College until he recovered further, conformed because they were unaware of any alternative options and had no idea how to proceed with finding out. The youth needed silence, space and considerably more time than other students to carry out set exercises, and was unable to cope in an environment which required him to change classrooms every fifty or so minutes. He became increasingly unhappy and distressed and frequently ran away from school, on one occasion hitch hiking from Wanganui to Palmerston North before the School realised he was missing. Eventually, he and his parents made the decision to remove him from school altogether. In the six or seven years since this time, according to the parents, their son has been on a sickness benefit, wandering "*aimlessly*" around the country, "*going nowhere*" and "*wasting his life.*"

Other families, recognising the need to implement a plan in order to help their relative (re)establish some sort of meaningful life, devised their own programmes, albeit with varying degrees of success. Virtually all of the injured relatives of family members interviewed were either unable to resume their prior occupations (although this was not always recognised immediately), or had yet to establish a career (as was the case with adolescents injured). In both scenarios, family members reported their relative needed to develop suitable work habits before participation in the workforce became a realistic possibility, for example, learning to interact in a socially appropriate manner, being physically presentable, punctual, reliable, and so on. Family members described being the primary or sole source of assistance to their relative in this process of skill acquisition.

As part of the plans developed, families helped the injured individuals set vocational goals which were then translated into a programme of specific activities to be performed on a day-to-day basis. Sometimes the approach taken involved the identification of a job suited to the injured individual's abilities at that time, with the individual starting the position as soon as they and their family considered they were ready. In one such case, the mother, believing her son was unlikely to be able to participate in competitive employment, arranged for him to carry out odd jobs for several local businesses on a part time basis, such as delivering mail and make the tea. The son, now much older, continues to carry out these same activities and it is anticipated by the mother that this arrangement will be ongoing. Because the researcher did not meet with the adult son, it was not possible to gauge the extent to which these activities satisfied his ambitions or reflected his capabilities, although the mother expressed her satisfaction with the arrangements and indicated her son was fairly content with his life. The non-involvement of professionals and the absence of specialist vocational input has been a continued feature of this family's post discharge life.

In other cases, families recognised a need for their relative to formally retrain for a more suitable occupation, requiring family members to identify appropriate courses and, in some cases, convince the relevant institutions to allow the brain injured individual to enrol.

Practical details also needed to be worked out, such as obtaining funding to meet the cost of the courses and resolving logistical details regarding travel and so forth.

In addition to providing practical support, families often needed to expend considerable energy building their relative's self confidence before the relative would contemplate participating in any form of vocational activity. One of the mothers interviewed described how her son had been told by a rehabilitation practitioner that he would never be the same as before the accident, which he had interpreted to mean he was essentially unemployable and unlikely to accomplish anything of significance in his life. His confidence, severely diminished as a result, was further decimated by his early, unsuccessful, attempts to obtain employment in areas similar to those he had performed prior to his injury - a period in which he had refused to acknowledge his inability to perform his premorbid vocational activities.

His family worked hard to help him regain skills they considered fundamental to vocational retraining, such as attention and concentration, literacy and numeracy skills, and behavioural management skills. They identified a suitable correspondence course and personally paid for him to participate, even though they privately felt the course itself had little academic merit, in the hope that successful completion might enhance his confidence and self esteem. While their relative required almost continuous support to complete the course, the resultant boost it gave to his confidence meant he was willing to undertake another, more advanced course training as a fitness instructor. Again, his family needed to help with his application, arrange funding and accommodation while attending the course and so forth, and provide almost continuous support to help him through the process. His mother commented,

*I had to talk him through the course the whole time he was up there. The first week was okay, but the second week they started into areas he didn't know much about, and he just... By the third week he wanted to come home on the first plane. And I was at work and he was calling me, toll calls, every half hour. And I literally had to talk him into staying. Saying 'Yes, you can do this!'. And he did stay and by Sunday he started to feel confident again.*



Obtaining compliance of the injured individual in vocational rehabilitation activities proved to be a challenge for some families, even in instances where the individual had been an active participant in the planning and implementation phases. As with other areas of patient management, the lack of professional input necessitated the use of a trial-and-error problem solving approach. The young man described above, who retrained as a fitness instructor, went on to obtain casual employment at a local gym. In conjunction with his own personal gym training, this employment became a critical component of his daily routine, boosting his self esteem, helping him manage ongoing problems with depression, providing him with a structure to his day which helped regulate his sleeping patterns and, in turn, improving his behavioural management.

The flexibility of his position at the gym, however, meant he was able to, and regularly did, decline offers of work. When that happened, he would sleep late, quickly altering his sleeping cycle, becoming increasingly agitated, prone to violent outbursts, and ultimately depressed and suicidal. His family were, and continue to be, enormously frustrated because they recognise his need for stability and structure and know that alterations to his routine have negative repercussions for the whole family as well as for him. Yet they were, and still are, unable to force him to accept offers of work or to adhere to his routine.

Parallels were evident between participants' experiences of vocational rehabilitation and of social and leisure-oriented community reintegration. The majority of injured relatives (79%) experienced at least some degree of difficulty with social activities post TBI, and a diminished social circle appeared fairly common (see chapter 7). Again, little pre-discharge planning appeared to have occurred, with families indicating they had been largely unprepared for either the magnitude of difficulties to be encountered in this area or for the role they needed to play in facilitating social reintegration.

Similar to vocational activity, family members responded to their relatives' social needs in a number of different ways, with varying degrees of forethought and success. Some families embarked on quite intensive programmes aimed at increasing the size of the relative's social networks or the quality of their interactions. Others did little, or were

unsuccessful in their efforts, finding their relative and, in some cases, themselves increasingly isolated.

The communities in which participants tried to involve their relatives were also quite varied. Some chose to promote involvement in both the general community and the disability/brain injury community, while others argued the disability community was inappropriate for their relative or inconsistent with their relative's preferences or abilities. The injured individuals themselves also displayed considerable differences in their preferences for social partners and their beliefs as to which communities constituted their peers. According to participants, some of the injured relatives were vehemently opposed to socialising with people with disabilities or brain injuries specifically, arguing they had nothing in common and would only be with 'normal people'. Other individuals, frustrated by 'normal people's' lack of understanding, preferred to socialise with brain injured individuals, finding they were more aware of their needs and limitations. This variability in preferences has been noted in the literature (e.g. Hubert, 1995; NZHIS, 1993; Tyerman, 1997).

The reintegration of injured relatives into general family life has been described elsewhere in the thesis. Changes in the nature and quality of relationships were common between family members and the injured relative and between the non-injured family members (see chapter 7), as were role changes (see chapter 10). Similar to other aspects of community reintegration, participants were critical of efforts made prior to discharge to prepare them for these changes, indicating they had been given insufficient guidance in adjusting to their changed relative or in establishing appropriate ways of interacting (see chapter 10). In the words of one participant, family members were "*left to sink or swim*" on discharge.

Followup. The issue of post discharge followup by Rehabilitation Centre staff was covered only peripherally in the present study; although clearly a crucial aspect of the rehabilitation process, it was considered by the researcher to lie outside the study's 'preparation' focus. Its brief inclusion here serves primarily as an acknowledgment of the integral part post

discharge followup plays in the rehabilitation process - a view endorsed by those participants who referred to topic during the course of the study.

According to Dash et al. (1996), there should always be some protocol for patient follow-up, regardless of where the injured individual is discharged to. Incorporating followup appointments into the discharge plans can help reassure families that they are not being abandoned by practitioners, as well as provide opportunities for practitioners to monitor progress and respond to any problems which may have arisen (Blazyk & Canavan, 1986).

Only a few participants mentioned followup visits although, as stated, this is quite possibly a reflection of the study's focus rather than comprising an objective measure of their occurrence. In those cases where followup visits were described, the purpose appeared to be the conducting of final evaluations, for example, to determine capacity to drive and so forth.

The lack of ongoing contact between Rehabilitation Centre staff and families has already been well-established in the study. As one mother stated,

*No one rings [you] up a couple of days later and says 'Has any of this happened' or whatever. Once [families] walk out that door, it's almost like 'We have no further responsibility for you'. 'You're on your own'.*

The general theme which emerged was that families would have liked some form of ongoing contact with a rehabilitation professional, for example, a key worker, whom they could approach for information, guidance, referrals etc. As was previously noted, families in need of such assistance were frequently uncertain who to approach and, while some willingly sought help from the Rehabilitation Centre, others were unsure whether this was acceptable. One mother commented,

*I think it would have been really good if the services... even if [staff from the Rehabilitation Centre] had rung up... kept the name in. I know they've got all sorts of patients, people going through rehab but somehow you need that case management... keeping the name current. Having a 'bring up' somehow so it keeps*

*coming up... and saying 'I wonder how these people are getting on... We'll just give them a phone call'. Because there were times when I was just about up the tree! Yet he was not at rehab so it wasn't appropriate to ring rehab. It wasn't really a mental health problem so it was not appropriate to ring mental health. It wasn't the G.P.s problem either.*

## Conclusion

Discharge from an inpatient rehabilitation facility represents a significant milestone in the process of recovery from TBI, signalling it is now appropriate for the injured individual to move on to the next phase of the care continuum - returning to live within the community. Because post discharge life is characterised by reduced professional involvement, the move to community living necessitates a transferral of responsibility for the injured individual's treatment and care - typically from specialist practitioners to the injured individual's family.

It is also a time of significant adjustment. As the injured individuals attempt to re-establish themselves within the community, their families are required to resume activities suspended during the crisis phase, make alternative arrangements for those tasks previously performed by their injured relative and establish routines to meet the relative's new care and support needs. All these requirements mean that the discharge period can often be an overwhelming time for families. Planning for this time, minimising unknowns and readying families for what is essentially a highly uncertain future, is consequently a critical component of families' preparation for life with a brain injured relative.

Within the context of the present study, discharge planning appeared a process endorsed by Rehabilitation Centre staff, by hospital management and by the family members of brain injured inpatients. According to participants, however, the approach taken to discharge planning at the Rehabilitation Centre suffered a range of limitations, stemming both from the actual mechanism used for conducting discharge planning at the Centre and from the way in which the mechanism was applied within the Centre.

A substantial portion of participants indicated they had not attended a planning meeting and of those who did, a range of issues subsequently identified were considered by participants to have diminished the overall usefulness of the experience. The wider process of discharge was similarly problematic. Weekend discharges were a common source of contention amongst families and, while many were willing (and sometimes eager) to have their relative return home for these visits, it was common for problems to arise which stemmed from insufficient planning. Final discharge was a similarly mixed time for participants. A lack of genuine understanding of the rationale for discharge sometimes characterised participants' accounts of the event, with time often serving only to reinforce their (mis)impressions rather than to provide greater insight. Yet again, insufficient planning, in a wider context of inadequate preparation, made the process of community reintegration unnecessarily difficult for both the brain injured relatives and their families.

A call was made for more comprehensive examination of community reintegration issues during the discharge planning process, with greater emphasis placed on the exploration of alternative discharge sites. Further, participants wanted some form of protocol for followup with staff established prior to discharge, preferably as part of an ongoing relationship. Ultimately, such a system would help to reduce the feelings of abandonment and isolation which, for some, remained painfully acute years after their relative's injury.

## **CHAPTER 13**

### **CONCLUSIONS: PROGRESSING A MODEL OF FAMILY PREPARATION IN A COMPLEX SOCIAL, POLITICAL AND ECONOMIC CONTEXT**

The process of preparation was, for the purpose of the present study, viewed as separate from the ongoing assistance required by families over the longer term, with the line between the two drawn at final inpatient discharge. Preparation was conceptualised as taking place while the injured relative was in the hospital environment, specifically the Rehabilitation Centre attached to a public base hospital, in readiness for inpatient discharge. In practice, this division is somewhat arbitrary. Families' need for input at all stages of the recovery process necessitates an overall package of assistance, encompassing both predischARGE preparation and ongoing input, characterised by a seamless transition between different services' inputs. The decision to focus on preparation over ongoing support stemmed largely from a belief that a more comprehensive understanding of preparation might be used to bring about fairly rapid improvement in families' experiences of brain injury, at least more rapidly than improvement which depended on substantial changes in the number and range of services provided. In other words, in the context of an incomplete continuum of care, effective family preparation might still occur, with better outcomes for both the injured relative and the family.

To meet the aims of the study, information was obtained on families' experiences of life with a brain injured relative, identifying the steps family members believed had been taken to prepare them for life with a brain injured relative, how family members felt about these preparation efforts, and how the preparation process might be improved should family members feel improvement was required. The present chapter discusses major findings in relation to family preparation as a whole and describes an empirically-based model of family preparation. This model is then reviewed in light of the social, political and economic contexts in which it is to be applied, and a pragmatic approach to the preparation of families described. The chapter concludes with a discussion of the study's limitations and recommendations for future research.

## Families' Experiences of Brain Injury and their Preparation for Life with a Brain Injured Relative

The study revealed a range of post discharge experiences amongst participants, mirroring those reported in the TBI literature for families generally. Brain injury affected multiple aspects of family members' lives and evoked responses which, while often similar of nature, varied in terms of onset, duration and intensity. The tasks performed by family members post TBI were numerous, diverse and frequently fundamental to both their injured relative's care and their family's general wellbeing. While family members acknowledged they had a responsibility to their relative following brain injury, many considered the level awarded to them had grossly exceeded that which could be considered reasonable - by theirs or anyone else's standards.

The picture which emerged from the present study was one of families ill-prepared to meet the challenges associated with TBI, and dissatisfied with the efforts they perceived had been made to ready them for long term caring during the phase of inpatient rehabilitation. The only contrary view was presented by those participants whose relatives had achieved either a full recovery (as defined by family) or a level of recovery which resulted in few ongoing obligations on their part, so that there was little need for the knowledge, skills and support so desperately required by family members whose relatives did experience ongoing difficulties.

Families identified information as being a key component of preparation, yet were typically dissatisfied with at least some aspects: quantity; quality (e.g. accuracy, applicability, consistency); and/or the provision process itself (e.g. timing of information provision, opportunity available for family-practitioner communication, medium used, opportunity for privacy, general exclusion of family members in the rehabilitation process). As a result, families lacked understanding of brain injury and the associated rehabilitation process.

Training for the caregiver, case manager and therapist roles was also identified as a key component of family preparation. To varying degrees, family members needed to learn

practical caregiving skills, how to access services within the community, and what they could do in instances where the services required were not available. Few had acquired this knowledge and skill through the formal preparation process, instead doing so independently, through an ongoing process of information seeking and trial-and-error, if at all.

Family members were similarly critical of efforts made by practitioners to determine, and to cater to, their emotional state post TBI, with the majority also indicating they had been inadequately prepared to cope with the emotional burden arising from life with a brain injured relative. This situation was complicated by the tendency of family members to reject offers of assistance in coping with emotional burden, even when the assistance offered reflected participants' visions of an ideal support service.

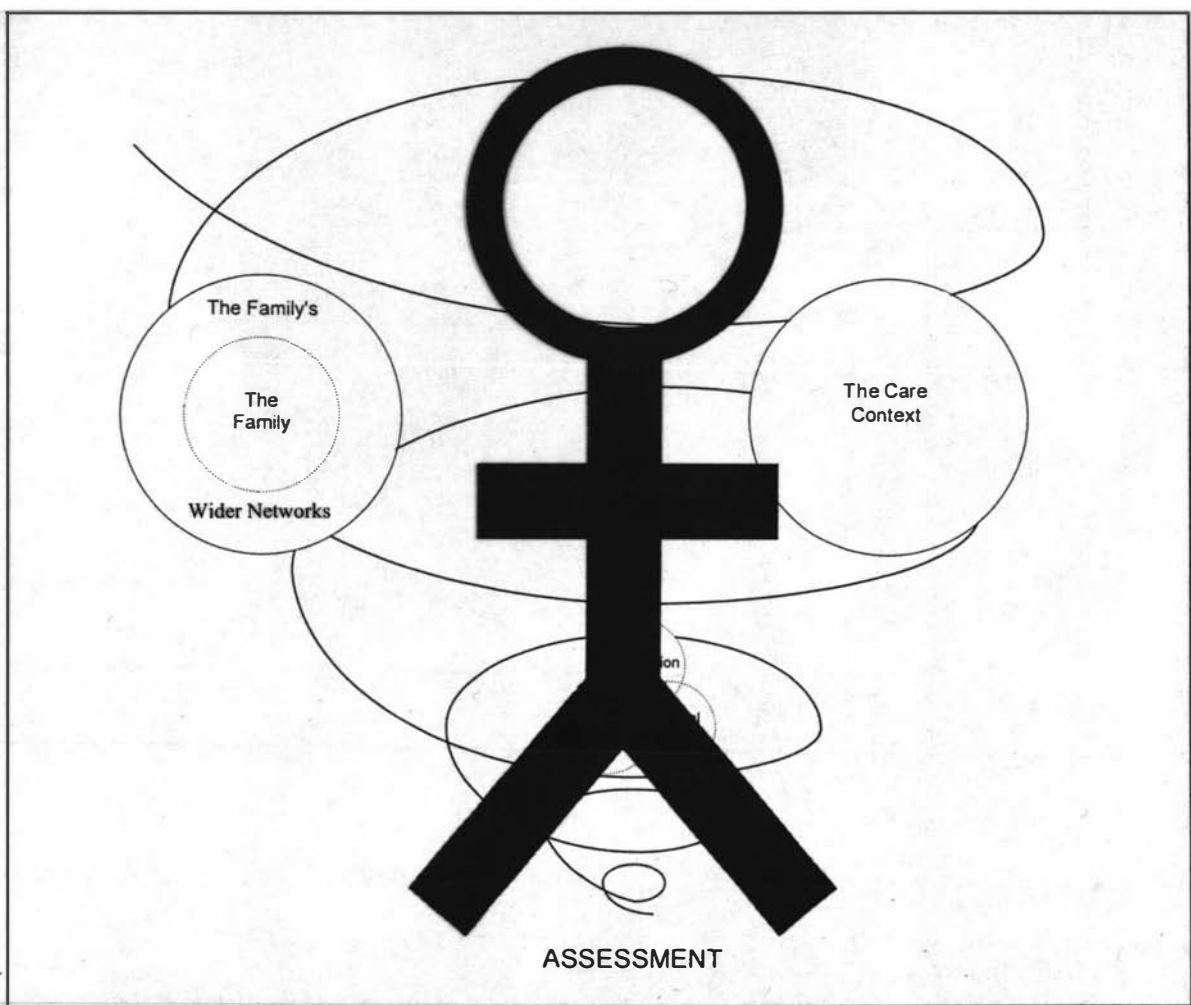
Discharge planning within the Rehabilitation Centre was another problematic area, both because of the actual mechanism used for conducting discharge planning by the Centre and because of the way in which the mechanism was applied within the Centre. As has been a dominant theme throughout the study, inadequate planning, along with inadequate preparation generally, meant families encountered challenges, first during weekend visits and then after final inpatient discharge, which they had little or no basis for understanding or managing.

Families' need for comprehensive preparation was heightened by the lack of post discharge assistance available. Family members were extremely disappointed that the preparation required had not been forthcoming during the time their relative had been an inpatient at the Rehabilitation Centre and, overall, were extremely disappointed with New Zealand's accident rehabilitation services. Certainly, they had expected much more in the way of assistance, both initially and over the longer term, than had been forthcoming after the relative's brain injury.



# A Model of Family Preparation

A primary goal of the present study was to develop an evidence-based model of family preparation for use in future preparation initiatives within the area of traumatic brain injury rehabilitation. The model presented here draws on both emergent themes in the present study and the literature, and depicts the elements and tenets of an ideal *system* of preparation. In that way, it differs from the more operational programmes presented in the literature which attempt to specify the precise topics and issues which need to be covered in an inpatient-based family education/training programme (e.g. Acorn, 1993; Grinspun, 1987; Hegeman, 1988).



**Figure 13.1 A model of family preparation**

### Components of the proposed model

The injured individual. The injured individual is an important element in the preparation model; it is the injured individual's abilities and needs that will determine the levels of assistance required. The individual is frequently seen in the context of the family. It is the family of the injured individual, however, in the context of their various networks and community supports, which is the primary focus for this model.

*Represented by: The injured individual is superimposed over the model, reflecting that the individual is fundamental to all aspects of the rehabilitation process. The separation of the individual from other components of the model reflects the model's primary focus on the family rather than the injured individual.*

The family. The family is comprised of interconnected elements (i.e. individual family members) and is part of a wider system which may comprise some of, all of, or more than, the following: extended family; friends; cultural, social, recreational, vocational, and spiritual networks.

*Represented by: The outer, solid circle around the family and their networks represents the totality of the family's networks at any one time. The broken line of the inner circle dividing the family from their networks represents the open system between these groups.*

The care context. The care context comprises the totality of professional and lay services available to a particular injured individual and their family at any given time, and the mechanism for coordinating those services. These services may be physically located in a variety of different settings, reflecting the need to travel to access some services. The services available will also change over time and, of those available, only some will be relevant to a particular family. Therefore, what constitutes the care context for a family is both a specific and dynamic phenomenon.

*Represented by: A closed circle*

The preparation process. The preparation process involves both members of the care context and members of the family and their wider networks. It is a non-linear process, with the knowledge, competencies and capabilities possessed by a family varying in a non-

uniform manner over time; this aspect of its nature is reflected in its spiral representation in the model. The links between members of the care context and the family are reflected in the overlap between the spiral and these two groups. Family preparation itself comprises, in varying combinations, the components of information provision, skills training, and support.

*Represented by: A spiral, encompassing the three components of family preparation. Each is surrounded by broken lines and each overlaps with the other components, reflecting their inter-connected nature.*

**Assessment.** Comprehensive assessment underlies every aspect of this model: assessment of the injured individual; the family (their social capital and needs); and the care context in which the injured individual and family will function post discharge.

*Represented by: Text, underlying the spiral preparation process which links the family and family networks with the care context.*

### **Tenets of the proposed model**

The process of family preparation is an interactive phenomenon, in that the preparation required by a particular family and by individual family members will vary, contingent upon the roles they will perform post discharge. These expected roles need to be clarified and articulated as early in the recovery process as possible. Decisions regarding the nature of roles to be performed by different family members need to be based on as much accurate information as possible about the injured relative's anticipated needs, the family's wishes and abilities, and the resources which will be available in the post discharge environment. In this way, the preparation process can be tailored to ensure families are prepared for the situation they will encounter and the anticipated demands associated with that situation. For example, in a low service area (e.g. rural), greater emphasis may need to be placed on family skills training, as opposed to a higher service area (e.g. a city), where the development of case management skills may be more relevant. This contrasts with the more common scenario of family members receiving a generic form of preparation which takes little account of their unique characteristics or the characteristics of their environment.

The need for comprehensive and accurate information necessitates assessment playing an integral role in this preparation model. Ongoing assessment and monitoring provides the information needed to tailor the preparation process to the specific circumstances of individual families. In the Rehabilitation Centre where the present study was located, the focus for assessment conducted during the inpatient phase was the injured relative. In this model, the focus widens to include the family - the strengths and capabilities they bring to the rehabilitation process as well as their needs - and the care context. Such an approach necessitates that those responsible for information-gathering possess the skills needed to conduct assessment on this broader scale; comprehensive training may be required before this is achieved.

Both of these domains - the family and the care context - are dynamic. Assessment, even repeated assessment during the inpatient phase, will only provide a snap shot at a particular point or period in time. Therefore a general goal of the preparation process should be to equip families for the situation which currently exists and to instill in them the skills to recognise and respond when changes in these domains occur.

The divisions between the three components which comprise the preparation process - information provision, skills training, and support - are somewhat arbitrary. In practice, a single act may include elements of all three components. For example, demonstrating a technique for managing an agitated individual may include a brief explanation of why the individual may become agitated (i.e. information) and encouragement of the family's capacity to manage the situation (i.e. support), as well as the obvious skill component. The relative balance of the three components will vary, guided by the unique characteristics of the given situation and, specifically, the nature of roles to be performed by the family members. Again, relevant variables would include the anticipated needs of the injured relative, the family's wishes and abilities, and the resources available in their environment.

The preparation process aims to optimise the ability of family members to facilitate favourable outcomes for both the injured individual and for the family, the underlying premise being that well-equipped families will be more capable of performing the tasks

associated with this function than families that are not well equipped. The desired output of the model therefore emphasises enhanced family capability. What can be achieved by different families, however, both during the time of inpatient treatment and over the longer term, is enormously variable and influenced by a wide range of factors. Further, what is achievable by individual families and family members is unclear at the outset. In this context, it is not possible to identify criteria or a target outcome relevant to all families. Consequently, the model takes an input/process focus, with the emphasis on ensuring the preparation process developed for each family incorporates the elements and characteristics described above. In this model, family preparation is an input- and process-oriented phenomenon rather than an outcome-oriented process.

### The Wider Context

The burden and cost to families assuming long term care of a brain injured relative is well established. It is also well established that the better families are equipped to assume care, the more positive the expected outcomes are likely to be for both the brain injured relative and for the family. This knowledge, however, has not always been translated into sound theory-driven practice.

The present study is not only one of the few conducted in NZ which address this topic, it has also been conducted during a period of radical and rapid change. The 1980s heralded an era of massive economic reform in NZ, emphasising fiscal restraint, market liberalism, free trade, and a narrow monetarist policy (Kelsey, 1995), reform which ultimately led, among other things, to the corporatisation and privatisation of state organisations and significant cuts in government programmes. Fiscal imperatives, along with a general ideological shift to the right amongst most political parties, were key instigating factors in those reforms (Boston, 1991; Rudd, 1991). During the 1990s, the Government sought to redesign NZ's welfare state, making radical changes across social welfare, health, accident compensation, housing, education, industrial relations and superannuation areas (Boston, 1992, 1999; Boston, Dalziel & St. John, 1999; Kelsey, 1995; P. McKinlay, 1990). At all

stages, neo-liberal theory, involving a move from collective to individual responsibility, has been applied (Kelsey, 1995).

The consequence of these changes regarding TBI is that family members are expected to assume care as soon as possible post injury and to carry the social and, to a slightly lesser degree, the financial cost of providing that care. While support is available, provision is tightly circumscribed and usually focused on the injured person, bounded by time, current institutional location and sometimes age of the injured person, rather than the person in the context of the family on which s/he depends. While the seemingly ungenerous and bureaucratic support is designed to minimise the cost to the public purse, should families burn out - a burnout largely attributable to the negligible support received by families and their battles with bureaucracies to obtain assistance - then society at large must assume an even greater cost and burden.

A dominant ethos is summed up in such slogans as 'core business' and 'sticking to the knitting'. Social services that had evolved in a demand-driven manner, becoming diverse and flexible to meet client needs, now divested themselves of services not considered 'core'. The task faced by families of negotiating bureaucracies increased accordingly in complexity and frustration, the more so when separation of funding and service provision, another key principle of characterising public sector reform, added to an already-complex web often involving multiple agencies. This scenario is illustrated through the case previously described, where life skills training for a particular brain injured individual was initially denied by ACC on the grounds that the agency able to provide the training had conducted the preliminary assessments which identified the need for training - a combined function forbidden by current funding regulations.

#### **A Pragmatic Approach to Family Preparation: Applying the Family Preparation Model**

The model above has outlined an approach to the preparation of families derived from the accounts of family members whom such a process is intended to benefit. The model was presented without acknowledgment of the social, political and economic contexts in which

the process of preparation actually occurs. Ultimately, however, the practical realities of these contexts cannot, and should not, be ignored. The question to be answered then is how, given the enormity and the pervasiveness of the constraints faced, can the theoretical model of preparation be applied in practice?

A reasonable aim is to reduce the divergence between existing practices (i.e. at the time of data collection) and those advocated through the model. In doing so, it is important to acknowledge that it is slower, more complex, and more demanding on practitioners to include families in the rehabilitation process and to conduct intensive processes of preparation, than it is to focus solely on the injured individual. In addition, educating family members about diagnostic and prognostic matters can encourage family members to develop sometimes unrealistic expectations for their injured relative and for themselves, a situation which raises professional, ethical and moral dilemmas.

At a micro (i.e. individual organisation) level, this approach can also be more expensive - problematic in light of the substantial pressure on health and welfare agencies to practise 'responsible' (i.e. minimal) spending. At the same time, however, substantial cost is likely to be incurred when families are ill-equipped and unsupported. When brain injured individuals fail to achieve their potential and their families burn out from the challenges of TBI, these costs are ultimately passed on to society. There are also costs to those working in the area, who experience their own conflicts as they struggle to reconcile organisational financial imperatives with professional training which typically advocates a humanistic, holistic approach. Taking a macro perspective, it becomes apparent that the costs associated with the recommended changes actually represent a redistribution of cost rather than new, additional costs. Further, many of the recommendations made are based on issues which are largely unrelated, or only loosely related, to the various constraints which have been discussed, thereby suggesting a potential for improved family experiences within individual organisations' existing constraints.

### Family involvement

The primary focus of the proposed model of preparation is the family. Making the family central to the activities of organisations explored in the study necessitates, in most cases, a considerable shift from existing practices. At a basic level, families need to be assured of their right to participate in the rehabilitation process and understand the ways in which this can be accomplished. Organisational policies on family involvement need to be developed, and harmonising these policies across the different organisations should ensure that families receive consistent messages about involvement and the value of their contributions through the various phases of recovery. A collaborative philosophy is needed that encourages practitioners to adopt a partnership model of practice with families, reflecting a move away from a 'culture of professional superiority' that pervades some organisations. Privacy legislation is currently used to exclude families; better knowledge of legislation amongst practitioners would help to ensure families are not excluded unnecessarily through an overly-cautious application of legislation.

The communities within which the injured individuals and their families exist play a key role in the provision of support and assistance over the long term. Under the proposed model, the preparation process would not only recognise these links but help families actively maintain, utilise and, where appropriate, expand them. Previously, Rehabilitation Centre staff were able to play a greater role in the injured individual's community reintegration process, for example, helping a brain injured youth's classmates prepare for the individual's return to school. A similar approach could be taken with the family, working with members of their wider networks to create a system of support to help them over the longer term.

To enable this broadening of focus from the individual to the family, a shift is needed in the allocation of resources. Under ACC's current policies, there are provisions to fund services for families, including counselling, providing that clear links can be established between the provision of services and the wellbeing/recovery of the injured individual. However, most of this assistance only becomes available after the individual is transferred to the



‘Serious Injury Team’, one year post injury, presenting a problem for the funding of inpatient-based family preparation initiatives.

Both the process of matching needs with services and the guidelines for funding such services need to be sufficiently flexible to enable families to obtain relevant assistance on a timely basis. Such flexibility in the management of claims is a key principle of the case management system adopted by ACC. The difficulties families in the study experienced in obtaining assistance for themselves, however, suggest problems currently exist in the translation of organisational policy to practice. Resolving the divergence between rehabilitation principles and ACC’s funding practices is central to many of the changes recommended here and, ultimately, to improved family experiences.

#### Planning and organisation of the preparation process

Comprehensive and thorough planning underlies effective family preparation. Through the planning process, relevant strands of information and people are drawn together to form a coherent and viable programme of family intervention. In the study, the approach taken to family preparation was considered to be *ad hoc* by participants, with initiatives variously criticised as unsuitable, untimely, and inconsistent in their underlying premises of families’ roles and capabilities. Greater attention to the planning stage should facilitate a more efficient use of resources and more successful family preparation than is currently the case.

#### Collaboration

Collaboration is central to the system of preparation advocated in this model. In the present study, the post discharge lives of brain injured individuals and their families were frequently characterised by an absence of involvement or by the untimely involvement of existing services. Closer collaboration between the lay and professional people who comprise the care context, and between these parties and families, might have substantially reduced the frequency with which this ‘falling through the cracks’ phenomenon occurred.

The placement of an ACC case manager at the Rehabilitation Centre emerged as an example of successful collaboration in the study, an initiative which greatly enhanced

ACC's visibility and facilitated ease of access between ACC and families. Further initiatives aimed at enhancing collaboration between service agencies would help to create a more integrated system of care. In conjunction with the development of an effective client referral mechanism - a mechanism patently absent in the context of the present study - it is more likely clients would receive relevant services on a timely basis, ultimately avoiding many of the isolation-based problems reported.

Effective collaboration might also help to circumvent problems arising from families' reluctance to accept offers of help. Headway, for example, may have secured greater family involvement in its activities had there been more awareness amongst family members of its purpose and of the potential benefits involvement could bring. Such an awareness could have been established through a more visible presence at the Rehabilitation Centre and active promotion of Headway's services by rehabilitation practitioners. With a role in the rehabilitation process more clearly defined and accepted than currently appears to be the case, Headway would also be in a stronger position to facilitate collaboration between families and provide families with the types of assistance they described themselves as having needed post TBI.

The extent and nature of collaboration within the wider service environment will significantly impact on the type of preparation required by families post TBI. In a well functioning service environment, with an integrated and effectively coordinated system of care, families and services are more likely to know of each other's existence and there is a reasonable likelihood that clients will experience a smooth transfer between different agencies. The demands on family members to facilitate such transfers themselves should therefore be considerably less than was the case for families in the present study, who struggled to function in the fragmented and somewhat disorganised service environment encountered. Consequently, family members' need to develop case management skills as part of the preparation process should be less in a collaborative environment.

The establishment of a more collaborative environment should also help to highlight existing gaps in service provision and, ideally, encourage organisations to organise their

services into a more coherent and streamlined care continuum. It will not, in itself, increase the number of services available and it is likely some families will continue to need training for therapist-type roles as part of their preparation. It should, however, help to ensure families and their relatives do not miss out unnecessarily on those services which are available.

In a discussion on community care practices, Means and Smith (1994) suggest it is tempting for social service agencies to “hide behind their difficulties”, blaming the State and pretending that no progress can be made in the existing climate (p. 234). However, some of the barriers to the establishment of a collaborative working environment do not stem from financial constraints but, rather, from professional, cultural and organisational boundaries. For this reason, considerable improvement is theoretically possible without significant increases in spending. Attitudes of professionals which hinder collaboration, for example, a distrust of other disciplines or agencies, can be altered through non-financial means, although financially-based incentives often do underlie strategies to foster collaboration (Means & Smith).

#### What constitutes a realistic outcome?

The desired outcome of preparation under this model centres on the readying of family members for life with a brain injured relative - life beyond inpatient treatment. What is actually achievable for any given family during the inpatient period, however, is as variable as the families themselves. The enormous differences between, and within, families: their educational and professional background; prior knowledge; coping skills; confidence; emotional state; readiness/willingness to participate in preparation-related activities and so forth, make it impractical to set uniform criteria for the measurement of ‘successful preparation’. There will be some families who will not be ready or willing to participate in preparation activities during the inpatient phase, regardless of the effectiveness or sophistication of the preparation mechanism in place. Kay and Cavallo (1991), for example, suggest there are some families who may not be ready for significant psychosocial interventions for several years post injury. Further, it is unreasonable to

expect that all families will be equally able to achieve mastery of preparation initiatives within the time frame allowed.

Aiming to equip families with all of the different knowledge and skills they might require post discharge, or expecting that families can be prepared for every situation they might encounter, are similarly unrealistic goals for any preparation process. Inevitably, unanticipated challenges will arise. Equally unrealistic is the expectation that 'successful preparation' will prevent families from experiencing difficulties or from becoming burdened by the tasks performed. No amount of preparation will achieve this. Client satisfaction presents considerable challenges as a measurement of outcome: even in ideal conditions, 100 percent satisfaction is an unlikely outcome for any type of family intervention. The distressing and unwelcome nature of brain injury, combined with the inability of practitioners to achieve what families really want - the return of their relative's pre-injury self - will invariably taint family members' perceptions of preparation efforts.

More realistic objectives would emphasis forewarning and the alleviation, rather than avoidance, of difficulties. Hubert (1995) acknowledges this in her own work, concluding,

None of these people, those who have been head-injured or their families, could have foreseen the extent of the disruption in their lives, but they could have been much better prepared. Forewarning, advice and continuous support from the beginning might not have eliminated stress and anxiety, but would certainly have alleviated them. (p. 104)

Family members may not possess all of the knowledge and skills they will ultimately require at the time of their relative's inpatient discharge; however, it is reasonable to expect they will know where to go for the assistance they require. In instances where that assistance is not directly available, established links with other organisations, and particularly with other families, would help them to determine how to proceed. In this way, it might be possible to avoid the 'reinvention of the wheel' phenomenon that so frequently characterises families' efforts in the area of brain injury.

Yet again, the crucial role of ongoing assistance, and the indivisibility of family preparation from that ongoing assistance, emerge as key themes. The limits to what can be achieved during the short period of inpatient rehabilitation necessitate that education, training and support continue to be provided to families over the longer term. How families ultimately fare, however, is inextricably linked with their early experiences and the guidance received.

### Study Limitations

Methodological issues, including sample and researcher bias are discussed, as are the ramifications of data aggregation and the generalisability of findings.

#### Sample bias

Number of participants. Although the response rate itself (41.2%) was considered satisfactory, the final number of family members participating in the study was less than that hoped for. Ultimately, the low number of participants imposed constraints on the nature of analysis which could be conducted, particularly attempts to compare responses of different participant subgroups. However, when considered within the wider context of the recruitment process - the convoluted process by which potential participants were contacted and the high probability that a proportion of participants included as 'non-responses' never received the invitation to participate - the rate is less disappointing. Given the ethical and practical constraints associated with access to medical records, it is difficult to perceive how more effective (i.e. direct) access to family members could have been assured without asking greater involvement of rehabilitation staff - problematic in light of their existing high workloads - and without unfairly excluding the brain injured individuals themselves.

Non-response bias. Over half of the participants did not respond to the questionnaire mailing although, as has already been discussed, the exact number who were not reached, as opposed to actually refused, is not known. The characteristics of those who did not respond are also essentially unknown. While there were very few male participating family members, or family members in relationship groups outside mother/spouse roles, this is typical for the brain injury caregiving population generally, as for most other caregiving

situations. It is unlikely that other relationship groups, such as fathers or sons, would have been represented in large numbers in the non-response group.

Research experience generally suggests that, in comparison to respondents, non-responding potential participants are often less educated, older, and come from a non-English speaking background (Bowling, 1997; de Vaus, 1995). In the context of brain injury, however, such individuals are often represented in disproportionately high numbers. In the present study, descriptive data collected on participants revealed that some fell into these categories (older, less educated and so forth), suggesting that non-participation in the study was not solely attributable to those participant characteristics.

It is likely that at least some of the family members who participated in the study were those who possessed the strongest views on the subject, consistent with literature suggesting those with most interest in the topic are more likely to respond to mail surveys (D. R. Cooper & Emory, 1995; Zikmund, 1994; Fowler, 1993). It is also likely that such family members may well be those whose lives, or whose relatives' lives, have been the most affected by brain injury and who, subsequently, have become sensitised to perceived deficiencies in preparation. McMordie et al. (1991) discuss this possibility in their research into client satisfaction with head injury services, suggesting that in cases where the prognosis is poor, such as with severe brain injury, lower consumer satisfaction might reasonably be expected. If those most inclined to respond are those who have been most severely affected by brain injury, and those most severely affected are apt to be more critical, then this would have considerable impact on the nature of findings obtained. Further, Bowling (1997) refers to the effects of 'mood bias', where people in low spirits may underestimate, or be more negative about, the amounts of activity and support available, which may also have been an influential factor in the present study.

In the present study, however, a wide range of experiences and views were represented. A number of family members indicated their relative had experienced a good recovery after the TBI and expressed satisfaction with preparation efforts made and with services generally, clearly contrasting with those who were critical about their experiences. This

range of experiences provides some balance to the overall story depicted by the findings. Beyond that, there is a need for care in the reading of the thesis, with readers mindful that findings may be biased towards dissatisfaction.

Selection bias. Participants in the first indepth interview phase were selected randomly. Those in the second indepth interviewing phase, however, were selected purposively, based on questionnaire responses, in order to provide a range of perspectives on the topic. One of the two participating Maori families was selected in order to provide a Maori perspective, while others were chosen because their questionnaire responses represented different positions in terms of difficulties encountered and general satisfaction with preparation efforts. Such an approach is consistent with Rosenwald's (1988) recommendation described below.

Low representation by non-Caucasians. Rosenwald (1988) argues that the homogeneity traditionally associated with quantitative research is inappropriate in the context of qualitative investigation, stating, "to be sure of obtaining a useful synthesis, we want observers at a range of vantage points rather than crowded on one side only" (p. 247). For this reason, Rosenwald suggests giving preference to "those who are candid, fluent, reflective and different from each other" (p. 260). Although the comments were made in relation to multiple case research, they are also relevant to the present study.

The ability of the researcher to select participants who differed ethnically in the present study was somewhat restricted, however, with only two participants indicating an ethnic affiliation other than Pakeha/New Zealander, both of whom were Maori. It certainly may be considered a limitation of the current research although, again, it is unclear whether this lack of ethnic variation was a characteristic of family members at the Rehabilitation Centre generally or whether it reflected a response bias.

The low number of Maori participants in the study was particularly disappointing as statistical information suggests this group may be represented in TBI statistics in disproportionately high levels and, therefore, there is particular value in learning more

about the experiences and needs of this group. The single interview which was conducted with a Maori family certainly produced some interesting findings, revealing experiences which sometimes differed quite markedly from those of other participants interviewed. Greater exploration of this and other non-Pakeha groups would have enhanced the study's findings considerably.

### Researcher bias

As is the case with qualitative research generally (Roberts, 1998c; Bowling, 1997), researcher bias was a consideration in the interview phases of the present study. I came to the study already holding some impressions of the general area and of the specific topic, based on previous academic learning, my experiences working with brain injured individuals and their families, as friend of someone living with the effects of TBI and, during later stages of the study, as caregiver of a youth who had sustained a brain injury, all of which had given me an intimate understanding of the pressures and frustrations associated with the family member role.

The multiplicity of roles possessed was ultimately of some advantage, as I was able to draw on the various associated perspectives when exploring issues during data collection phases. Making my background known to participants, as I did during some of the interviews, was useful in that participants appeared more willing to share information, particularly their criticisms, once they learned I had also experienced brain injury from 'their side' – (i.e. not only as a practitioner or academic). I also chose to disclose, during the only interview conducted with a Maori couple, that my partner and partner's children were also Maori and that, consequently, I had experience with both Maori- and Pakeha-based services - a disclosure which had a positive effect on the degree and nature of topics discussed and on the interview generally.

As Sandelowski (1986) notes, however, the closeness of the researcher to the subjects' experiences can have negative, as well as positive, effects on a study's credibility. In recognition of the possible threats to the study's "truth value" (Sandelowski, 1986, p. 31), efforts were made by the researcher to maintain a neutral stance in order to diminish their



potential effects of participants' accounts. Acknowledging my background, without necessarily describing specific experiences, was a technique utilised to help accomplish this objective, in conjunction with constant self monitoring during interviews and evaluation of transcripts after each interview.

### Aggregation of ratings

Participants commonly indicated they had both good and bad experiences with particular professional groups and organisations, often naming individual practitioners whom they felt fell into these divergent groups. Questions and the response categories provided in the questionnaire, however, typically required participants to respond in an aggregate fashion. The ratings subsequently derived, therefore, represent a composite view of the different groups and organisations. While this is not necessarily a limitation of the present study, it is a feature which should be accounted for by those examining findings.

### Generalisability of study findings

In the strictest sense, findings of the present study are applicable only to that group of family members who participated in the present study. It is incautious to generalise the findings to the wider group of family members initially identified for possible participation in the study, (family members whose relatives attended to the Rehabilitation Centre as inpatients following TBI during the period 1988-1997), because nothing is known about the characteristics of this non-response group. Although the extreme variation in responses evident amongst participating family members raises the possibility that the views of non-responding participants may have been aptly described within the existing range of accounts, it is not possible to say whether or not this is actually the case with any degree of certainty.

It is possible, however, to identify themes from the present study which, while not strictly generalisable to other populations, may at least be of some relevance in a broader setting. The context in which TBI rehabilitation occurred in the present study has many similarities to that in many other geographic areas (i.e. an inadequate continuum of care and inefficient/ineffective mechanisms for organising care within that continuum), not only

within NZ but internationally (see chapters 2 & 3). Consequently, there are many commonalities between the experiences of family members in the present study and their counterparts elsewhere. Family members' subsequent needs were often similarly comparable to those previously identified in the TBI literature generally, for example, for accurate information, access to knowledgeable and competent practitioners, access to relevant services in a timely manner and so forth.

At the same time, the NZ context has features which make it somewhat unique amongst nations, particularly in regard to its system of funding accident rehabilitation. In contrast to some countries, it is not necessary within NZ to pursue legal action in order to fund a person's rehabilitation. Consequently, it is not necessary to wait until such money is obtained before rehabilitation can commence and the need for lengthy delays in treatment may potentially be avoided. However, the funding provided post TBI is quite regulated, and brain injured individuals and their families may lack the same level of autonomy in determining the services to be used post TBI as would be the case if they were awarded lump sum compensation to be used at their discretion.

New Zealand's cultural background is also unique. New Zealand's bicultural policy and resultant attempts to make mainstream services more inclusive and more reflective of Maori culture are changing the way mainstream services are provided (e.g. ACC, 1998) (although it may be argued these changes are occurring inconsistently and fairly slowly). The integral role of whanau within the Maori culture, and the need to consider people as part of a wider network, rather than simply as individuals, means the role of families generally is increasingly being recognised by service providers. Continued social and political pressure may help to ensure future services are more family-focused than has historically been the case, with considerable positive ramifications for the way in which families are treated post TBI.

## Conclusion

Brain injury, particularly when it is severe, leaves in its wake a population of individuals who are reliant to varying degrees, and for varying lengths of time, on others for their care and support. In many cases, these individuals are male, young and only beginning to establish a life independent of the family that raised them. Statistically, they are also more likely to have a history of engaging in high risk behaviours, and to come from a lower socio-economic background and from a family where the two biological parents do not live together.

In the absence of an adequate continuum of care, it is typically the families of these individuals who step in to meet the challenges posed by this most complex and variable condition and by the gaps in service provision. While fairly heated debate continues as to the desirability of this situation, the renewed emphasis on community care and families as the mainstay of care provision for vulnerable individuals generally, makes it unlikely significant change will occur in this practice in the near future.

If, as it seems, we are to continue asking what has historically been asked of families in respect to recovery from brain injury, however much this practice has been criticised by various parties involved in TBI rehabilitation, there is a need for considerable improvement to the way in which families are prepared for the experience. Certainly this is the case within the context of the present study, and the many similarities found between the experiences of these family members and family members described elsewhere in the literature suggest this may also be true on a scale far wider than that covered by this study.

Vast experience led Lezak, one of the world's foremost authorities on brain injury, to conclude,

Counseling these families to help them work through their years of pain is a poignant reminder of how little time and effort it would have taken in the beginning to spare them at least some of their particular hell. (1986, p. 249)

Findings from the present study support this view, having highlighted the enormously debilitating impact brain injury can have on unprepared families over time.

At the same time, however, the study has also highlighted the incredibly complex nature of the phenomenon entitled 'family preparation'. While hindsight may lead many families to conclude that preparation efforts failed to ready them for the tasks which lay ahead, closer examination reveals a myriad of obstacles which can potentially interfere with family preparation. Some of the factors relate to the families themselves, specifically their willingness and capacity to participate in preparation-related activities. Further complicating the situation are the multitude of economic, social and political constraints imposed by the external environment, constraints which can lead to practices amongst professionals which are in conflict with their training and experience.

In combination, these factors strongly influence what is accomplished during the period of inpatient treatment. They do not, however, always dictate what can be accomplished. The present study has revealed considerable capacity for improvement in the preparation of families, much of which can occur within the context of existing constraints. Through a broadening in focus, greater acknowledgment of the uniqueness of families, more comprehensive planning, and enhanced collaboration between the various parties involved in brain injury rehabilitation, the experiences of families can be radically improved in both the short and long term.

While efforts to reduce the burden on families continue, primarily through the development of a more comprehensive continuum of care, the economic constraints currently facing health and welfare systems make it unlikely that the resultant change will be of a magnitude sufficient to eliminate the difficulties families currently face. This serves only to increase the need for comprehensive and well-organised family preparation. Application of the family preparation model developed through the present study is an important step towards the achievement of this outcome.

## Recommendations for Future Research

The following recommendations are made for future research:

- to investigate the experiences and needs of groups under-represented in the present study, including male family members and non-Caucasian families (in particular, Maori and Pacific Island families). This will require purposive sampling as random sampling techniques have traditionally been unsuccessful in facilitating involvement of these groups in brain injury-related studies;
- to conduct a study involving several rehabilitation facilities, including those with reputations for excellence, identifying the characteristics which differentiate 'excellent' and other environments;
- to implement and evaluate the model developed in the study, focusing particularly on its feasibility and its relevance to different subgroups of family members;
- to evaluate the relevance of this model outside the NZ context, identifying the commonalities and differences between the NZ situation and the international environment investigated.

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## **APPENDICES**

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## A1. Information Sheet: Phase 1 Interviews

12 March 1997

### **How prepared are families for hospital discharge of a family member who has acquired a head injury?**

#### **INFORMATION SHEET**

My name is Rachel Winthrop. I am a postgraduate student in the Department of Rehabilitation Studies at Massey University, Palmerston North. I am currently carrying out a study based at Palmerston North's Rehabilitation Unit, as part of a Masterate of Philosophy in Rehabilitation Studies. I have asked Gail Russell, Senior Clinical Psychologist at the Rehabilitation Unit, to send this letter to some of the people who have been involved in the Rehabilitation Unit and who may be willing to provide information on their experiences there.

#### **What is this study about?**

This study seeks to identify how prepared families felt they were when a member of their family was discharged from hospital after acquiring a head injury. I would like to know what measures were taken to prepare the family for living with or providing support to a family member with a head injury, and how satisfied families felt with this preparation. The study provides an opportunity for families to make suggestions on how the preparation process may be improved for other families, if improvements are felt to be necessary. Ultimately, the study will help to increase existing knowledge of the way in which families can best be prepared to support the individual with the head injury, both in their rehabilitation process and in the long term.

#### **What would I have to do?**

Each family is asked to identify a single person within that family who may be considered the main support person for the individual with the head injury. It is this person who is invited to participate in this research. I would like to interview that person to obtain information about the measures that were taken to prepare the family for the discharge from hospital of their family member. The person and I will be the only people present at the interview, held at a convenient location. The interview will be recorded on a cassette tape, which will be destroyed at the completion of the study. Only myself and the research supervisor, Steve Humphries, will have access to the tapes. It is anticipated the interview would involve approximately one hour of your time.

Attached to this information sheet is a sheet titled 'Consent Form'. Could you please return this to Gail Russell if you are prepared to be interviewed. Small extracts from the interviews may be included in the final research report. These will be anonymous quotations. In signing the consent form, you are giving permission for this to occur. If you would like to receive a



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summary of the research findings at the completion of this study, please indicate this on the consent form.

**When choosing whether or not to participate in this study:**

- You have the right to decline to participate: This study is being carried out through Massey University. Participation in this study will NOT affect the services you or your family may currently, or in the future, receive from Palmerston North Hospital.
- You have the right to refuse to answer any particular questions and to withdraw from the study at any time.
- You have the right to ask any questions about the study at any time during participation.
- You have the right to provide any information on the understanding that your name will not be used in any way in this study.
- You have the right to be given access to a summary of the findings of the study when it is concluded.
- You have the right to agree to participate in the study under the conditions set out in the Information Sheet.

If you have any queries regarding this study, please do not hesitate to contact me. You may leave a message for me with the primary research supervisor, Steve Humphries, on 3569099 ext. 7356 or you may wish to speak with Steve directly. Gail Russell (second research supervisor) may also be contacted on 3508570. Thank you for your consideration of this study.



Rachel Winthrop



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## A2. Information Sheet: Phase 2 Interviews

30 April, 1998

### **INFORMATION SHEET**

Approximately nine months ago, you participated in the first phase of this study which involved the completion of a questionnaire. The questionnaire sought to identify the steps taken, and the perceived effectiveness of steps taken to prepare families for the hospital discharge of their relative following acquisition of a head injury. It also sought to determine the extent to which families felt prepared for the hospital discharge of their relative, and their satisfaction with the preparation process. The completed questionnaires provided useful statistical information in these areas.

A limitation of questionnaires is that they force participants to select their responses from those already set by the researcher – by ticking the boxes. It is difficult for participants to explain their answers, or to give an alternative answer when none of the possible options given by the researcher seem appropriate. A lot of valuable information that participants could provide is lost as a consequence.

In this new stage of the research, I would like to explore some of the areas that were covered in the questionnaire in greater detail. I would also like to explore some new areas which I could not include in the questionnaire (as it would have taken weeks to complete, as opposed to the hours it did take many of you!). In particular, I would like to find out more about the following areas:

- what it has been like living with, or being involved with, your head injured family member;
- what your role **has been** in regard to your head injured family member, their rehabilitation, and their life in general;
- what you feel your role **should have been** in regard to your head injured family member, their rehabilitation, and their life in general;
- what could have been done to better prepare you for life with a head injured family member.

I would like to interview you as part of this second stage of the study. It would involve a fairly unstructured discussion on the areas listed above, as well as any other areas you feel are relevant to the topic. If you would like, other family members who have been affected by your relative's head injury are also welcome to participate in the discussion. Please feel free to discuss this research with your relative who has the head injury. You may wish to emphasize that the focus of the research is on **family members** with a head injured relative rather than on the head injured relative themselves, and that you will be discussing the head injury in relation to **your own** life rather than to theirs.



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To enable me to obtain as much information as possible from the discussion, I would like to record the discussion on a cassette tape, which will then be transcribed onto paper. If you wish, following the discussion, I will send you a copy of the transcription to read. Where you feel it is necessary, you are welcome to add or amend comments you have made, in order to clarify points. Both the tape recording and interview transcripts will be destroyed when they are no longer required for the purpose of this study. Only myself and the University research supervisors will have access to the tapes and transcripts. I would expect the discussion to take approximately one hour, although this will obviously depend on the amount of information you wish to discuss.

A second form is attached to this information sheet. Could you please complete and return this to me as soon as possible if you are prepared to be interviewed. I will also need to obtain written consent from you at the time of the interview, indicating that you are willing to participate in this study. Small extracts from the interviews may be included in the final research reports. These will be anonymous quotations. In signing the consent form, you are giving permission for this to occur.

**Please be aware:**

- You have the right to decline to participate: This study is being carried out through Massey University. Participation in this study will NOT affect the services you or your family may currently, or in the future, receive from Palmerston North Hospital.
- You have the right to refuse to answer any particular questions and to withdraw from the study at any time.
- You have the right to ask any questions about the study at any time during participation.
- You have the right to provide information on the understanding that your name will not be used in any way in this study.

If you have any queries regarding this study, please do not hesitate to contact either myself via the department of management systems (ph 3505194), or Dr Nicola North (the research supervisor) on 3504378. Again, thank you for your support with this study, and I look forward to hearing from you.

Yours sincerely

Rachel Winthrop  
Department of Management Systems  
Massey University



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Please return this form in the enclosed envelope if you are willing to meet with me to discuss your experiences of head injury and family preparedness. Please be aware the interview will be tape recorded to help me remember the information, and that no one outside of the Massey University research team will have access to the tapes or tape transcripts. The interview can be held at a venue of your choice, including at your own home or at an office here at Massey.

So I can contact you, could you please complete the following details:

Name of the person/s to be interviewed: \_\_\_\_\_

\_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone Number: (please indicate if it is a day or night-time phone number):

\_\_\_\_\_

\_\_\_\_\_

Thank you





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### A3. Consent Form: Interviews

**How prepared are families for hospital discharge of a family member who has acquired a head injury?**

#### **CONSENT FORM**

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

I agree to participate and I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researchers on the understanding that my name will not be used in any way in this study. I also understand that, following the interview, I can request a transcript of the interview. If I feel it is necessary, I can amend information I have provided on this transcript so that it accurately represents my intended meaning.

I agree to the interview being audio taped. I also understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

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

Signed: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_

I **wish / do not wish** to be sent a summarised copy of the research findings at the conclusion of this study.

This report is to be sent to:

Name (if different from above): \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_



## **How Prepared Were You When Your Family Member Was Discharged From The Palmerston North Rehabilitation Unit?**

### **INFORMATION SHEET**

Hello.

#### **Who is this letter to?**

This letter has been mailed to you via the Rehabilitation Unit at Palmerston North Hospital. It is addressed to you because your name is on the medical records held at the Rehabilitation Unit. You are asked to give this letter to the family members who has had the most involvement with you since your head injury was sustained. The rest of this letter applies to the family member you have chosen, but please feel free to read the rest of this letter.

#### **What is this letter about?**

The purpose of this letter is to invite you to participate in a study investigating brain injury and family preparation. This study seeks to identify how prepared families felt they were when a member of their family was discharged from the Rehabilitation Unit after acquiring a head injury. I would like to know what measures were taken to prepare the family for living with or providing support to this family member with the head injury, and how satisfied families feel with this preparation.

#### **Who am I?**

My name is Rachel Winthrop and I am currently working towards a Masterate of Philosophy in Rehabilitation Studies at Massey University. Prior to returning to University, I worked in the area of Mental Health in Auckland. The research supervisor for this study is Dr Steve Humphries, at the Department of Rehabilitation Studies at Massey University.

#### **What would you have to do?**

Enclosed with this letter is a questionnaire. You are asked to **complete and return** this questionnaire to me in the attached self-addressed envelope **by Friday 11 July**. If you want to ask questions about any aspect of this questionnaire, please ring me on (04) 3864268, Steve Humphries on (06) 3569099 ext 7356, or Gail Russell on (06) 3508570.

#### **What benefits are there in participating?**

- The study provides an opportunity for you to give feedback that will be provided to staff at the Rehabilitation Unit. For some of you, this may be the first opportunity you have had to provide such feedback in a confidential way.
- The information obtained from this study will help to identify how families can best be prepared to support the individual with the head injury, both in their rehabilitation process and in the long term.



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Ultimately, this information can be used to improve the preparation process for families.

- Additionally, each participant in the study is able to receive a summary of the research findings, should they wish.

### **Confidentiality and Consent**

This letter has been sent to you via the Rehabilitation Unit to maintain confidentiality of hospital records. At no stage will I know your identity unless you complete the form attached to this letter requesting a summary of the research findings. Your completed questionnaire will be returned directly to me and will not be seen by anyone at the Rehabilitation Unit at any point. In that way, neither myself nor staff at the Rehabilitation Unit will know who has provided a particular response. Additionally, your identity will not be revealed in any research reports produced during the study.

You are not required to sign a separate consent form for this study - I will assume you consent to participate in this research when you complete and return the questionnaire to me. Small extracts from the questionnaire responses may be included in the final research report. These will be anonymous quotations. Again, your agreement to this is assumed if you return the completed questionnaire.

### **Your rights**

- You have the right to decline to participate - This study is being carried out through Massey University. Participation in this study will NOT affect the services you or your family may currently, or in the future, receive from Palmerston North Hospital.
- You have the right to refuse to answer any particular questions and to withdraw from the study at any time.
- You have the right to ask any questions about the study at any time during participation.
- You have the right to provide information on the understanding that your name will not be used in any way in this study.

Again, if you have any queries about this study, please do not hesitate to contact me on (04) 3864268, Steve Humphries on (06) 3569099 ext. 7356, or Gail Russell on (06) 3508570.

Thank you

Rachel Winthrop



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A5. Followup Letter: Questionnaire

4 July 1997

To whom it may concern

(The family member who is the main support person for the person with the head injury and who is completing the questionnaire.)

**RE: HOW PREPARED WERE YOU WHEN YOUR FAMILY MEMBER WAS  
DISCHARGED FROM THE PALMERSTON NORTH REHABILITATION UNIT?**

Hello.

This is a follow-up letter to remind you about the study I am carrying out at Massey University. If you are prepared to participate in the study, would you please complete and return the questionnaire to me by **Friday 11 July**. If you require a new questionnaire, please ring Letitia Cooksley on (06) 3505184. **If you are not interested in participating, you need not take any further action and I will not contact you further. Thank you for your consideration of this study.**

Yours sincerely

Rachel Winthrop  
Department of Rehabilitation Studies



A6. Request for Summary of Findings

**How prepared are families for the hospital discharge of a family member who has sustained a traumatic brain injury?**

I wish to be sent a summarised copy of the research findings at the conclusion of the study.

This report is to be sent to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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## A7. Summary of Findings

30 April 1998

Dear...

About nine months ago, you complete a questionnaire as part of a study titled *Perceptions of family preparedness for the hospital discharge of a family member following acquisition of a TBI*. I would like to thank you for the effort you made to do this, and for the considerable amount of time you spent completing the questionnaire. Since then, I've analysed your responses which has resulted in some very interesting findings. For your information, I have listed some of the main findings below.

- The study involved 33 family members who had a brain injured relative who had attended the Palmerston North Hospital's Rehabilitation Unit. This included 28 women, four men and one family member who did not indicate their gender;
- 23 of the family members felt their life had been affected a great deal as a result of their relative's head injury, while only 2 family members felt it had not been affected at all;
- 30 of the brain injured relatives represented in the study were men and three were women;
- Almost all of the family members wanted to receive general information on brain injury, diagnostic and prognostic information on their relative, and practical information about brain injury and its management, when their relative was in the Rehabilitation Unit. On average, over half said they received little or no information in these areas;
- On average, over half of the family members either did not receive the results of assessments carried out on their relative while they were in the Rehabilitation Unit, or they did not know if assessments had been carried out;
- The sources of emotional assistance used most often by family members included Rehabilitation Unit psychologists (used by 24 of the family members), friends (used by 20 of the family members), and Rehabilitation Unit nurses (used by 19 of the family members). The least used sources included family support groups (used by 4 family members), private counsellors, and religious sources (used by 7 family members each);
- 12 of the family members believed either none or only a little of the information they received from Rehabilitation Unit staff about brain injury and their relative would actually apply to their relative, while 17 believed either some or a great deal would apply;
- 17 of the family members felt the impact of their relative's brain injury on their own lives was greater than they had been led to believe it would



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- be by Rehabilitation Unit staff, 11 felt it was the same, while 2 felt it was less;
- 21 of the family members felt Rehabilitation Unit staff had made little or no effort to prepare them for the impact their relative's brain injury would have on their own lives, while 12 family members felt the staff had made some or a great deal of effort;
  - Most of the brain injured relatives needed help in some areas of their lives following discharge from the Rehabilitation Unit. The majority of family members knew their relatives would need this help before they were discharged from the Rehabilitation Unit, but few family members knew where to get the help from;
  - On average, approximately half of the family members indicated they needed but did not receive any training to help them assist in their relative's ongoing rehabilitation;
  - 18 of the family members felt some or many changes were needed to the way in which information was provided to family members, while 8 believed few or no changes were needed;
  - At the time of their relative's discharge from the Rehabilitation Unit, 30 of the family members expected life with a head injured relative would be difficult or somewhat difficult. Only 24 of the family members actually found the discharge period to be difficult or somewhat difficult, while 28 found the longer term difficult or somewhat difficult;
  - At the time of their relative's discharge from the Rehabilitation Unit, 18 of the family members felt unprepared or somewhat unprepared for life with a head injured relative. In hindsight, 22 of the family members believe they were actually unprepared or somewhat unprepared;
  - At the time of their relative's discharge from the Rehabilitation Unit, 17 of the family members felt dissatisfied or somewhat dissatisfied with the efforts made to prepare them for their relative's discharge and for life after discharge. In hindsight, 21 of the family members felt dissatisfied or somewhat dissatisfied with the preparation efforts made.

As I explained, the above is a very general summary of the major findings of the study. If you would like to receive a more technical summary of the findings, please contact me via the Department of Management Systems, Massey University, Private Bag 11222, Palmerston North. Again, thank you for your support in the conducting of this research and if you have any questions or comments you wish to make, please do not hesitate to contact me.

Yours sincerely

  
Rachel Winthrop

B. Questionnaire

How Prepared Were You When Your Family Member Was Discharged From The Rehabilitation Unit?

This survey needs to be completed by the family member who is the main provider of support to the person with the head injury. It is confidential and will not be seen by anyone other than the researchers. Your identity will not be revealed in any way in the research reports produced. It is expected the survey will take approximately 30 minutes to complete.

Most questions in this survey will focus on you (the support provider). The term 'your relative' refers to your family member with the head injury. The term 'TBI' stands for 'traumatic brain injury' and refers to the brain injury sustained by your relative.

If you require more space than is provided when answering questions, please feel free to continue your response on a separate piece of paper. If you do this, please make sure it is clear which question the answer relates to.

Some questions may require you to select one answer from a list of possible responses provided. This may be done by ticking the answer that best describes your experience or feelings.

*For example:*

1. *How satisfied were you with the information you were received on ACC allowances?*

<i>Dissatisfied</i>	<i>Somewhat dissatisfied</i>	<i>Indifferent</i>	<i>Somewhat satisfied</i>	<i>Satisfied</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you very much for your time and help with this study. Please remember to return the survey to me in the self-addressed envelope enclosed.



BACKGROUND INFORMATION

For Office  
Use Only

A. Information About Yourself

1. Gender: Male Female  
☐ ☐

1  
☐

2. Your age: \_\_\_\_\_

3  
☐☐

3. With which ethnic group(s) do you identify?  
(E.g. Chinese, Maori, Pakeha/European, etc.) \_\_\_\_\_

☐☐

4. What is your relationship to your relative (family member with the head injury)? (E.g. mother, brother) \_\_\_\_\_

6  
☐☐

5. Please describe briefly your work or professional experience. (E.g. occupation, qualifications).  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

☐☐

6. Were you living with your relative **at the time** they acquired a TBI? Yes No  
☐ ☐

10  
☐

7. Have you lived with your relative at any time **since** they acquired a TBI? Yes No  
☐ ☐

☐

8. Are you currently living with your relative? Yes No  
☐ ☐

☐

9. If your relative was not living with you before the TBI but has lived with you since then, was this move because of the TBI? Yes No  
☐ ☐

13  
☐

B. Information About Your Relative

For Office  
Use Only

1. Gender:	Male	Female		14
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Your relative's current age:			<input type="checkbox"/> <input type="checkbox"/>	
3. How old was your relative when they acquired a TBI?			<input type="checkbox"/> <input type="checkbox"/>	
4. Please answer the following questions about your relative's rehabilitation.				
a. Which hospital wards did your relative attend after sustaining a TBI and approximately for how long? (E.g. surgical, ICU, general, orthopedic, psychiatric etc.)				21
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
b. What year did your relative attend the Palmerston North Rehabilitation Unit?			<input type="checkbox"/> <input type="checkbox"/>	
c. How long was your relative an inpatient at the Rehabilitation Unit?			<input type="checkbox"/> <input type="checkbox"/>	
d. Where did your relative go to live after they were discharged from the Rehabilitation Unit? (E.g. family home, flatting, etc.)			<input type="checkbox"/> <input type="checkbox"/>	
5. If you know it, please indicate the term that the medical/rehabilitation team used to describe the severity of your relative's head injury.				28
Don't know	Mild	Moderate	Severe	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Did your relative lose consciousness following the TBI?

Don't know

☐

Yes

☐

No

☐☐

7. How long was your relative unconscious or in a coma following the event that caused the TBI? *(Please tick one of the boxes)*

Not applicable

☐

Less than 5 minutes

☐

From five minutes to one hour

☐

From one hour to one day

☐

From one day to one week

☐

From one week to four weeks

☐

More than one month

☐

Don't know

☐☐

30

## TBI IMPACT

### A. Impact on Your Relative

**For Office  
Use Only**

1. **Based on your observations**, please indicate *(by ticking in the following table)* whether your relative has had any of the following problems, where:

- **no difficulty** means problem is not present;
- **mild difficulty** means problem is present but has minimal impact on daily living;
- **moderate difficulty** means problem is present with a noticeable impact on daily living;
- **severe difficulty** means problem is present and has a major impact on daily living.

	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty
1. Loss of muscle strength, paralysis, poor coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Blurred or loss of vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Loss of hearing or ringing in ears	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Loss of memory, concentration, difficulty planning, organising, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Mood problems, depression, anxiety, changes in emotion, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Change in speech or difficulty in being understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Changes in behaviour, e.g. low motivation, anger problems, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Opportunity for participation and advancement in employment	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Opportunity for participation in social, leisure and recreation activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Ability to live independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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2. The following table requires you to make various comments about the support your relative has needed since leaving the Rehabilitation Unit.

**For Office  
Use Only**

A. Below is a list of areas of functioning that may have been affected in your relative following the TBI. Please use the list to complete the table.	B. Has your relative needed help or support with these areas since leaving the Rehabilitation Unit?		C. Did you know your relative may need this support before they left the Rehabilitation Unit?			D. Who told you your relative may need this support? (E.g. nurse, ACC case manager, etc)	E. Did you know which people or agencies could provide this support before your relative left the Rehabilitation Unit?		
	Yes	No	Yes	No	Not applicable		No	Yes	I knew there were no services available
1. Physical functioning: <i>E.g. strength, movement, coordination</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Memory, concentration, planning & organising, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Mood & emotion: <i>E.g. anxiety, depression</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Personality & behaviour: <i>E.g. anger problems, low motivation</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Employment or educational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Social, recreational & leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Household maintenance and self-care activities: <i>E.g. washing, cooking</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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<sup>42</sup> <sup>4</sup>  
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B. Impact on Yourself

1. Please indicate (by ticking the appropriate box) the ways in which your life has been affected following your relative's TBI.

	Not affected at all	Somewhat affected	Affected a great deal	Not applicable
1. Your life overall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Your participation in employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Your attendance at school or training programmes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Your participation in social and leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Your household/domestic routines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Your relationships with other family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Your relationships with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Ability to leave injured person without supervision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9. Your ability to have holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How much of an effort did Rehabilitation Unit staff make to prepare you for the impact your relative's TBI may have on your life?

None                      A little                      Some                      A great deal

☐                      ☐                      ☐                      ☐

3. Has the actual impact on your life been consistent with what you were led to believe it would be by Rehabilitation Unit staff?

Much less                      Less                      As expected                      More                      Much more

☐                      ☐                      ☐                      ☐                      ☐

For Office  
Use Only

47

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PROVISION OF INFORMATION

1. Prior to your relative sustaining a TBI, how much did you know about TBI?

Nothing      A little      Some      A great deal  
☐      ☐      ☐      ☐

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2. The following table requires you to make various comments about information as you work across the table.

A. Below is a list of topics that you may have required information on when your relative was in the Rehabilitation Unit. Please use the list to complete the table.	B. Did you <u>need</u> information on this topic when your relative was an in-patient at the Rehabilitation Unit?		C. <u>How much</u> information were you provided with when your relative was an in-patient at the Rehabilitation Unit?				D. How <u>useful</u> was the information you did receive?			
	Yes	No	None	A little	Some	A great deal	No use	Some use	Very useful	Not applicable
1. Traumatic brain injury (TBI) in general	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Specific information about your relative's particular brain injury ( <i>i.e. diagnosis</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The expected outcome for your relative ( <i>i.e. prognosis</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. What the TBI would mean at a practical ( <i>day-to-day</i> ) level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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5  
☐   ☐   ☐  
  
9  
☐   ☐   ☐  
  
☐   ☐   ☐

3. How much information would you have liked to receive about aspects of TBI while your relative was in the Rehabilitation Unit?

Less than I did receive      The same amount      More than I did receive  
☐      ☐      ☐

14  
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For Office  
Use Only

4. The following table requires you to select **one** box in column B that best describes your experience of the assessments carried out by staff at the Rehabilitation Unit.

A. Assessment areas	B. When your relative was in the Rehabilitation Unit, they may have been assessed in some of the areas listed in column A. Please select the single box that best describes <u>your</u> experience.				
	My relative did not need assessments in this area	I don't know if assessments were carried out in this area	Assessments were carried out but I did not receive the results	I received the assessment results but with an inadequate explanation	I received the assessment results with a good explanation
1. Physical functioning: <i>E.g. strength, movement, coordination</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Memory, concentration, planning & organising, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Mood & emotion: <i>E.g. anxiety, depression</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Personality & behaviour: <i>E.g. anger problems, low motivation</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Ability to participate in employment or educational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Ability to participate in social, recreational & leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Ability to perform household maintenance and self-care activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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5. If you did not receive any assessment results, please explain why you think this was.  
(E.g. the Privacy Act prevented information being disclosed, etc.)

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6. The following table requires you to comment on the information provided by the various people and agencies listed below (Column A).

**For Office  
Use Only**

A.	B. How easy was it to understand the information they provided? (E.g. Was it technical, Full of jargon?)				C. How useful was the information they provided to you?			D. Was there an opportunity to discuss the information with these people? (E.g. discuss assessment results, raise concerns, ask questions, discuss expectations, etc.)			
	Easy	Quite easy	Quite hard	Hard	Not useful	Somewhat useful	Very useful	Never	Sometimes	Frequently	Always
1. ACC rehabilitation officers, including case manager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Headway/ Head Injury Society workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Staff at the Rehabilitation Unit (Make an 'overall' assessment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Nursing staff at the Rehabilitation Unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Medical staff at the Rehabilitation Unit (excluding nursing staff)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Physiotherapy staff at the Rehabilitation Unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Social work staff at the Rehabilitation Unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Psychologists/ Neuropsychologists at the Rehabilitation Unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Occupational therapists at the Rehabilitation Unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<input type="checkbox"/> <sup>23</sup>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> <sup>29</sup>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> <sup>35</sup>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> <sup>41</sup>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> <sup>47</sup>	<input type="checkbox"/>	<input type="checkbox"/> <sup>49</sup>

7. In general, was the information you received from Rehabilitation Unit staff provided at the most suitable time? (E.g. when it was most needed? When you were ready to hear it?)

Never      Sometimes      Frequently      Always  
☐      ☐      ☐      ☐

☐ 50

8. Overall, do you believe the Rehabilitation Unit staff possessed an adequate level of knowledge about TBI?

Staff possessed an      Staff possessed an      Staff possessed a  
inadequate knowledge      adequate knowledge      comprehensive knowledge  
☐      ☐      ☐

☐

9. Overall, did you believe the information you received on brain injury from Rehabilitation Unit staff would actually apply to your relative's situation? (E.g. did the information seem overly pessimistic? Optimistic? Not taking account of what you knew about your relative?)

Believed none      Believed a little      Believed some      Believed a great  
would apply      may apply      may apply      deal would apply  
☐      ☐      ☐      ☐

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Please explain:

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10. In general, did the exchanges of information between staff at the Rehabilitation Unit and yourself take place in an appropriate location? (E.g. In a place that was quiet? Free from distractions? Private?)

Never      Sometimes      Frequently      Always  
☐      ☐      ☐      ☐

☐

11. Was the information provided by the various staff at the Rehabilitation Unit consistent (i.e. in agreement) with each other?

Inconsistent      Somewhat      Somewhat      Consistent  
inconsistent      inconsistent      consistent  
☐      ☐      ☐      ☐

☐

12. Did the rehabilitation professionals involved with your relative encourage other people to be involved in your relative's rehabilitation (E.g. workmates, teachers, friends, etc.)?

Never      Occasionally      Frequently      Always  
☐      ☐      ☐      ☐

☐ 55

13. Do you believe the policies and operating practices at the Rehabilitation Unit promote the sharing of information between staff and families?

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Not at all               | A little                 | To some extent           | A great deal             |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

56  
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14. Overall, what was the most **common** way in which you received information?

- |                                |   |                               |
|--------------------------------|---|-------------------------------|
| Mostly verbal<br>(I.e. spoken) | Mostly written<br>(E.g. pamphlets, books) | Mostly visual<br>(E.g. video) |
| <input type="checkbox"/>       | <input type="checkbox"/>                  | <input type="checkbox"/>      |

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15. In general, what is the most **useful** way for you to receive information?

- |                                |   |                               |                                 |
|--------------------------------|---|-------------------------------|---------------------------------|
| Mostly verbal<br>(I.e. spoken) | Mostly written<br>(E.g. pamphlets, books) | Mostly visual<br>(E.g. video) | Combination<br>(Please specify) |
| <input type="checkbox"/>       | <input type="checkbox"/>                  | <input type="checkbox"/>      | <input type="checkbox"/>        |

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16. Do changes need to be made to improve the way information is provided to family members?

- |                          |                            |                           |                           |
|--------------------------|----------------------------|---------------------------|---------------------------|
| No                       | A few changes<br>necessary | Some changes<br>necessary | Many changes<br>necessary |
| <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/>  | <input type="checkbox"/>  |

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Please explain:

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You may wish to take a short break  
before completing the remainder of this questionnaire.  
Please feel free to do so.

EMOTIONAL SUPPORT

For Office  
Use Only

1. Do you believe staff at the Rehabilitation Unit were sensitive to (i.e. took account of) **your** emotional needs regarding your relative's TBI?

Never                      Sometimes                      Frequently                      Always  
☐                      ☐                      ☐                      ☐

☐

2. Were attempts made by staff at the Rehabilitation Unit to determine **your** emotional needs or the extent to which **you** were coping with the TBI?

None                      A few attempts                      Many attempts  
☐                      ☐                      ☐

☐

3.

A.	B. Did Rehabilitation Unit staff ever emphasise the need for you to be emotionally prepared (i.e. ready) to cope with the areas listed below (Column A)?		C. At the time of your relative's discharge from the Rehabilitation Unit, how prepared (i.e. ready) did you feel to cope with the areas listed below (Column A)?			
	Yes	No	Unprepared	Somewhat unprepared	Somewhat prepared	Prepared
1. Your relative's emotional responses to their TBI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Your relative's behavioural and emotional disturbances resulting from the TBI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Your own emotional responses to your relative's TBI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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**For Office  
Use Only**

A.	B. Which of the people listed below (Column A) provided you with the support, information or skills you needed to cope with your own or your relative's emotional/behavioural responses to the TBI?  Yes (Provided support etc.)      No (Services not used)	C. Looking back now, which of the people listed (Column A) would you like to have been involved in aspects of your emotional preparation?  Yes (Involved)      No (Not involved)	
1. Rehabilitation Unit Social Worker	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> 9 <input type="checkbox"/>
2. Rehabilitation Unit Psychologist	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> 10 <input type="checkbox"/>
3. Support group for families affected by TBI	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
4. Head Injury Society Fieldworker	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> 15 <input type="checkbox"/>
5. Private Counsellor	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
6. Friends	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> 19 <input type="checkbox"/>
7. Rehabilitation Unit Nurses	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
8. Other families at the Rehabilitation Unit	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> 29
9. Religious (e.g. Chaplain, Priest, Minister, etc)	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
10. Other: A. _____ B. _____	<input type="checkbox"/> <input type="checkbox"/>  <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>  <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>  <input type="checkbox"/> 29 <input type="checkbox"/>

PLANNING FOR DISCHARGE

For Office  
Use Only

1. Did you attend any group meetings with the rehabilitation team to plan your relative's rehabilitation and discharge?

Yes                      No  
☐                      ☐

☐'

\* If you answered 'no', please go to question 6

2. Who initiated the meeting(s)? (E.g. social worker, ACC case manager, yourself.)

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3. How useful were these meetings to you?

No use                      Minimal use                      Somewhat useful                      Extremely useful  
☐                      ☐                      ☐                      ☐

☐''

Please explain:

4. Please describe any records you received of the content of the meeting (E.g. a copy of the minutes of the meeting.)

☐

5. How useful were these records of the meeting to you?

No use                      Minimal use                      Somewhat useful                      Extremely useful                      Not applicable  
☐                      ☐                      ☒                      ☐                      ☒

☐''

Please explain:

6. Your relative may have continued some parts of their rehabilitation and therapy after they were discharged from the Rehabilitation Unit. *For example, physiotherapy, reading recovery, behavioural therapy, etc.* An expectation may have existed that you would be able to help your relative carry out their therapy and rehabilitation programmes once they returned home. I would like to know if staff at the Rehabilitation Unit prepared or taught you how you could help your relative carry out their programmes, **before** your relative was discharged from the Unit. *Please tick **one** box below in Column B that best describes your experiences, for each of the areas listed in Column A.*

**For Office  
Use Only**

A.	B.	My relative did not need therapy after discharge in this area	I required preparation in this area but received none	I received preparation and it was not useful	I received preparation and it was somewhat useful	I received preparation and it was very useful
1. Physical functioning: <i>E.g. strength, movement, coordination</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Memory, concentration, planning & organising, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Emotion & mood problems: <i>E.g. anxiety, depression</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Personality & behaviour: <i>E.g. anger or motivation problems</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Employment or educational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Social, recreational & leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Household maintenance and self-care activities: <i>E.g. washing, cooking</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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FEELINGS ABOUT YOUR PREPARATION

1. At the time your relative was discharged from the Rehabilitation Unit, how difficult did you expect it would be? (E.g. the discharge itself, the transition to life outside the Rehabilitation Unit, supporting your relative in on-going rehabilitation, etc.)

Difficult      Somewhat difficult      Somewhat easy      Easy

☐                      ☐                      ☐                      ☐

☐

2. At the time your relative was discharged from the Rehabilitation Unit, how prepared did you feel for the discharge and life following discharge?

Unprepared      Somewhat unprepared      Somewhat prepared      Prepared

☐                      ☐                      ☐                      ☐

☐

3. Looking back at it now, how difficult was the discharge period?

Difficult      Somewhat difficult      Somewhat easy      Easy

☐                      ☐                      ☐                      ☐

☐

4. Looking back at it now, how difficult was the time following the discharge period?

Difficult      Somewhat difficult      Somewhat easy      Easy

☐                      ☐                      ☐                      ☐

☐ 4

5. Looking back at it now, how prepared were you really for the discharge and life following discharge?

Unprepared      Somewhat unprepared      Somewhat prepared      Prepared

☐                      ☐                      ☐                      ☐

☐

6. Which aspects of being the primary support person to your relative were you well prepared for? (E.g. emotional disturbances, concentration deficits, fatigue, etc.)

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7. Which aspects of being the primary support person to your relative were you **not** well prepared for? (E.g. emotional disturbances, concentration deficits, fatigue, etc.)

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☐ 7

8. **At the time of discharge**, how satisfied were you with what had been done to prepare you for your relative's discharge and life after discharge?

Dissatisfied      Somewhat dissatisfied      Somewhat satisfied      Satisfied

☐                      ☐                      ☐                      ☐

☐

9. **Looking back at it now**, how satisfied are you with what was done to prepare you for your relative's discharge and life after discharge?

Dissatisfied      Somewhat dissatisfied      Somewhat satisfied      Satisfied

☐                      ☐                      ☐                      ☒

☐ 9

Please explain:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

10. If there has been a change between your satisfaction level at time of discharge and how you currently feel (i.e. between questions 8 and 9), what is the reason(s) for this change?

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☐ 10

11. If you would like to comment on your satisfaction with preparation, please do so here.

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12. If you would like to comment on any aspect of this questionnaire, please do so here.

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**Thank you.**

**You have now completed the questionnaire.**

**Please return it in the self-addressed envelope enclosed with this questionnaire. Please remember to include the completed attached form if you wish to receive a summary of the research findings.**

C1. The provision of information to family members during inpatient rehabilitation

Information topics	Did you need information during the inpatient phase?		How much information were you provided with during this time?				How useful was the information received? <sup>a</sup>		
	Yes	No	None	A little	Some	A great deal	No use	Some use	Very useful
General information on TBI	87% (27)	13% (4)	20% (6)	40% (12)	23% (7)	17% (5)	5% (1)	55% (12)	41% (9)
Diagnostic information on relative	94% (29)	7% (2)	19% (6)	39% (12)	23% (7)	19% (6)	8% (2)	54% (13)	38% (9)
Prognostic information on relative	97% (30)	3% (1)	19% (6)	36% (11)	26% (8)	19% (6)	12% (3)	52% (13)	36% (9)
Practical aspects of TBI	87% (27)	13% (4)	38% (12)	25% (8)	25% (8)	13% (4)	17% (3)	44% (8)	39% (7)

<sup>a</sup> Includes only those who reported having received information.

C2. Feedback provided to family members by Rehabilitation Centre staff on their relative's assessments

Assessment area	My relative did not need assessments in this area	I don't know if assessments were carried out	Assessments were carried out but I did not receive the results	I received the results but with an inadequate explanation	I received the results with a good explanation
Physical functioning	(-)	19% (6)	34% (11)	13% (4)	34% (11)
Cognitive functioning	(-)	12% (4)	30% (10)	15% (5)	42% (14)
Emotional functioning	(-)	31% (10)	25% (8)	16% (5)	28% (9)
Behavioural functioning	(-)	31% (10)	25% (8)	19% (6)	25% (8)
Vocational functioning	(-)	33% (11)	21% (7)	9% (3)	36% (12)
Social functioning	(-)	44% (14)	22% (7)	9% (3)	25% (8)
Daily living	3% (1)	47% (15)	13% (4)	9% (3)	28% (9)
Mean (SD)	(-)	31% (12.5)	24% (6.7)	13% (4)	31% (6.4)

C3. The post discharge assistance needs of brain injured relatives: Family members' pre-discharge knowledge

Areas of functioning	Has your relative needed assistance since leaving the Rehabilitation Centre?		Did you know before discharge that your relative may need this assistance? <sup>a</sup>		Who told you your relative may need this assistance? <sup>b</sup>	Did you know prior to inpatient discharge who could provide this assistance? <sup>c</sup>	
	Yes	No	Yes	No		Yes	No
<b>Physical functioning</b>	66% 21	34% 11	86% 18	14% 3	ACC 12% Doctor 24% Knew by self 24% Nurse 18% Physiotherapist 6% RU staff in general 18%	56% 10	44% 8
<b>Cognitive functioning</b>	87% 27	13% 4	67% 18	33% 9	ACC 10% Doctor 25% Knew by self 15% Nurse 10% Psychologist 15% RU staff in general 25%	35% 6	65% 11
<b>Emotional functioning</b>	73% 22	27% 8	55% 12	46% 10	ACC 6% Doctor 38% Knew by self 19% Nurse 13% Psychologist 6% RU staff in general 19%	38% 3	63% 5
<b>Behavioural functioning</b>	80% 24	20% 6	58% 14	42% 10	ACC 11% Doctor 42% Knew by self 11% Nurse 11% Psychologist 11% RU staff in general 16%	25% 3	75% 9

<sup>a</sup>Includes only those family members whose relatives required post discharge assistance.

<sup>b</sup>Includes only those family members whose relatives required post discharge assistance.

<sup>c</sup>Includes only those family members who were aware before discharge that their relative may require assistance.

C3. The post discharge assistance needs of brain injured individuals: Family members' pre-discharge knowledge (Continued)

Areas of functioning	Has your relative needed assistance since leaving the Rehabilitation Centre?		Did you know before discharge that your relative may need this assistance? <sup>a</sup>		Who told you your relative may need this assistance? <sup>b</sup>	Did you know prior to inpatient discharge who could provide this assistance? <sup>c</sup>	
	Yes	No	Yes	No		Yes	No
<b>Vocational functioning</b>	80% 24	20% 6	74% 17	26% 6	ACC 16% Doctor 21% Friends 5% Knew by self 16% Nurse 16% Psychologist 5% RU staff in general 21%	39% 5	62% 8
<b>Social functioning</b>	72% 23	28% 9	59% 13	41% 9	ACC 6% Doctor 35% Friends 6% Knew by self 24% Nurse 12% Psychologist 6% RU staff in general 12%	36% 4	64% 7
<b>Daily living</b>	63% 20	38% 12	79% 15	21% 4	ACC 6% Doctor 24% Knew by self 29% Nurse 12% Psychologist 12% RU staff in general 18%	33% 4	67% 8
<b>Mean (SD)</b>	74% (8.5)	26% (8.7)	68% (11.8)	32% (12)		37% (9.4)	63% (9.4)

<sup>a</sup>Includes only those family members whose relatives required post discharge assistance.

<sup>b</sup>Includes only those family members whose relatives required post discharge assistance.

<sup>c</sup>Includes only those family members who were aware before discharge that their relative may require assistance.

C4. Mean levels of difficulty reported by family members according to the amount of information received during the inpatient phase

Timeframe	General information on TBI		Diagnostic information on brain injured relative		Prognostic information on brain injured relative		Practical aspects of TBI	
	None - A little	Some - A great deal	None - A little	Some - A great deal	None - A little	Some - A great deal	None - A little	Some - A great deal
Predischarge expectation of post discharge difficulty	3.7 <i>t</i> (28)= 2.77,	3.1 <i>p</i> = .010	3.6 <i>NS</i>	3.3	3.5 <i>NS</i>	3.4	3.6 <i>NS</i>	3.3
Actual difficulty experienced during discharge period	3.5 <i>t</i> (26)= 2.34,	2.7 <i>p</i> = .027	3.4 <i>NS</i>	2.8	3.5 <i>t</i> (26.87)=2.41,	2.7 <i>p</i> = .023	3.4 <i>t</i> (28)= 2.30,	2.7 <i>p</i> = .029
Actual difficulty experienced over longer term	3.7 <i>t</i> (28)= 2.23,	3.1 <i>p</i> = .034	3.7 <i>t</i> (29)= 2.35,	3.1 <i>p</i> = .026	3.8 <i>t</i> (29)= 2.59,	3.1 <i>p</i> = .015	3.8 <i>t</i> (30)= 3.26,	2.9 <i>p</i> = .003

*Note.* Mean levels of difficulty are derived from the following difficulty ratings: 1= easy, 2= somewhat easy, 3= somewhat difficult, 4= difficult.



C5. Mean levels of preparedness reported by participants according to the amount of information received during the inpatient phase

Timeframe	General information on TBI		Diagnostic information on brain injured relative		Prognostic information on brain injured relative		Practical aspects of TBI	
	None - A little	Some - A great deal	None - A little	Some - A great deal	None - A little	Some - A great deal	None - A little	Some - A great deal
Preparedness levels at time of discharge	1.8 <i>NS</i>	2.6	1.9 <i>t</i> (28)= 2.16, <i>p</i> = .039	2.5	1.9 <i>t</i> (28)= 2.06, <i>p</i> = .049	2.5	1.9 <i>t</i> (29)=2.624, <i>p</i> = .014	2.7
Preparedness levels reported in hindsight	1.6 <i>NS</i>	2.3	1.6 <i>t</i> (29)= 2.06, <i>p</i> = .049	2.3	1.7 <i>NS</i>	2.2	1.7 <i>t</i> (30)= 2.28, <i>P</i> = .030	2.4

*Note.* Mean levels of preparedness are derived from the following preparedness ratings: 1= unprepared, 2= somewhat unprepared, 3= somewhat prepared, & 4= prepared.

C6. Mean levels of satisfaction reported by participants according to the amount of information received during the inpatient phase

Timeframe	General information on TBI		Diagnostic information on relative		Prognostic information on relative		Practical aspects of TBI	
	None - A little	Some - A great deal	None - A little	Some - A great deal	None - A little	Some - A great deal	None - A little	Some - A great deal
Satisfaction levels at time of discharge	1.7 <i>t</i> (27)= 5.31, <i>p</i> = .000	3.2 <i>p</i> = .000	1.8 <i>t</i> (28)= 3.27, <i>P</i> = .003	2.9 <i>P</i> = .003	1.8 <i>t</i> (28)= 3.64, <i>p</i> = .001	2.9 <i>p</i> = .001	1.8 <i>t</i> (29)= 4.84, <i>p</i> = .000	3.3 <i>p</i> = .000
Satisfaction levels reported in hindsight	1.6 <i>t</i> (27)= 3.99, <i>p</i> = .000	2.9 <i>p</i> = .000	1.6 <i>t</i> (28)= 4.18, <i>p</i> = .000	2.9 <i>p</i> = .000	1.6 <i>t</i> (28)= 3.42, <i>p</i> = .002	2.8 <i>p</i> = .002	1.6 <i>t</i> (29)= 5.74, <i>p</i> = .000	3.2 <i>p</i> = .000

*Note.* Mean levels of satisfaction are derived from the following satisfaction ratings: 1= dissatisfied, 2= somewhat dissatisfied, 3= somewhat satisfied, & 4= satisfied.

### C7. Family members' perceptions of information and information providers

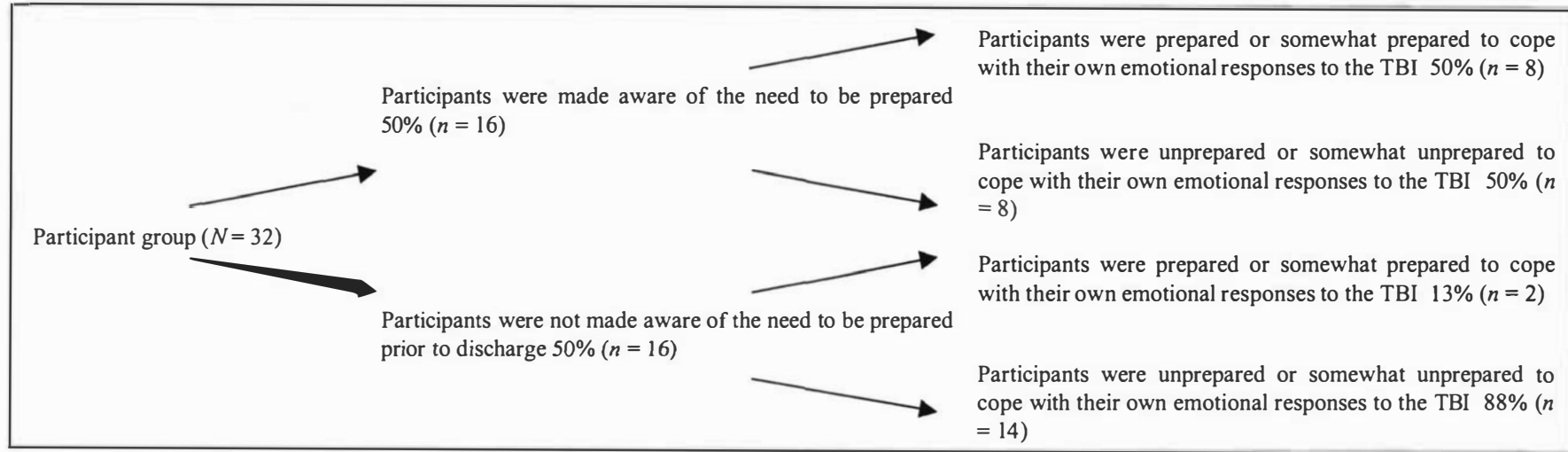
Rehabilitation professionals	How easy was it to understand the information provided?				How useful was the information provided?			Was there an opportunity to discuss information?			
	Easy	Quite easy	Quite hard	Hard	Not useful	Somewhat useful	Very useful	Never	Sometimes	Frequently	Always
<b>PART I: ORGANISATIONS</b>											
<b>ACC staff</b>	30% (7)	39% (9)	13% (3)	17% (4)	21% (5)	46% (11)	33% (8)	32% (8)	32% (8)	12% (3)	24% (6)
<b>Headway representatives</b>	35% (7)	55% (11)	5% (1)	5% (1)	10% (2)	43% (9)	48% (10)	24% (5)	33% (7)	10% (2)	33% (7)
<b>Rehabilitation Centre staff</b>	23% (6)	46% (12)	27% (7)	3.8% (1)	8% (2)	62% (16)	31% (8)	15% (4)	37% (10)	15% (4)	33% (9)
<b>PART II: REHABILITATION CENTRE STAFF</b>											
<b>Rehabilitation Centre nurses</b>	39% (10)	35% (9)	23% (6)	3.8% (1)	19% (5)	41% (11)	41% (11)	15% (4)	35% (9)	23% (6)	27% (7)
<b>Rehabilitation Centre medical staff (not nurses)</b>	35% (9)	46% (12)	12% (3)	7.7% (2)	15% (4)	50% (13)	35% (9)	(-)	60% (15)	12% (3)	28% (7)
<b>Rehabilitation Centre physiotherapists</b>	39% (9)	39% (9)	13% (3)	8.7% (2)	21% (5)	46% (11)	33% (8)	28% (7)	28% (7)	20% (5)	24% (6)
<b>Rehabilitation Centre social workers</b>	41% (7)	24% (4)	18% (3)	17.6% (3)	26% (5)	42% (8)	32% (6)	30% (6)	35% (7)	10% (2)	25% (5)
<b>Rehabilitation Centre psychologists</b>	32% (8)	40% (10)	12% (3)	16% (4)	12% (3)	36% (9)	52% (13)	17% (4)	46% (11)	4% (1)	33% (8)
<b>Rehabilitation Centre occupational therapists</b>	44% (11)	36% (9)	12% (3)	8% (2)	17% (4)	50% (12)	33% (8)	23% (6)	35% (9)	15% (4)	27% (7)

Note. (-) represents zero respondents.

C8. Training for post discharge roles received by family members during the inpatient phase

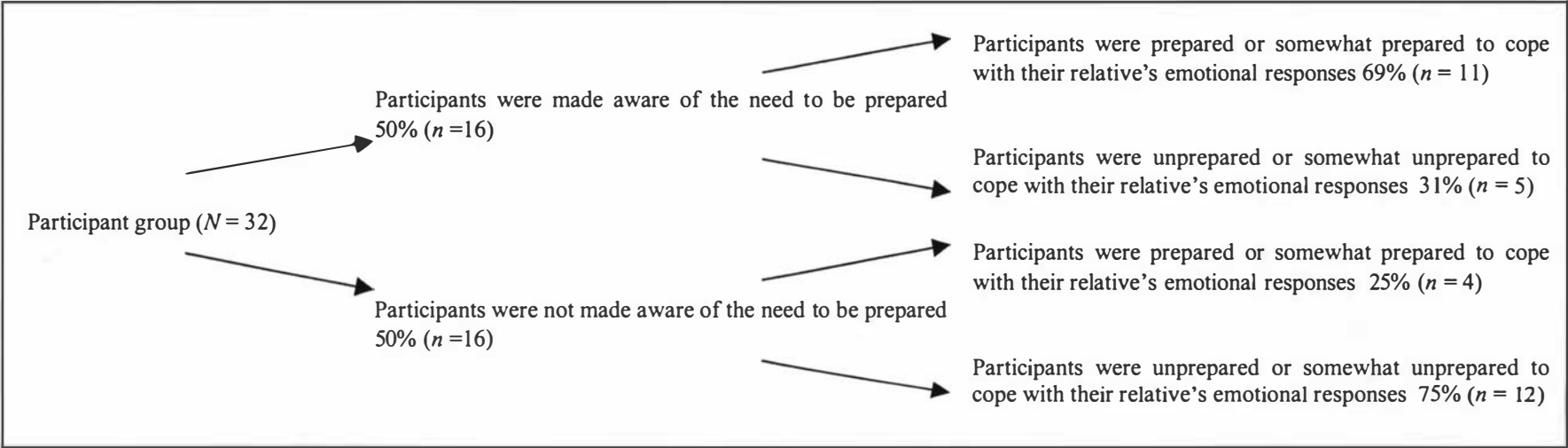
Area of functioning	Which option best describes your experience of the training you received to help you assist your relative with their ongoing rehabilitation and therapy, while your relative was an inpatient at the Rehabilitation Centre?				
	My relative did not need therapy in this area	I required preparation in this area but received none	I received preparation in this area and it was not useful	I received preparation in this area and it was somewhat useful	I received preparation in this area and it was very useful
<b>Physical functioning</b>	19% (5)	41% (11)	7% (2)	30% (8)	4% (1)
<b>Cognitive functioning</b>	11% (3)	52% (14)	7% (2)	19% (5)	11% (3)
<b>Emotional functioning</b>	8% (2)	56% (14)	16% (4)	12% (3)	8% (2)
<b>Behavioural functioning</b>	12% (3)	52% (13)	16% (4)	12% (3)	8% (2)
<b>Vocational functioning</b>	21% (5)	50% (12)	4% (1)	17% (4)	8% (2)
<b>Social functioning</b>	21% (5)	54% (13)	8% (2)	8% (2)	8% (2)
<b>Daily living</b>	16% (4)	56% (14)	4% (1)	12% (3)	12% (3)
<b>Mean (SD)</b>	15% (5.2)	52% (5.2)	9% (5.1)	16% (7.3)	8% (2.6)

C9. Preparedness levels based on awareness of the need for preparation: Family members' own emotional responses to TBI



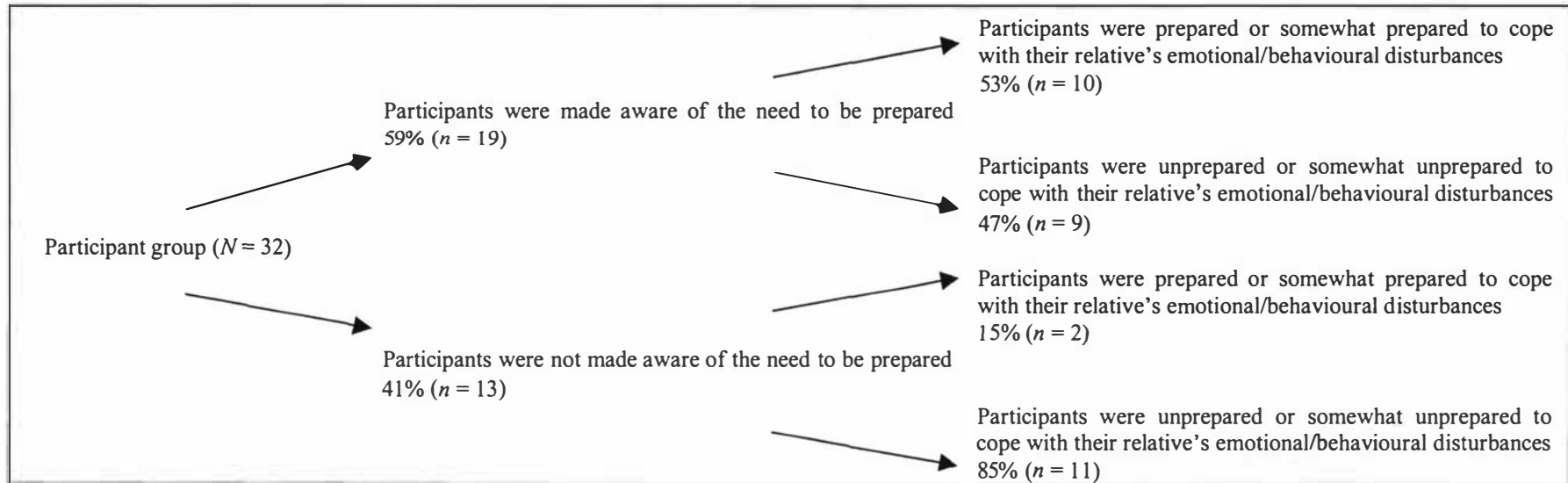
*Note.* Participants who were aware of the need to be prepared to cope were more prepared ( $M = 2.4$ ) than those who believed they were not made aware, ( $M = 1.5$ ),  $t(30) = 2.57$ ,  $p = .015$

C10. Preparedness levels based on awareness of the need for preparation: The relative's emotional responses to TBI



*Note.* Participants who were aware of the need to be prepared to cope were more prepared ( $M = 2.6$ ) than those who believed they were not made aware, ( $M = 1.8$ ),  $t(30) = 2.53, p = .017$

C11. Preparedness levels based on awareness of the need for preparation: The relative's emotional/behavioural disturbances



*Note.* Family members who were made aware of the need to be prepared reported feeling significantly more prepared ( $M = 2.3$ ) than those who believed they were not made aware ( $M = 1.5$ ),  $t(30) = 2.32$ ,  $p = .027$