Living with Traumatic Brain Injury: Views of Survivors and Family Members

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Abstract: Living with Traumatic Brain Injury: The Case of Ireland

Aim: This study is principally focused on the experiences of survivors of Traumatic Brain Injury (TBI) in Ireland and family members.

Literature: The literature draws mainly from the discipline of sociology and the following sub-disciplines: the sociology of health and illness, the sociology of organisations, disability, illness narratives and family theory.

Conceptual Framework: The overarching analytical framework utilises and builds on the traditional biomedical model of TBI, acknowledging that the biomedical model has much to inform with regard to TBI. However, this study examined the wider implications of TBI on individuals, families, health professionals, government and society. Therefore, a holistic model is appropriate to supplement the traditional approach. This was found to be useful for considering TBI in the Irish context and allowed for the inclusion of social aspects of interest.

Methods: This research utilised a mixed methods approach. A retrospective study which involved a quantitative data gathering exercise resulted in the development of substantial data sets of admissions to the only two specialised neurosurgical units in Ireland: these were Beaumont Hospital, Dublin and Cork University Hospital. Qualitative interviews with survivors and family members were conducted. The purposive sample selection of survivors and family members was drawn from the hospital datasets referred to above.

Findings: Key findings focus on the considerable adjustment necessary for many of the survivors of TBI. The chaos that entered people's lives, the shift from independence to dependence, the loss of friends, jobs and previous routines influenced their experience of recovery. Lack of public awareness regarding brain injury and the reaction of others to disability had a profound effect on how survivors managed everyday encounters and social interactions. Survivors reported being 'written off' by health and social care providers. However, survivors in this study had definite goals and aspirations and many stated they felt 'lucky to be alive'. The theme 'lucky to be alive' and the perspectives of survivors offer an alternative argument to the often widely held societal belief that the survivor 'would be better off dead' than brain damaged and disabled for life.

Key findings from family members of TBI survivors focus on the adaptation required. Parents not being able to retire and spouses having to become 'breadwinners', as well as carers, are unexpected changes. Family encounters with healthcare providers were sometimes problematic. Some participants reported being told to remove their loved ones from acute hospitals because they were 'bed-blocking'. Family members and TBI survivors shared the view that rehabilitation and post-rehabilitation supports and services in Ireland remain fragmented and poorly resourced.

Key conclusions are drawn from the research findings and recommendations developed to improve recovery processes and quality of life for TBI survivors and their families.
Declaration

I hereby declare that the sources which I have used in this research have been acknowledged in the body of the thesis and in the bibliography, and that the rest of the work is my own. The thesis does not exceed 100,000 words in length.

This thesis represents my own work and it has not been submitted in whole or part by me or any other persons for the purpose of obtaining another qualification.

Signed: ........................................

Date: ...........................................
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Chapter 1

Introduction

1.1. Introduction

This research is principally focused on the experiences of survivors of Traumatic Brain Injury (TBI) in Ireland and family members. This is a timely and much-needed study. Brain injury is a leading cause of death and disability worldwide (International Brain Injury Association, 2010:1). Every year in Ireland, approximately 10,000 people sustain a traumatic brain injury. Road traffic accident, assault, falls and sporting injuries are the main causes; eighty percent of victims are male and 7 out of 10 are aged less than 25 years at the time of injury (Headway, 2009:1).

International studies of head injuries suggest that many survivors of moderate to severe head injury suffer significant and persistent disability (Thornhill et al., 2000). Studies of the long-term social and economic consequences for survivors of TBI in Ireland are few. However, the common experience for people with TBI is social rejection, isolation, poverty, being ‘written off’, inappropriate and inadequate accommodation options, a lack of advocacy, a lack of rehabilitation, medical and professional dominance, lack of agency and negative public attitudes about brain injury (Sherry, 2006:26).

This chapter outlines briefly the research context, research aims, objectives and questions. It further outlines the literature reviewed, the analytical approaches identified in the literature and the mixed methodological approach adopted.

1.2. Overall Aim

The main aim of the study is to build a greater understanding of the experiences of TBI adult survivors from a social perspective, drawing on relevant sociological theories.

1.3. Definitions

In this study TBI adult survivors are identified as people aged 16 to 64 years at the time of injury. TBI is defined as ‘a brain injury caused by an external physical force that may produce a diminished or altered state of consciousness’ (Brain Injury Association, 2009:1). More specific and technical definitions regarding TBI are provided in Chapter 2 (Literature Review).
1.4. Key Objectives

The key objectives of this study are to:

- examine the common causes and effects of TBI in Ireland; (literature review and secondary data review)
- provide quantification of how many people aged 16–64 sustain a traumatic brain injury in Ireland between a specific time period and with reference to the total populations
- explore the key issues identified by NGOs and health care providers; (qualitative data collection and analysis)
- build on the existing body of research to offer more holistic explanations of the changed context of the lives of TBI survivors, and those of family members/significant others (qualitative data collection and analysis).

The study uses a quantitative approach in order to provide a background on TBI in Ireland and a qualitative approach to gain a deeper understanding of the issues which affect survivors and their families.

1.5. Research Questions

The key research questions are as follows:

i) What are the key changes experienced in the lives of TBI survivors?
ii) How have the lives of family members of TBI survivors changed?
 iii) What are the perspectives of TBI survivors and their families regarding the health and social care supports and services?
 iv) Based on the perspectives of TBI survivors and their families, how could health and social services be developed to respond better to their needs?

1.6. Background Context

Four key aspects of the research context in relation to traumatic brain injury are:

i) Traumatic Brain Injury (TBI) is a major – but largely ignored – public health issue in Ireland.

ii) No accurate statistics exist on the incidence and prevalence of TBI in Ireland.

iii) Therefore, the cause of injury and the long-term effects, as well as responses, are significantly under-explored.

iv) This research aims to fill important gaps – both in the literature, and to identify more appropriate supports and services.
1.7. Contribution to the Field

The literature mainly borrows from the discipline of sociology and the sub-disciplines the sociology of health and illness, the sociology of organisation, illness narratives and family theory. The research findings will contribute to these fields related to TBI.

1.8. Relevance of this Research

Much of the existing literature on chronic illness largely ignores the concept of biographical disruption, as described by Bury (1991) in his thinking on chronic illness. He describes the onset of chronic illness as 'a sudden, unexpected and life-changing event which brings a range of unforeseen challenges' (Bury, 1991: 12).

Brain injury is a classic example of biographical disruption, as brain injury is so sudden and unexpected, people are not prepared and the cognitive (as well as physical) changes make it a more difficult adjustment than physical impairment alone.

There are important gaps in the literature addressed by this research. They include:

- a predominance of professional accounts of TBI, but largely a neglect to date to record the voices of survivors;
- an absence of literature on survival/recovery from TBI in the Irish context;
- gaps in the chronic illness literature specifically on TBI, e.g. biographical disruption;
- a failure to date to adequately address people with brain injuries, within the social model of disability.

This literature is drawn on in the development of the analytical framework of the research.

1.9. Structure of the Thesis

The thesis is developed as follows:

- **Chapter Two: Literature Review and Analytical Framework**

A number of broad areas of the literature was explored to refine the research questions and to inform the focus of the study. The chapter is presented in ten thematic sections: i) defining key terms of relevance to the research; ii) background of TBI internationally and in Ireland; iii) clinical aspects of TBI; iv) impact of TBI; v) rehabilitation and its outcome measurements; vi) disability classification tools; vii) experience of TBI at an individual
level; viii) illness narratives; ix) experience of family members and significant others of TBI survivors and x) current provision of rehabilitation services for people with TBI.

Conceptual Framework

The overarching analytical framework utilises and builds on the traditional biomedical model of TBI. While this is accepted for its utility, a more holistic model is appropriate to supplement the traditional approach. This was found to be useful for considering TBI in the Irish context in totality and allowed for the inclusion of social aspects of illness (rehabilitation and adjustment).

Some of these social aspects include at the micro level (individuals and family members), the following theorists:

- Bury, 1991: (biographical disruption);
- Goffman, 1963 (visible and invisible stigma, ‘passing’, disclosure);
- Frank, 1995 and Kleinman, 1988 (illness narratives);
- Sherry, 2006 (social model focused on brain injury);
- Sherif and Hovland, 1961 (social judgement theory);
- Oliver, 1986 (social model of disability);
- Hammell, 2006 (rehabilitation).

At the meso level, theoretical approaches take account of factors such as the hospitals as institutions, and health and social care professionals. Some key theoretical examples are:

- Charles Perrow, 1963 (hospitals)
- Etzioni, 1975 (sociology/goals of organisation);
- Strauss, 1978 (negotiated order theory/occupational ideologies).

At the macro level, international, European Union (EU), national and regional factors related to social policy were considered including the work of the following: Mason and Goddard (2009); Kind (2005); Jacobs (2009).

In summary, a top-down analytical approach using existing relevant theories was utilised to inform the analysis of the data generated by the qualitative investigation (i.e. the transcripts of interviews with survivors and carers / family members and others).

- Chapter Three: Methodology

The research utilised a mixed methods approach with significant quantitative and qualitative elements but more strongly inclined towards the latter. This enabled me to address my research objectives and questions.
**Quantitative Methods**

To contextualise the issue of TBI, a retrospective study was undertaken utilising primary sources of data from the patient admission systems in two acute hospitals. This involved quantitative data gathering and analysis and the development of substantial data sets of TBI admissions to the only two specialised neurosurgical units in Ireland: Beaumont Hospital (BH), Dublin and Cork University Hospital (CUH).

Specifically it involved a review of 310 hospital patient records in CUH for people treated in a two year period between January 2005 and December 2006. Of the records reviewed, 194 patients met the study criteria. A database of these records was developed for analysis. In addition, an existing database of head injury admissions to Beaumont Hospital was reviewed covering the period June 2006 and June 2007. One-hundred-and-thirty-four (134) patients met the study criteria in this case. This database is held by Trauma Audit Research Network (TARN) at Manchester University. A new dataset was developed from these records for the purposes of this study.

While the time periods of analysis vary, it should be noted that Beaumont Hospital receives almost twice as many cases as CUH and these are often of greater severity. However, while both hospitals had admissions of moderate and severe TBI, mild TBI is often not recorded as it is treated in the primary care setting.

**Qualitative Methods**

A rationale for gathering qualitative data and adopting a mixed method approach was so that the narratives of TBI survivors and their families were complemented with additional quantitative data. Qualitative interviews with survivors, family members, carers, NGO spokespeople and health care providers were conducted. This purposive sample selection was drawn from the datasets referred to above. It should be noted that gathering data from the TBI population in Ireland was resource intensive and logistically difficult due to their geographical rural dispersement.

In-depth qualitative semi-structured one-to-one interviews were conducted with 16 TBI survivors and 11 family members, as well as 23 health professionals, and seven (7) support staff members working in the community and/or the NGO sector.

**Comparative Observation in USA**

While this research is limited to Ireland, a period of observation took place in the USA to provide insights as to how this type of research is done there and to learn from their experiences. This study visit was made to the 'state-of-the-art' facility at the Medical University of South Carolina, Charleston.
- **Chapter Four: Quantitative Findings on TBI in Ireland**

This chapter presents the key quantitative findings from two hospital datasets. The first dataset relates to people who presented at the Accident and Emergency Department, Cork University Hospital with symptoms of brain injury, and were either admitted or discharged home. The second dataset is part of a larger dataset on injury compiled at Beaumont Hospital, Dublin.

- **Chapter Five: Qualitative Findings on TBI Survivor Perspectives**

This chapter presents the findings from the interview data with 16 survivors of moderate or severe TBI. Thematic analysis of the data built up an understanding of the needs of those living with a Traumatic Brain Injury (TBI) in Ireland. Themes explained and developed include: survivor experiences of TBI; encounters with healthcare professionals and service providers; and views on appropriateness of services to needs. The findings are discussed drawing on an overarching biomedical and holistic analytical framework.

- **Chapter Six: Qualitative Findings on Family Members of TBI Survivors**

The purpose of this chapter is to present the findings from the 11 qualitative one-to-one interviews with family members of people with TBI. The themes addressed in this chapter include: what are the experiences of family members of survivors after a TBI, and experiences of the rehabilitation and post-rehabilitation services in Ireland.

- **Chapter Seven: Conclusions and Recommendations**

The final chapter provides a summary of the findings of this study to enhance a greater understanding of TBI in Ireland. It makes recommendations with regard to good practice in supports and services generally in the area of TBI, and implementation in an Irish context. A number of areas for further research are identified.

Chapter 2 presents the findings from the Literature Review and presents the Analytical Framework of the research.
Chapter 2

Literature Review

2.1. Introduction

The purpose of this chapter is to review the literature on survivor experiences of living with a traumatic brain injury (TBI). Both empirical research and theoretical literature was examined. It was conducted by exploring the following research themes:

i) the key changes experienced in the lives of TBI survivors;
ii) the changes in the lives of family members of TBI survivors;
iii) the perspectives of TBI survivors and their families regarding the health and social care supports and services;
iv) the current provision of health and social services for TBI survivors in Ireland.

These themes are to help address the key objectives of this study, which were to:

- examine the common causes and effects of TBI in Ireland;
- provide quantification of how many people aged 16–64 years sustain a traumatic brain injury in Ireland between a specific time period and with reference to the total populations.

2.2. Contribution to the Field

The literature draws from the discipline of sociology and the sub-discipline the sociology of health and illness, the sociology of organisation, disability, illness narratives and family theory. My research findings will contribute to these fields.

2.3. Identified Gaps in the Literature

As stated briefly in Chapter One, I argue that a number of gaps exist in the literature and were identified as part of my review. These include:

- a noticeable absence of literature on survival/recovery from TBI in the Irish experience;
- a predominance of professional bio-medical accounts of TBI, that largely neglect more sociological perspectives that record the voices of survivors;
- gaps in the chronic illness literature specifically on TBI, e.g. biographical
disruption;
- a failure, to date, to adequately address people with brain injuries, within the social model of disability.

These gaps are examined in greater detail throughout this chapter.

2.4. Development of an Analytical Framework

The literature review assisted with the development of the analytical framework by identifying useful theories and approaches to explain the changed context of the lives of TBI survivors, and those of family members/significant others. This study builds on the biomedical model but favours a more holistic model (while acknowledging that the biomedical model has much to inform with regard to TBI, especially during the acute phase of the illness). The study looks at the wider implications of TBI on individuals, families, health professionals, Government and society. Therefore, the holistic model is preferable for this analysis as it builds in micro theories that are discussed at each level. This is particularly useful from the sociology disciplinary perspective, which adopts a broader approach than medical models alone. Further to this, these approaches are used in the development of an overarching macro analytical framework which is discussed in greater detail below (section 16) and in Chapter 7.

2.5. Outline of this Chapter

The chapter is presented in five sections as follows:

i) Defining Key Terms of Relevance to the Research
ii) Background of Traumatic Brain Injury Internationally and in Ireland
iii) Clinical Aspects of TBI
iv) Impact of TBI
v) Rehabilitation and its Outcome Measurements
vi) Disability Classification Tools
vii) Experiences of TBI at an Individual Level (independence to dependence; disability – impairment; stigma; dramaturgy; selfhood and identity; social inequality)
viii) Illness Narratives
ix) Experience of Family Members and Significant Others of TBI Survivors
x) Current Provision of Rehabilitation Services for People with TBI.

The conceptual approaches for the analytical framework are presented and discussed in a later section. This includes a top-down analytical approach using existing relevant theories to inform the analysis of the data generated from the interviews.
2.6. Defining Key Terms

Traumatic Brain Injury (TBI) is the term given to any injury to the brain as a result of a blow to the head, even if unconsciousness does not occur (Moss et al., 1996; IBIA, 2010a). The severity of TBI is categorised as mild, moderate or severe according to the Glasgow Coma Scale or GCS (see Appendix A). TBI can be distinguished from other causes of acquired brain injury brought about by a medical or congenital condition, such as a stroke or brain tumour (Webb, 1998: 542).

Neurosurgery is the surgical discipline focused on treating the central, peripheral nervous system and spinal cord diseases amenable to surgical intervention. Conditions may be traumatic (TBI) and non-traumatic, including brain tumours, spontaneous intra-cranial haemorrhage and aneurysms (Phillips, 2009: 13).

Rehabilitation is defined as 'the process of active change by which a person who has become disabled acquires the knowledge and skills for optimal physical, psychological and social function' (British Society of Rehabilitation Medicine, 2008).

Social problem theory can be defined as 'a social phenomenon or social condition that is perceived to potentially or directly threaten the social order' (Jamrozik and Nocella, 1998: 18).

2.7. The Background to Traumatic Brain Injury (TBI) Internationally and in Ireland

In this section, the subject of TBI is placed in context by examining the incidence at an international level, as well as in Ireland. This study draws widely on the work of international organisations which have contributed to the development of data gathering, including the World Health Organisation (WHO), United Nations (UN) and the European Commission.

2.7.1. International Incidence: The Statistics

Traumatic brain injury is a leading cause of death and disability in the young adult population of most developed countries (International Brain Injury Association, 2006; Finfer and Cohen, 2001). In the European Union, brain injury accounts for one million hospital admissions per year.

A reasonably accurate estimation of the Europe-wide TBI incidence rate is 235 per 100,000 people with an average mortality rate of 15 per 100,000 (Taglaferri et al., 2006). This figure was derived from findings of national studies in Denmark, Sweden, Finland,
Portugal, Germany, and from regions within Norway, Sweden, Italy, Switzerland, Spain, Denmark, Ireland, the U.K. and France. The TBI severity ratio of hospitalised patients was about 22:1.5:1 for mild: moderate: severe cases, respectively (Taglaferri et al., 2006). Injury in general is the leading cause of death for individuals aged between 0 and 40 years (World Health Organisation, 2003).

In England and Wales, trauma patients with a traumatic brain injury had a tenfold higher mortality rate than injured patients without head injury (1989–2003); improvements in trauma care have delivered greater benefit to patients without brain injury (Patel et al., 2005).

The magnitude of traumatic brain injury in the USA is apparent from the following statistics: about 1.4 million head injuries of all types (including skull and facial fractures) occur each year in the US. About 235,000 individuals sustain brain injuries severe enough to require hospitalisation, while 1.1 million people are released from hospital within 24 hours (Centers for Injury Prevention and Control, 2009). Traumatic brain injuries account for one-third or an estimated 30.5 per cent of all injury deaths in the United States (Faul et al., 2010). This translates to a total of 56,000 people each year (Kraus and MacArthur, 1996).

Direct medical costs and indirect costs of TBI, such as lost productivity, totalled an estimated $60 billion in the United States in 2000 (Finkelstein et al., 2006). About three-quarters of TBIs that occur each year are concussions or other forms of mild traumatic brain injury (Center for Disease Control and Prevention, 2003). The approximate breakdown of incidence between mild, moderate and severe TBI (USA) is as follows:

- Mild TBI - 131 cases per 100,000 people
- Moderate TBI - 15 cases per 100,000
- Severe TBI - 14 cases per 100,000 (with pre-hospital deaths included – 21 cases) (Brazinova, 2003).
- This rate of 160 per 100,000 of the population is lower than the reported rate for Europe—which was 235 per 100,000 of the population (Taglaferri et al., 2006). The causes of TBI in the US are similar to almost all countries: falls account for 28 percent, road traffic incidents 20 percent, struck by or against events 19 percent and assaults 11 percent (Langois et al., 2004). Five point three million Americans (2 per cent of the US population) have a life-long or long-term need for help to perform activities of daily living as a result of TBI (Thurman et al., 1999).
2.7.2. Incidence of TBI in Ireland

The limited literature that currently exists in Ireland on TBI (Headway Ireland, 2009; Phillips, 2008) was reviewed. Data gathering is sparse, inconsistent and fragmented. In Ireland, each year approximately 13,000 people sustain a traumatic brain injury. For every traumatic brain injury death, at least two other people survive with permanent disability (TARN, 2008). Two-thirds are male and the majority are young, i.e. between the ages of 16 and 24 years at the time of injury (Rehab Group, 2004; Thurman et al., 1999). People in age groups 15–29 years of age are three times more likely to sustain a brain injury than any other group (Headway Ireland, 2009). See Appendix B for details on Headway Ireland.

A recent report indicates that the median age has been increasing over the past two decades in Ireland, and in other high income countries; the mean age in Ireland is now 42 years (Phillips, 2009). Phillips (2009) also noted that alcohol use was reported for one-in-four cases of Traumatic Brain Injury (TBI) in Ireland. Four in every five assaults involved alcohol, and alcohol was associated with a greater incidence of severe injury.

The proportion of cases of TBI from external causes varied considerably and several reports observed an association of alcohol use with TBI (Tagliaferri et al., 2006). Alcohol consumption has been shown to be a contributing factor for the high incidence of traumatic brain injury (Phillips, 2009). It also affects diagnosis, management and recovery from TBIs (Hyder et al., 2007).

BRI (2008) – (see Appendix B for details of BRI) state that there are approximately 50,000 people in Ireland with long-term problems after TBI alone – that is 1.2% of the population. International evidence is similar. For example, an estimated 62.3 per 100,000 adults age 15 and over are living in the community (USA) with enduring functional impairments due to TBI (excluding most survivors of mild TBI) (Moscato et al., 1994). Phillips (2009) states graphically that ‘improved hospital survival figures mask the greater tragedy of those who survived their injuries, sometimes desperately disabled for the rest of their lives’ (Phillips, 2009:2). Falls are the main cause of traumatic brain injury in Ireland, accounting for three in every five cases (Phillips, 2009). Other causes are road traffic accidents, sport, self-harm, assault and accidents with animals.

2.7.3. Lack of Available Data

As already indicated, there is a significant absence of data on TBI in Ireland. However, Ireland is not unique in this area. Data on disability resulting from TBI are limited in many countries. Brazinova (2003) points out that prevalence and extent of disability is not well-documented because mild cases may not be hospitalised, and estimates are often
based on existing disabilities. Other reasons are: discrepancies in data collection, and the difference in findings of diagnostic imaging at different time intervals (Brazinova, 2003). At present, it is not known how many people are living in Ireland with the disabling effects of this type of injury, and estimates are dependent on data from other countries. The main reason is the complete absence of a comprehensive database on injury. According to Phillips (2009), a consultant neurosurgeon, ‘no national mechanism exists for capturing the incidence, management and outcome of TBI presenting to the Irish health care system. Aetiology, incidence and estimates of disability are inferred from international data, which may not be representative of the Irish population’ (Phillips, 2009:9).

However, some datasets do exist, for example; the Central Statistics Office (CSO), the Road Safety Authority, Garda Siochana, as well as smaller scale datasets, such as data transfer from Beaumont Hospital to the Trauma Audit Research Network (TARN) databases in the UK (TARN, 2009). In Ireland, some researchers, such as Phillips argue that a national trauma registry, including official statistics on brain injury, is required as a matter of urgency to provide on-going monitoring of national service provision (Phillips, 2009:7).

In summary, TBI is increasing in incidence - the WHO has projected that by the year 2020, TBI will be the third highest cause of mortality in the developing world (Maas, 2007). In order to address the long-term as well as the immediate needs of TBI survivors, high-quality comprehensive data collection mechanisms are required (Maas, 2007). Ireland lags behind other countries in relation to data collection on TBI. Therefore, it is difficult to get an accurate quantification of the extent of the problem of TBI in Ireland.

2.8. Clinical Aspects of TBI

This section focuses predominantly on health professionals’ bio-medical accounts of TBI. The bio-medical literature is, however, not without relevance as it provides a better understanding of the clinical bio-medical interventions often necessary at the early stages of recovery, and without which survival may not be possible. This literature is therefore examined here.

Brain injury is mostly represented pessimistically, which might impact negatively on the survivor experience of TBI. General influencing factors of outcome in later stages of recovery after traumatic brain injury have been identified as: the severity of injury, pre-injury socio-demographic factors, post-injury rehabilitation and environmental variables, such as the level and type of local employment (Ownsworth and McKenna, 2004; Asikainen et al., 1998; Fleming et al., 1999).
Specific factors are identified as predictors of outcome after traumatic brain injury (Fleming et al., 1999). These include:

- the severity of the initial condition as measured by the Glasgow Coma Scale (a measurement which is used to predict prognosis - (see Appendix A) (Teasdale and Jennett, 1974);
- duration of post-traumatic amnesia;
- age;
- educational level and
- occupational status

(Fleming et al., 1999).

Factors such as pre-injury functioning capacities and magnitude of neurological damage greatly influence the rate of recovery (Mussack et al., 2002). De Guise et al. (2006) found that the duration of Post-Traumatic Amnesia (PTA) was the most important predictor of outcome after a traumatic brain injury, and not just a Glasgow Coma Score (GCS). The effect was worst for patients who had PTA longer than 24 hours. They contend that a patient still in PTA after seven days of acute care will require rehabilitation. Similar conclusions were reached by Zafonte et al. (1997). This predictor is important for discharge planning (de Guise et al., 2006) and in helping to chart the need for rehabilitation services.

A high Glasgow Coma Score (Khan, 2003); participation in higher education and young age at time of injury are associated with positive outcomes (Nakase-Richardson et al., 2007). An explanation as to why a higher level of education was found to be an important influence on rate of recovery after a TBI may lie in the pre-injury health status of the better educated. They are more likely to engage in physical exercise, have better nutrition, be more compliant with medical treatment and have better social networks (de Guise et al., 2006). Stern (2002) argues that the brain compensates by using alternative mechanisms. He termed this cognitive reserve theory. Further studies, such as those of Kesler et al. (2003) and de Guise et al. (2006) support this theory. The mechanism of compensation is evident very early on and has an effect even within days of the injury (de Guise et al., 2006). Sbordone et al. (1995) found that survivors of a severe TBI continue to make gradual improvements in functioning for at least 10 years post-injury.

The National Institute for Health and Clinical Excellence (NICE) clinical guideline 56 for Head Injury Management (NICE, 2007) is used as a guide for the triage, assessment, investigation and early management of head injury in infants, children and adults. The guideline is evidence-based, and offers best practice for the care of all patients who present with a suspected or confirmed traumatic head injury with or without other major trauma (NICE, 2007:7). Such guidelines are particularly important in developing best practice
in relation to the clinical care of people with TBI. For example, a long lapse between admission and rehabilitation is identified as a factor which negatively influences long-term outcome for the survivor (Rappaport et al., 1989).

**Outcome Prediction following TBI**

Outcome is difficult to assess (Fleming et al., 1999). However, return to work within a short time frame, has been seen as an important measure of long-term outcome (Crepeau and Scherzer, 1993). Although the largest group of TBI survivors are young adults, many survivors, particularly those with a severe TBI, do not return to work (Family Caregiver Alliance, 2009). Ability to return to work is highly correlated to the limitations placed on the survivor by the brain injury or related injuries (Greenspan et al., 1997; Ip et al., 1997). As few as ten per cent of severely injured survivors maintain jobs and friendships through the second decade post injury (Prigatano and Ben-Yishay, 1999). McMordie et al. (1990) found in their study of 177 survivors, that 45 per cent of the sample study did engage in some work-related activity, while only 19 per cent were in competitive employment positions. Factors which were related to return to work after head injury were: age when injured, sex, length of loss of consciousness and motor and ambulation impairment. Many of those who did return to competitive employment did so in less demanding positions than they held pre-injury.

However, drawing on international experiences, certain initiatives demonstrate that, with specific help it is possible to resume prior activities. For example, Schutz (2007) established that the systematic training techniques in the use of external aids for memory and time management, which he employed in his study with nine severely injured graduates, had positive effects in gaining employment and in other areas, such as parenting. This technique which he terms the ‘Third Generation Program’ is broken into four main steps - Targeted Deficit Recognition Training, Error Analysis, Targeted Situation Recognition and Team Meetings. This revised model also places emphasis on self-therapy and family assist therapy. The results showed that each individual, ‘demonstrated superior instrumental adaptation in school or work, sustained across a period of many years’ (Schutz, 2007:53). Some acquired new skills of education and work, a few entered new marriages, undertook new parenting duties and established new social and work relationships. The study is limited by low numbers in the sample, but it is significant in demonstrating that devoting time, and using specific techniques, can have positive results for people with severe traumatic brain injury.

To conclude, there are no definitive outcome indicators following TBI. This makes it difficult to predict long-term prognosis. Therefore, planning of future services is problematic - i.e. rehabilitation and post-rehabilitation supports and services. Further,
Clinicians cannot inform families of survivors of TBI with any certainty as to what level of improvement can be reached.

2.9. Impact of TBI

The increased incidence of TBI in the developed world has prompted many to question the reasons for this. Brock et al. (1995) describe this type of injury as a silent epidemic of modern times due to its contemporary prevalence. Advances in medical technology in the past 20 to 30 years at the pre-hospital and acute phase, as well as greater motor vehicle safety, mean that the chance of survival has increased significantly in recent times. Webb (1998) states that ‘Over and above the rather obvious sociological and economic causes for an increase in head injury - prosperity, mobility and the (particularly ‘masculinist’) cultural adulation of speed, cars, motorbikes- the principal reason for the increase in the prevalence of TBI is cruelly ironic’ (Webb, 1998:542).

Traumatic Brain Injury (TBI) has far reaching effects on family and personal relationships, due to its effect on cognitive, physical and behavioural characteristics (Morton and Wehman, 1995). International studies of head injury suggest that many survivors of moderate and severe head injury endure significant and persistent disability (Thornhill et al., 2000). Traumatic Brain Injury (TBI) is distinctive in that it produces major changes that manifest themselves differently in each individual (Chamberlain, 2006). A person with a head injury may be affected in several ways: physical, which involves how the body works; cognitive, which influences how the brain thinks, learns and remembers; or emotional and behavioural problems, i.e. outbursts of inappropriate emotions. It is important to note that not everyone with head injury will have problems in these areas. However, a brain injury is often a sudden and negative change that radically interrupts an individual’s life. Other outcomes, such as movement ability, strength, coordination, balance, as well as sensation, can also be affected negatively by traumatic brain injury (Brazinova, 2003). The experience of traumatic brain injury can include denial, frustration, inflexibility, apathy, intolerance, impulsiveness, poor judgement, agitation, lack of inhibition, poor reasoning, decreased social skills, and increased acts of aggression and destruction (Pryor, 2004; Discharge, 1999; Sandel and Mysiw, 1996; Brazinova, 2003). Physical capabilities that are unfamiliar, unpredictable, confusing and disturbing are not well-understood by the individual or by others. Loss of executive functioning causing disability is often the aspect which is least well-understood by those close to the survivor, and can seriously impair ability to function with everyday tasks (Chamberlain, 2006). Executive functioning involves dealing successfully with initiation and drive (starting behaviour), response inhibition (stopping behaviour), task persistence (maintaining behaviour), organisation (organising actions and thoughts), generative thinking (creativity, fluency and cognitive flexibility) and awareness (monitoring and modifying one’s own behaviour) (Millis et al., 2001).
2.9.1. Women and TBI

Little attention has been afforded to gender differences and TBI in the literature. This has been noted by Sherwin (2010), who points out that research into the adjustment of women to brain injury is falling behind that of disability in general and intellectual disabilities in particular. She further states that while the typical survivor of TBI is a young male, who is often engaged in high risk behaviour, women are more likely to be victims of motor vehicle accidents or abuse. A further area of neglect in the literature according to Trudel (2006) and Nosek (2006) is the area of female sexuality and reproduction following TBI.

Nosek (2006) states that ‘the dysfunction can be separated into physical problems (lack of energy and pleasure), psychological (changed body image as a result of the physical injury) and educational (ability to satisfy a partner, positioning etc.)’ (Nosek, 2006:42).

The gender dimension of TBI needs urgent attention if women are to be included in all areas of care and treatment. According to Sherwin (2010), ‘associated with a gender-specific holistic approach, vocational rehabilitation and counselling is often overlooked as women’s earning power is less and because it is believed to not be vital to her sense of self. This bias can also express itself in a failure to prepare young women to enter the job market’ (Sherwin, 2010:1).

In summary, from the review of this literature, it is clear that TBI can result in life-changing physical and cognitive impairments for survivors. TBI further impacts on families and interpersonal relationships. As the survivor profile is mostly young (16–24 years) and male at the time of injury, their specific needs are addressed mostly in line with members of society with other chronic illnesses, but their needs are different. Gender differences have received less attention particularly the needs of women who are survivors of severe TBI.

2.10. Rehabilitation and its Outcome Measurements

In this section, further literature on the rehabilitation of TBI survivors is considered. Rehabilitation is the only intervention which is deemed appropriate at the recovery stage following TBI. Brain injury rehabilitation services are increasingly defined by the needs of patients rather than the diagnosis (Turner-Stokes et al., 2009). The separation of services for the 16 to 65 year age group from older adults in the United Kingdom and elsewhere reflects an effort to address the specific needs of younger adults who may have different goals, such as returning to work or parenting. They may also live longer with the consequences of injury than the older population (Turner-Stokes et al., 2009:2). The literature documents that the health status of a person with TBI is closely related to access to rehabilitation services, as well as ability for adaptation to changes in life.
circumstances. From this perspective, specialised rehabilitation centres are viewed as an excellent environment to promote positive behaviour, attitudes and skills, while at the same time benefiting the hospitals concerned in health terms (Schultz, 2007; Boake and Diller, 2005; Wood, 1990).

Rehabilitative interventions may include some or all of the following: medical and nursing care, neuro-psychology, social support, cognitive and behavioural therapy, physiotherapy speech and language therapy, occupational therapy, home support, training and vocational rehabilitation (Kiernan, 2004; Heary et al., 2001). The majority of people with head injuries need cognitive rehabilitation and not physical rehabilitation (Kiernan, 2004). Brain injury rehabilitation programme models, as discussed by Bergquist et al., 1994 and Trexler et al., 1994. These include several key components:

- multi-disciplinary approach to rehabilitation,
- individualised treatment planning,
- comprehensive, goal orientated treatment planning and intervention and,
- staff with specific expertise in brain injury rehabilitation

(Bergquist et al., 1994, cited in Mc Corkel et al., 2003).

A multi-disciplinary team approach is generally used with people with traumatic brain injury (NIH, 2007). Turner-Stokes et al. (2009) found in their systematic review that the effectiveness of multi-disciplinary rehabilitation is not yet established in the acquired brain injury population comprising concentrations of young adults (aged 16 to 65 years). This, however, may be a methodology problem and, as the authors suggest, rehabilitation for brain injury is such an individualised and long-term process, it can be difficult to draw conclusions from research projects (Turner-Stokes et al., 2009:2).

According to Turner-Stokes et al. (2009), a multi-disciplinary approach is however effective in the patients who have had strokes, particularly in the groups where young adults predominate. Turner-Stokes et al. (2009) also point out that the problems following acquired brain injury vary and consequently, different interventions and combinations of interventions are required to suit the needs of patients with different problems (2009:2). According to Chesnut et al. (1999), ‘today, a person’s path to rehabilitation after sustaining brain injury may be determined by the mechanism of injury, the resources of the community, the person’s employment or financial status, the consent of the family, and/or the accuracy of the emergency department diagnosis’ (Chesnut et al., 1999:6).

Gladman et al. (1993) suggest that younger patients respond better in specialised environments. Turner-Stokes et al. (2009) recommend that patients discharged from in-patient rehabilitation should have access to out-patient or community-based services appropriate to their needs. People with TBI typically make the most significant gains in the first six
months (Connor, 2002). Turner-Stokes et al. (2009) suggest that patients presenting at the acute stage with moderate or severe brain injury should be routinely followed up to assess their needs for rehabilitation. She states that ‘intensive rehabilitation appears to lead to greater gains’ (Turner-Stokes et al., 2009:2).

The setting of international standards for rehabilitation of people with acquired brain injury is a key aim of many providers of services. The Commission on Accreditation of Rehabilitation Facilities (CARF) is an international, third party, independent, consultative accreditation process. Its aim is to develop and revise state of the art standards representing programs in health and human services. The second job is to apply the standards in a peer review, on-site survey process. CARF’s process is a quality framework with a focus on performance improvement that addresses both the business and the clinical service delivery system of the provider. Throughout its history and till this day CARF is a “field driven process” meaning consumers, providers, payers, and regulators all interact with CARF and develop and revise standards (McDonnell, 2010: 1).

According to McDonnell (2010), many countries are developing rehabilitation strategies, and more brain injury providers in these countries are also advocating for specialised brain injury rehabilitation. She suggests that greater use of technology be used to spread the innovations and development of brain injury services with providers throughout the world.

**Conclusion of section**
In this section, key issues identified by NGOs and health care providers were examined. Benefits of early rehabilitation, based on need, were identified.

**2.10.1. Referral to Rehabilitation Services**

According to Mechanic (1998), rehabilitation is guarded by the medical profession and decisions about access are made on scientific judgements based on need, which treatments are most likely to be effective and which cases deserve priority. Many researchers claim that decisions are often made using highly selective processes and interpretation of potential (Hughes and Griffiths, 1997). It has long been recognised that not all survivors of TBI gain access to rehabilitation (Cope, 1995), nor for a long enough period. Foster and Tilse (2003) developed a useful model for TBI and the complex process of referral following acute care, in response to what they judged to be widespread inconsistency in referral to rehabilitation. They contend that healthcare providers and other service providers may be
influenced by factors other than current standards, when making decisions about referral to rehabilitation and post-rehabilitation following traumatic brain injury (Foster and Tilse, 2003). The model provides a framework that can be used to explore the pattern of referrals and the practices of health professionals, the criteria used in the selection of candidates for referral to rehabilitation, and the processes employed. On-going care needs, after the acute phase of treatment has ended, are directed mainly to minimise the effects of TBI (Foster and Tilse, 2003). Clark et al., (1991) argue that as well as clinical indicators, social and demographic markers are often used to determine risk). Foster and Tilse (2003) argue that the factors influencing referrals incorporate three main components: 'characteristics of the individual with TBI, the activities of health professionals in the process of referral, and the context of care in which referral decisions are made’ (Foster and Tilse, 2003:2208).

The Concept of ‘Deservedness’

Decisions on referral are often influenced by deservedness of the recipient and the person’s social position (Griffiths and Hughes, 1993). Social judgement theory (Sherif et al., 1965; Unsworth, 1995), a theoretical perspective most closely associated with Sherif and Hovland (1961) offers one explanation. According to Social Judgment Theory, judgements are made on a number of zones:

i) the latitude of non-commitment (zone of positions we neither accept nor reject); and

ii) the latitude of rejection (zone of positions we reject) (cited in O’Keeffe, 1990:15).

The central idea of this theory is that attitude change is mediated by judgmental practice and its effects are used to influence people (Krebs, 1999). It is suggested that the construction of dependency of disabled people and the stereotyping of people with brain injury may act as a factor in deciding who gets rehabilitation and post-rehabilitation support, and who should be denied it. Oliver (1990) points out that it is not unusual for certain disabilities to become defined as social problems through the successful efforts of powerful groups to market their own self-interests. Often brain injured people are presented in terms of being a burden to society, not deserving of further care (Munford and Sullivan, 1997) and a drain on scarce resources. The reasons are twofold: (i) discourses on TBI are largely influenced by the medical ideology that struggles with disorders which cannot be cured, and (ii) the cause of TBI may be associated with high risk behaviour, with the implication that this is a personal responsibility issue.

Discourses suggest that hospitals do not have a duty of care towards people who cannot be cured. Thomas (1999b) points out that this is possible because of the ability of the medical profession to control the public’s perception on the purpose of hospitals. The hospital is an organised way to exclude people who cannot be cured (Thomas, 1999b). Perrow’s (1963)
analysis of hospitals suggests that these organisations have multiple goals, and recognises that these goals have the potential to create tension and conflict. Goals and outcome measurements created for the sole purpose of saving money often ignore the complex needs of people with long-term illness. People who have chronic illness or disability are seen as not responding to treatment by doctors and therefore are not deserving of hospital care (Age Concern, 1993). The goals of a hospital are not always apparent. Delayed discharges of patients from acute hospitals continue to attract media attention in Ireland. The assumption that most people affected by this are older adults, who are there while they wait for nursing home beds, is not entirely accurate. Many are young adults who have survived traumatic brain injury and are forced to wait for a place at the country’s only rehabilitation unit. The scale of this problem is demonstrated by the following figures released this year: ‘the number of delayed discharges nationally continued to be high in July at 899 - the average for 2009 is 831’ (O'Regan, 2009:5).

2.10.2. Perceived Aims of Rehabilitation

According to Pain et al. (1998), the aim of rehabilitation is to enhance the quality of life of clients affected by illness or impairment. However, Hammell (2006) argues that this is not achievable through minimising impairments, enhancing physical abilities or increasing physical independence because, ‘neither quality of life nor psychological distress correlate with physical function, independence or degree of impairment’ (Hammell, 2006:189). She further adds that ‘while increased function and independence may be useful objectives, they are not sufficient to imbue life with quality and are inadequate responses to the reality of disability’ (Hammell, 2006:189).

Hammell (2006) wrote extensively about the transition from a valued to a devalued bodily state following injury or illness. She calls the stage in between the two phases as the ‘liminal’ phase (defined as an in-between stage), and reminds us that it is during this phase rehabilitation is most likely to occur (Hammell, 2006:111). Murphy et al. (1988:238) suggest that because of problems created by impairments, and those imposed by societal practices, ‘liminality’ is an inevitable consequence of impairment. This prompts Murphy (1990) to imply that disabled people never regain a ‘whole’ status, and are always ‘neither dead nor fully alive’ (1990:131). Becker (1997) states that ‘following a disruption, people experience a period of limbo before they can begin to restore a sense of order in their lives’ (Becker, 1997:119).

Bury (1991) describes biographical disruption whereby the routine and structure of everyday life is disrupted. This disruption is profoundly influenced by the individual’s stage in life, roles, interests and their economic and social resources (Hammell, 2004a). People going through this stage are cut off from their old status but not yet incorporated
into their new found positions (Marks, 1999). According to Hyde et al. (2004), the extent to which a trauma or disease is disruptive to self and the capacity of the person to rebuild their biography depends on factors such as: the severity of the condition, and the extent to which an illness or infirmity causes stigma, the stage of the life course that a person confronts the illness, the impact of gender, ethnicity and social class, in terms of the cultural norms, belief systems and the social context of family, friends and the resources made available. Seymour (1998) suggests that the denial in clinical rehabilitation models of the experience of bodily limitations, and how in forging a new sense of self, people are forced to confront dominant social values and structural values that impact on embodied experience.

Similarly, Ylvisaker and Feeney (2000) state that historically professionals working in medical rehabilitation, ‘have attempted to reduce the underlying impairment with medication and exercises that target the neuro-psychological breakdowns presumed to be responsible for the manifest disability’ (Ylvisaker and Feeney, 2000:411). TBI is an individual and often invisible experience and recovery is often hampered by a lack of understanding by healthcare professionals (Chamberlain, 2006) as well as wider society. The feeling of loss and grief, as expressed by TBI survivors (Nochi, 2000; Frank, 1991; Kothari and Kirschner, 2003), is poorly understood. Coelho (2002) points out that recovery is only possible when a survivor regains the ability to test reality, and to recognise grief and loss. Nochi (2000) in his study found that survivors needed to construct a reality of the world which included TBI because it was now an integral part of their being. Nochi (2000) argued that survivors need to separate themselves from TBI and disability in order to incorporate it into a new self-image (cited in Chamberlain, 2006:411).

2.10.3. Mismatch of Goals in Rehabilitation

According to Hammell (2006), rehabilitation marks a disruption in a life, brought by illness or injury, and is a time of uncertainty and change. Watkins et al., (2001) observe that this is compounded by a mismatch between goals of the treating team and the aspirations of the survivor and may result in disappointment and the increased vulnerability of the client. Sacks (1996) further suggests that, there is a forced conversion for the individual to undergo a new way of being in the world. Hammell (2006:41) comments that debilitating illness represents the stripping away of physical ability and the withdrawal of social privileges and opportunities reserved for ‘normals’. Similarly, Murphy et al. (1988) reflect that ‘physically outside the boundaries of society, rehabilitation may constitute a sort of initiation process into a new, disabled, persona’ (Murphy et al., 1988, cited in Hammell, 2006:136).
However, it should be noted that, Hammell (1995) does not blame professionals for their lack of awareness of the realities of living with an impairment. In contrast, other writers, such as Cant, 1997, cited in Hammell, 2006:49) are unimpressed by therapists, describing them as ‘negative and pessimistic’. Further Kemp (2002, cited in Hammell, 2006:49) describes them as ‘controlling’ and Corring and Cook (1999:79) even as ‘indifferent to clients as human beings and untrustworthy’. Finally, Finkelstein (2004:207) accuses them of a slavish adherence to procedural ‘red tape’.

Goble (2004) acknowledges that, while health professionals often work in alliance with disabled people, many disabled people are expected to surrender to the superior knowledge and expertise of the service provider. Townsend (1998) contradicts this by saying that the way rehabilitation services are organised and the centralised locations of these services appear to be designed more for the organisation and the professionals rather than the service users. Disability literature, in the main, in the view of Hammell (2006), expose rehabilitation services for their inadequacies. For example, Johnson (1993) describes the services as simply irrelevant, while Northway (1997, cited in Hammell, 2006:5) considers them as ‘oppressive’. All of this according to Abberley (1995) and Dalley (1999), reinforce status differences and powerlessness.

Some reports from former rehabilitation clients and research evidence portray professionals as coercive, dominating and manipulative (Abberley, 2004:241). Similarly, Swain et al. (2003) depict professionals as, ‘controlling, distant, privileged, self-interested, domineering and the gate-keepers of scarce resources’ (Swain et al., 2003:133).

Goble (2004) also states:

there is often subtle pressure placed on disabled people to be grateful for this caring attention and time devoted to them, and to conform to a passive sick role in order to be as little bother as possible to the busy, caring professionals. To step outside the parameters of this role is to risk being characterised as ungrateful, or even to invite further psycho-medical diagnosis, as in the judgement that the person is failing to adjust to his or her condition (Goble, 2004: 43).

Work Practices

In terms of work practices, Hammell (1995) observes that, rehabilitation therapists only work on weekdays, and then only on hours that suit their own privileged lifestyles. She continues to suggest that there is a need to change practice and allow for client input. This is because it would reflect, in her view, the priorities of clients and not just those of the professionals. Hammell (2006) questions which outcomes are important to clients. She asks: ‘to what
extent have specific rehabilitation services enabled clients to get their lives “back on track” and how successfully have specific rehabilitation services enabled clients to challenge those discriminatory attitudes and societal practices that reduce their life opportunities?’ (Hammell, 2006:137). Shapiro (1993) suggests that disabled people need to quickly acquire skills of self-confidence to overcome a world of prejudice and discrimination. Hammell (2006) acknowledges that generally rehabilitation therapists are well meaning and committed, and do not set out to deliberately to become agents of social control, their positioning in a hierarchical structure means that decisions are generally made by them and not by the person treated by them.

Hammell (2006:23) further adds that rehabilitation professionals have generated their own set of accepted norms: ‘normal posture’, ‘normal gait’. Martin (2000:195) observed that most rehabilitation professionals are trained to perceive themselves as experts in their disciplines. This argument is also supported by McKnight (1981) who noted the tendency of professionals is, ‘to define the output of their services in accordance with their own satisfaction with the result’ (McKnight, 1981:32). Hammell (2006: 23) further contends that the, ‘ideology of normalcy serves to reinforce professional power’.

The power to define ‘normalcy’ lies with dominant groups in society. The practice of labelling is an inevitable process of the powerful labelling the less powerful (Pfeiffer, 2000:1081,cited in Hammell, 2006:30). Hammell (2006) argues that within rehabilitation, those who yield power: ‘doctors, nurses, therapists, are socially privileged to judge the ways in which people deviate from valued cultural norms’ (Hammell, 2006:22). Rehabilitation imposes, ‘a version of normalcy that pressures disabled people to fit in by appearing and functioning as much like non-disabled persons as possible’ (Kielhofner, 2004:241). Abberley (1995) and Johnson (1993) point out that rehabilitation should be providing clients with the knowledge and tools to resist the marginal status to which social norms strive to restrict them. Hammell (2006) argues that professionals use tactics to adjust client’s expectations downwards. This process of ‘getting reali (Hammell, 2006:123) is designed to enable them to accept or adapt, what (Hammell, 2006:124) describes as their new lowly status and its diminished opportunities and privileges. French and Swain (2001) suggest that the reasons lie with rehabilitation professional’s ideology of normality and their claim to expert status (Hammell, 2006:149). Oliver (1996) regards the ideology of normality as the foundation of rehabilitation. He is critical of the methods used to advance the notion of normality, ‘surgical intervention and physical rehabilitation, whatever its cost in terms of the pain and suffering of disabled individuals, is always justified and justifiable’ (Oliver, 1996:37).

Cognitive impairment is characterised by a route into a world of discrimination and abandonment and powerlessness. Powerlessness derives from a lack of decision-making power (Young, 1990). Kay-Toombs (1992) described the experience of neurological impairment as the body refusing to yield to one’s demands. The body can both humiliate the self and destroy life possibilities (Gadow, 1982). Hammell (2006:190) contends that the self is generally used to refer to one’s sense of self, *who I am, and what I am*. The concepts of self and identity develop out of social interaction (Millward and Kelly, 2003). The failure of the mind and brain is synonymous with loss of self. Thomson (1997) argues that the process of devaluing groups in society is more to do with asserting the *normality* and *superiority* of the dominant group. Hammell (2006) concludes therefore that the negative media imagery of disabled people is to show how *different* they are from us. Murphy et al. (1988) claim, ‘most rehabilitation establishments are ineffective in preparing people for the social conditions they will face … instead of being advised to become reconciled to their social condition, the disabled should be told to fight their way out of it’ (Murphy et al., 1988:241).

Sherry (2006) a survivor of a severe traumatic brain injury, is in full agreement with this contention. His lone struggle in an effort to gain acceptance after his injury, prompted him to become an activist on behalf of other survivors, and to highlight the social inequality experienced after their traumatic brain injuries. Little attention has been afforded in the literature to people with cognitive impairment. So much so, that people with intellectual impairment deal with a much more complex task in struggling to attain independence, in the sense of autonomous control over their lives (Goble, 2004). Stevens (2002) points out that the disabled people’s movement has not been particularly supportive of people with cognitive impairment. While physically impaired activists have honoured *bodily difference*, self-advocacy groups representing people with cognitive impairment, have had to start by rejecting the labels foisted on them. Goodley (2005) even suggests these labels undermine them as human beings. According to (Goble, 2004), ‘the rights of people with intellectual impairments to hold, or to keep hold, of their property, money, freedom of movement, sexuality, and even their life itself, has constantly been, and continues to be, challenged through the courts and in public, political and philosophical debate’ (Goble, 2004:45).

**Conclusion of Section**

While it is acknowledged in the literature that health professionals do not consciously use their expertise to reinforce the concept of normality in people with disability, they, nevertheless, operate within rigid guidelines and outcome measures (i.e. performance indicators). However, these performance indicators are clearly not relevant for people with
TBI. The powerlessness that accompanies cognitive impairment can be aggravated by the rigid approach taken by rehabilitation professionals.

2.11. Disability Classification Tools

While the previous section reviewed literature on the referral processes and dynamics used by health professionals, this section identifies other types of classification tools used to judge functioning, disability and health in all patients.

Many classification tools, such as the World Health Organisation’s International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980), and the later International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), attempt to provide a framework for classifying the consequences of injury and disease (Hammell, 2006). Classifications, such as ICIDH and the ICF, however, legitimise and allow experts to authoritatively identify abnormality (Dollard, 1995). The standard or the norm used to measure disability is as close to non-impaired normality as possible (Hurst, 2000). These WHO classification systems have led to the further creation of two measures – the Quality-Adjusted and Life Year (QALY) and the Disability-Adjusted Life Year (DALY). These are accepted by health economists worldwide (Murray and Acharya, 1997). However, critics of these measures point out that they are merely a way of justifying the distribution of social and economic resources (Hammell, 2006:27).

QALYs are years of healthy life lived; DALYs are years of healthy lives lost (Arnesen and Nord, 1999). The QALY judges quality of life by assessing the degree of disability, based on physical mobility, as evaluated by an expert panel (Williams, 1996; Hammell, 2006:27). The Global Burden of Disease study provides a quantitative overview of the burden of disease world-wide, expressed in DALYs (Arnesen and Norheim, 2007). This study is a collaboration between WHO, the World Bank, and Harvard School of Public Health (Murray and Lopaz, 1996). In other words, the DALY (which is a negative of QALY) is defined as a tool to measure the burden of disease and impairment (Anand and Hanson, 1997, cited in Hammell, 2006:28). The DALY approach is increasingly cited as a powerful tool for decision-makers in international health (Arnesen and Norheim, 2007; Bobadilla et al., 1994).

To arrive at a DALY score, a value judgement score is used to assess the time lived with impairment and the level of reduction in functional capacity (Hammell, 2006). Priestley (2003) implies that the DALY therefore regards time lived with impairment as time lost. Further, in the Global Burden of Disease approach, future burdens are discounted at a rate of 3 per cent per year, and the value of the lifetime is weighted so that years of life in childhood and old age are counted less (Norheim, 2008). Both classifications are influenced by the belief that the value of life is determined purely by health status (Arnesen
Hammell remarks that ‘these instruments are based on the premise that people who deviate from a set of physical ‘norms’ cannot attain a positive life quality under any circumstance’ (Hammell, 2006:27). Classification systems such as DALY and QALY use value scores, according a higher value to a person without a disability than to one with a disability. This give credibility and credence to the widely held cultural notion that a life with disability is a life not worth living and, so would be better off dead than disabled (Hammell, 2006). Many disability writers (French, 1994; Oliver, 1996) have drawn attention to the lack of concern accorded by health professionals to this ideal of normalcy. Critics point out that quality of life judgements mirror exacting values and cultural expectations (Wolfensberger, 1994). This has prompted Singer et al. (1995) to observe that QALYs place all disabled people on a lower status than those of the general population. Ideologies about a life worth living, reliant on the assumption of a perfect body, are highly problematic. Little evidence exists to show that a life without disability is any more fulfilling or satisfying than one with disability (Wolfensberger, 1994). Metts (2001:452) believes that the creators of DALYs relied too heavily on the estimations of medical experts rather than inviting input from disabled people themselves. This view is shared by Arnesen and Norheim (2007) who comment that ‘the most difficult part of any approach combining data on quality of life and length of life is how to measure quality of life. How should one value health states numerically on a scale of zero to one?’ (Arnesen and Norheim, 2007:16).

The concept of quality of life is therefore vaguely defined. Different people as well as different cultures, may have diverse opinions of the main elements of a good life (Arnesen and Norheim, 2007). Some suggest we bear in mind that QALYs and DALYs are organisational systems aimed at the rationing of healthcare (Abberley, 2004). In reality, classification systems are almost always about distribution of resources. Consequently, to use the notion of quality of life, raises the question ‘who judges?’ (Abberley, 2004:241), and what are the driving forces?
Diagram 1 is an example of disease burden measured in Disability-Adjusted Life Years (DALYS): Estimates 1990 and Projections 2020

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause</th>
<th>% total</th>
<th>Rank</th>
<th>Cause</th>
<th>% total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lower respiratory infections</td>
<td>8.2</td>
<td>1</td>
<td>Ischaemic heart disease</td>
<td>5.9</td>
</tr>
<tr>
<td>2</td>
<td>Diarrhoeal diseases</td>
<td>7.2</td>
<td>2</td>
<td>Unipolar major depression</td>
<td>5.7</td>
</tr>
<tr>
<td>3</td>
<td>Perinatal conditions</td>
<td>6.7</td>
<td>3</td>
<td>Road traffic accidents</td>
<td>5.1</td>
</tr>
<tr>
<td>4</td>
<td>Unipolar major depression</td>
<td>3.7</td>
<td>4</td>
<td>Cerebrovascular disease</td>
<td>4.4</td>
</tr>
<tr>
<td>5</td>
<td>Ischaemic heart disease</td>
<td>3.4</td>
<td>5</td>
<td>Chronic obi pulmonary disease</td>
<td>4.2</td>
</tr>
<tr>
<td>6</td>
<td>Cerebrovascular disease</td>
<td>2.8</td>
<td>6</td>
<td>Lower respiratory infections</td>
<td>3.1</td>
</tr>
<tr>
<td>7</td>
<td>Tuberculosis</td>
<td>2.8</td>
<td>7</td>
<td>Tuberculosis</td>
<td>3.0</td>
</tr>
<tr>
<td>8</td>
<td>Measles</td>
<td>2.7</td>
<td>8</td>
<td>War</td>
<td>3.0</td>
</tr>
<tr>
<td>9</td>
<td>Road traffic accidents</td>
<td>2.5</td>
<td>9</td>
<td>Diarrhoeal diseases</td>
<td>2.7</td>
</tr>
<tr>
<td>10</td>
<td>Congenital abnormalities</td>
<td>2.4</td>
<td>10</td>
<td>HIV</td>
<td>2.6</td>
</tr>
</tbody>
</table>

(Source: Murray and Lopez, 1996)

Metts (2001:452, cited in Hammell, 2006:29) strongly criticises DALY for its failure to distinguish between the disability caused by impairment, and the social and environmental factors that impact on individual experiences. Health and social care resources are allocated according to ‘ableist value judgements’ (Hammell, 2006:30). She goes on to state that ‘one could argue that impairments are experienced disproportionately among people who are socially disadvantaged’ (Hammell, 2006: 29).

Conclusion of section

Classification tools such as DALYs and QALYs, designed to use value scores, place more worth on a year lived without a disability (or indeed a chronic illness) than on a year without a disability. How these judgements are made is important in gaining an insight to the distribution of resources. The impact of such categorisation is evident in a range of ways, such as social inequality and in access to a variety of life opportunities. Literature on these themes is reviewed in later sections.
2.12. Experiences of TBI at an Individual Level

Drawing on the literature reviewed in sections 2.10 and 2.11, the current ways of working for health professionals do not allow for adequate responses to the rehabilitation needs of people with TBI. This is due to their rigid adherences to guidelines and outcome measures (performance indicators). The use of classification tools such as QALYs and DALYs further reinforces this. The literature in this section places in context the disparity between the goals set by various healthcare professionals and advocates of the Disability Movement. It also draws attention to the significance of the cultural context of survivors of TBI, and their everyday encounters and experiences. It addresses issues of independence to dependence; the concept of suffering; disability – impairment; stigma; dramaturgy; selfhood, identity and social inequality.

2.12.1. Independence → Dependence → Independence

Goble (2004:42) contends that promotion of independence is a central reference point for most health professionals working in services for disabled people. Researchers such as Gignac and Cott (1998:739) list a number of ways a loss of physical independence has consequences: (i) on an individual level in terms of psychological well-being and quality of life; (ii) in terms of employment opportunities; (iii) on a social level in terms of social stigma and marginalisation, and (iv) on a political level in terms of rights, opportunities and discrimination.

However, the concept of independence and dependence is contested, and greatly depends on the definition of disability used (French, 1993; Finkelstein and Stuart, 1996; Oliver, 1993). The perspective which remains dominant in society is one which depicts disabled people as dependent because their bodies, senses or minds are somehow ‘defective’ and don’t allow them to function independently (Goble, 2004:42).

Health professionals working to narrow definitions of disability, such as DALY, focus on deficit rather than ability (Goble, 2004). Programmes are designed by rehabilitation professionals to reduce the gap between the performance of the disabled individual and the normative standard as far as possible (Goble, 2004:42). This system promotes the passivity of service users, allowing health professionals to guide and direct the agenda (Goble, 2004). Abberley (2004:241) summarises interview data with occupational therapists, ‘you’ve established targets and met them. Your on-going task is to set goals and targets that are attainable. We can’t allow people to fail. The client cannot be allowed to fail, failure being a waste of scarce resources’. Abberley (2004:242) remarks that a significant feature of the views of therapists, drawing on her study data, is the absence of responsibility on their part for targets not attained. Blame falls into three categories: lack of financial resources, ‘the system’, and the customer/client. This fits with the neo-liberal notion of
personal responsibility. Further to this Wistow (2002) adds that ‘the language of enabling will need to be replaced more fully by that of empowerment’ (Wistow, 2002:54).

Whiteneck (1994) notes that rehabilitation professionals document the degree of assistance required to accomplish various activities of daily living (ADLs) - see Appendix C. These aspects have little influence on quality of life, and rarely measure outcomes in terms of their clients’ ‘active participation in their community, engagement in productive activities or quality of life’ (Whiteneck, 1994:16).

Factors which contribute to a life worth living are as Christiansen (1999) suggests based upon subjective, qualitative factors. Factors identified by researchers as fundamental to a life worth living are:

- ‘the need for a positive sense of self-worth
- a need to establish continuity within disrupted biographies
- a need to belong and contribute to families and communities
- a need to experience meaning and purpose in everyday life
- a need to exercise choice and exert control over their lives’

( Hammell, 2006:190).

Hammell (2006) states that rehabilitation is not just about teaching exercises, mobility and self-skills; rather it should be about enabling people to reconstruct their biographies and to achieve a sense of continuity between their previous and present selves (Hammell, 2006: 124). She argues that ‘fundamentally, it is also about assisting people to exit a liminal social status of diminished rights’ (Hammell, 2006:124).

Rehabilitation, because of its alliance with biomedicine, has endeavoured to address the consequences of impairment (Hammell, 2006), while almost ignoring the effect of stigma, cultural norms and notions of social worth for the individual’s sense of self (Bury, 1991). Bury (1982) points out that the effect of disruption to the body, which is often experienced as disruption to the physical self, also has the effect of disrupting one’s sense of self (Bury, 1982).

Conclusion of section

This literature on the concepts of dependence and independence applied by health professionals is useful and appropriate when considering the contemporary health and social services available to TBI survivors. At present, health services are working with a narrow and traditional approach to people with disability. It needs to embrace a more holistic model of care.
2.12.2. The Concept of Suffering

Discourses around suffering continue to develop in the sociological and medical fields. Wilkinson (2005) reviews the work of Frank (1995; 2001, cited in Wilkinson, 2005: 38) and Kleinman and Kleinman (1991; 1997, cited in Wilkinson, 2005: 24) who wrote extensively on people’s experience of illness. While the meaning of suffering is difficult to define, Lawson (2009: PAGE NO) points out that people use narratives to give meaning and voice to their concept of suffering over time. A clinician, Cassell (2004:32), argues that suffering as experienced by people, ‘occurs when an impending destruction of the person is perceived and continues until the integrity of the person can be restored in some manner’ Cassell, 2004: 32, cited in Seymour, 2007). Similarly, Seymour’s (2007) view is that suffering is widespread, without respect for time or culture. Therefore, according to Charmaz (1983) physical pain, psychological distress and the damaging effects of medical procedures all cause the chronically ill to suffer as they experience their illnesses. However, she warns that ‘a narrow medicalized view of suffering, solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated chronically ill adults’ (1983:1). It was found in her study of 57 chronically ill persons, that their suffering entailed the crumbling away of a positive self-image. As a result of their illnesses, which intrude in their lives, they experience social isolation, feel discredited and are considered a burden to others (Charmaz, 1983:1).

Neuropsychologist Luria’s influential book, The Man with a Shattered World (1987), recorded one man’s struggle to make sense of life after suffering a brain injury during the Second World War, at the age of 23. This man lost his ability to read, write and speak and had impaired vision, memory loss and other cognitive impairments. He became unable to perceive the right side of his own body and so it was invisible to him, due to this impairment. Objects he did see often appeared as fragmented pieces rather than whole objects. Luria, who had a special interest on the effects of brain injury, treated him over the course of 26 years.

His work has contributed to narrative studies of suffering and its importance in using this research method to interpret people’s experience of suffering. Wilkinson (2005, cited in Williams, 2011:1) questions whether sociology is adequately able to support the development of forms of thinking and imagination that enable us to understand the sufferings of others. However, sociology has made a good start and perhaps the work in this area will influence healthcare delivery.
2.12.3. Disability - Impairment

Section 2.12.1. above illustrated how dependence to independence is the central aim of rehabilitation by health care professionals. This section, documents other perspectives of researchers like Bury (1991;2000) and Hill (2004), who point out that disability cannot be totally separated from impairment.

Bury (2000) argues that disability is caused by impairment - whether this is associated with disease, genetic disorders, accidents, trauma or active pathology. He further contends:

the denial of many causal relationships between illness, changes in the body, and disability comes up against the daily realities experienced by the chronically sick and those who care for them, whether in the community or in health care systems ... The point needs to be stressed ... that in any overview of disability in modern society, chronic illness remains its most significant cause

(Bury, 2000:179).

Brain injury is usually viewed by the medical profession as a tragedy (Oliver, 1986). The emphasis on normality and social conformity is high on the agenda of health professionals and family (Hill, 2004; Baird, 1992). Kwiotek, (2006) urges the liberation of impairment from its sole medical double (that is disability), and explore its socio-cultural dimensions in the Irish context, and in doing so create a distinction between disability and impairment. Hill (2004) argues that the medical world finds it difficult to distinguish between impairment and illness. Therefore, the individuality of a patient is overshadowed by the labels placed upon them by healthcare staff. The focus is all too frequently on loss and deficit, and influenced by public as well as professional ignorance and apathy towards disability and brain injured people (Berry and Jones, 1991; French, 1994).

2.12.4. Stigma

The concept of stigma is frequently associated with disability. The experience of stigma is culturally influenced. This literature is particularly appropriate because it draws attention to the individual’s challenge in attempting to reintegrate to their community after a TBI. According to Susman (1994) and Morris et al. (2005), the response of others to the changes brought on by the brain injury can pose a greater problem for the individual than the physical effects of the disability. Erving Goffman (1963) defined the concept of stigma as a social construct. His themes of disability and stigma focus attention on the way societal response has a negative impact on the reality of living with a brain injury. Goffman (1963:45) uses the term 'normal' to distinguish between those in society that are not visibly stigmatised or disabled. He summarises the techniques used by those with disabilities in
order to manage their self-concept as to either hide or to accept their disability. If they choose to accept the disability, it becomes a sort of 'master status' (Goffman, 1963:45). He adds that 'the stigmatised person learns and incorporates the standpoint of the 'normal', acquiring thereby the identity and beliefs of the wider society' (Goffman, 1973:45). The pressure to appear normal is extraordinarily challenging for survivors. Goffman (1963) argues that a person has two possible options: either to hide the effects of the injury, making it invisible to others and thereby avoiding stigma, or to disclose all information and, in doing so, risk labelling and stigma (Goffman, 1963; Joachim & Acorn, 2000).

TBI is a unique disability, the effects being individual to each survivor. The problems can be invisible, and many can give the impression of being able to function without disability (Chamberlain, 2006). If a socially acknowledged representation of the disease cannot be reached because of its invisibility, survivors will not even find social resources that take their problem into account; furthermore in this situation, they risk being morally discredited if they do not perform normally (Lonardi, 2007). This passing off for normal by the brain injury survivor is what may well disadvantage them in their dealings with others, adding significantly to their pressures (Higham et al., 1996). A society obsessed with bodily perfection, where choice is paramount, social or physical expulsion of those with mental disorders is all too possible (Wade, 1998), and what Wade (1998:545) terms 'normality's high ground and the shadowed valleys of "abnormality"'.

Freidson (1965) showed that labels can be influential in categorising and stigmatising people with disabilities. Galvin (2005) argues that the spoiled identity as described by Goffman (1963), accompanies the loss of the ability to be independent, engage in paid work and/or to be considered attractive or desirable (2005:395). Key body and mind changes, as after traumatic brain injury, cause the self to be unsettled and uncertain (Chamberlain, 2006). Recovery is hampered by memory loss, disruption to emotions and experiences (Chamberlain, 2006), therefore allowing for grieving for a life lost must be part of the recovery plan.

Goffman (1963) also points out that loss of control is stigmatising, and special attention is necessary to avoid this. He argues that it is essential for the stigmatised person to avoid embarrassing others with out of control actions, in situations where control is expected. Thus, he contends that the responsibility lies with the ill person in terms of how they present themselves and therefore the individual must always avoid embarrassing others. Goffman called this 'passing', or the keeping from public view, a spoiled identity (Frank, 1995:23). A theme identified by Nochi (1998a) is that of loss of self in the eyes of others. People with acquired brain injury experience discontinuity between whom they were before and who they are in the present (Osborn, 1998; Stewart, 2000). Nochi (1998a) considered that people who did not have a changed sense of self after a TBI are using some form of compensatory tactic. Hill (2004) argues that the degree and nature of any
cognitive impairment will often determine how people with TBI judge the changes in themselves.

The search for answers and a cure is part of this initial phase after brain injury. It is what Lonardi (2007) terms the search for a rational explanation. There is an urgency to get this clarification. For many, this continuum is essential for the transition to the next phase - the sickness dimension, which is the socio-cultural representation of the disease (Lonardi, 2007). Hill (2004), a TBI survivor herself, outlines why language is as important as the terms used. She points out that being told that one is brain damaged is very different from being told that one’s brain is severely injured with the suggestion that improvement and progress is possible (2004:2).

Goffman (1963) argues that the body is associated with the exercise of human agency in that individuals can control and monitor their bodily functions (Shilling, 2005). This body management is what Goffman terms the bureaucratisation of the spirit, and is what one would expect in everyday encounters. Illness and disease can be seen as a loss of predictability to which some people adapt easily but which others find catastrophic (Frank, 1995:75). Scambler (2006) differentiates between ascribed deviance and achieved deviance. He argues that ascribed deviance, exemplified by most instances of chronic illness, is deviance for which the bearer is not held responsible; while achieved deviance, like drug use or burglary, carries the extra and sometimes heavy burden of culpability. Cultural stereotyping involves expecting people with certain conditions to conform to an accepted typecast (Scambler, 2008a).

Sociological accounts of hospital and clinical settings have illustrated the powerlessness of the patient, a powerlessness reinforced by the ceremonial order of the clinic (Chapman, 1983:16). Patients are often being figuratively stripped of their identity (Goffman, 1961:52). There is, however, an opposing body of literature which argues that TBI survivors are unaware of reality and are not affected by grief and loss (Goldstein et al., 1998). Findings from a study by Roundhill et al. (2007) indicate that expression and control of emotions are important in adjusting to loss after brain injury. Adaptation by the survivor to changed circumstances after traumatic brain injury is often influenced by the individual’s psychological reactions (Lishman, 1987).

2.12.5. Dramaturgy

Some authors suggest that the key changes experienced by TBI survivors force them to develop key strategies in order to cover up for memory loss and so on. Dramaturgy (Goffman, 1963) proposes that everyday encounters need to be stage managed; the different persona one presents in the course of the day – each one appropriate to the setting in which one finds them. Goffman’s work forces consideration of how this acceptance is vital to a
person’s self-worth and identity. Shilling (2005) further adds that a bodily appearance that is tainted and fails to fit the general categorisation of acceptance will be viewed as unacceptable by wider society. This then becomes a spoiled self-identity (Shilling, 2005), the label having been interpreted by the individual as significant enough to push them outside the boundaries of acceptance. Body management (including being cognitively able), therefore, is essential to the acting out of roles and to a person’s acceptance as a valued member of the social order (Shilling, 2005).

2.12.6. Selfhood and Identity

According to the existing literature, TBI Survivors may be forced to assume a new identity. Brain injury is described as, ‘experienced at the intersection of the person and the environment’ (Tate and Pledger, 2003: 292). A brain injury is a sudden and negative change that radically interrupts an interdependent selfhood (Heller et al., 2006). Identity is linked to memory (Hill, 2004). The previous and familiar self may need to be left behind and a new identity forged after a TBI. Heyink (1993) illustrates the phases people with TBI go through: i) the pre-TBI (the usual self), ii) the post TBI body with deficit and iii) a normally functioning body they think they will have in the future. A recognition of the limitations of the now changed body and the development of a self that incorporates any impairment and disability is needed (Hill, 2004).

Hill (2004) also points out that over time people stop comparing themselves to their pre-injured selves and instead accept an image of themselves which accommodates the consequences of their injury. Tyerman and Humphreys (1984) argue therefore that research should be guided by the brain injured as well as their close associates. In a study of changes in self-concept following brain injury, they found that almost three quarters of the seventy-five severely injured participants had changed as a person.

This was the same as the finding of the study by Howes et al. (2005) on women’s experience of brain injury. The women in this case stressed that the cognitive, social and physical changes caused the most unease. As a part of this change, the women stressed they changed as social beings after the injury. Howes et al. (2005) state that these changes related to difficulties in social interaction, finding particular problems dealing with groups of people, and negative reactions from others. This is similar to how Ciocca (1995:2846) described the considerable difficulties experienced in interpersonal relationships and intimacy in marital relationships. Sexual dysfunctions affecting desire, arousal or orgasm can all be aspects after TBI (Bélanger, 2009). Dis-inhibition and hyper-sexuality can also become a social handicap for the survivor and their acquaintances (Bélanger, 2009).

The depression and denial phase after injury, which is part of the mourning phase, can last as long as five years after injury (Levin et al., 1996), creating extreme negative effects on
self-esteem and family relationships (Rittman et al., 2007). Morton and Wehman (1995) point out that survivors of a severe brain injury are likely to experience prolonged anxiety and depression, and are at high risk of loss of friendships and social support (Morton and Wehman 1995). This is borne out by Sherry (2006) who argues that many survivors experience social isolation and depression.

Phillips (1990) suggests that a brain injured person may be viewed as damaged goods. The common experience for people with brain injury is social rejection, isolation, poverty, being written off, inappropriate and inadequate accommodation options, a lack of advocacy, a lack of rehabilitation, medical and professional dominance, lack of agency and negative public attitudes about brain injury (Sherry, 2006). It is, however, important to note that Dijkers (2004) identified some positive effects of TBI: appreciating the little things in life; insight into self and others, and ending substance abuse or self-destructive behaviour.

Conclusion of section

In summary, Bond et al. (2003) contend that individuals with brain injuries and their families will be best served if systems of care can take into account, either implicitly or explicitly, the reality of the multiple aspects of selves that characterise each actor in a network of interconnected systems that constitutes our social universe. Heller et al. (2006) argue that this type of injury can cause extreme alterations in identity and the structure of the self as a result of changes in personal traits and abilities, social context, and family dynamics. Physical changes, such as in appearance, and cognitive changes can affect the survivor self-image (Nochi, 1998b). Curran et al. (2000) argues that race, gender and class are also factors which determine how well (or badly) survivors cope with the changes brought by the injury.

2.12.7. Social Inequality - TBI

The links between poverty and ill-health have long been established. Many reports show a clear link between lower social class, lower educational qualifications, lower incomes and poor health and higher rates of injury (Layte et al., 2007; Harvey, 2007). According to Layte et al. (2007), differences are wider again if chronic illness is considered as the measure of health. While 23 per cent of the general population report a chronic illness, 47 per cent of the consistently poor and 38 per cent of the income poor report a chronic illness. In contrast only 16 per cent of men in the higher professional and managerial class have a chronic illness. This rises to 27 per cent among men in the unskilled manual social class. The pattern is similar for women, although the class differential is even higher (14 per cent versus 31 per cent).
Analyses also showed that low income groups are less likely than higher income groups to receive specialist care (Layte et al., 2007:66). It may be that higher income groups are more likely than lower income groups to be referred for specialist care, or that they spend less time waiting for this care, although there is no direct evidence for this (Barry et al., 2001). Injury rates are higher in the lower income groups, particularly amongst young males (Barry et al., 2001). In a report published in 2001 on health inequalities in Ireland, based on 1996 research data, unskilled manual men were eight times more likely to die from an accidental cause than higher professional men (standardised ratio 136 versus 17) (Barry et al., 2001).

Layte et al. (2007) point out that ‘the pattern of health in the population closely follows the pattern of social inequalities in terms of income, education, social class and poverty’ (Layte et al., 2007:66). He suggests that policies to reduce socio-economic inequalities in health cannot be dealt with by the Department of Health and Children alone. Health services can only intervene after health inequalities have formed elsewhere in society. It is further suggested that ‘policies to reduce inequalities will need to be developed and implemented, on a cross-departmental basis, preferably with strong inter-departmental co-ordination’ (Layte et al., 2007:66).

The European Social Inclusion Report (2001) highlights that disabled people are more likely to be in poverty, more likely to be unemployed (and long-term unemployed) and less likely to have medium and higher educational qualifications. A range of means is suggested to address these problems. These include offering disabled people better training and qualifications, thus making them more employable. The US Rehabilitation Research and Training Center (RRTC) (2007:6) on ‘Community Integration of Persons with TBI’ states as their mission that all persons with TBI should have access to information, resources, and services that maximise participation in their communities and that treating professionals have the necessary information to meet the needs of persons with TBI (RRTC, 2007). The aim should be to identify community integration needs among traditionally underserved populations, including members of racial/ethnic minority groups and those living in rural areas. Aspects of community integration, including traditionally under-emphasised areas, such as friendship, intimacy, and creative expression, need to be addressed, and therefore attitudinal barriers to community integration of persons with TBI be reduced (RRTC, 2007).

The National Disability Strategy (NDS) for Ireland was launched in 2004. It promised to support equal participation for people with disabilities. The key elements of the strategy are:

- the Disability Act 2005,
- the Education for Persons with Special Educational Needs (EPSEN) Act 2004,
sectorial Plans for services (prepared by six Government Departments),
the Citizens Information Act 2007, and
a multi-annual investment programme of €900 million targeted at high-priority
disability support services.

Social Partnership Agreement between Government and Social Partners - was agreed
in 2006 and sets the following long-term or high-level goals related to people with
disabilities:

- every person with a disability would have access to an income which is sufficient to
  sustain an acceptable standard of living,
- each would be in conformity with their needs and abilities, have access to appropriate
care, health, education, employment and training and social services,
- they would have access to public spaces, buildings, transport, information, advocacy
and other public services and appropriate housing,
- each person would be supported to enable them as far as possible to lead full and
  independent lives, to participate in work and in society and to maximise their
  potential and,
- carers would be supported and acknowledged in their caring role.

Dolan (2007) argues that The National Disability Strategy, as set out in ‘Towards 2016’, is
an excellent commitment but is of no value to people living with disability. He contends
that disabled people do not have access to a range of services and supports, such as
therapy services, personal assistance, housing and accommodation, health, education and
employment services. Other areas of difficulty include access to public spaces, buildings,
transport, information and advocacy (Dolan, 2007). He further adds that the
strategy is an acceptance that this State has not done the right thing by its
disabled citizens. In effect it acts as an apology for the wrongful exclusion
of disabled people from all aspects of Irish life and it sets out an intention to
redress the situation. The promise of the National Disability Strategy is that
these people, our fellow citizens, members of our families and communities,
will have a life. A life of opportunity

(Dolan, 2007:3).

Conclusion of section
The literature reviewed in this section centres on the social positioning of TBI survivors
and their families. They share with other disability groups difficulties of access to
employment, and they are at greater risk of poverty than the general population. People
in lower socioeconomic groups have a higher incidence of injury and certain diseases. The association between chronic illness and poverty is by now well recognised, and this literature is considered relevant to the research questions. Furthermore, information gathering relating to disability and access to services, such as education, is crucial.

2.13. Illness Narratives

The use of illness narratives is central to gaining an understanding of the changed context of the lives of TBI survivors and their families. Illness narratives document key changes experienced by TBI survivors and add to the body of existing theories to explain the changed context in their lives.

Few studies representing the views of survivors exist, particularly, those with moderate or severe injury, with the consequential neglect of patient’s illness experience (Bell, 2001; Reissman, 2002; Langellier, 2001). The voice of the patient and the experience of acute illness is virtually absent from sociological literature (Rier, 2000). Apart from a few exceptions, such as a study by (Rier, 2000) on his first-hand account of his own critical illness, Sherry (2006) and Hill (2004), both survivors of severe TBI, most studies are conducted from the standpoint of doctors (Zussman, 1992) and nurses (Asch et al., 1997). The family and carer perspective has also been fairly well documented (Heimer and Straffen, 1995). However, the brain injured person’s own perspective on the acute and post-acute phase of their illness has been neglected (Tyerman and Humphreys, 1984), apart from the work of professionals such as Luria (1974) who documented the experience of a TBI survivor. This research aims to address this gap.

Serious illness compels the person to rethink their purpose and end goal. Ill people have to think differently; they learn by telling their stories and by the reaction of others to these stories (Blaxter, 2004). Prigatono (1991) argues that the expression of the individual conscious experience is an effective indicator of the supports necessary to facilitate adjustment and guide therapy.

Illness stories do not just describe the experience, they are repair work, creating a new self (Blaxter, 2004). After brain injury, there are multiple losses with which to cope (Howes et al., 2005). Narratives can also be emancipatory, allowing self-reflection and expression (Chamberlain, 2006). People with TBI may be able to carry a catalogue of self-narratives, drawing on substitute ways to facilitate the coping process (Nochi, 2000).

Frank’s (1995) influential book ‘The Wounded Storyteller’ shows how the medical notes (the official record of the patient’s illness) offers only the official voice (Reissman, 2002). Frank (1995, 2004) suggests that the body’s suffering during illness creates a need for stories; the story can play an important role in ‘repairing narrative wreckage, as the self is
gradually reclaimed in the act of telling’ (Smith and Sparks, 2007: 219). These personal narratives about illness and injury serve to give voice to the body, so that the altered body and mind can once again become recognisable (Frank, 1995). Thus, as wounded storytellers (Frank, 2004), the experience of events is given due recognition, inspiring confidence that these are lives worth reclaiming (Smith and Sparks, 2007).

Frank (1995) was one of the first to recognise that ‘illness stories mix and weave different narrative threads’ (Frank, 1995: 76). None may actually conform exactly to one of the three narrative types he describes. The i) restitution, ii) quest and iii) chaos narratives each fit different phases of recovery from TBI. The restitution narrative is about making a full recovery and returning to being the same as before, ‘yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again’ (Frank, 1995: 77). The quest narrative, on the other hand, affords the ill person a voice, ‘they accept illness and seek to use it’ (Frank, 1995: 115, (emphasis in original)). Chaos narratives imagine a life never getting better, the telling of the story is not even possible because the suffering is too great for the self to be told (Frank, 1995: 115).

Kleinman (1995), acknowledges that the ‘patient’s and the family’s moral needs to have a witness to the story of suffering, to find support for the experience of illness, and to collaborate with others in the struggle to fashion a meaningful interpretation of what is at stake for them in their local world’ (Kleinman, 1995: 33). Kleinman (1988) outlines three different representations of illness: a biomedical episode (disease), a personal experience (illness) and a socio-cultural event (sickness). Each phase is influenced and determined by the experience the person has with:

- the biomedical aspect (doctors, hospitals, procedures, therapies);
- how the disease was represented by people or groups (family, friends, community, work colleagues) (Lonardi, 2007: 1622);
- coping strategies employed - avoidance of social situations, hiding physical aspects, such as memory
- loss (Lonardi, 2007).

Practitioners, such as doctors and nurses, are trained to distance themselves from their patients. Protocol demands they practice their skills in an objective fashion, thus discounting the illness experience as too far removed from scientific evidence, and therefore without credible foundation. However, illness narratives are increasing in popularity amongst health practitioners who recognise their value as a teaching resource and as a device for building new knowledge (Charon, 2001). Prior (2007) suggests that the role of language provides insight into how professional and lay people understand aspects of medicine and inherited pathologies.
In conclusion, allowing people to tell stories of their illness experience has significant merit and must be viewed as an approach worth considering for all patients. Person-centred care is a laudable goal for all health professionals. Listening to patients about their experiences is one way of attempting to achieve this objective.

2.14. Experience of Family Members/Significant Others

In previous sections the literature mainly dealt with the impact of TBI on the survivor. However, TBI also may have far reaching effects on others and can change the entire dynamic of families because it involves not only the individual who survives the injury, but the entire family system (Kosciulek et al., 1997; Williams & Kay, 1991). This section examines the literature in relation to family members/significant others of TBI survivors. The last section briefly discusses existing gaps in the literature in relation to TBI. Family difficulties following head injury frequently include increased burden, psychological distress, and social isolation associated with negative changes in their family member's cognitive functioning, personality and behaviour (Kosciulek et al., 1997; Florian et al., 1991). As a result, family caregivers often experience anxiety, shock, disbelief, denial, and frustration (Degeneffe, 2001; Mathis, 1984). Consequently, the impact of head injury is at least as great for families, and often family members are more distressed than the injured person (Kosciulek et al., 1997; Brooks, 1991).

Grieving of family members

Grieving is a normal and universal process which comes sometime after the initial shock of being told that a loved one has been in an accident and is almost always overwhelming. The five stages of grieving as defined by Kubler-Ross (1969) are an essential process and help to maintain a form of normalcy while experiencing grief (King, 2004). These stages include shock and denial, anger, the bargaining stage, depression and acceptance. The final stage, acceptance, Kubler-Ross cautions, 'should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain has gone and the struggle is over' (Kubler-Ross, 1969: 113). According to Kubler-Ross (1969), the effects of grief ease with time as the individual passes through the various grieving stages (King, 2004). Emotional and social grief amongst relatives and care givers does not lessen over time (Brooks et al., 1986; Gillen et al., 1998).

Care-giving

Responsibility for caring long-term is often met by the survivor's family (Kneafsey, 2004). Davies et al. (2000) point out that this is largely because of the patchy and uncoordinated nature of service provision for survivors of TBI. The challenges of providing care to a survivor of severe brain injury are enormous. However, it is often only at the point
of discharge from the acute services the true nature of service need becomes apparent (Kneafsey, 2004; Serio et al., 1995). Families then realise the inadequacy of the available supports and advice regarding day-to-day situations (Webb, 1998).

Providing care to a survivor of severe brain injury is demanding. Families and carers experience profound changes (Jumisko, 2007; McLaughlin and Carey, 1993), and are often ill-equipped to deal with managing challenging behaviour (Rosenthal and Young, 1988) and adjusting to sexual expression (Sachs, 1991). Fulfilling obligations of care to survivors places, ‘a substantial burden on families, both physically and emotionally and may ultimately be detrimental to the person with the injury’ (Kneafsey, 2004: 605). Much evidence implies that brain injury affects families at different levels: socially, emotionally, and financially (Kosciulek et al., 1997). Factors such as the caregiver’s previous skills, competence, patterns of living, and ways of relating to the person with TBI (Degenette, 2001: 10) can impact on how the family copes after brain injury. Chronic illness, particularly brain injury, disturbs the family network system and influences the relationship the ill person has with close family and significant others (Jumisko et al., 2007; Kuyper and Wester, 1998; Ohman and Söderberg, 2004). During the acute phase of the illness, relatives describe how their whole world focus is on the ill person (Engstrom and Söderberg, 2004). During this period, which may last for months, close relatives experience frustration, anger and uncertainty (Ohman and Söderberg, 2004). They are forced to put their lives on hold for an indefinite period of time (Svavarsdottir, 2006).

**Gender of Caregivers**

Perlesz et al. (2000) suggest that primary caregivers, such as mothers and wives, experience worse psychological distress than other caregivers. Wade et al. (1996) found significantly higher levels of stress in parents of children with moderate or severe traumatic brain injury than amongst parents of a control group (orthopaedic injuries). Abnormal levels of stress were also found in a study by Hawley et al. (2003) of parents of traumatically brain injured children, regardless of severity. Stress is defined by Monat and Lazarus (1985) as a characteristic of the relation between the individual and the environment.

According to Verhaeghe et al. (2005:1002), ‘a stressor is a stimulus that the individual perceives as threatening, because the person thinks or feels that the individual is inadequate in terms of being able to react to it’. Duff (2006) argues that the family of a person with a TBI is obliged, in order to maintain accord, to negotiate their goals, habits and roles. Webb (1998:544) points out that in so far as head injury has an effect on interpersonal relations ‘and especially between those of a now newly-dependent child and a parent-carer, then we can see a profound dislocation in a whole range of assumptions about reciprocity and exchange in the life course of the family’. Highly gendered role performance is evident
throughout the literature, with mothers providing most of the care to brain injured sons (Knight et al., 1998). Webb (1998) argues thus:

the ambivalences that mark the tussle between labour and love as the imperative to parenting are reawakened with a vengeance as what was once seen to have been finished becomes a new and unexpected moral obligation ... the present and the future are collapsed in a radically revised assumptive world


Higham et al. (1996:185) document a mother’s observations, which demonstrates the impact of caring for a grown son after a brain injury:

It’s like having a baby back in the house, but a baby that isn’t going to grow up ... he’s never going to be independent of me, he’s always going to be dependent on someone looking after him ... I’m always going to be here as a carer ... you know for a fact you are going to die before he is

(Higham et al., 1996:185).

Historically, women were the people most likely to be involved in the caring role, caring being viewed as natural to women and not requiring much skill. In contemporary society, caring work is undervalued, and policy makers in many countries continue to ignore the sacrifices made by family members, who give up the chance of paid employment to care for dependent relatives. Despite the change in social structure, and the increasing involvement of women in paid work, older and dependent people continue to be cared for by family members at home, rather than in institutions. For example, in Ireland just over four and a half per cent of older people occupy continuing care beds (Department of Social and Family Affairs, 2002). However, smaller families mean there are fewer children to care for dependent relatives, and this is a factor which determines the likelihood of care by family members continuing.

Share et al. (2007) point out that women have an important role, as healthcare providers, particularly in caring for others and mediating with healthcare providers. According to Hodgins and Kelleher (1997) within Irish society, there is a firm belief that women will take full responsible for care duties. They contend that the caring role is, ‘intrinsically bound up with definitions and conceptions of femininity’ (Hodgins and Kelleher, 1997:43). Share et al. (2007) also state that ‘in everyday discourses, the Irish mother continues to occupy the role of primary carer and life-giver, leading to pressures and tensions in the attempt to manage both work and domestic spheres’ (Share et al., 2007:257).
Social Impact on Families

The social impact of brain injury on families and carers can be profound, as evidenced by Kozloff (1987), who found that as time went by, friends and other non-family members distanced themselves. The ultimate consequence of this change is the social isolation of families with responsibility for care provision (Kosciulek et al., 1997). This and later evidence points to the increased vulnerability of family members who require help in their own right to cope with these changes (Kosciulek et al., 1997). According to Degeneffe (2001) role changes and added responsibilities present each family member with different concerns and challenges. For example, parents may face prolonged parenting responsibilities, often when they are expecting to have finished (Degeneffe, 2001). Jacobs (1989) suggests that many spouse caregivers stay in the marriage out of concern for the injured survivor. Sachs (1991) points out that the injured parent may no longer be able to assist with parenting; siblings are also expected to assume different roles, taking on additional chores (Rosenthal, 1989). Degeneffe (2001) proposes that caregivers can be helped to cope through involvement in the rehabilitation process, which may facilitate feelings of empowerment, rather than helplessness. However, the challenge for many caregivers is to understand the nature of treatment because of its highly technical nature. Giddens (1991) argues that the formation of ‘expert systems’ of knowledge, such as medical knowledge, has resulted in the ‘deskilling’ of lay people. This expert knowledge impacts on everyday life by undermining lay knowledge (1991: 138).

Conclusion of section

In summary, care giving has traditionally been gender biased having been largely undertaken by women. There is an abundance of literature on the gendering of care, and only a selection is presented here. TBI can have distressing and devastating consequences for families and carers. New and unfamiliar roles of care giving are often forced on family members of dependent survivors with no prior warning or specialised training.

2.15. Current Provision in Ireland

The literature reviewed in this section is relevant in order to contextualise the current provision of health and social care in Ireland. The availability of appropriate services for TBI survivors is vital if their full potential is to be achieved. While the social and financial cost of some non-fatal illnesses is self-evident, creating a supportive atmosphere to maximise social well-being for vulnerable groups is a key aim of Ireland’s Department of Health and Children’s Health Strategy: Quality and Fairness, A System for You (2001a). This raises questions as to whether, and in what way, public policy can support the concept of social gain, and can adopt the definition of health as used by the World Health
Organisation (WHO), ‘a complete state of physical, mental and social well-being and not merely the absence of disease or infirmity’ (WHO, 1999: 22).

Current policy aims to help people with disabilities to achieve their full potential including living as independently as possible (Department of Health and Children: Statement of Strategy 2008–2010 (2008). Concern is expressed in this latest report about the level of morbidity in young men arising from road traffic accidents. Concerns, however, centre on implications for the health services – i.e. the accident and emergency, rehabilitation and disability sectors (DoHC, 2008:37, section 1:10). Currently, a rehabilitation strategy is being developed by the Department of Health and Children to address the needs of people with neurological conditions [approximately 700,000 people in Ireland]. This is described as ‘a broad set of recommendations to guide a national framework of services’ (O’Grady, 2008:1). This has been welcomed by patient groups and health care professionals working in this area. The National Development Plan 2007–2013, ‘Transforming Ireland – A Better Quality of Life for All’, shares the key goals of greater social inclusion and balanced regional development. It planned to provide: €49.6 billion for social inclusion measures (children, people with disabilities); €33.6 billion for social infrastructure (housing, health, justice) and €25.8 billion for human capital (schools, training and higher education). The ‘New Right’ ideology of personal responsibility (Power, 2009) has impacted on how resources are distributed to people with disability. Scambler (2006) offers a conceptual model of stigma acknowledging that the labelling, stereotyping, distancing from others and loss of status that characterise stigma, are only made possible by the differential distribution of social and economic resources and political power.

2.15.1. Neurosurgical and Rehabilitation Services in Ireland

Neurological medical services in Ireland are considered poor, falling well below the general acceptable level in any other western European country (BRI, 2008). Timely neurosurgery is unavailable except in Dublin and Cork (BRI, 2008). There are two neurosurgical units in Ireland, one in Dublin at Beaumont Hospital (a national unit) with 85 beds, and the other at Cork University Hospital which has 19 beds. People with brain injury may be admitted to any hospital in Ireland, and are later transferred to one of the two main neurosurgical centres if their condition warrants specialist treatment. Some may be direct admissions to one or other of the two neurosurgical centres.

Phillips (2009) in The National Report on Traumatic Brain Injury, highlighted that Ireland has only 10 neurosurgeons - the lowest number per head of population in Europe. In the same report Phillips (2009) argued that delayed CT (see Appendix C) scans, journeys in excess of 100 km and weekday only ambulance services hampered the treatment of patients with severe brain-injury (Mullen, 2009). Estimates of provision found that Ireland
had one neurologist per 210,000 people. The next worst is the UK, with one per 164,000 while France, in comparison has one per 39,000 (Phillips, 2009). Phillips (2009) points out, ‘the level of care being provided to some patients at times is less than optimal. Future TBI management strategies must address both the prevention of injury and the provision of appropriate services in line with international best practice’ (Phillips, 2009:7). The challenge in treating patients with traumatic brain injury is the recognition that each will probably require different treatment (National Specialised Services Definitions Set, 2001). Kiernan (2004:16) asserts that patient needs vary and their requirements change over the different stages of recovery:

- ‘Acute care;
- Post-acute in-patient rehabilitation in a specialised unit;
- Community rehabilitation;
- Post-acute rehabilitation – support for disabled, family and carers’.

The National Rehabilitation Hospital, Dublin (NRH) has 123 beds serving a population of 4.2 million people. It is not a facility dedicated solely to the rehabilitation of brain injury, rather it is required to treat people with a variety of physical injuries including spinal cord damage. Only one in four people awaiting neuro-rehabilitation succeed in gaining a place at this facility (O’Connell, 2008). At any time, there are approximately 120 acquired brain injured people waiting for access to the NRH; waiting times are 3–18 months and only 40 beds are assigned to brain injury rehabilitation (Delargy, 2008). Ryall (2002) argues that any benefits gained at the acute phase of recovery are lost because of long delays in accessing rehabilitation. Salter et al. (2006) demonstrated in their study of people with stroke, that functional ability at discharge, even allowing for the severity of functional deficit at admission, is affected by speed of treatment, patients admitted earlier experienced greater functional improvement (2006: 116). The average length of stay (LOS) in the NRH in 2000 was 40.2 days (Department of Health and Children, 2003). This is much shorter than the recommended length for most rehabilitation programmes after brain injury. This is possibly due to the shortage of available places in this facility.

As previously mentioned, Ireland has the lowest level of rehabilitation consultants in Europe. The European average is 2.8 per 100,000 people, but in Ireland it is 0.15 per 100,000. Based on Dutch standards, there should be 74 consultants while currently in Ireland there are just six in place (Delray, 2007). According to Ó Cionnaith (2009), patients are waiting for up to six months for rehabilitation at the NRH. Most of these patients remain in acute hospitals whilst waiting transfer to this specialised centre (Browne, 2004). According to the NRH, patients admitted in 2008 spent between two and four months receiving specialist in-patient treatment before transferring to outpatient services. Patients are admitted from all parts of Ireland, but most are resident in the Dublin or Leinster
region (52 per cent), while only 24 per cent are from the South (Ó Cionnaith, 2009). There are only 15 neuro psychologists working in this specialty in Ireland. Every brain injured patient needs immediate access to a multi-disciplinary team. Additionally, it can take one year after the event for patients to get to grips with the fact that they are having cognitive difficulties as they try to return to work. (Culliton, 2009). Because of the large work load of neuro psychologists it is unlikely patients get a timely referral. A proposed €200 million hospital development planned for the NRH is now on hold with a possibility of the entire project being shelved (Culliton, 2009).

**Conclusion of sub-section**

It is evident from that Ireland lags behind many other developed countries in the provision of rehabilitation and post-rehabilitation (places and specialists). While strategies aimed at providing services on a needs basis, is a key objective of government policy, little has changed for individuals requiring treatments and therapies after a TBI. The next subsection examines the status of rehabilitation in an attempt to understand why funding and resources for this area of care are limited.

**2.15.2. Rehabilitative Medicine: the ‘Cinderella’**

Rehabilitative medicine remains the ‘Cinderella’ of the health services (Pinto et al., 2005:37). Greenwood and McMillan (1993) note that head injury rehabilitation attract far less funding in comparison to acute services. Rehabilitation facilities for those with spinal cord injury (SCI) are much better developed, even though the ratio of TBI to SCI is in the region of 260 to 1 (SCI, 2009). Gains following neuro-rehabilitation have been recorded as low by some authors, in terms of showing limited benefit, generalisation or mixed results regarding memory and maintenance of gains over time (Sohiberg and Mateer, 2001). Watkins et al. (2001) attributes this on the inadequate resources afforded to rehabilitation, staff with insufficient experience, or the patient’s disabilities too profound to benefit significantly.

Two of New Zealand’s leading rehabilitation experts called on their government to end rehabilitation’s reputation as the ‘Cinderella’ of medicine. Anwar and Reid (2009), made the plea at the biennial Australasian rehabilitation conference in Queensland on 21st July 2009. Reid said rehabilitation was always considered the second-class citizen of the health world because it provided work not as glamorous as acute surgery or critical care medicine. President Mary McAleese, in her address to the Irish and British Rehabilitation Association’s Conference, spoke about the status of rehabilitation:

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1 Samir Anwar a rehabilitation specialist and Duncan Reid, a former Olympic Games physiotherapist
For patients it can be a very lonely and even frightening journey, a journey made easier by good company on the road, the company of good carers and a wide range of professionals who have made this work their vocation ... What was not so long ago pretty much a Cinderella area of health and social services and civic awareness is now a sphere of formidable advocacy and huge attitude change. Policy and practice have moved apace and you are the people who have stoked the engines that brought fresh momentum and traction to this important area of care. Your work has allowed rehabilitation to be managed much more coherently and intelligently than ever before, freeing up hope and opportunities in the lives of patients and their families (McAleese, 2009:1).

Currently, in Ireland, post-rehabilitation services aimed at reintegrating survivors in the community (education and vocational training, social supports etc), are practically non-existent. Essential services provided by the NGOs in this area - Headway, Acquired Brain Injury Ireland (previously The Peter Bradley Foundation), BRI and Quest, are at an early stage of development and do not have a presence in all areas of Ireland. Payne (2000) pointed out that 80 per cent of brain injured patients discharged from the National Rehabilitation Hospital (NRH) in Dun Laoghaire, Dublin, failed to receive the treatment recommended to them. Almost one-quarter received no follow up treatment at all. His findings also suggest that a typical patient had only one visit from a public health nurse and six sessions of physiotherapy after discharge. Non-governmental organisations (NGOs) have succeeded in complementing the state provision by running services for people with specific needs (Harris and Enfield, 2003). A model of service provision, controlled and organised by non-disabled staff is now recognised by disabled people as falling far short of the ideal (Harris and Enfield, 2003).

2.15.3. The Concept of Access

The concept of access has been the central tenet of the recent policy reports. For example, the current health strategy ‘Quality and Fairness: A Health System for You’ (2001), states its core objective as, ‘all patients should have access to a high quality service, within a reasonable time, irrespective of whether they are public or private patients’ (DoHC, 2001:74).

This implies that treatment is available on a needs basis, rather on whether the individual has the ability to pay. As others have noted, the needs basis is not clearly defined (Goddard and Smith, 2001; Culver, 1995). The health strategy ‘Quality and Fairness: a Health System for You’ (2001) has been critiqued for its failure to achieve its stated goals of making equity central to the health system in Ireland and achieving fair access for all to

- Does it relate to an individual’s level of illness or the capacity to benefit from treatment?
- To what extent should non-clinical contributions to need such as an individual’s social circumstances, be considered?
- How is the relevant concept of health status to be measured? In particular, many studies rely on self-reported illness and the predisposition to report illness may vary systematically between groups;
- At what stage should need be measured? For example, two identical individuals may present to the health services with differences in immediate clinical need because previous health care has been less effective for one individual than the other (Goddard and Smith, 2001:1150).

Social Policy Advocates, such as patient action groups, promote the notion of access to services as the embodiment of the highest standards in healthcare. Donabedian (1980) presents three categories of quality: structure, process and outcome. Goddard and Smith (2001) argue that in different ways, variations on each of these aspects of quality could affect the patient. According to Starfield (1993), poor quality in terms of structure might lead to inappropriate use of health care services; poor quality process might lead to dissatisfaction and deter compliance; poor quality outcome is in itself undesirable, and may in turn deter future users.

Starfield (1993) also contends that even though various indicators of access exist, it is largely utilisation that is observed, thereby assuming, ‘that the decision as to whether to accept the offer of treatment, leading to observed utilisation, rests with the individual, often of course, under the guidance of health care professionals’ (Goddard and Smith, 2001:1159). It is therefore, a demand and supply issue, rather than access (Aday and Anderson, 1981) which has consumed policy makers here and elsewhere. However, the existence of a range of issues that affect supply and demand for services (Goddard and Smith, 2001) must be investigated. Taking a narrow approach to understanding lack of access has led Goddard and Smith (2001) to speculate, ‘many studies focus on one potential cause of inequity (such as social class) and fail to take account of the full range of factors which could potentially influence utilisation rates between groups (which might also embrace, say, income, housing and geography)’ (Goddard and Smith, 2001:1159). Access to rehabilitation for TBI survivors is hindered by a lack of personal income and resources. They may also be geographically dispersed and dependent on public transport. Factors such as these impact on utilisation rates.
2.15.4. Government Support for Carer Givers

Support available to carers of TBI survivors is essential in achieving the long-term goal of independent living. Financial support is provided by the state in certain circumstances to those engaged in full-time care of incapacitated people. Carer's Allowance is a payment to people living in Ireland who are looking after someone who is in need of support because of age, physical or learning disability or illness, including mental illness. The Carer's Allowance is not payable to everyone but is mainly aimed at carers on low incomes who live with and look after certain people who need full-time care and attention (Source: Department of Social and Family Affairs, 2009). The introduction of financial remuneration in the form of a carer's allowance marked progress for many carers, who had lobbied for years for recognition of their role and their economic circumstances. However, in most cases, the amount provided falls short of even the minimum wage because of the long hours and the high demands of caring (O'Flynn, 2008; Young et al., 2008). The recent announcement that Government is not to go ahead with a National Carers' Strategy was disappointing to family carers who finally felt that they were getting the recognition they deserved (Carers Association, 2010).

In summary, the stated core objective of successive health strategies is to provide a high quality service on a needs basis. This implies that all patients should have access within a reasonable time, irrespective of factors such as age, geographic location or ability to pay. The reality for many individuals seeking treatment in Ireland is very different. This is due to the shortage of the services survivors of TBI need such as neuro-rehabilitation. Government support for carers of survivors is also considered inadequate and uncertain, adding to the stress and burden of caring for a dependent relative.

2.15.5. Gaps in the Literature

Much of the existing literature has focused on the clinical aspects of traumatic brain injuries. Several studies have concentrated on the rehabilitation stage of the patient after the acute phase has ended (Cowen et al., 1995); community integration (Fleming et al., 1999; Mills et al., 1994), services provided by family and carers (Watanabe et al., 2001), and in forecasting outcomes at later stages after rehabilitation (Wade and Halligan, 2004; Thornhill et al., 2000). The primary aim of rehabilitation following traumatic brain injury is to aid reintegration in the community with a timely return to productive activity (Rosenthal, 1990).

Most research has focused on the phase directly before rehabilitation begins, which is particularly valuable from a clinical standpoint for predicting outcome (Cowen et al., 1995). Studies that have concentrated on community reintegration (Fleming et al., 1999; Mills et al., 1994) and forecasting outcome at later stages after rehabilitation (Brzuzy and
Corrigan, 1996) are also helpful. Rigorous research into neuro-rehabilitation is recognised as sparse (Cicerone et al., 2006), as are studies on long-term social aspects, such as relationship issues. The most significant contribution from this perspective is the research conducted by survivors of TBI (Hill, 2004; Sherry, 2006). This thesis aims to build and add to these contributions by focusing on the social aspects of TBI.

2.16. Analytical Framework

In this section, the analytical and theoretical framework which guides the current study is presented. It involves three levels of analysis: micro, meso and macro, and is developed from a review of the current literature. This approach allows for developing deeper understanding on the complexity of life for survivors of TBI and family members.

First, drawing on the existing literature, some theoretical considerations in relation to TBI are considered.

2.16.1. Some Theoretical Considerations

Concepts from various theoretical approaches and empirical studies were explored and, throughout the research process, the benefits of alternative conceptual explanations were recognised. Kearney and Hyle (2006) argue that any single theoretical framework has strengths and weaknesses, and choosing to utilise multiple frameworks the research can provide greater insights. As the study progressed, particularly after collection of the data commenced and initial analysis was undertaken, alternative explanations for the experiences of survivors, family members and health professionals were sought. For example, it was clear that the bio-medical model has an important function, particularly at the early stages after injury. However, any one model is not adequate to deal with the range of issues with which TBI survivors are forced to cope and social aspects are not addressed. Therefore the study favours a holistic model rather than a narrow biomedical approach. It considers the wider implications of TBI on individuals, families, health professionals, Government and society.

The micro level analysis addresses the research questions to build an understanding of key changes experienced by the survivor and family members of survivors of TBI. TBI in this research draws on theoretical frameworks, utilised in the research on chronic illness (micro). Relevant work / theories are as follows:

- Bury, 1991 (biographical disruption);
- Goffman, 1963 (visible and invisible stigma, ‘passing’, disclosure);
- Frank, 1995 (illness narratives and concept of self)
- Kleinman, 1988 (illness narratives);
- Sherry, 2006 (argues that the social model does not adequately serve survivors of brain injury).

Meso level analysis was considered appropriate in order to explore the issues and build understanding of the organisational structures of hospitals and healthcare organisations in relation to TBI survivors and their family’s experiences. Relevant work/theories addressing external factors (at meso level) are as follows:

- Charles Perrow, 1965 (hospital organisation)
- Etzioni, 1975 (goals of organisations)
- Strauss, 1978 (negotiated order theory/occupational ideologies).

The macro level analysis concentrated on the literature in relation to the cause and effect of TBI in an international, European Union (EU) national and regional context. These external factors also impact on experiences. Relevant work here relate to various aspects of social policy including the work of Goddard, (2009); Kind (2006); and Jacobs (2009).

2.17. Micro Level of Analysis

The individual is the main focus in this research. The key theories used here centre on chronic illness and illness narratives and emphasise the implications of illness on individuals, particularly their long-term ill health.

2.17.1. Chronic Illness

Currently, models of illness assume an underlying relationship between disease and illness (Wade and Halligan, 2004), underpinned by the strongly held cultural belief that a cure is possible with the correct use of medical resources (Kirmayer et al., 1994). This assumption has created not just an over-medicalisation of commonly experienced nonmedical conditions but has focused attention on discovering the pathology rather than understanding the complete scale of the illness (Wade and Halligan, 2004). Acknowledging that the biomedical approach is appropriate in the treatment of many organically-based illnesses, its dominance has an intense effect on social policy, as well as interactions between disabled and non-disabled people (Sherry, 2006). Funding is determined by diagnosis and, ‘resources are primarily allocated for the diagnosis and specific treatment of disease’ (Wade and Halligan, 2004: 1399).

This narrow approach overlooks the social factors which determine how well or poorly a patient responds to treatment. It also undermines the benefits of rehabilitation and post-rehabilitation, or the use and provision of technology and equipment. The WHO’s
‘International classification of functioning, disability and disease’ (2001) recognises that disease has consequences at different levels and must be placed in the context in which they occur (Wade and Halligan, 2004). Social representations of illness are influenced by the discourses used in the public domain and these then become the models for a shared knowledge of a given illness (Blaxter, 2007). Herzlich (1973) uses a framework to illustrate how individuals perceive illness and its effects. The three metaphors she uses are:

- Illness as destroyer, involving loss, isolation and incapacity: if I was very seriously ill, if nothing more could be done, then it would be family life wouldn’t exist anymore
  

- Illness as liberator: freedom from burden: For me illness is breaking off from social life, from life outside and social obligation, it’s being set free


- Illness as occupation, freedom from responsibility, except for the need to fight the disease: From the moment you know what’s in front of you it seems to me the only thing to do is to gather your strength and fight


Brain injury or any chronic illness results in a considerable change to that person’s life, and is often filled with uncertainty. This is mentioned frequently with reference to predicting its trajectory and outcome (Locker, 2008). Bury (1982) described this transformation as biographical disruption, in which social relationships, individual identity, self-reliance and independence may be compromised (Conrad, 1987; Corbin and Strauss, 1987; Lonardi, 2007). The biographical disruption (Bury, 1982) that occurs after brain injury is frightening and worrisome. Channaz (1987) notes that chronically ill people are involved in a constant struggle to lead valued lives and remain positive. Williams (1996) argues that people with chronic illness must embark on the process of narrative reconstruction of which they are a significant part.

**Family Systems Theory**

Family Systems theory developed by Bowen (1988) is valuable as an explanation and to understand the coping strategies of members of the survivor’s family. Cameron (2001:4) states that ‘the emotional process in systems generates predictable patterns of behaviour some of which are only activated during times of elevated anxiety in the system’. He also contends that the caring professions need to recognise that each part of the system operates individually rather than assume that all systems function the same. Highly gendered performance of roles is evident throughout the international literature, with
mothers providing most of the care to brain injured sons (Knight et al., 1998). Hodgens and Kelleher (1997) further note that caring responsibilities are often expected of women.

2.18. Meso Level Analysis

In order to contextualise the relationship between health and social care providers and survivors of TBI and their families, theories of organisation were utilised in this section.

2.18.1. Functionalism of Organisational Theory

Brain injury needs to be understood against the background of the encounters and interaction with healthcare professionals and social care providers. Theories from the sub-discipline of sociology of organisation contextualise these experiences. For example, according to Day and Day (1977:129) negotiated order theory calls into question the structural, functional and rational bureaucratic explanations of organisations, such as hospitals. This theory, associated with Strauss et al. (1998), presents a communications model involving an analysis of the labour divisions in large organisations. Doctors, nurses, physiotherapists, occupational therapists and other healthcare providers, all share a common goal - the health and well-being of the patient in their care. However, Day and Day (1977:129) argue that within each of these groups are different types of ideologies and practices. Negotiated order theory draws attention to the tension created by the artificial boundaries which have developed by the various agencies involved in the provision of health and social care. These varying occupational identities bring 'different types of training and professional socialisation, varying amounts of expertise, and different personal backgrounds, and significantly, they occupy quite different hierarchical positions within the hospital' (Day and Day, 1977:129).

They further add that differences occur within occupations determining hierarchical position (Day and Day, 1977). According to Day and Day (1977), there is a multitude of ideological practices in each of the occupational categories which determine how and by whom care is delivered. Upadhyay (2003) even suggests that there exists a blame culture within occupational groups and between hospitals and community care professional staff. Etzioni (1961) produced a classification system in an attempt to explain power and control. The criterion he selects for the development of his typology is that of compliance (Clegg and Dunkerley, 1980). Compliance, he argues, is universal, existing in all social forms, and is a major factor in the, 'relationship between those who have power and those over whom they exercise it' (Etzioni, 1961:4).

The definition of compliance is, 'the relation in which the actor behaves in accordance with a directive supported by another actor's power and to the orientation of the subordinated
actor to the power applied’ (Etzioni, 1961:4). Further, Etzioni (1961) contends that ‘compliance relations are a central element of organisational structure’ (Etzioni, 1961:21). Plainly then, compliance is dependent on the obedience of one party, and is essential to the smooth running of the organisation. Trust vested in health professionals due to their superior knowledge, is an important component in the success or failure of the relationship between service user and service provider.

According to Chamberlain (2006:415), a lack of understanding from decision makers about the provision of services and support has a profound effect on the survivor’s physical and emotional well-being. A lack of empathy and understanding towards survivors by health professionals and community adds to their distress and emphasise the invisibility of their suffering (Chamberlain, 2006; Streadman-Pare et al., 2001). Chamberlain (2006:416) further contends that the process involved in accepting a medical diagnosis, as in the case when the body is provisionally in poor functioning order, is having to accept a temporary identity as a person in a ‘special medically-legitimated place in the social order’ (Chamberlain, 2006:416). Tishelman and Sachs (1998, cited in Chamberlain, 2006:416) argue that even when the survivor moves to the chronic phase of illness, the diagnostic label enables the person to accept a normal yet medicalised self (Chamberlain, 2006:416). The recovering self is without clear guidance by the medical profession, because they also lack a clear understanding of how brain injury affects each individual (Chamberlain, 2006:416). Chamberlain (2006) argues that ‘in the absence of available legitimizing discourses from the labour force, medical and friendship networks, individual selves create alternative identities. Thus, the recovered self is an individual who is reproduced as a neo-liberal person who is autonomous, responsible and self-governing’ (Chamberlain, 2006: 416).

Pryor (2004) identified that some nurses in the respective brain injury rehabilitation units lacked the necessary expertise to predict aggressive behaviour in this group. She concluded that while too much stimulation and too many restrictions could generally explain much of the irritation, ‘the style of staff interaction with patients with acquired brain injury played a significant part in determining a patient’s response to both the staff member and the situation’ (Pryor, 2004:979). Giddens (1991) suggests that bodily competence is central to communication, social interaction and security. He argues that the notion of maintaining cultural competence is an ability to sustain roles and relationships, rather than choice, autonomy and reflexive practice based on risk and expert knowledge.
2.19. Macro Level Analysis

As discussed above, the social model, while being valuable, is limited in its scope. The use of additional models is fundamental to understanding the experiences of TBI survivors and to building up a strategy of how to address the complexity of their needs.

Shakespeare and Erickson (2000) contest the narrow explanation offered by the social model. They suggest instead an adequate social theory of disability would and should include all the dimensions of bodily experiences, such as social, cultural, political and psychological, rather than claiming that disability is either medical or social. Shakespeare and Watson (2001) take the position that the social model developed in the 1970's, is now no longer relevant. The social model of disability, as identified by Oliver (1990), ceases to regard disability ‘as a consequence of altered or damaged bodies, whether as a result of illness or of trauma, and instead see it as a product of features of the physical and social environments which lead to social exclusion’ (Bury, 2005:73).

The medical model offered the more traditional explanation of disability (Kuhn, 1970), which effectively reduced all disability to medical rationalisations. However, Shakespeare and Watson (2001) argue that much opposition to the medical model is an opposition to being defined solely on the basis of impairment. Many academics (Sutherland, 1981; Antonvsky, 1979) believe that illness and impairment are a normal condition of human existence. Impairment, therefore, is not the core component of disability (Shakespeare and Watson, 2001), but rather it displays the vulnerability of our embodiment. Shakespeare (1992) goes further by suggesting that the origins of hostility to disabled people may lie in the tendency of non-disabled people to deny their vulnerability and frailty. Impairment cannot be ignored because these are the experiences that offer real challenges: pain, infection, aches, insomnia etc. The sense of loss associated with injury or impairment is real. Morris et al. (2005) found in their study of people with brain injury, that some had begun to come to terms with losses and accept their new self and abilities; while others were unable to accept their losses.

Bury (2005) urges a rethink with regard to the separation of disability (caused by society), from impairment (defined as restricted activity and participation). Oliver (1996) insists that ‘disablement is nothing to do with the body. It is the consequence of social oppression’ (Oliver, 1996: 35). Oliver (1996) further argues that impairment is related to the body, as it is ‘nothing less than a description of the physical body’ (Oliver, 1996:35). Recently, other authors (Barnes and Mercer, 2003) attempted to draw attention to the significance of impairment in terms of its consequences and the meaning attached to its consequences (Bury, 2005). Activities of daily living may need adjustment, as well as other practical matters related to the altered body (Bury, 2005).‘The significance of a disorder relates to how visible it is, which part of the body is affected, and how these issues are located

55
within a particular culture' (Bury, 2005:75). Certain impairments carry negative connotations (Barnes and Mercer, 2003). Cognitive impairment, so often associated with brain injury, has certain implications for social interaction (Barnes and Mercer, 2003). The social model of disability pays little attention to the role and function of the body, and in doing so it has theorised the body in neutral terms, 'as a passive or neutral repository of "impairment"' (Bury, 2005:75).

This is at odds with Kelly and Field (1996:245) who argue that identity development is through a series of complex processes between physical appearance, behaviour, age, gender and ethnicity. They contend that essential to becoming credible in society is to 'give the impression of some degree of control, use and presentation of our bodies' (Kelly and Field, 1996: 246). Disability threatens to upset this ability to present an acceptable social and cultural façade, and leads to a sequence of doubts about 'self-management' (Bury, 2005:76). Thus, the body and specifically, the non-conforming body, is undeniably tied up with self-identity formation and maintenance.

2.20. Theoretical Approaches Examined, but not Utilised

Various concepts were explored and were used with reference to the subjects of study in developing a theoretical framework for this research. Throughout the research process, the benefit of alternative conceptual explanations was recognised. Theories which were considered for this study included:

- Social theories, such as cultural institutions (social policy influences), group behaviour (individual attitudes towards people with disabilities).
- Individual theories, for example, theories of interpersonal actions and sociology of the body.
- Decision making theory.
- Complex systems theory and hermeneutics.

2.21. Conceptual Modelling

The holistic model builds in more of the micro theories that I discuss at each level and does not exclude them. I have also encapsulated these approaches into my overarching 'macro' analytical framework which is discussed in in Chapter 7.
Table 1: Display of the three levels of Analysis

<table>
<thead>
<tr>
<th>Factors/Strategies</th>
<th>Factors/Strategies</th>
<th>Level of Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Factors Coping Strategies/</td>
<td>Management within family/ outside</td>
<td>Micro</td>
</tr>
<tr>
<td>External Factors</td>
<td>Awareness/Attitudes/ Knowledge</td>
<td>Micro</td>
</tr>
<tr>
<td>Public encounters</td>
<td>Stigma of visible injury</td>
<td>Micro</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encounters with healthcare providers</td>
<td>Agendas set by healthcare</td>
<td>Meso</td>
</tr>
<tr>
<td>Inadequate resources</td>
<td>professionals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rehabilitation, post- rehabilitation, training and employment</td>
<td>Macro</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.22. Conclusion

There are important gaps in the literature which this research will aim to fill. They include:

- a predominance of professional accounts of TBI, but largely a neglect to date, to record the voices of survivors;
- an absence of literature on survival/recovery from TBI on the Irish experience;
- gaps in the chronic illness literature specifically on TBI, e.g. biographical disruption;
- a failure to date, to adequately address people with brain injuries, within the social model of disability.

At present, much of the literature in the area of chronic illness has largely ignored the concept of what Bury (1991) describes as biographical disruption in his thinking on chronic illness. I consider brain injury to be a classic example of biographical disruption, which Bury describes as ‘a sudden, unexpected and life-changing event which brings a range of unforeseen challenges’ (Bury, 1991: 12). As brain injury is so sudden and unexpected, people are never prepared and the cognitive (as well as physical) changes make it much harder to deal with. As the survivor profile is mostly young (16–24 years) and male at the time of injury, their specific needs are different compared to members of society with other chronic illnesses. It is evident that there are no definitive outcome indicators following TBI. This makes it difficult to predict long-term prognosis and, therefore, planning of future services is problematic. However, it does not mean that with more detailed investigation of experiences of TBI, a measure of the need cannot be predicted.

It is evident from this literature that rehabilitation and post-rehabilitation services are underdeveloped in Ireland. Additionally, health professionals are over-reliant on the biomedical model of care for people with TBI. An holistic model aimed at addressing the varying needs of survivors and supporting family members should be aspired to.
for this group. As a start, allowing people to tell their stories of their illness experience has significant merit and must now be viewed as an approach worth considering for all patients.

The next chapter, Chapter 3, Research Methodology, will detail the methods used in this research study on the experiences of TBI survivors and family members.
Chapter 3
Research Methodology

3.1. Introduction
This chapter details the overall methodology used in the study. In particular, the reasoning behind the choice of subject, the method of sampling, the data collection instruments, the sources of and access to data and the approach to data analysis, are presented in detail. Finally, the issues of validity, reliability and generalisability are considered.

A mixed methods approach was adopted, as this was thought appropriate in order to meet the research aims and objectives. The initial collection and analysis of secondary quantitative data of admissions of TBI to Beaumont Hospital and CUH) is shaped by the absence of a comprehensive secondary source of data in relation to the topic in question. Qualitative data was collected from TBI survivors and family members, in order to gain a deeper understanding of the issues around TBI.

3.2. Aim and Objectives of the Study
The main aim of the study is to build an understanding of the experiences of the lives of TBI adults from a sociological perspective. This indicates the appropriateness of data collection which included semi-structured interviews and provided useful narratives. This is based on research directed by four research questions: what are the key changes in the lives of TBI adults; what are the key changes in the lives of family members of a TBI survivor; what are the perspectives of TBI survivors and their families regarding the health and social care supports and services, and how can appropriate health and social services be developed, based on the perspectives of TBI survivors and their families.

A reminder that the key objectives of this study were to:

- examine the common causes and effects of TBI in Ireland (based on data sets and empirical studies);
- build on existing research to explain the changed context of the lives of TBI survivors, and those of family members/significant others.

These objectives lend themselves to a mixed methods approach, with emphasis on a qualitative methodology.
3.3. Theoretical Perspective

Various theoretical perspectives, based on the existing body of knowledge, were identified from the literature on TBI (Chapter 2). This enabled the construction of an analytical framework at micro, meso and macro levels. The emphasis of this research is on the micro-level (individual survivors and family caregivers).

3.4. Qualitative Research Design-Limitations

Participants selected constitute a purposeful sample (Patton, 1990). Rather than generalisation of the findings, the study affords particularisation (Stake, 1995) and specialisation (Patton, 1990) - i.e. an in-depth examination of the experience of TBI, from the perspective of survivors and family members. The study will serve as a guide to policy makers, and will provide a rethink for healthcare professionals and practitioners about the manner in which care is delivered. Some constraints related to resources and time, i.e. the tasks were limited to one researcher, and there were time constraints within a PhD Programme.

3.5. My Experience in the Area of TBI

I trained as a nurse and midwife and worked in clinical practice and health care for many years. Following on from this, I worked for a specialised medical company that produced nutritional products, and I was responsible for best practice training of medical and nursing staff in the use of these products. This allowed me to develop good presentation techniques, training skills and networking across health and social care sectors. I graduated with a Masters in Sociology (Applied Social Research) on the theme of 'Delayed Discharges of Older People from Acute Hospitals'. Expertise gained in the workplace, combined with an ability to teach and present research findings to a wide audience will have positive benefits for health and social care users, as well as health care providers, the voluntary sector, academics and policy makers.

3.6. Situating the Researcher in the Context of the Research

The field of sociology and the specialist sub-field of health and illness, builds on my practitioner experience in health and further and higher education. I recognise that many areas of health provision and practice in Ireland are under researched. TBI survivors and their families are often too vulnerable to seek the necessary services and rely on existing expertise to address their needs. This research aims to highlight this.

My nursing background was particularly useful in negotiating access to the hospital sites, because it gave me an understanding of the constraints and pressures staff experience in
hospital settings. In relation to objectivity, one of the key aspects of qualitative research is the significance placed on the role of the researcher. I approach this from the stance that it is not possible to separate researcher from the research process. In order to be as objective as possible, a number of strategies were employed. These included:

- adopting an audit of TBI admissions to the only two neurosurgical centres in Ireland, to ensure the selected sample broadly represented the type of person affected by TBI and,
- using multiple data collection methods for triangulation purposes, while at the same time, searching for negative evidence or contradictory data.

3.7. Research Strategy and Research Design

This thesis used a multi-strategy methodology involving a quantitative research approach to precede a qualitative inquiry. Combining mixed methods has long been acknowledged as suitable for interpretive sciences (Kearney et al., 2001). For example, Lincoln and Guba (1985) contend that 'the naturalistic and conventional paradigms are so often-mistakenly equated with the qualitative and quantitative paradigms, respectively. Indeed, there are many opportunities for the naturalistic investigator to utilise quantitative data probably more than are appreciated' (Lincoln and Guba, 1985:198).

Accordingly, both methods were used in this study, beginning with the quantitative data. A quantitative approach was implemented in order to contextualise the subject of TBI in Ireland. Empirical data on admissions to the only two neurosurgical units in Ireland in a specified period (January 2005 to December 2006 in the case of CUH and June 2006 to June 2007 in the case of Beaumont Hospital), offered an overview of the numbers, the demographics and other characteristics of the population, the circumstances of injury and outcome following TBI.

This was followed by a qualitative data collection method, namely interviews, which provided an insight into the lives of survivors and their families. Interviews with health and social care providers, as well as staff working with one of the brain injury NGOs, allowed for the exploration of the key issues identified by NGOs and health care providers. These interviews provided a further source of data to inform interpretation of the findings of study of survivors and their families. The main emphasis of the investigation was on survivors and family caregivers. A cross-sectional research design was utilised – i.e. a snap-shot of the incidence of the condition and the experiences of survivors of TBI and their family care givers at a single point in time. This research design was implemented via a purposive sampling approach to recruit survivors and family members combined with secondary data analysis of hospital datasets on TBI (with injury occurring in a defined period as outlined above). The secondary data analysis contextualised the incidence and
profile of people more likely to sustain TBI and also provided the main source for identification of potential participants (survivors and family member) to recruit for the qualitative investigation.

The data collection in the qualitative research was heavily dependent on narrative methods (i.e. interviewees telling their stories to the researcher). The data analysis stage drew on strengths of ‘grounded theory’ (Glaser and Strauss, 1967) – in the coding of the transcripts of interviews from survivors and family members, building up concepts and categories and generating theory from the data. The analysis is thematic. The conceptual framework and thematic analyses were developed based on findings from the literature review (i.e. most relevant existing theories), personal experience and the data generated from the data collection (transcripts of interviews).

3.8. Applicability of the Research Methods to the Topic

An holistic approach was adopted methodologically (qualitative and quantitative), analytically and conceptually (biomedical and holistic models). This was appropriate to the inclusive nature of the subject under examination. However, using holistic design can pose risks because in particular the focus may be too wide to gain any real depth of understanding of the issues under investigation. This was not the case here as the majority of those with moderate or severe head injury were likely to be admitted to one or other of the two neurosurgical units in Ireland. Therefore, the logical approach in order to gain an understanding of the numbers, the causes and the effects of TBI was to access and document all cases admitted over a certain time period. Several considerations have been identified to judge the appropriateness and quality of research design. Kidder (1981:7) identified four tests:

- Construct validity – establishing correct procedural methods;
- Internal validity
- External validity – establishing how the findings of the study can be generalised
- Reliability.

3.9. Use of Qualitative Methodology

A qualitative method of enquiry, as Creswell (1998:15) points out, is a way of developing an understanding of social problems, based on distinct procedural traditions of inquiry, which construct a multifaceted picture, through the analysis of the participants’ comprehensive views on the issues at hand. This approach presented some challenges in terms of providing usable interviews with people who had varying degrees of cognitive impairment, from which to develop findings. For example, one of the survivors used his wife as a proxy
to give his interview, offering me the opportunity to utilise a lesser tried method of data collection than traditional techniques. Conducting qualitative interviews with survivors of moderate and severe TBI was innovative, as few previous researchers sought the views of this group. Instead, they relied on using secondary sources of information or clinical descriptions of TBI.

Bogdan and Biklen (1998) document the characteristics of a qualitative study. It should be carried out in a naturalistic setting emphasis is on words rather than numbers, concerned with processes rather than outcomes, perspectives from the participant's view are of utmost importance, and theory is either generated from the data or findings are made inductively' (Bogdan and Biklen, 1998:4). This study satisfies all these requirements: data emerged in natural settings, mostly in people's own homes; data was mainly descriptive and taken from the perspective of the survivor or a family member, and findings from the data were closely related to the personal and individual experiences of the informants.

3.10. Hospital Data

The research domain is defined as the population of adults between the age of 16 and 64 years, and treated for TBI at either one of the only two neurosurgical units in Ireland between January 2005 and December 2006. The experience of living with a moderate or severe Traumatic Brain Injury, following discharge from one of these two hospitals, was explored through qualitative inquiry.

Two hospitals were chosen as study sites for the following reasons:

- Beaumont Hospital and Cork University Hospitals are the only two neurosurgical units in Ireland;
- experts in this field could be accessed for information;
- records of TBI patients could be accessed and reviewed with agreement with the hospitals and strict ethical guidelines;
- survivors could be contacted for their perspectives;
- the method ensured an overview of the current admission rate of head injury within a two year period and, it provided a purposive theoretical sample for the qualitative aspect of the research.

The study is bounded by time: the initial injury must have occurred in the previous two years at the time of investigation, and by space: the survivors must now be living in the 26 counties of Ireland. One case was included even though the injury had occurred over two year previously.
3.11. Possible Alternative Approaches Considered to Gaining Access to Data

Rather than selecting hospitals as sites to access people with TBI and recruit them to the study, the alternative approaches would have been to access participants through one of the Non-Government Organisations (NGO's) such as Headway Ireland, The Acquired Brain Injury Ireland (previously called The Peter Bradley Foundation), QUEST or BRI. As some people affected by TBI may not be aware of these services, they would have been missed in the selection of a sample that could be generated from information provided by these organisations. The TBI population is chronically under-served in Ireland, which means people may be dispersed and difficult to contact. Those known to NGOs may not be completely typical of the population. Additionally, NGOs in this field do not have a presence in all areas of the country. Further, people are often discharged without any information on the disability service system, including supports provided by brain injury organisations in the voluntary sector.

3.11.1. Access for this Research

Initial contact with key informants in this study was made by e-mail. This was followed by a formal written letter explaining the purpose of the study, with a request for an interview. One was to a Neurologist at Beaumont Hospital, Dublin, who has a high profile and is critical of the government's resource allocation for neuro-rehabilitation. This Neurologist explained that a heavy workload would not permit any involvement in the study, but suggested a newly appointed Neurosurgeon as a possibility. His reply to my request was prompt and positive. I met this Neurosurgeon at their consulting rooms in Beaumont Hospital, where I was given an interview for almost an hour. A number of useful suggestions offered a focus of the study and a list of the people to be contacted.

Follow up contact was made via email or telephone, particularly regarding ethical approval from Beaumont Hospital. For ethical approval it is necessary to have a consultant at the hospital to lead any research being done there. Contact was also established with the manager of the Hospital In-Patient Enquiry (HIPE) Department at Beaumont Hospital, who put me in touch with the Research Nurse responsible for inputting data to the TARN database. Contact was made with the Ethics Committee and the Liaison Nurse, with responsibility for patients who have Acquired Brain Injury. Further contact was made with her via email and telephone calls.

A similar approach was used in Cork. The three Neurosurgeons at Cork University Hospital were contacted by letter. One did not reply; another replied with a number of important points outlined, but he did not commit to leading the study at the hospital, which was also a requirement by the Ethics Committee there. However, the third Neurosurgeon responded
positively agreeing to help and offering valuable advice on how best the study should be approached. I arranged to meet the Neurosurgeon in their office on the Neurosurgical Ward at Cork University Hospital. A full and frank interview was given. Concerns centred on the issue that there is no place to send the survivors of TBI once they had been treated there. Many more meetings were conducted with the Neurosurgeon, as well as contact by email, letter and telephone. The Neurosurgeon introduced me to the Manager of HIPE at the hospital.

Contact was established with key stakeholders, such as a Consultant at the National Rehabilitation Hospital. An interview was arranged after a letter of information was sent. This Consultant was chosen because of their level of knowledge and interest in the present state of provision of neuro-rehabilitation, and their vision for the future. A Public Health Specialist, who had conducted and published a study in 2004, on service provision for people with acquired brain injury in the Midland Health Board region, agreed to be interviewed. Her experience of collecting data on the subject was informative and provided me with ideas on how best to approach the task. A Disability Coordinator with the Health Services Executive (HSE) Western Region was interviewed on their experience of providing services and supports to people with Acquired Brain Injury in Counties Galway, Mayo and Sligo.

Interviews were also conducted with a number of staff at the NGOs. These included a Neurosurgeon, a Neuropsychologist, Researchers, Chief Executive Officers (CEOs) of two NGOs and a number of key support workers from the voluntary sector. Details of key informants who provided background/context information for this study, and assisted with access to sites and medical records are summarised in Table 2. Without the cooperation and good will of the various healthcare professionals and administration staff, this study would not have been possible. Their knowledge of the healthcare systems and their expertise on TBI, added considerably to the study. Their perspectives allowed me to formulate a plan on how to gain access to survivors of TBI. This also enabled me to gain an understanding of the constraints and barriers the health professionals and NGOs work under. Due to time and resource constraints interviews were not taped. However, notes were taken which provided a valuable resource and contributed to the interpretation of data from survivors and family members, who were the main focus of the study.
Table 2: Details of key informants in relation to site access and medical records.

<table>
<thead>
<tr>
<th>Research Informant Type</th>
<th>Number of Informants</th>
<th>How Selected</th>
<th>How Interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant Neurosurgeon</td>
<td>2</td>
<td>Selected by Researcher</td>
<td>1 hour interview x 3 visits</td>
</tr>
<tr>
<td>Consultant Neuro-Psychologist</td>
<td>1</td>
<td>Selected by Researcher with NGO</td>
<td>1 hour interview x 2 visits</td>
</tr>
<tr>
<td>Researcher with NGO</td>
<td>1</td>
<td>Selected by Researcher</td>
<td>1 hour x 2 visits</td>
</tr>
<tr>
<td>Research Nurse</td>
<td>1</td>
<td>Selected by Manager of HIPE</td>
<td>1 hour x 1 visit</td>
</tr>
<tr>
<td>CEO of NGO</td>
<td>2</td>
<td>Selected by Researcher</td>
<td>1 hour x 2 visits</td>
</tr>
<tr>
<td>Public Health Doctor</td>
<td>1</td>
<td>Selected by Researcher</td>
<td>1 hour x 1 visit</td>
</tr>
<tr>
<td>Liaison Nurse</td>
<td>1</td>
<td>Selected by Consultant Neurosurgeon</td>
<td>Telephone, letter and e-mail communication</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>1</td>
<td>Selected by Consultant Neurosurgeon</td>
<td>1 hour x 1 visit</td>
</tr>
<tr>
<td>Consultant Managers of HIPE</td>
<td>2</td>
<td>1 Selected by Neurosurgeon; 1 selected by Researcher</td>
<td>1 hour x 1 visit each</td>
</tr>
<tr>
<td>Regional Coordinator Disability Services HSE</td>
<td>1</td>
<td>Selected by Researcher</td>
<td>1 hour x 1 visit</td>
</tr>
<tr>
<td>Key support workers</td>
<td>4</td>
<td>Selected by Researcher</td>
<td>1 hour x 1 visit each</td>
</tr>
</tbody>
</table>

3.12. Complementary Methods Utilised: Gaining a Comparative Perspective in the USA

During the course of the study I went on a study trip to observe first-hand how data is collected on TBI at an internationally renowned research centre in the USA. Presently there are 16 TBI Model System Centers and four TBI Model System Longitudinal Follow-up Centers (IBIA, 2010b), one of which I visited. This centre is based at the Medical University of South Carolina (MUSC) in Charleston, and has become known for its wide range of research projects on TBI, such as a study on the unmet needs of people with TBI, and a study of TBI in the prison population of South Carolina.

At this centre, I observed the modern and well equipped rehabilitation and research facilities. This visit was facilitated and hosted by the Associate Professor at the Biostatistics and Epidemiology, Department of Medicine, at the Medical University of South Carolina. While there, I was introduced to senior researchers and assisted in every possible manner. The collection of data on TBI is noticeably better developed there compared to the situation in Ireland. Therefore, this visit was most worthwhile as it allowed me to gain a deep understanding of possibilities with regard to a systematic data collection, analysis and potential uses of data. The Traumatic Brain Injury Model System (TBIMS) provides a framework to examine the organisation of services for people with traumatic brain injury (TBI) and their families. This internationally respected American model system is a prospective, longitudinal multi-centre project, designed to study the course of recovery and outcome following delivery of a co-ordinated system of care (internal factors). This system
spans the continuum of pre-hospital, emergency care to post-acute intervention focused on community re-integration. These services must fully consider and respond effectively to the short and long-range needs of persons with TBI and their families. It is particularly useful here in order to contextualise the acute and rehabilitative phases of the survivor’s treatment (IBIA, 2010a).

The Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) located at Craig Hospital in Englewood, Colorado, serves as a central resource for researchers and data collectors within the Traumatic Brain Injury Model Systems (TBIMS) program (IBIA, 2010b). The primary purpose of the TBINDSC is to advance medical rehabilitation by increasing the rigor and efficiency of scientific efforts to longitudinally assess the experience of individuals with traumatic brain injury (TBI). The TBINDSC provides technical assistance, training and methodological consultation to sixteen TBIMS centers in the conduct of evidence based TBI rehabilitation interventions (IBIA, 2010b). It examines the course of recovery and outcomes following the delivery of a co-ordinated system of acute neuro-trauma and inpatient rehabilitation. The Database includes large scale follow-up to 15 years post-injury. As of December 2009, the database contained information on 8,775 persons with TBI (IBIA, 2010b). The TBINDSC and the TBIMS program are programs funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (IBIA, 2010b).

3.12.1. Possible Future Collaboration between Ireland and the USA

This section summaries my observations from visiting the TBIMS centre in Charleston, South Carolina. Building partnerships for future projects was an important objective of my visit because the US is at a much more advanced stage in terms of data collection on TBI, compared with Ireland. The differences are mainly in terms of the type and size of the studies and the fact that in the US, there exists a legislative basis to submit information on TBI. As already discussed, longitudinal studies, both quantitative and qualitative, spanning 15 years, provide valuable information on TBI. Disseminating and promoting collaboration through projects, exchanging materials, creating networks and using digital bases, were discussed. The ideas for future cooperation which evolved during meetings and discussions, included conducting studies on recurrent mild TBI (especially in relation to sport) and best practice in terms of developing a registry of brain injury in Ireland, where one does not presently exist. How the practices, strategies and projects could be applied in Ireland were explored. For example, data extraction and analysis on TBI would be of enormous benefit to healthcare professionals and policy makers, but is a costly financial resource exercise. Recommendations are constantly being made for
methodological improvements in both data collection for the TBIMS and future outcome surveillance. In this way, the team of researchers in the Charleston centre have developed considerable experience and skill in this area. They had recently been awarded a sizable grant to investigate TBI in a prisoner population in South Carolina. A large scale project on Epilepsy was also being conducted at this centre.

In summary, the US model systems (TBIMS and SCTBIFR) and datasets are complementary, each having different strengths for understanding factors that impact long-term recovery after TBI. It can be concluded from my visit that these provide useful possible future modelling for Ireland. However, much depends on appropriate resources being made available to support this work.

3.13. Ethical Considerations

3.13.1. Ethics Committee Approval

Approval was sought for this research and was received from the Ethics Committees at the University of Limerick, Beaumont Hospital and Cork University Hospital. Copies of approval letters are enclosed in Appendix G.

Gaining approval formed a significant part of the methodological process. The procedures took a long time. The steps were as follows:

- I submitted an application form together with the research proposal to the Research Ethics Committee at the University of Limerick. The Committee granted approval on condition that Ethics Committees at the relevant hospitals also approved.
- An application was submitted to the Research Ethics Committee at Beaumont Hospital, Dublin for approval to begin both the quantitative and qualitative data collection. The application process included completing a detailed application form, and appending information sheets on the study and drafts of individualised consent forms for each group of participants: survivors of TBI; family members/significant others of TBI survivors; and healthcare professionals (hospital and community). Subsequently, assent as well as consent forms were requested for survivors of TBI. Further revised submissions and amendments were sought by the Committee, before approval was granted ten months after the initial application was submitted.
- Ethical approval was also required for Cork University Hospital in order to access the data from patient notes and to conduct qualitative interviews with those selected for the samples. Approval was sought from the Research Ethics Committee at CUH. Applications are processed by the Research Ethics Committee at University College.
Cork. Conditional approval was granted within one week, subject to agreement by the Department of Risk Management at CUH. Permission was granted by the Department of Risk Management after a Consultant at the hospital signed an agreement explaining the purpose of the study.

3.13.2. Seeking Consent from Survivor Participants and their Families

Consent was sought from all participants. No data collection process was instigated until the participant had returned the signed consent (or assent) form. Consent and assent forms are included in Appendix F. Gaining informed consent can be difficult for people with severe brain injuries – in particular, those under guardianship. In these cases, assent is provided via a guardian. This only applied to one participant in the study, who had expressive aphasia (an inability to communicate effectively through speech). This participant used his wife as a proxy. Informed consent was signed by all the others prior to the interviews being arranged and conducted.

Richardson and Macmullen (2007) suggest that consent is far from straightforward as a principle, let alone in practice (Sin, 2005; Wiles et al., 2005). Malone makes the following comment: ‘as a purely legal remedy, informed consent is successful; as protection from ethical quagmires, the device misses the mark’ (Malone, 2003: 813). O’Neill (2006) also points out that there are numerous difficulties with the concept of informed consent. At the core of the consent issue is the concept of capacity: the decision as to whether a person has or has not, or to a diminished extent, the ability to understand both that to which they are being asked to agree and the implications of such agreement. Good (2009) acknowledges that the matter of determining capacity may be especially complex in some disability research, and raises the question of who should determine this matter of capacity. According to Parahoo (1997), the issue of consent in relation to people being interviewed by health professionals, even if it is in their own homes, imposes an obligation on them to help, either out of a sense of gratitude for care they have received or may receive in the future. Initially, some participants in this study had the impression that I was part of the nursing staff at one of the hospitals. I explained my role in the study and reassured them that refusing to take part would not affect any future care.

The issues of interviewing survivors of brain injury, particularly in gaining consent, building rapport, retaining participants for future studies and not building unreasonable expectations with regard to outcomes, needs to be considered at all times (Rehabilitation Research and Training Center, 2007). Researchers need to be sensitive to the history of exclusion of people with disabilities from research and of the abuse of people with disabilities by some forms of research (Good, 2009). The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) state that ‘states should
facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities' (UN, 1993: 22). Good (2009) writing on behalf of the National Disability Authority further states that ‘ethical disability research is located within an understanding of the inequality and exclusion currently experienced by many people with disabilities. It focuses on the disadvantages imposed by disabling societies on people with physical, sensory, intellectual impairments or experiencing mental distress’ (Good, 2009:1). Researchers must also incorporate into their research strategy recognition of the complexity and diversity that exists within the disability community (Good, 2009). According to Zappone (2003), the lived experience of disablement is shaped by the impact of disabled people’s social circumstances and contexts. Qualitative research is always dependent on the willingness of participants to participate in an exercise that may not be of any benefit to them.

3.13.3. Anonymity/Confidentiality

Anonymity and confidentiality are not the only ethical issues which must be considered by researchers (Parahoo, 1997). However, these are factors that require the particular attention of researchers. Protecting confidentiality, supposes that people wish to protect their identities (Mattingly, 2005). However, Lincoln and Guba (1989) point out that ‘confidentiality and anonymity obviously cannot be guaranteed in naturalistic enquiry’ (Lincoln and Guba, 1989: 233). In health research, there is also an implicit presumption that the information gathered by researchers could be potentially shameful or in other ways harmful if participants were personally identified (Mattingly, 2005:466). The confidentiality concerns, so important early in the research relationship, very often shift. Instead, participants may want their stories to reach an outside audience and to reach others in a way that makes participants – and not just the researchers – visible (Mattingly, 2005:455). The response rate in this study was good and data show that many participants were anxious to talk to the researcher about their experiences. Experience is defined as, ‘the stories people live. People live stories, and in the telling of them reaffirm them, modify them and create new ones’ (Clandinin and Connelly, 1994: 415). Shaw (2003:466) points out that ethical issues are raised by the fact that, as we encourage service users to tell their stories, we become characters in those stories and thus change those stories. This can be positive, and be one way of helping someone to reassess a problem. But it also carries risks and re-emphasises that selection and evaluation must be done with care and not as ‘a raid on mislaid identities’ (Abse, 1989: 46).
3.13.4. Other Ethical Issues

Qualitative interviews involve in-depth probing which has the potential to violate a person's right to privacy (Parahoo, 1997). Ethical consideration must be of major importance in any type of research, with every stage being guided by appropriate sets of guidelines. The National Disability Authority, 2009 (NDA) uses the following definition of ethics in research, 'a set of standards by which a particular group or community decides to regulate its behaviour – to distinguish what is legitimate or acceptable in pursuit of their aims from what is not' (Flew, 1979:112).

Soobrayan (2003) suggests that 'there is no single set of rules or practices that govern the ethics, truth and politics of a research project' (Soobrayan, 2003: 107). Ethical decisions taken throughout this study were based on guidelines acquired through consultation with a range of ethical bodies. Examples of these are the Sociological Association of Ireland (SAI) which provide an Irish set of general social research guidelines; the National Disability Authority (NDA) who issue guidelines for research involving people with disabilities; and The International Association for the Scientific Study of Intellectual Disability (IASSID), which has developed guidelines specifically for research involving people with intellectual disabilities. The NDA use a set of core values to underpin ethical guidelines: 'respect for the human rights dignity; equality; diversity' (Good, 2009:21). In order to adhere to these core values, the following factors are recommended for consideration: well-being and avoidance of harm; collaboration; consent; respect and, equality and diversity (Good, 2009:21). Parahoo (1997) warns that the actions of the interviewer before, during and after the interview have the possibility of harming respondents. The rights of individuals must be protected at all stages of the research process. With this in mind, guidelines issued by the above associations acted as guiding principles of the study.

3.14. Data Collection Methods

The strategy used for the data collection is a mixed methods approach. Table 3 provides a timeline outlining procedures and the methods used.

The tasks included:

- literature review;
- policy review
- development of preliminary scoping (regarding potential study sites, study subjects, access, ethics)
- procedures (access, sampling) and
- primary data gathering.
Table 3: Methods of Data Collection: Purpose & Timeline

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Purpose</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literature Review</td>
<td>To gain an understanding of current relevant issues, both nationally and internationally.</td>
<td>Extensive review completed January 2008. Revised and updated throughout 2009.</td>
</tr>
<tr>
<td>Documentary Analysis</td>
<td>To gain context/background information.</td>
<td>January 2007-January 2009</td>
</tr>
<tr>
<td>Quantitative Data Collection</td>
<td>To extract information on all admission of TBI to two neurosurgical hospitals. Purpose was to provide a background of TBI in Ireland.</td>
<td>December 2007- June 2008</td>
</tr>
<tr>
<td>Qualitative Interviews with Survivors</td>
<td>To gain an insight into the experiences of survivors of TBI, and to record these experiences.</td>
<td>September 2008 - Spring 2009</td>
</tr>
<tr>
<td>Qualitative Interviews with Family Members</td>
<td>To gain an insight into the experiences of survivors of TBI, and to record these experiences.</td>
<td>September 2008 - Spring 2009</td>
</tr>
<tr>
<td>Field notes</td>
<td>A method of recording the researcher's journey, and as a means of checking for verification of each case.</td>
<td>From the start of project in January 2007</td>
</tr>
</tbody>
</table>

3.14.1. Primary Data Collection Samples

In terms of the quantitative strategy, the purpose of which was to profile the TBI population. Data sets were developed at Beaumont Hospital and at Cork University Hospital (CUH).

3.14.2. Selection of the Quantitative sample at CUH

As an initial step, data collection involved an examination of In-Patient Enquiry System (HIPE) at Cork University Hospital (CUH) of all those discharged in the previous two years. HIPE is a computer-based discharge abstracting system designed to collect demographic, clinical and administrative data on discharges and deaths from acute general hospitals nationally. The Hospital In-Patient Enquiry (HIPE) unit is located in the Department of Medical Records at Cork University Hospital. As a first step, from the HIPE data it was possible to identify all patients discharged from Cork University Hospital between 1st January 2005 and 31st December 2006, with a primary or a secondary diagnosis of head or facial injury.

All admissions through the Accident and Emergency Department with a diagnosis of head or facial injuries through HIPE records were also noted. From this, the population of the study defined as survivors between the age of 16 and 64 years was identified. A total of 310 cases were identified in this way and a request was issued for the relevant patient notes. Hard copy notes are used due to the absence of an electronic system, which has yet to be implemented in this hospital. Files were made available for examination in the
Medical Records Department at the hospital. Each file was examined in detail to ensure the inclusion criteria were met. These criteria were as follows: aged between 16 and 64 years, admitted since 2005 with a traumatic brain injury; 116 were eliminated at this stage, mostly because the etiology did not indicate a traumatic event. A total of 194 appropriate medical records were considered suitable for inclusion.

3.14.3. Abstraction of Data from Medical Notes at Cork University Hospital

The information collected from 194 patient records (hard copies) is displayed in Table 4 below.

Table 4: Data Abstracted from medical notes at CUH

| Hospital Number | Date of Birth | Gender | Occupation | Date of Admission | Route of Admission/transfer | Date of Discharge/transfer | General Practitioner | Next of Kin | Health Insurance | Marital Status | Etiology | Past History | Alcohol Present | Past History of Drug or/and Alcohol Abuse | Hospital Consultant | Glasgow Coma Scale on arrival at Emergency Department (also GCS recorded by Emergency Medical Technicians at scene of accident, if available) | Loss of Consciousness (Length of time) |
|-----------------|---------------|--------|------------|------------------|-----------------------------|---------------------------|----------------------|-------------|----------------|---------------|----------|-------------|----------------|------------------------------------------|----------------------|---------------------------------------------------------------------------------|

3.14.4. Selection of the Quantitative sample -Beaumont Hospital, Dublin

Contact was established with key informants: a Consultant Neurosurgeon and the Acquired Brain Injury Liaison Nurse. With their guidance, a plan was formulated, which included making contact with the administrators of HIPE. It was envisaged that a similar strategy to that employed in Cork University Hospital be used here. However, a policy exists in Beaumont Hospital that only a maximum of ten patient files per day are made available to researchers. This would have required me to spend several months at the hospital which I was unable to do.
Fortunately, a data collection process had begun on all injuries admitted to the hospital between June 2006 and June 2007. The information on trauma was part of a collection procedure managed by TARN (Trauma Audit Research Network) at Manchester University. The information at Beaumont Hospital was entered onto the TARN database by a nurse trained in research methods. The decision to allow full access to this database was made by the Trauma Committee at the hospital. They requested that I formally apply for permission by writing to the doctor in charge of this project (the transfer of data to TARN). Access was granted for six months with an option to renew for longer if required. I requested the TARN dataset, selecting the following patient information: gender, age, characteristics of the injury (causes and circumstances), transfer status, description of the injuries based on the Abbreviated Injury Scale - See Appendix D, healthcare details as well as clinical outcome (alive/dead at hospital discharge or 30 days whichever is sooner). Injury Severity is calculated by TARN staff (Alexandrescu et al., 2008).

A total of 235 cases of people admitted with head injury were identified by TARN. An additional TARN dataset used in this study outlined details of arrival date and time, age, gender, injury mechanism, location (public place, road etc.), alcohol involvement, history of alcohol abuse, past history, length of stay in Intensive Care Unit, Glasgow Coma Scale, Outcome (alive/dead), length of stay in days, transfer type, transfer from, discharge destination, Glasgow Outcome Scale (overall condition on discharge) (Appendix C) ISS, Code 1–10 Severity score, Description of injury. One hundred and thirty-four [134] cases fitted the inclusion criteria for the study.

Microsoft EXCEL was used to manage the data. Ultimately, the data were later exported to SPSS 15 and to PASW 17 for analysis. Presentation and comparison of the quantitative data from both Cork University Hospital and Beaumont Hospital, Dublin are presented in Chapter 4 of this thesis.

<table>
<thead>
<tr>
<th>Site</th>
<th>Number of Patient Records Examined</th>
<th>Number of Patient Records Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beaumont Hospital</td>
<td>235</td>
<td>134 (electronic)</td>
</tr>
<tr>
<td>CUH</td>
<td>310</td>
<td>194 (hard copies)</td>
</tr>
</tbody>
</table>

Table 5: Number of Patient Notes Identified for the Quantitative datasets of Hospital Admissions.
3.15. Sampling: Qualitative

3.15.1. Primary Data Qualitative Sample Selection

Creswell (1998:118) states that researchers designing qualitative studies need clear criteria and need to justify their decisions by providing brief rationales for the specific strategies used. He suggests using Miles and Huberman's (1994:28) typology of 16 strategies for purposive sampling. According to Miles and Huberman (1994), the purpose of this type of sampling should be to illustrate subgroups and facilitate comparisons. As previously mentioned, a stratified purposive sample of survivors was selected in order to include both men and women from different regions of Ireland, who had sustained a severe or moderate traumatic brain injury. The sample of family members was chosen because of their involvement with survivors of TBI.

The identification of potential TBI participants was achieved through a purposive selection of a stratified sample from both hospital datasets (CUH and Beaumont Hospital). The categories in which cases were stratified were as follows:

- Gender
- Location in Ireland (residence)
- Severity of Injury.

This was necessary in order to include survivors from different parts of Ireland, both male and female TBI survivors and those with moderate or severe TBI. Letters of invitation were sent out to each participant with a return slip and a stamped addressed envelope. An additional letter addressed to a family member or a significant other, with an accompanying return slip was included. This correspondence was sent on official hospital letterhead and signed by the hospital consultant at each site. Potential participants in the study were fully informed that they could withdraw from the study at any time. See summary Table 6:
Table 6: Details of the Recruitment of Participants for the Qualitative part of the Study

<table>
<thead>
<tr>
<th>Research Participant Type</th>
<th>Survivor of TBI</th>
<th>Survivor of TBI</th>
<th>Family Members/Significant Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants invited</td>
<td>12</td>
<td>34</td>
<td>4</td>
</tr>
<tr>
<td>How Selected</td>
<td>CUH</td>
<td>Beaumont Hospital</td>
<td>NGO</td>
</tr>
<tr>
<td>Number of Replies</td>
<td>10 (replies included 5 patients who declined to participate)</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Number of Participants</td>
<td>Not Applicable</td>
<td>19</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>Invited at Second Attempt</td>
<td>Not Applicable</td>
<td>8 agreed</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>Number of replies at Second Attempt</td>
<td>+ 8 refusals</td>
<td>Not Applicable</td>
<td>+ 7 refusals</td>
</tr>
<tr>
<td>Number of Participants Interviewed</td>
<td>5</td>
<td>8</td>
<td>3</td>
</tr>
</tbody>
</table>

The initial response rate using this method was (10 responses from 12 invitations) from the CUH patient records. However, the initial response rate from the Beaumont dataset was very low (only two responses out of 34). A second letter, return slips and a stamped addressed envelope were posted three weeks after the initial contact. This invoked a better response, ten more survivors and 11 family members agreed to be interviewed. Three people were recruited through Headway, Ireland, two females and one male. This approach was necessary because no female in the hospital datasets agreed to be interviewed. One of these survivors was invited to take part in the study, even though he had sustained the TBI over twenty years previously. I was interested in hearing of his experience because he had regained his ability to speak after nineteen years. A total of 27 people were interviewed in this way (16 survivors and 11 family members), and the participants were represented in relation to age, gender and geographic location. There were two females and fourteen males in the survivor sample. See summary Table 7:
Table 7: Details of how participants were identified for interview.

<table>
<thead>
<tr>
<th>Research Participant Type</th>
<th>Survivor of Moderate TBI</th>
<th>Survivor of Severe TBI</th>
<th>Survivor of Severe TBI</th>
<th>Family Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants Interviewed</td>
<td>1</td>
<td>4</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Which Hospital/Dataset</td>
<td>CUIH</td>
<td>CUIH</td>
<td>Beaumont Hospital</td>
<td>None</td>
</tr>
<tr>
<td>How Selected</td>
<td>Letter of Invitation,</td>
<td>Letter of Invitation</td>
<td>Referred by Manager</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information Sheet,</td>
<td>Information Sheet,</td>
<td>of an NGO.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a Reply form and a</td>
<td>a Reply form</td>
<td>a Letter of Invitation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stamped Addressed</td>
<td>Stamped Addressed</td>
<td>Information Sheet, a</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Envelope</td>
<td>Envelope</td>
<td>Stamped Addressed</td>
<td></td>
</tr>
<tr>
<td>How Interviewed</td>
<td>1 hour Interview</td>
<td>1 hour Interview</td>
<td>1 hour Interview</td>
<td></td>
</tr>
</tbody>
</table>

One family member explained that his brother did not want to participate in the study as his accident was the subject of a court case and he was ‘tired of answering questions’ about his injuries. The family member persuaded him explaining this would be a more constructive exercise. He telephoned days after the interview to explain that his brother (the survivor) enjoyed the experience and was in much better form since the meeting. The positive benefits of having someone to listen while survivors recount their personal experience cannot be underestimated.

Two survivors replied but said they had made a very good recovery so preferred not to take part, three replied in the negative and no reply was received from two people. Valid reasons included: lack of availability - one mother said her son was serving a nine month prison sentence for his part in the accident. Another wrote that her son was too severely injured as a result of an accident that claimed the life of another son, while another was due to sensitivity reasons to the injury experience. The family sample consisted of one spousal caregiver, nine parental caregivers and one sibling. Participants who agreed to be interviewed were contacted and meetings were arranged. Survivors and family members were interviewed in their own homes, apart from the three people who were contacted through Headway, Ireland. These interviews were conducted on Headway premises. A further seventeen people made up of NGO spokespeople and health care providers were interviewed- see Table 7 above. These participants all worked closely with brain injured people, either as medical practitioners, nurses or as service providers of training, education, advocacy or other services. These interviews were not taped but notes were taken.
Consent was granted by each participant (survivors and family members) after I was satisfied that they understood the purpose and the nature of the study as well as their role in it. A time lag was observed in each case. In all cases, participants received full and comprehensive detailed information on the study two weeks before the interview. Interviews were tape-recorded and varied between 40 minutes and 120 minutes. Notes were kept on the interview experience. To understand the 'lived experience', qualitative interviews, with the sample of brain injured survivors, took the form of illness narratives. They are referred to here as 'interviews'. This approach allowed this group of participants to 'tell it as it was', without the restraint of structure or boundaries. Inclusion criteria for the survivor sample included the ability to communicate sufficiently, the ability to understand what the study was about and aged between 16 and 64 years at the time of injury. Inclusion criteria for the family/significant other sample, included being related to a survivor of TBI, or having a significant role in the survivors life, such as being the principle carer.

3.16. Issues in Conducting Qualitative Interviews

Rarely has anyone interviewed the survivors of TBI themselves. During the pilot stage (two interviews), issues related to the participant’s understanding and memory of the event were found not to pose an obstacle. In fact, I was surprised at how willing the participants (survivors) were to allow me to explore their experiences. The qualitative interview is recognised as a powerful tool (Myers and Newman, 2007) but many academics have cautioned about the potential problems and pitfalls (Webb et al., 1966). Webb et al. (1966) point out that interviews, ‘intrude into the social setting they would describe, they create as well as measure attitudes, they elicit atypical roles and responses, they are limited to those who are accessible and will co-operate’ (Webb et al., 1966:16). Myers and Newman (2007) argue that the qualitative interview involves interrogating someone who is a complete stranger. Trust between the participant and the interviewer is an important element and may influence the type of information which can be divulged (Myers and Newman, 2007).

Methodological Considerations regarding Qualitative Interviews with Family Members

Similar to Jumisko et al. (2007), the participants had a strong desire to share their experiences with the researcher. It was possible to get a rich understanding of being a family member (and/or a main carer) of a TBI survivor. The female participants showed a great willingness to narrate their stories and relate to how they provide personal care for their loved one. It was obvious they derived great satisfaction from this role. On the other hand, while there was also a willingness on the part of the male participants to contribute to the discussion, in some cases there was an obvious sadness in the way they recounted
their experiences. The researcher was mindful of the sensitivities of the participants, and allowed them plenty of time to narrate their stories.

3.16.1. Interview Schedule for Survivor Participants

One-to-one semi-structured interviews conducted with survivors were tape recorded. The questions were centred on:

- how much did you know about brain injury before it happened to you?
- how much information did you get about brain injury?
- how do members of the public treat you?
- if and how has life changed since the injury?
- what is your relationship with support and service providers?
- how good are the supports and services?
- what are your own personal challenges/ambitions?

A range of sources were used for devising and developing the questions, for example, the Traumatic Brain Injury Model System (TBIMS) in the United States of America. Much experience has been accumulated over many years by the American research teams who collect data on traumatic brain injury.

3.16.2. Interview Schedule for Family Participants

One-to-one semi-structured interviews conducted with family members were tape recorded. The questions were centred on:

- how much did you know about brain injury before it happened to (NAME of Survivor)?
- if and how has life changed for you since the injury?
- what is your relationship with support and service providers?
- what would you like to see happen now?
3.17. Methods of Analysis

3.17.1. Computer software Analysis of Quantitative Findings

Quantitative data was entered on, and analysed using, SPSS. The purpose was to explore the data set and to identify associations between key variables. While data were abstracted, the purpose was to contextualise the problem of TBI in Ireland. The analysis focused on descriptives to provide a profile of patients with TBI. Tests of statistical significance were conducted to establish relationships / association between some of the key variables. The findings are presented in Chapter 4 of this thesis. These data include a profile of patients in terms of key demographic, socio-economic and other characteristics recorded in the datasets, the cause of traumatic brain injury and severity of injury at the Beaumont Hospital and Cork University Hospital.

3.17.2. Analysis of Qualitative Data

Qualitative interviews were transcribed and analysed for thematic analysis using Nvivo 8, a qualitative software data analysis package, suitable for the coding of qualitative data. These were password protected. As a data protection measure, the audio tapes of collected data were stored in a locked filing cabinet in my home office, together with copies of the interview transcripts and the quantitative data.

Analysis of the qualitative data involved coding of themes / concepts, and through a process of comparing transcripts and grouping / linking themes grouping these into sub-categories and later grouping the sub-categories into core categories. A senior researcher, with experience in qualitative research confirmed that the analysis was appropriate and logical for the type of data collected. Service providers at one of the NGOs and health professionals, including two neurosurgeons and a neuropsychologist, reviewed the analysis for accuracy. A number of key themes (132 themes; 43 sub-themes) were identified that enabled the researcher to meet the main objective of the research – to build an understanding of the experiences of the lives of TBI adults from a social perspective, drawing on relevant social theories. Building up from concepts and sub-categories, core categories were identified in the process of data analysis, borrowing from the strengths of grounded theory. For instance, the core category of the survivor's path to recovery was identified. The sub-categories of survivor’s changed roles following TBI were identified as: societal barriers to active participation following TBI and the environmental factors influencing recovery.

In terms of addressing the research questions in relation to how the lives of family members of TBI survivors have changed, the core category of adaptation was identified. A number of sub-categories were identified including: getting the news; the reality of survivor’s
condition; the response of healthcare professionals to the family member's anxieties and questions; milestones/hope for the future; realisation of change, and reclaiming their own lives. Fit refers to how adequately the categories express patterns in the data (Glaser, 2001). According to Glaser (1978) constant comparison, coding and memo taking is essential for the analysis of the data. This was undertaken in this study. Data were coded by using the participants' own words and entered in Nvivo nodes. These codes were identified as concepts. In the process of constantly comparing the data generated in the transcripts, the concepts were linked and grouped into categories and these were mapped systematically, and then defined. Glaser and Strauss (1967) describe the process of identifying a code category thus: a core category emerges that described the majority of the variation that occurs most frequently in the data (Corbin, 1986; Glaser and Strauss, 1967).

Data analysis starts during, and continues after, the data are collected (Merriam, 1988). Schedules were made during collection in order to analyse the emerging data, and details are outlined here. Strauss and Corbin (1990) suggest developing a clear analytic story during the selective coding phase, specifying the relationship between categories, and fully developing the multiple perspectives or variations in each component (Creswell, 1998). During this open coding phase, the researcher examines all the data: transcripts, field notes, self-reflective memos to document personal reactions to participants' narratives (Creswell, 1989), as well as any material relevant to the study. The development of codes and categories which represents the data in this case (processes and issues linked to survival and coping strategies) occurs next. These categories are then compared and contrasted. A helpful way to display this visually is the use of large poster boards in order to map codes and show how these work up to or can be merged to form the categories. This was done in the course of the data analysis, going back to the transcripts (and actual words used by participants).

Axial coding follows, which puts data back together in new ways. Finally, selective coding is used, which is the process of 'selecting one core category, systematically relating it to other categories, validating those relationships by searching for confirming and disconfirming examples, and filling in categories that need (ed) further refinement and development' (Strauss and Corbin, 1990:116). Codes and categories are sorted, compared and contrasted until saturated. Because of human cognitive bias towards confirmation (Mahoney, 1991), an active search for disconfirming evidence is essential to achieving rigor (Creswell, 1998). A search for disconfirming evidence was a continuous process during the data collection and analyses phases of the study. Categories are identified and presented as open coding; and then a diagram of a theory linked to causal factors, interventions, and contextual factors. This is followed by axial coding (specific strategies and consequences), and selective coding (e.g. theoretical propositions that explain the experience) (Creswell,
1998: 224). An example in this research, for instance, is the category: surreal experience of family members.

The use of a constant comparative methodology to identify themes across the narratives is well-documented by many researchers (Markovic, 2006; Ryan and Bernard, 2003; Strauss and Corbin, 1990). Ryan and Bernard (2003) suggest that the most common method of identifying themes is to identify repetitions across narratives (Markovic, 2006). To establish verification, Strauss and Corbin (1990) recommend the use of seven criteria. In summary these are: selection criteria; the major categories that emerged; the events that led to the creation of these categories; how categories influenced the theoretical sampling process; the hypotheses pertaining to conceptual relations (that is, among categories), and the grounds in which they were formulated and tested; and, how and why the core category was selected. In order to assure the reader, it is necessary to show how the study meets these criteria, A Miles and Huberman (1994) audit trail that charted the research process and the development of codes, categories and theory were undertaken. For the present study, this consisted of documenting the research activity – interviews, observations, transcriptions, and early coding activity. This included the long list of codes generated initially, and the process of organising these into the categories which evolved from Nvivo analysis.

3.18. Use of Aspects of Narrative Analysis as a Method

Life narratives are an admirable way of gaining an understanding of what a person is experiencing and the strategies employed to cope with change brought about by illness. The data collection had a strong element of this approach, but it was not used in its strictest sense, as in rigorous discourse analysis. In the course of a narrative, an individual will reorganise their experience, outline their actions and communicate their position in the social world (Blaxter, 2004). This especially applies to people who have experienced a life changing episode, such as a traumatic brain injury. Many medical writers, such as Kleinman (1988), Brody (1987) and Coles (1989) argue for the greater use of narrative as a form of data collection and analysis. They claim that stories replicate human feelings and lived experience, and ‘that healing essentially involves the telling, the hearing and the unravelling of stories’ (Manning and Cullum-Swan, 1994:465).

The stories are unique, leading Frank (1995) to contend that the social scientific idea of establishing reliability, getting the same answer to the same question at different times - is not possible as the stories change in line with the experiences. Narrative analysis takes the outlook of the teller, a story with a beginning, a middle and an end. The analysis needs to reflect the variety of forms, the multiplicity of settings and the range of audiences in which this can take place (Manning and Cullum-Swan, 1994). However, they warn that content
and narrative analysis struggle with the problem of the contextualisation of a story within personal or group experience. Frank (1995) argues that, ‘a published narrative of an illness is not the illness itself, but it can become the experience of the illness’ (Frank, 1995:22).

3.19. Participatory Action Research

The notion of using elements of Participatory Action Research (PAR) methodology was given consideration. This may have been ambitious given that this technique is usually applied to community projects. Tandon (1989) cautions that PAR is an alternate organisation of knowledge production based on the participants’ role in setting the agenda, involvement in the data collection and analysis, and directing the use of findings. It does however often use the oral traditions of communication and dissemination of knowledge (Hall, 1993) and the preferred way to communicate the practice of PAR seems to be through the description of cases (Reason, 1994). Therefore, for this study I used elements of PAR by aiming to empower the participants to become involved by relating their experiences or telling their stories. However, it was not possible to fully involve the participants in the research process.

3.20. Issues of Rigor

The rigour of any study is a measure of the quality of that research. Validity, reliability and generalisability, are the features used to judge the essential value of a study, as well as its strengths (Sarantakos, 2005). While validity has its roots in the quantitative paradigm, and is used to measure accuracy and precision (Sarantakos, 2005), it is also a fundamental part of qualitative research (Lancy, 1993). Qualitative researchers endeavour to achieve validity through the construction of appropriate methods of data collection and analysis (Volmerg, 1983). To judge the quality of the research, various measures are employed. Miles and Huberman (1994) propose a number of strategies for testing or confirming findings (Sarantakos, 2005). These include: being able to compare the findings to other studies; by checking accuracy of data with participants in the study and the capability of the conclusions to be followed and tested.

Peer review, debriefing and external auditing was done consistently during all stages of the study. Regular discussions were conducted with academics at the University of Limerick and Mary Immaculate College, Limerick. Professional staff at Beaumont Hospital, Dublin, Cork University Hospital, National Rehabilitation Hospital, Dublin and Headway Ireland, provided interpretations on the findings of the study. Conference papers were presented which resulted in constructive and fresh perspectives on the research findings as themes were emerging. However, Sarantakos (2005) contends that validity is not a criterion for qualitative research, but rather researchers need to demonstrate methodological excellence.
He states that, ‘research performance in a professional, accurate and systematic manner’ (Sarantakos, 2005:87).

This study met the criterion for validity for a number of reasons. First, the quantitative datasets provide data on the profile of people with TBI in Ireland, and this was used in the purposive sampling method. Secondly, the data collection process with survivors and families was intense and substantial. Thirdly, the accuracy of the qualitative data was compared with the findings of other studies. Reliability is a gauge of objectivity, and has been described by Sarantakos (2005) as a measure of reliance if the method produces the same result, wherever it is repeated. Several tests are available for quantitative data and involve a considerable amount of statistical analysis and explanation (Sarantakos, 2005). Qualitative research, however, requires measurements of reliability quite different to quantitative research. According to McCall (1979), efforts at reliability are centred on setting up a list of possible errors which should be avoided. Flick (1998) suggests the following to ensure reliability: ‘prolonged engagement and persistent observation; peer review or debriefing; analysis of negative cases; checking ‘the appropriateness of terms of reference of interpretations and their assessment’; member checks (communicative validation); external auditing’ (Flick, 1998:231).

This study meets and exceeds the standard for reliability by addressing each of the criteria listed above. Prolonged engagement and persistent observation in the field: even though the interviews are relatively short, the time spent with survivors of TBI and family members was prolonged, in some cases it took a full day to collect one hour of interview data. This was mainly due to survivors having short spans of concentration. They were easily fatigued due to their injuries. Analysis of negative cases is a process of accounting for all cases. The study followed this procedure to ensure that all cases, including data that contradicted existing evidence, were accounted for. Member checking was done with family members and to some extent with the survivors. This was due to difficulties TBI survivors had with memory so were not able to confirm the data.

Transferability or generalisability is the ability to generalise the findings of a study beyond the boundaries of the group studied (Sarantakos, 2005). The design of sampling procedures aims to ensure that findings can be generalised, by using typical cases in the sample. The mixed method strategy employed in this study ensured a level of generalisability. However, I do not claim that my findings are universal or generalisable, but present a perspective of TBI from survivors and family members at a given time and location (Ireland). In summary, efforts were made at all stages to ensure rigour and to adhere to the criteria for validity, reliability and transferability.
3.21. Conclusion

In this chapter, a detailed account of the research strategies and methods used in the study are discussed. It has highlighted the strengths of adopting a mixed methods approach. The study used both quantitative and qualitative research methodologies. Data are gathered from a number of research sites in order to estimate the incidence of TBI in Ireland and to access survivors and family carers and recruit them to the research and other relevant informants (health care professionals). Such an approach allows for as many different perspectives and sources as possible to be included in this study. The research is based on a cross-sectional design with a purposive sampling strategy for the qualitative investigation. The primary data gathering in the qualitative investigation is contextualised in the secondary analysis of hospital datasets of TBI over a defined period. The conceptual framework is developed from a review of the literature in the first instance, personal experience and, further developed on the basis of the data generated and findings of the research. The qualitative research methods draw on strengths of grounded theory (in the analysis of data), narrative methods (in the interviews) and thematic analysis.

The study went through a series of stages. This included a substantial literature review, the examination of earlier research models and the development of a research instrument. Features relating to validity, reliability and transferability were applied to the data collection and analysis procedures. Findings from this study aim to satisfy the criteria for a rigorous study. This research has been a learning experience on a (i) methodological, (ii) practical, and (iii) theoretical level. One of the most interesting challenges of the research has been developing inclusive research methods for a vulnerable population with cognitive impairment. Specifically, the use of a proxy in one interview, sitting alongside a participant with expressive aphasia (a serious communication disorder), is also an extraordinary example of an adjusted interview protocol. This interview technique – using both consent of the proxy and assent of the person with the verbal impairment – is a practical methodological approach to working with non-verbal people (or people with limited verbal capacities).

In the next chapter, Chapter 4, the quantitative data is presented in detail. The Chapter is entitled: ‘Profile of people with Traumatic Brain Injury and severity of injury: Analysis of hospital datasets’.
Chapter 4
Profile of people with Traumatic Brain Injury and severity of injury: Analysis of hospital datasets

4.1. Introduction

In this chapter, the findings of the quantitative data from two hospital datasets are presented. This places Traumatic Brain Injury (TBI) in context, by documenting the characteristics of patients admitted to the two neurosurgical units in Ireland. It presents a profile of patients in terms of key demographic, socio-economic and other characteristics recorded in the datasets, the cause of traumatic brain injury and severity of injury. The purpose of the chapter is to provide a profile and quantification of TBI in the Irish context.

There are some differences in the type and detail of information available from the two hospital datasets. The first dataset relates to people who presented at the Accident and Emergency Department at Cork University Hospital with symptoms of brain injury, and were either admitted or discharged home. It is based on information from patient records and includes data on demographic and selected socio-economic characteristics of patients, as well as causes and severity of injury.

The second dataset is part of a larger dataset on injury compiled at Beaumont Hospital, Dublin. This dataset includes basic information on demographic characteristics and more detailed information on injury including causes and severity of injury. These data were collected at Beaumont and sent to the TARN (Trauma Audit Research Network) for analysis. TARN, located at Manchester University in the United Kingdom (UK), has the largest trauma database in Europe with over 200,000 cases. Its function is to collect and analyse clinical and epidemiological data and therefore to provide a statistical base to support clinical audit and to aid the development of trauma services and inform the research agenda.

(TARN, 2009).

Beaumont Hospital is located in North Dublin and has approximately 620 beds, of which 81 are protected for neurosurgical cases. It is the main teaching hospital for the Royal College of Surgeons in Ireland, and the national referral centre for neurosciences in Ireland.
More than seventy percent of all admissions to the National Neurosurgical Centre (NSC) are emergencies, and include a large proportion of patients with head injuries. The volume of truly elective admissions to the NSC in Beaumont Hospital is restricted by the exceptional demand for emergency and urgent elective care' (Phillips, 2009:14).

Cork University Hospital is the major tertiary referral hospital in Munster, with 25 neurosurgical in-patient beds. It is the teaching hospital of University College, Cork.

Patients who are admitted to one of the neurosurgical units are either referred from their own Emergency Departments or are transferred from other acute hospitals in the Republic of Ireland. Occasionally, Irish patients are repatriated from abroad.

A 24-hour referral and advice service is provided by the two neurosurgical units for other acute hospitals in the Republic of Ireland. It is known as the Neurosurgical Advice Service (NAS) and covers all neurosurgical conditions.

4.1.1. Case Definition

For the purpose of data extraction the following criteria were used:

a) Any blow to the head or face - even if it did not result in loss of consciousness;
b) Head injury, from minor to very severe;
c) Alive (Patients with TBI which lead to immediate or later death in hospital were excluded).

Age categories were collapsed in the older age patients (which were fewer in number), creating a broad age category of 47–64 years. Some causes of injury (industrial and other) were also collapsed, as were the categories of severity in the Beaumont Hospital datasets. These categories were 'not severe' and 'not very severe'. This was done in order to perform more accurate statistical tests. Notably, in terms of 'industrial' causes of TBI, many occurred on farms and involve animals.

In relation to severity of injury, the following measures are used: the Glasgow Coma Scale (GCS) is a measurement score derived from values from three component tests (eye, motor and verbal scales) used to assess levels of consciousness. Injuries are classified as severe (GCS 3–8), moderate (GCS 9–12) or mild (GCS 13–15) see Appendix A for details.

The length of unconsciousness is the method used by the Trauma Audit Research Network (TARN, 2010) in coding for degree of severity, whereas Cork University Hospital uses GCS as an assessment of severity. The Glasgow Coma Outcome (GCO) is a scale that
assesses the outcome of serious cranio-cerebral injuries, based on the level of regained social functioning. Scores and their meaning are as follows:

- Dead (Score 1);
- Vegetative (Score 2);
- Severely disabled (Score 3): able to follow commands/ unable to live independently;
- Moderately disabled (Score 4): able to live independently/ unable to return to work or school;
- Good Recovery (Score 5): able to return to work or school

(Jennett and Bond, 1975).

The Disability Rating Scale (DRS) is considered a more accurate assessment tool and has now replaced the GCO scale in some contexts (Hall et al 1985). The scale ranges from a maximum score (29) which indicates an extreme vegetative state to (0) indicating no disability.

4.2. Database Development

4.2.1. Cork University Hospital (CUH)

Secondary data were collected on the patients, from medical notes, who presented at the Accident and Emergency Department at the hospital during a two year period from 1st January 2005–31st December 2006. These patients were either admitted to the hospital, or in the case of most mild traumatic brain injuries, were discharged home after a period of observation. Some patients were transferred from other acute hospitals in Ireland, and one patient was repatriated from a London hospital. All patients were aged between 16 and 64 years at the time of injury on admission.

A total of 510 cases were identified from records held by the Hospital In-Patient Enquiry (HIPE) system. Of these, 301 patient notes were requested from the medical records department. Data were extracted from 194, as these were deemed to fit the criteria regarding age and the type of injury.

4.2.2. Beaumont Hospital (BH)

Beaumont Hospital has been documenting and supplying data to TARN on the various types of injury treated there since June 2006. The data used in the newly developed dataset covers all admissions to the hospital between June 2006 and July 2007. At the time of data collection in July 2007, no electronic data of admissions prior to June 2006 was available.
Patients were aged between 16 and 64 years and were alive on discharge from the hospital. Based on the analysis of the dataset, 134 patients were judged to fit the criteria for the study in terms of age and type of injury.

4.3. Results

4.3.1. Demographic Profile

The combined hospital data show that in terms of the breakdown of patients by gender, males are four times as likely to sustain a traumatic brain injury than females.

In terms of age, of those patients presenting at CUH and Beaumont Hospital, the largest numbers / proportion was in the age group 16–23 years. The next largest group is aged between 24–35 years. This is in keeping with previous reports which found that injury is more likely between the ages 15 to 29 years (Headway, 2009).

In terms of the age and gender of patients presenting at Beaumont Hospital and CUH, data show that males in all age groups are more likely to sustain a TBI than women. There are too few numbers of women sustaining brain injury for the results to be meaningful (women comprise just under one-fifth of patients in the combined data set). Similar to males, the highest percentage of women with brain injury is in the youngest age groups; similar to males, the percentage of females sustaining a brain injury decreases in the older age groups up to age categories 46 years.

However results of Pearson Chi-Square test - 12.365 (df 9), \( p = 0.194 \) indicates no statistically significant association between age and sex among victims of traumatic brain injury. Furthermore, a gamma value of -.016, \( p = .819 \) confirms no linear pattern of association exists here.

Comparison with data from the 2006 Census of Population (CSO, 2006) indicates that TBI occurs in 4.7 people per 100,000 (Beaumont Hospital data) and 3.4. people per 100,000 (Cork University Hospital) of the population in the 16 to 64 year age group - see Table 8.
<table>
<thead>
<tr>
<th>Age</th>
<th>Male</th>
<th></th>
<th>Female</th>
<th></th>
<th>Total</th>
<th></th>
<th>Population (CSO,2006)</th>
<th>Total Population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BH</td>
<td>%</td>
<td>CUH</td>
<td>%</td>
<td>Total</td>
<td>%</td>
<td>BH</td>
<td>%</td>
</tr>
<tr>
<td>16-23</td>
<td>35</td>
<td>32.2</td>
<td>67</td>
<td>42.9</td>
<td>102</td>
<td>38.4</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>24-35</td>
<td>34</td>
<td>31.2</td>
<td>39</td>
<td>25</td>
<td>73</td>
<td>27.5</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>36-46</td>
<td>18</td>
<td>16.5</td>
<td>29</td>
<td>18.6</td>
<td>47</td>
<td>17.8</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>47-64</td>
<td>22</td>
<td>20.1</td>
<td>21</td>
<td>13.5</td>
<td>43</td>
<td>16.3</td>
<td>9</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>109</td>
<td>100</td>
<td>156</td>
<td>100</td>
<td>265</td>
<td>100</td>
<td>25</td>
<td>100</td>
</tr>
</tbody>
</table>

Age groups 16 – 64 years: 2,849,155

Beaumont Hospital (1 year): 134 represent 4.7 people per 100,000 of the population in this age group.

CUH (2 years): 194 (97 x 1 year) represents 3.4 people per 100,000 of the population in this age group.
4.3.2. ‘Next of kin’, marital status, occupation and health insurance status.

At CUH but not at BH, data were also available on the patient’s ‘next of kin’, marital status, occupation and the patient’s health insurance status. In terms of whether or not patients had private health, the majority 112 (58%), were admitted as public patients, while a further 65 (34%) had private health insurance. Five patients were covered by either travel insurance (three with E111 and one from the USA with travel insurance) or occupational health insurance.

Reflecting the young age profile of patients presenting with brain injury, the largest numbers named a parent (84 mothers and 29 fathers) as next of kin followed by a spouse (39) or partner (10).

In terms of marital status where recorded (182 patients), the vast majority were single 135 (74%). Some 20 percent (37) are married or cohabiting and 6 percent (10) separated/divorced or widowed.

4.3.3. Socio-economic and other characteristics of patients presenting at CUH with TBI

The CUH hospital dataset records occupation of patients. Information on occupation was used to classify patients by socio-economic grouping and social class. The socio-economic group of persons aged 15 years or over who are at work is determined by their occupation and employment status. Unemployed or retired persons aged 15 years or over are classified according to their former occupation and employment status (CSO, 2002). Some patients, furthermore, did not state their occupation.

In terms of occupation, the highest incidence occurred in patients who work in skilled manual occupations (social class 4), which includes trades, such as carpentry, plumbing and electrical work - generally, male occupations. Occupational classification is based on that used by the Central Statistics Office (Ireland) and applied in the Census of Ireland. This classification system is based on the UK Standard Occupational Classification 4, with modifications to reflect Irish labour market conditions (CSO, 2006). For those patients where occupation is not recorded (rather principal economic status and other categories), approximately one-quarter of all patients (50) were categorised as students or school pupils reflecting again the young age profile of patients; thirteen people were unemployed at the time of injury; one individual stated he was homeless and one a prisoner – see Table 9.
Table 9: Patients Presenting at CUH by Occupation or Activity

<table>
<thead>
<tr>
<th>Occupation / Activity</th>
<th>Count</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher Professional</td>
<td>5</td>
<td>2.6%</td>
</tr>
<tr>
<td>Lower Professional</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Non-Manual</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Skilled Manual</td>
<td>31</td>
<td>16%</td>
</tr>
<tr>
<td>Semi-Skilled</td>
<td>4</td>
<td>2%</td>
</tr>
<tr>
<td>Un-Skilled</td>
<td>15</td>
<td>7.7%</td>
</tr>
<tr>
<td>Own Account</td>
<td>11</td>
<td>5.7%</td>
</tr>
<tr>
<td>Farmers</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Agricultural workers</td>
<td>3</td>
<td>1.5%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>15</td>
<td>7.7%</td>
</tr>
<tr>
<td>Housewife</td>
<td>5</td>
<td>2.6%</td>
</tr>
<tr>
<td>Student</td>
<td>50</td>
<td>26%</td>
</tr>
<tr>
<td>Retired/Homeless/Prisoner</td>
<td>3</td>
<td>1.5%</td>
</tr>
<tr>
<td>Not Stated</td>
<td>34</td>
<td>17.5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>194</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

4.4. Cause of TBI

Both datasets contained information on the causes of TBI. Across all patients, road traffic accidents (RTA) accounted for the largest number of injuries, followed by combined falls of greater and less than two metres. RTA is an umbrella term for accidents which may involve motor vehicles, motorcycles, bicycles or pedestrians. The percentage of injuries relating to falls is higher in Beaumont Hospital (BH) than in CUH. Stricter Health and Safety Regulations may have contributed to the low number of TBI from occupational causes at both hospitals.

Sports' injuries accounted for over 18 percent of TBI at CUH, while only a half a percent at Beaumont Hospital. This finding may be related to the data selection process employed at CUH. All cases admitted to the accident and emergency department there were counted, even though the majority were mild TBI cases and were discharged after a period of observation. The Beaumont Hospital dataset only recorded patients who were admitted to the neuroscience unit at the hospital.

The combined data from Beaumont and Cork University Hospital shown that the relationship between age and the cause of TBI is statistically significant with higher incidence of TBI in younger age groups Pearson Chi-Square 74.761 (df 15), $p = 0.000$ – see Table 10. There is also a relationship between cause of TBI and gender as indicated by a Pearson Chi square $= 58.175$ (df 15), $p = 0.000$ – see Table 11.
### Table 8: Age and Gender of Patients in Beaumont Hospital and Cork University Hospital Datasets

<table>
<thead>
<tr>
<th>Age</th>
<th>Fall&lt;2 metres</th>
<th>%</th>
<th>Fall&gt;2 metres</th>
<th>%</th>
<th>RTA</th>
<th>%</th>
<th>Assault</th>
<th>%</th>
<th>Sport</th>
<th>%</th>
<th>Other</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-23</td>
<td>14</td>
<td>23.3</td>
<td>6</td>
<td>15.8</td>
<td>55</td>
<td>61.1</td>
<td>9</td>
<td>27.3</td>
<td>28</td>
<td>45.9</td>
<td>10</td>
<td>21.7</td>
<td>122</td>
<td>37.2</td>
</tr>
<tr>
<td>24-35</td>
<td>18</td>
<td>30</td>
<td>7</td>
<td>18.4</td>
<td>18</td>
<td>20</td>
<td>9</td>
<td>27.3</td>
<td>24</td>
<td>39.3</td>
<td>13</td>
<td>28.2</td>
<td>89</td>
<td>27.1</td>
</tr>
<tr>
<td>36-46</td>
<td>10</td>
<td>16.7</td>
<td>9</td>
<td>23.7</td>
<td>13</td>
<td>14.4</td>
<td>9</td>
<td>27.3</td>
<td>5</td>
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<tr>
<td>47-64</td>
<td>18</td>
<td>30</td>
<td>16</td>
<td>42.1</td>
<td>4</td>
<td>4.5</td>
<td>6</td>
<td>18.1</td>
<td>4</td>
<td>6.6</td>
<td>9</td>
<td>19.7</td>
<td>57</td>
<td>17.4</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>100</td>
<td>38</td>
<td>100</td>
<td>90</td>
<td>100</td>
<td>33</td>
<td>100</td>
<td>61</td>
<td>100</td>
<td>46</td>
<td>100</td>
<td>328</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 10: Cause of TBI and Age in Patients Presenting at Beaumont Hospital and Cork University Hospital

<table>
<thead>
<tr>
<th>Age</th>
<th>Cause</th>
<th>%</th>
<th>Total</th>
<th>% of total</th>
<th>BH</th>
<th>%</th>
<th>CUH</th>
<th>%</th>
<th>Total</th>
<th>% of total</th>
<th>BH</th>
<th>%</th>
<th>CUH</th>
<th>%</th>
<th>Total</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-23</td>
<td>Fall&lt;2 metres</td>
<td>17.7</td>
<td>47</td>
<td>17.7</td>
<td>13</td>
<td></td>
<td>5</td>
<td>13.1</td>
<td>13</td>
<td>20.6</td>
<td>60</td>
<td></td>
<td>21</td>
<td>10</td>
<td>114</td>
<td>27.4</td>
</tr>
<tr>
<td></td>
<td>Fall&gt;2 metres</td>
<td>10.6</td>
<td>28</td>
<td>10.6</td>
<td>13</td>
<td></td>
<td>5</td>
<td>13.1</td>
<td>10</td>
<td>15.8</td>
<td>38</td>
<td></td>
<td>17</td>
<td>10</td>
<td>90</td>
<td>27.4</td>
</tr>
<tr>
<td></td>
<td>RTA</td>
<td>26.4</td>
<td>70</td>
<td>26.4</td>
<td>20</td>
<td></td>
<td>9</td>
<td>23.8</td>
<td>20</td>
<td>31.8</td>
<td>53</td>
<td></td>
<td>37</td>
<td>11</td>
<td>194</td>
<td>27.4</td>
</tr>
<tr>
<td></td>
<td>Assault</td>
<td>10.6</td>
<td>28</td>
<td>10.6</td>
<td>5</td>
<td></td>
<td>5</td>
<td>13.1</td>
<td>5</td>
<td>7.9</td>
<td>33</td>
<td></td>
<td>32</td>
<td>11</td>
<td>63</td>
<td>18.6</td>
</tr>
<tr>
<td></td>
<td>Sport</td>
<td>21.5</td>
<td>57</td>
<td>21.5</td>
<td>4</td>
<td></td>
<td>4</td>
<td>10.5</td>
<td>4</td>
<td>6.3</td>
<td>61</td>
<td></td>
<td>36</td>
<td>18</td>
<td>134</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>13.2</td>
<td>35</td>
<td>13.2</td>
<td>10</td>
<td></td>
<td>4</td>
<td>26.4</td>
<td>11</td>
<td>17.6</td>
<td>35</td>
<td></td>
<td>46</td>
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<td>46</td>
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<td>156</td>
<td>100</td>
<td>25</td>
<td>100</td>
<td>38</td>
<td>100</td>
<td>63</td>
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<td>134</td>
<td>194</td>
<td>328</td>
<td>100</td>
<td>328</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 11: Cause of TBI and Gender of Patients Presenting at Beaumont Hospital and Cork University Hospital

<table>
<thead>
<tr>
<th>Cause</th>
<th>Sex</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>BH</td>
<td>%</td>
</tr>
<tr>
<td>Fall&lt;2 metres</td>
<td></td>
<td>31</td>
<td>28.4</td>
</tr>
<tr>
<td>Fall&gt;2 metres</td>
<td></td>
<td>16</td>
<td>14.8</td>
</tr>
<tr>
<td>RTA</td>
<td></td>
<td>26</td>
<td>23.9</td>
</tr>
<tr>
<td>Assault</td>
<td></td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Sport</td>
<td></td>
<td>25</td>
<td>22.9</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>10</td>
<td>9.1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>109</td>
<td>100</td>
</tr>
</tbody>
</table>
4.5. Severity of TBI

Severity of injury is recorded differently in each hospital site. Therefore, data are presented and analysed separately. Severity of injury is assessed in CUH using the Glasgow Coma Scale (GCS). GCS scores range from 3 to 15 with lower scores indicative of more severe injury; 13–15 is considered mild TBI, 9–12 moderate injury and a GCS less than 9 is a severe injury (Phillips, 2009).

The stage at which the GCS is assessed and the skill level of the assessor determines the accuracy of the score. Some cases in this study were transferred from other hospitals where initial GCS were taken. The GCS documented here is the score recorded on arrival at the Accident and Emergency Department in CUH. Data on GCS was missing in some cases (N=157 from a total of 194). Beaumont Hospital’s assessment for the severity of injury is based on the method employed by TARN, where the length of unconsciousness is used for severity coding purposes (TARN, 2010).

The explanation used is that:

sometimes the anatomical injury identified (even at post mortem) is inadequate to fully describe the severity of a head injury. In such cases it is conventional to utilise the length (or less satisfactorily) the level of unconsciousness using the Glasgow Coma Scale score (Nee et al 2010:4).

The convention used is based on the Abbreviated Injury Scale – 1990 Revision: AIS90 (Association for the Advancement of Automotive Medicine, 1990). However, according to TARN (2010), the Probability of Survival of each injured patient can now be more accurately calculated using age, gender, Glasgow Coma Scale and the Injury Severity Score.

On admission to Beaumont Hospital, twenty-nine cases (21.7%) were assessed as having ‘a very severe injury’. ‘Severe injury’ was recorded in 51 cases (38.1%). As such, almost 60 percent of the total caseload was assessed as having ‘severe’/‘very severe’ injury on admission. This shows a much higher rate of severity of TBI than the CUH sample, where 5.7 percent of all cases had a severe injury, 4.4 percent moderate and the vast majority (89.8%) sustained a mild injury.

The explanation of this is that Beaumont Hospital is the National Neuroscience Centre in Ireland and therefore the more serious cases of TBI are referred here from other hospitals in Ireland. In addition the cases recorded by TARN were patients admitted to Beaumont Hospital, while all cases of TBI admitted to the Accident and Emergency Department at Cork University Hospital were included in the CUH dataset. The majority of mild cases
of TBI are treated by General Practitioners or local hospitals and, therefore, would not present for treatment at a specialised neurosurgical unit.

Table 12: Severity of TBI and Age of Patients Presenting at Beaumont Hospital

| Age   | Severity | % Not Severe | % Moderate | % Severe | % Very Severe | % Total |%
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>16-23</td>
<td>6</td>
<td>12</td>
<td>29.3</td>
<td>14</td>
<td>27.4</td>
<td>10</td>
</tr>
<tr>
<td>24-35</td>
<td>1</td>
<td>15</td>
<td>36.7</td>
<td>16</td>
<td>31.4</td>
<td>7</td>
</tr>
<tr>
<td>36-46</td>
<td>3</td>
<td>7</td>
<td>17</td>
<td>8</td>
<td>15.7</td>
<td>4</td>
</tr>
<tr>
<td>47-64</td>
<td>3</td>
<td>7</td>
<td>17</td>
<td>13</td>
<td>25.5</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>100</td>
<td>41</td>
<td>100</td>
<td>51</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 13: Severity of TBI and Sex (Gender) of Patients Presenting at Beaumont Hospital

| Sex   | Severity | % Not Severe | % Moderate | % Severe | % Very Severe | % Total |%
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>8</td>
<td>61.5</td>
<td>31</td>
<td>75.6</td>
<td>43</td>
<td>84.3</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>38.5</td>
<td>10</td>
<td>24.4</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>100</td>
<td>41</td>
<td>100</td>
<td>51</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 14: Severity of TBI and Age in Patients Presenting at CUH

| Age   | Severity | % Mild | % Moderate | % Severe | % Total |%
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>16-23</td>
<td>60</td>
<td>42.8</td>
<td>2</td>
<td>33.3</td>
<td>65</td>
</tr>
<tr>
<td>24-35</td>
<td>37</td>
<td>26.4</td>
<td>1</td>
<td>16.7</td>
<td>40</td>
</tr>
<tr>
<td>36-46</td>
<td>23</td>
<td>16.4</td>
<td>2</td>
<td>33.3</td>
<td>29</td>
</tr>
<tr>
<td>47-64</td>
<td>20</td>
<td>14.4</td>
<td>1</td>
<td>16.7</td>
<td>23</td>
</tr>
<tr>
<td>Total</td>
<td>140</td>
<td>100</td>
<td>6</td>
<td>100</td>
<td>157</td>
</tr>
</tbody>
</table>

Table 15: Severity of TBI and Sex of Patients Presenting at Cork University Hospital

| Sex   | Severity | % Mild | % Moderate | % Severe | % Total |%
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>114</td>
<td>81.4</td>
<td>3</td>
<td>50</td>
<td>72.7</td>
</tr>
<tr>
<td>Female</td>
<td>26</td>
<td>18.6</td>
<td>3</td>
<td>50</td>
<td>27.3</td>
</tr>
<tr>
<td>Total</td>
<td>140</td>
<td>100</td>
<td>6</td>
<td>100</td>
<td>157</td>
</tr>
</tbody>
</table>

Severe TBI was more common in the younger age groups of patients presenting at Beaumont Hospital. However, results of a Pearson Chi-square test (5.998 (df 9), p = 0.740)
show age is not statistically significant in terms of severity. This is also evident with a gamma value of 0.057, \( p = 0.591 \) which indicates no linear association between age and severity of injury - see Table 12.

In terms of severity and sex (gender), the pattern of severity indicates that males are more likely to be severely injured than females. A Pearson Chi-Square 7.187 (df 3), \( p = 0.06 \) indicates that the result is marginally statistically significant; the gamma statistic is -0.438, \( p = 0.008 \) shows the strength of this association is weak - the negative value indicates that males are likely to be more severely injury than females see Table 13.

Falls (28.4%) and RTAs (14.2%) were the main causes of severe and very severe brain injury in patients who presented at Beaumont Hospital. A Chi-Square of 30.249 (df 15), \( p = 0.01 \) indicates a statistically significant relationship between cause of injury and severity of TBI - see Table 16. The majority of cases in the CUH dataset are in the mild category. Similarly to Beaumont Hospital in terms of severe injury, there is a fairly even spread across age groups with the greatest number of cases (4) in the 36-46 year age group. Statistical significance is not indicated by a Pearson Chi-Square: 4.222 (df = 6), \( p = 0.647 \). Similarly, a Gamma value of -0.262, \( p = 0.168 \) shows no statistically significant linear relationship between age and severity of injury - see Table 14.

In the case of gender and severity of TBI in patients who presented at CUH, similar to BH, males were more likely than females to sustain severe TBI. However, this is not supported by the result of a Chi-Square test: 3.848 (df = 2) \( p = 0.146 \) which shows no statistically significant relationship between gender and severity of TBI at CUH – see Table 15. Small numbers of cases overall, larger numbers of patients at BH and treatment at BH of the more severe cases of TBI are explanatory factors of this result.

RTA (3.2%) was the most common cause of severe TBI in patients who presented at CUH. However, the numbers are too low to draw conclusions on any possible relationship between cause of TBI and the severity of TBI. The result of a Pearson Chi-square test confirms this: 8.954 (df 10), \( p = 0.536 \) - see Table 16.
### Table 16: Severity of TBI and Cause in Patients Presenting at Cork University Hospital

<table>
<thead>
<tr>
<th>Cause</th>
<th>Severity</th>
<th>Mild</th>
<th>%</th>
<th>Moderate</th>
<th>%</th>
<th>Severe</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fall&lt;2 metres</td>
<td></td>
<td>16</td>
<td>11.4</td>
<td>1</td>
<td>16.7</td>
<td>1</td>
<td>9.1</td>
<td>18</td>
<td>11.5</td>
</tr>
<tr>
<td>Fall&gt;2 metres</td>
<td></td>
<td>12</td>
<td>8.5</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>9.1</td>
<td>13</td>
<td>8.3</td>
</tr>
<tr>
<td>RTA</td>
<td></td>
<td>35</td>
<td>25</td>
<td>4</td>
<td>66.6</td>
<td>5</td>
<td>45.5</td>
<td>44</td>
<td>28</td>
</tr>
<tr>
<td>Assault</td>
<td></td>
<td>22</td>
<td>15.7</td>
<td>1</td>
<td>16.7</td>
<td>1</td>
<td>9.1</td>
<td>24</td>
<td>15.3</td>
</tr>
<tr>
<td>Sport</td>
<td></td>
<td>30</td>
<td>21.5</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>9.1</td>
<td>31</td>
<td>19.7</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>25</td>
<td>17.9</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>18.1</td>
<td>27</td>
<td>17.2</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>140</td>
<td>100</td>
<td>6</td>
<td>100</td>
<td>11</td>
<td>100</td>
<td>157</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 17: Severity of TBI (based on TARN criteria for assessment of severity) and Cause in Patients Presenting at Beaumont Hospital

<table>
<thead>
<tr>
<th>Cause</th>
<th>Severity</th>
<th>Not Severe</th>
<th>%</th>
<th>Moderate</th>
<th>%</th>
<th>Severe</th>
<th>%</th>
<th>Very Severe</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fall&lt;2 metres</td>
<td></td>
<td>4</td>
<td>30.7</td>
<td>13</td>
<td>31.7</td>
<td>17</td>
<td>33.4</td>
<td>5</td>
<td>17.3</td>
<td>39</td>
<td>29.1</td>
</tr>
<tr>
<td>Fall&gt;2 metres</td>
<td></td>
<td>2</td>
<td>15.4</td>
<td>3</td>
<td>7.3</td>
<td>8</td>
<td>15.6</td>
<td>8</td>
<td>27.5</td>
<td>21</td>
<td>15.7</td>
</tr>
<tr>
<td>RTA</td>
<td></td>
<td>6</td>
<td>46.2</td>
<td>12</td>
<td>29.3</td>
<td>8</td>
<td>15.6</td>
<td>11</td>
<td>37.9</td>
<td>37</td>
<td>27.6</td>
</tr>
<tr>
<td>Assault</td>
<td></td>
<td>1</td>
<td>7.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td>Sport</td>
<td></td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>26.8</td>
<td>12</td>
<td>23.6</td>
<td>2</td>
<td>6.9</td>
<td>25</td>
<td>18.7</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4.9</td>
<td>6</td>
<td>11.8</td>
<td>3</td>
<td>10.4</td>
<td>11</td>
<td>8.2</td>
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<tr>
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<td>41</td>
<td>100</td>
<td>51</td>
<td>100</td>
<td>29</td>
<td>100</td>
<td>134</td>
<td>100</td>
</tr>
</tbody>
</table>

### 4.6. Alcohol and Age, Sex and Cause of TBI

In almost half the cases of TBI (48.5%) admitted to Beaumont Hospital, alcohol was consumed by the injured person. At CUH, 27.8 percent of total cases were reported to have consumed alcohol. Beaumont Hospital data show that in those cases where alcohol was consumed, falls were the cause of injury in the largest number of cases (41), or just under two-thirds of those in this category (63%) – i.e. alcohol consumed. Similarly, in CUH 29% were injured as a result of a fall.

In Beaumont Hospital, severe injury was recorded in twenty-eight cases (42.4%) from a total of 66 cases where alcohol was consumed. The breakdown by gender in cases where alcohol was consumed is 55 males (84.6%) and 10 females (15.4%). This represents a ratio of male: female of 5.5:1. Data on those who had not consumed alcohol showed 54 (78.2%) males and 15 (21.7%) females, which represents a ratio of male: female of 3.6:1.

The combined data from BH and CUH show that age and gender are associated with the incidence of alcohol being consumed (applying to a greater extent with patients in younger
age groups, and with males). These relationships with alcohol are both strongly statistically significant (Gender and alcohol consumed: Pearson Chi-Square 668.933 (df 16) p = 0.000; Age and alcohol consumed: Pearson Chi-Square 26.507 (df9) p = 0.002) - see Tables 18 and 19.

In terms of severity of TBI and involvement of alcohol of patients presenting at CUH, a predominance of mild TBI cases reduces the possibility of significance. Pearson Chi-Square 4.365 (df2) p = 0.113 shows no association between severity and alcohol. Likewise, a Gamma of 0.366, p = 0.163 indicates no association - see Table 21a.

In patients presenting at Beaumont Hospital, severity of TBI and where alcohol was a factor, a Pearson Chi-Square 11.380 (df3) p= 0.010 shows there is a relationship here that is statistically significant. The association is confirmed by a gamma: -.428, p = 0.001, indicating a higher probability of severe injury if alcohol is consumed – see Table 22.

Table 18: Alcohol Consumed and Gender of Patients Presenting at Beaumont Hospital and Cork University Hospital

<table>
<thead>
<tr>
<th>Sex</th>
<th>Alcohol Consumed</th>
<th>Alcohol Consumed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BH %</td>
<td>CUH %</td>
<td>Total</td>
</tr>
<tr>
<td>Male</td>
<td>55</td>
<td>84.6</td>
<td>45</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>15.4</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100</td>
<td>58</td>
</tr>
</tbody>
</table>

Table 19: Alcohol Consumed and Age of Patients Presenting at Beaumont Hospital and Cork University Hospital

<table>
<thead>
<tr>
<th>Age</th>
<th>Alcohol Consumed</th>
<th>Alcohol Consumed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BH %</td>
<td>CUH %</td>
<td>Total</td>
</tr>
<tr>
<td>16-23</td>
<td>16</td>
<td>27.6</td>
<td>32</td>
</tr>
<tr>
<td>24-35</td>
<td>18</td>
<td>27.6</td>
<td>34</td>
</tr>
<tr>
<td>36-46</td>
<td>12</td>
<td>34.5</td>
<td>32</td>
</tr>
<tr>
<td>47-64</td>
<td>19</td>
<td>10.3</td>
<td>25</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100</td>
<td>123</td>
</tr>
</tbody>
</table>
Table 20: Alcohol Consumed and Cause of TBI in Patients Presenting at Beaumont Hospital and Cork University Hospital

<table>
<thead>
<tr>
<th>Cause</th>
<th>Alcohol Consumed</th>
<th>Alcohol Consumed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>BH</td>
<td>%</td>
</tr>
<tr>
<td>Fall &lt; 2m</td>
<td>28</td>
<td>8.5</td>
</tr>
<tr>
<td>Fall &gt; 2m</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>RTA</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Assault</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sport</td>
<td>9</td>
<td>2.7</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>1.5</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 21: Alcohol Consumed and Severity of TBI (based on GCS) in Patients Presenting at Cork University Hospital

<table>
<thead>
<tr>
<th>Alcohol Consumed</th>
<th>Severity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Yes</td>
<td>39</td>
<td>27.8</td>
</tr>
<tr>
<td>No</td>
<td>101</td>
<td>72.2</td>
</tr>
<tr>
<td>Total</td>
<td>140</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 21a: Alcohol Consumed and Severity of TBI (based on TARN assessment criteria) in Patients Presenting at Beaumont Hospital

<table>
<thead>
<tr>
<th>Alcohol Consumed</th>
<th>Severity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not Severe</td>
<td>Moderate</td>
</tr>
<tr>
<td>Yes</td>
<td>22</td>
<td>66.6</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>33.4</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>100</td>
</tr>
</tbody>
</table>
4.7. Previous History of Alcohol / Drug Abuse

The findings from Beaumont Hospital show that 20 percent of males (11 of a total of 55 cases) and 18 percent of females (two of 11 cases) had a previous history of alcohol abuse. In CUH over eleven percent of patients who presented there with TBI had a past history of alcohol or/and drug abuse. Of these, one person sustained a severe brain injury, while the remainder had mild traumatic brain injuries. In addition to TBI, 46 people (23.7%) sustained other injuries which ranged from mild abrasions to complex fractures requiring in-patient treatment.

4.8. Outcome following Injury

The Glasgow Outcome Scale (GOS) was recorded on the patients discharged from Beaumont Hospital and provides a means of assessing how well the survivor has recovered since admission. Similar information was not available elsewhere in any systematic way.

![Figure 1: Patients presenting at Beaumont Hospital by Outcome (Glasgow Outcome Scale)](image)

Of the total of 131 cases, seventy-nine (60.3%) made a good recovery; 36 (27.5%) had moderate disability; 12 cases (9.2%) were severely disabled and a small number (4 cases) or 3.1 percent were left in a permanent vegetative state following brain injury - See Figure 1.

The relationship between the severity of TBI and outcome is not significant (Pearson Chi-Square 6.207 (df 9) p = 0.719 and gamma -.005 p = 0.966). Some possible explanations
for this unexpected result are the low numbers in each category, or the possibility that the test for severity might be a poor indicator of outcome - see Table 23.

The impact of age and gender on outcome is not significant (Age: Pearson Chi-Square 12.341 (df) p = 0.195; Gender: Pearson Chi-Square 3.588 (df 3) p = 0.309).

Gamma value: -.071 p = 0.568 for age and gamma: -.235, p = 0.247 for gender also show no association between these variables - see Tables 24 and 25.

Table 22: Outcome (based on Glasgow Outcome Scale) and Severity of TBI in Patients Presenting at Beaumont Hospital

<table>
<thead>
<tr>
<th>Outcome based on Glasgow Outcome Scale</th>
<th>Severity</th>
<th>Not Severe</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permanent Vegetative State</td>
<td></td>
<td>0</td>
<td>2</td>
<td>5.2</td>
<td>1</td>
<td>3.6</td>
</tr>
<tr>
<td>Severe Disability</td>
<td></td>
<td>1</td>
<td>7.6</td>
<td>4</td>
<td>10.3</td>
<td>7.8</td>
</tr>
<tr>
<td>Moderate Disability</td>
<td></td>
<td>6</td>
<td>46.2</td>
<td>9</td>
<td>23</td>
<td>11</td>
</tr>
<tr>
<td>Good Recovery</td>
<td></td>
<td>6</td>
<td>46.2</td>
<td>24</td>
<td>61.5</td>
<td>35</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>13</td>
<td>100</td>
<td>39</td>
<td>100</td>
<td>51</td>
</tr>
</tbody>
</table>

Table 23: Outcome (based on Glasgow Outcome Scale) and Age of Patients Presenting at Beaumont Hospital

<table>
<thead>
<tr>
<th>Age</th>
<th>Permanent Vegetative State</th>
<th>Severe Disability</th>
<th>Moderate Disability</th>
<th>Good Recovery</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-23</td>
<td>3</td>
<td>75</td>
<td>41.6</td>
<td>9</td>
<td>25</td>
</tr>
<tr>
<td>24-35</td>
<td>0</td>
<td>1</td>
<td>8.4</td>
<td>9</td>
<td>25</td>
</tr>
<tr>
<td>36-46</td>
<td>0</td>
<td>4</td>
<td>33.3</td>
<td>6</td>
<td>16.6</td>
</tr>
<tr>
<td>47-64</td>
<td>1</td>
<td>25</td>
<td>16.7</td>
<td>12</td>
<td>33.4</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
<td>100</td>
<td>100</td>
<td>36</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 24: Outcome (based on Glasgow Outcome Scale) and Sex of Patients Presenting at Beaumont Hospital

<table>
<thead>
<tr>
<th>Outcome based on Glasgow Outcome Scale (GSO)</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permanent Vegetable State</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Male</td>
<td>50</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
<td>16.7</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>12</td>
<td>1110</td>
</tr>
<tr>
<td>Severe Disability</td>
<td>10</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>Moderate Disability</td>
<td>83.3</td>
<td>16.7</td>
<td>100</td>
</tr>
<tr>
<td>Good Recovery</td>
<td>28</td>
<td>8</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>77.8</td>
<td>22.2</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>12</td>
<td>79</td>
</tr>
<tr>
<td>Total</td>
<td>84.8</td>
<td>15.2</td>
<td>99</td>
</tr>
<tr>
<td>Total</td>
<td>107</td>
<td>24</td>
<td>131</td>
</tr>
<tr>
<td>Total</td>
<td>81.7</td>
<td>18.3</td>
<td>100</td>
</tr>
</tbody>
</table>

4.9. Transferring Hospital and Destination of Discharge

The Beaumont dataset included information on the hospital from which the patient was transferred if relevant (i.e. patient was not admitted to Beaumont Hospital on injury) and hospital destination of discharge. These data are presented here. A small number of patients were transferred to CUH from other hospitals in the Munster region and one was repatriated from London.

In almost all cases transferred to Beaumont Hospital, patients were sent back to the referring hospital within a short time to continue their treatment. For example, the largest numbers of transferees are from the large hospitals based in the greater Dublin area - St. James's Hospital (13 cases) and the Mater (13 cases). Eight cases were transferred from University College Hospital, Galway. This seems to reflect larger numbers coming from hospitals based in areas with larger populations. However, Mayo which is a largely rural area transferred nine cases to Beaumont Hospital.

Sixty-four percent of patients who were transferred to Beaumont from other hospitals either sustained a severe or a very severe brain injury. This is to be expected given the role of Beaumont Hospital as a National Neuroscience Centre.

After a period of treatment, patients were discharged to a number of destinations.

Twenty eight cases (20.9%) were transferred to other institutions. A further 45 cases (33.6%) were sent to other acute hospitals. As previously discussed, these cases were returned to their referring hospitals or were sent to specialist units, for example, orthopaedic units.

Five cases were discharged to the National Rehabilitation Hospital; one patient remained in hospital thirty days post admission; 43 cases (32.1%) were discharged home with a relative, 10 (7.5%) to their own home; while 2 cases (1.5%) needed full-time nursing home care. Of these, one was aged 20 to 23 years and the other 47 to 57 years- see Table 26.

102
Table 25: Discharge Destination of Patients Presenting at Beaumont Hospital:

<table>
<thead>
<tr>
<th>Discharge Destination</th>
<th>In-Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other Institution %</td>
<td>Other Acute Hospital %</td>
</tr>
<tr>
<td>28</td>
<td>20.9</td>
</tr>
</tbody>
</table>

Total: 134

4.10. Pre-Existing Conditions

The Beaumont Hospital dataset also provides information on whether or not the patients admitted with TBI had pre-existing conditions. The majority 62.4 percent (83 cases or approximately two-thirds) did not report any pre-existing medical conditions. Table 27 shows the number of cases with pre-existing primary medical conditions. Alcohol abuse was the most common pre-existing condition and accounted for 12 cases (8.9%).

Table 26: Pre-existing Conditions in Patients Presenting at Beaumont Hospital

<table>
<thead>
<tr>
<th>Pre-Existing Conditions</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug Addiction</td>
<td>2</td>
</tr>
<tr>
<td>Depression</td>
<td>5</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>12</td>
</tr>
<tr>
<td>Alcohol</td>
<td>1</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>26</td>
</tr>
<tr>
<td>None</td>
<td>83</td>
</tr>
<tr>
<td>Not Stated</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>134</td>
</tr>
</tbody>
</table>

4.11. Surgical Procedures -BH

Surgical intervention was required in 104 patients. Craniotomy (see Appendix A) was the most common procedure undertaken, accounting for 66 cases (63.4%). Of these 36 (54.5%) had a severe or very severe traumatic brain injury. Other surgical procedures included burrhole of cranium, evacuation of a wound and elevation of tension band. Over half (55.7%) of those who required surgical intervention had either a severe or very severe traumatic brain injury.
4.11.1. Diagnosis

A diagnosis relative to the patient’s injury is presented in Appendix H. The seriousness of injury is apparent from the list and type of injury the patients presented with at Beaumont Hospital. Cerebrum haematoma was the most frequent diagnosis - (62 people), accounting for 46.3 percent.

4.12. Conclusion

In conclusion, this chapter presents two datasets of activity from the only two neurosurgical centres in Ireland. This provides a background on TBI in relation to the demographics of the people injured, the causes of TBI and the outcome following this event. This quantitative data, though clinical in nature, offers a valuable insight into TBI and is essential to the study as a means of placing in context the entire issue of TBI.

Systematic data collection on TBI is all but absent in Ireland. Likewise, according to Phillips (2009) there are only a limited number of national TBI studies available within Europe.

It is evident from the results presented here from both hospital datasets, that males are more likely to sustain brain injury than females. Furthermore in terms of the age, there is a higher incidence of TBI in younger age groups (16 to 23 years).

The data from Beaumont Hospital and CUH shows an association between the severity of TBI and age which is statistically significant. RTA and sport are the most likely cause of TBI in the younger age groups. The Beaumont Hospital data show that severe or very severe injury was recorded in 17.9% of the 16–23 age group, followed by 11.9% in the age group 24–35 years. The CUH data show a total of seven percent sustained a severe injury, of which fewer than two percent were in the younger age group.

Occupation, recorded on patient notes at CUH, showed that approximately one-quarter of patients (50) were categorised as students or school pupils, reflecting again the young age profile of patients; thirteen people were unemployed at the time of injury; and two from particularly vulnerable social groups. Occupations varied widely with the highest incidence in the manual skilled category (36% of 87 cases who reported that they were currently in employment). Notably, Beaumont Hospital data showed that the combined total of falls less than 2 metres and more than 2 metres were responsible for the majority of all brain injury cases (54.8%). The results were different in CUH: road traffic accidents (RTA) accounted for the largest number of injuries (29%).

Beaumont Hospital data shows almost 60% of those admitted with traumatic brain injury were in the very severe / severe category. This shows a much higher rate of severe and
very severe TBI than the CUH sample (7% of total had a severe brain injury there). The reason for this marked difference is that Beaumont Hospital is a national neuroscience centre in Ireland and tends to get transfers of the more serious TBIs from other hospitals throughout the country. These people are usually returned to their referring hospitals or are sent to specialist units within a short time. There is no possibility of double counting between BH and CUH because no transfers were recorded between these hospitals during the time periods.

Falls and RTAs were the main causes of severe brain injury. Assault accounted for fourteen cases of severe injury. Tests on severity of TBI and cause of injury show that variations here are statistically significant.

Significantly, alcohol was involved in almost one-quarter of cases at CUH, and was a feature in almost half the cases of brain injury admitted to Beaumont Hospital. BH data show: of those who had consumed alcohol, 35.1% sustained an either a severe or a very severe injury, compared with 24.7% who had not consumed alcohol. CUH data show severe injury was recorded in 2.4% of those who had consumed alcohol, compared with 4.4% with the same degree of severity who had not consumed alcohol. The association between the cause of TBI and alcohol consumed in patients presenting at Beaumont Hospital and CUH is statistically significant. The CUH data is consistent with Phillips' (2009) findings that alcohol use was reported in one - in four cases of Traumatic Brain Injury (TBI) in Ireland. In conclusion, the combined data from BH and CUH show those drinkers, particularly young male drinkers are more likely than non-drinkers to sustain a TBI.

No pre-existing conditions were recorded in over 62.4% of the patients admitted to Beaumont Hospital. Again, this is not surprising given the young age of most of those suffering TBI. Surgical intervention was required in the majority of patients admitted to Beaumont Hospital, once more indicating the severity of their injuries.

In summary, the ‘typical’ patient presenting at Beaumont Hospital with TBI is male and aged between 16 and 23 years at the time of injury. The injury is likely to be severe or very severe and the probable cause is a fall or a road related accident. Alcohol was involved in half the patients presenting here. The Glasgow Outcome Scale (GOS), a method of assessing the patient’s level of recovery following TBI, indicated that a small proportion of cases (four patients) remain in a permanent vegetative state following TBI, and a relatively small proportion (twelve people) are severely disabled as a result of the injury. Patients were transferred to various settings, such as their own home, other institutions or The National Rehabilitation Hospital. The seriousness of injury is evident from the data on surgical procedures necessary and the diagnosis.
In summary, from the CUH data it can be concluded that the ‘typical’ patient is male, aged between the age of 16 and 23 years, a student or working in a manual skilled occupation. The most common cause of injury was road traffic accident, followed by injuries caused by sport. Over 89% presented at CUH with mild TBI, and almost 6% had a severe TBI. Alcohol was involved in one in four cases of TBI. Over eleven percent had a past history of alcohol and/or drug abuse. Of these four (8.3%) people had a severe brain injury.

The next chapters present the findings of the qualitative research with the data collection and analysis focused on the survivor’s experience of TBI (Chapter 5) and experiences of family members of survivors (Chapter 6).
Chapter 5
The Voice of Survivors of Traumatic Brain Injury

5.1. Introduction

The main aim of the study is to build a greater understanding of the experiences of TBI adult survivors from a social perspective. A qualitative approach which involved in-depth interviews with survivors provided an understanding of the key changes experienced by TBI survivors. Qualitative research methods are especially suited to revealing meanings people give to their experiences (Hosmand, 1989; Polkinghorne, 1994). Thematic analysis of the data from interviews conducted with survivors enable the presentation of findings in this chapter, and promote an understanding of the process of recovery following a Traumatic Brain Injury (TBI). Recovery is defined as a ‘process of gradual reconnection with life’ (Kartalova-O’Doherty and Tedstone Doherty, 2010:10).

The chapter begins with a brief description of the participants, with reference to the main categories used in the hospital datasets. In terms of the qualitative findings, the core category of ‘recovery’ was identified from the detailed analysis of interview data with survivors. The categories from which this core category emerged are:

i) changed roles following TBI;
ii) societal barriers to active participation following TBI;
iii) environmental factors influencing recovery and
iv) the survivor’s path to recovery.

A number of sub-categories were identified in each category. These were generated from the concepts identified (based on words actually used by survivors) in the interview process (transcripts).

5.1.1. Survivor Profiles

The sample of survivor participants who successfully completed qualitative interviews consisted of fourteen males and two females. Conforming to age criteria for the study, the participants were aged between 16 and 64 years at the time of injury. All are Irish, apart
from one male, who is originally from Africa, but has been living in Ireland for eight years prior to the injury. The participants had all sustained either a moderate or severe traumatic brain injury; the oldest participant was aged 53 years and the youngest were two males aged seventeen at the time of injury. The cause of injury ranged from assaults (two), falls (three), a horse accident (one) and road traffic accidents (ten). A table with full details is presented in Table 27. This includes details which relate to age, gender, cause of injury, severity of TBI - Glasgow Coma Scale

(Appendix A) on initial admission to hospital, Glasgow Outcome Scale (see Appendix C) on discharge, time since injury in years, long-term and short-term memory and educational level prior to injury.

Table 27: Outline of survivor participants who gave qualitative interviews

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Glasgow Time since injury (years)</th>
<th>Level of Education</th>
<th>Cause</th>
<th>Memory (self-reported)</th>
<th>Glasgow Outcome</th>
<th>Regional Location In Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td>51</td>
<td>Male</td>
<td>3</td>
<td>2</td>
<td>Degree</td>
<td>RTA</td>
<td>ST very poor</td>
<td>South</td>
</tr>
<tr>
<td>43</td>
<td>Male</td>
<td>3</td>
<td>1.6</td>
<td>Junior Cert</td>
<td>Quad Bike</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
<td>Male</td>
<td>3</td>
<td>1.2</td>
<td>Junior Cert</td>
<td>Pedestrian</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>Male</td>
<td>6</td>
<td>1</td>
<td>Leaving Cert</td>
<td>Assault</td>
<td>No change</td>
<td>5</td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>3</td>
<td>1.4</td>
<td>No qualifications</td>
<td>RTA</td>
<td>ST fair</td>
<td>3</td>
</tr>
<tr>
<td>49</td>
<td>Male</td>
<td>7</td>
<td>1.8</td>
<td>Junior Cert</td>
<td>Motorbike</td>
<td>No change</td>
<td>5</td>
</tr>
<tr>
<td>30</td>
<td>Male</td>
<td>3</td>
<td>2</td>
<td>Degree</td>
<td>Fall &lt; 2 metres</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>32</td>
<td>Male</td>
<td>6</td>
<td>1.4</td>
<td>None</td>
<td>RTA</td>
<td>No change</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>3</td>
<td>1.2</td>
<td>Junior Cert</td>
<td>RTA</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>47</td>
<td>Male</td>
<td>3</td>
<td>1.8</td>
<td>Junior Cert</td>
<td>Occupational Fall &gt;2 metres</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>27</td>
<td>Female</td>
<td>No Record</td>
<td>2.2</td>
<td>Leaving Cert</td>
<td>RTA</td>
<td>LT fair</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>Female</td>
<td>No Record</td>
<td>2.4</td>
<td>Leaving Cert</td>
<td>Pedestrian</td>
<td>ST good</td>
<td>3</td>
</tr>
<tr>
<td>40</td>
<td>Male</td>
<td>3</td>
<td>2.5</td>
<td>Junior Cert</td>
<td>Horse accident</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>Male</td>
<td>3</td>
<td>2.3</td>
<td>Leaving Cert</td>
<td>Fall &gt; 2 metres</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>26</td>
<td>Male</td>
<td>3</td>
<td>1.3</td>
<td>Leaving Cert</td>
<td>Assault</td>
<td>ST poor</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>Male</td>
<td>No Record</td>
<td>32</td>
<td>None</td>
<td>RTA</td>
<td>ST poor</td>
<td>3</td>
</tr>
</tbody>
</table>
5.1.2. Findings and Theory

Recovery from a moderate or severe TBI is an on-going process for the survivor. A number of categories were identified, which formed a model to describe the process of recovery for survivors (the core category). Recovery was mainly influenced by the level of adjustment required and societal and cultural influences regarding brain injury. The sub-category of finding a path to recovery is also presented and discussed. This gives hope for the future, realising ambition, 'taking control' and discovering the importance of advocacy.

The categories and sub-categories identified are illustrated in Figure 2: Theoretical model for surviving a moderate or severe traumatic brain injury.

Figure 2: Theoretical model for surviving a moderate or severe traumatic brain injury

The process of recovery is influenced by factors, such as the available supports and services and the attitude of healthcare professionals. The three main categories above - changed role requiring adjustment, societal barriers to active participation and environmental factors, share certain characteristics.
5.2. Changed roles following TBI requiring adjustment

Under this main category, the sub-categories identified and discussed in this section are as follows:

- Changed role
- Uncertainty
- Friendships
- Isolation and Loneliness
- Dependence/Independence issues.

Survivor experience is largely influenced by the severity of the injury, the visibility of injury and whether it is accompanied by a physical impairment. Of the 16 participants, only three were without one or more physical disability. Physical disabilities range from mobility problems, problems with hearing, smell, sight, speech and taste issues, lack of coordination, and paralysis of one or both upper arms. Fourteen of sixteen survivors had some cognitive disability, such as memory and concentration issues. Three participants reported being depressed since the injury. In summary, all but two of the participants had impairments as a result of their injury, and only one person said they had made a complete recovery.

**Changed Roles Requiring Adjustment**

Brain injury is an unexpected, abrupt event which requires considerable adjustment. The position held by survivors before the injury, whether attending school or college, playing sports, working at occupations they enjoyed or being a parent, were suddenly interrupted and in some cases ended forever. The following statements illustrate some of these changes:

'\text{A huge change. I can't drive, I can't play football, I can't go to college. I mean they were my three big things'. (Gary)'}

'It is totally different. I had a job, I had a girlfriend ... now none' (Rob).

'I'm hyper, I will say I wouldn't say I get depressed but I can't sleep. Say, right, going to bed now last night at twelve o'clock I was awake at half five again this morning, and that was a good night'. (Jack)

'It's very different now. 'Cos see I was at school, now I can't go. But I am getting classes in the rehab. I'm not allowed to drive, I can't play sport'. (Hugh)
‘I had been living in the Caymen Islands and I did not want to come back to (Name of City) or (Name of Town) so I struggled not to go back here. But it just came to a point where I just had to come back home’ (Sarah).

‘See, I suppose since the accident there is very little I can do. I can’t even go out into the street ... I’d fall. And that’s ... for me that’s sad, because I still haven’t got my balance properly’ (Dan)

‘I can’t go back to a full time job, which was a plasterer, you know. I mean if I get another knock to the head, well that’s it like, I won’t get another chance, I am restricted that way as well, I was a sporty man but I am restricted with sport, I can’t play’. (Rob)

‘Since the accident a year ago, well there’s nothing really to do for me ... so ... I plan to go back to school ... I know I’ve missed out on a lot at school. I sit around all day. I don’t want to have to sit around all day doing nothing all day’ (Sam).

I’ll never get eyesight or hearing in my left, I have only ten percent eyesight in my right and sixty percent hearing and there is nothing that can be done for it, no operation or anything, no technology there to improve that. Basically because of my eyeball; my eyeball is perfect but at the back of the eye most of the optic nerves are damaged and severed and there is nothing can, there is no technology, no operation that can repair those ... Ah ... my central nervous system is still not working.

(Dan).

Interviewer: What is your experience of having a head injury’?

Jack: Well to tell you the honest to God’s truth I don’t know because I can’t remember. Well I’ll just come to the main points I can’t make up my mind, I honestly can’t, Well like even if (Name of Wife) even asked me what do you want for breakfast, I couldn’t tell her ... whatever she puts up in front of me I’d say that will do me, cos I’m very bad like that do you know. I can’t grieve anymore, I honestly can’t, cos my best friend died two weeks ago, 'tis two weeks today and I can’t grieve, you know. I’m ‘cranky’ alright I will admit that I’m ‘cranky’ and very bitter and I put that down to the accident (Jack).
Themes discussed in this section are further illustrated in Table 28 below. Based on the words used by survivors, the repetition of the negative (‘can’t’, ‘won’t’, ‘don’t want’, ‘not allowed’, ‘wasn’t’, ‘nothing’) and the intonation in interviews, the impact of the changes and adjustments necessary are negative and difficult for survivors. This impression runs throughout the interviews.

Table 28: Changed roles following TBI

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>A ‘huge’ change</td>
<td>‘A huge change. I can’t drive, I can’t play football, I can’t go to college’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Different</td>
<td>‘I’m hyper, I will say I wouldn’t say I get depressed but I can’t sleep’.</td>
<td>Jack</td>
</tr>
<tr>
<td>Not allowed</td>
<td>‘It’s very different now. ‘Cos see I was at school, now I can’t go. I’m not allowed to drive, I can’t play sport’.</td>
<td>Hugh</td>
</tr>
<tr>
<td>Did not want to</td>
<td>I did not want to come back to (Name of City) or (Name of Town) so I struggled not to go back here’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Can’t do</td>
<td>‘See, I suppose since the accident there is very little I can do. I can’t even go out into the street … I’d fall’.</td>
<td>Dan</td>
</tr>
<tr>
<td>Can’t do</td>
<td>‘I can’t go back to a full time job’</td>
<td>Rob</td>
</tr>
<tr>
<td>Can’t do</td>
<td>‘I won’t get another chance, I am restricted that way as well, I was a sporty man but I am restricted with sport, I can’t play’.</td>
<td>Rob</td>
</tr>
<tr>
<td>Sad</td>
<td>And that’s … for me that’s sad, because I still haven’t got my balance properly …’</td>
<td>Dan</td>
</tr>
<tr>
<td>Nothing to do</td>
<td>‘Since the accident a year ago, well there’s nothing really to do for me … so … I plan to go back to school … I know I’ve missed out on a lot at school. I sit around all day. I don’t want to have to sit around all day doing nothing all day’.</td>
<td>Sam</td>
</tr>
<tr>
<td>Nothing can be done to help</td>
<td>‘… there is nothing that can be done for it, no operation or anything, no technology there to improve that’.</td>
<td>Dan</td>
</tr>
<tr>
<td>Can’t remember</td>
<td>‘Well to tell you the honest to God’s truth I don’t know because I can’t remember’</td>
<td>Jack</td>
</tr>
<tr>
<td>Indecisive</td>
<td>‘I can’t make up my mind, I honestly can’t’</td>
<td>Jack</td>
</tr>
<tr>
<td>Mood swings</td>
<td>‘I’m ‘cranky’ alright I will admit that, I’m ‘cranky’ and very bitter and I put that down to the accident’.</td>
<td>Jack</td>
</tr>
<tr>
<td>Lack of empathy</td>
<td>‘I can’t grieve anymore’</td>
<td>Jack</td>
</tr>
</tbody>
</table>

**Friendships**

The sense of being left behind when others have moved on was evident in conversations with survivors. Some participants made excuses: ‘people have their own lives now’; ‘they have all gone to college’; ‘they have moved away’. This is in some sense understandable given the age profile of the survivors. Young people are at a crossroads in their lives eager...
to establish themselves in work and relationships, which may take them to a new location far from home, hence the disconnect with their old communities.

Gary expresses his feelings about the loyalty of his friends following his injury:

Gary: It’s like this, when you get a brain injury you will know who your true friends are. I know who they are now.

Interviewer: Did some fall away?

Gary: Ex-girlfriends, all the girls went. ‘Cos once you are playing football, driving around and the next thing you cannot even say hello.

Interviewer: Your male friends?

Gary: They’re all great

Friends have moved on like, most of my friends are married now and some of them have children so they have their own lives but I do have one or two good friends. When this happened me I was going out with a fella, I was 18 and I had just met him in August, that happened me the following April and I was going out with him until I was 20 but I was with him through it all but I suppose there is only so much like that ... I was a different person and I wasn’t aware of that at the time, you see that’s part of the problem and I couldn’t accept that.

(Ann)

I have to say young women they are the biggest challenge, it’s gas I was going with this girl, my father is dead fifteen years right and there was this girl I started going with her then, but she ‘dossed’ school and came down with me then the day my Dad was buried, and so I thought the world of her. So after my accident I was above in Dun Laoghaire I was to be going back to the west ... but we just started seeing each other again and we were happy out but for whatever reason she lost her job in (Name of Town) ‘cos she works in an auctioneers. So since she had no job she went to Spain ‘cos her sister lives there with her niece. And ever since she went to Spain she told me to F... off.

(Gary).

Many formed new friendships and as they reconstructed different identities and embraced their changed circumstances.

I have made loads of new friends, both inside and outside the organisation (an NGO) and I have discovered some older friends who have come back. People
surprise you the whole time, how good and how bad they can be so am ... it’s been, well I would say it’s been a positive experience.
(Sarah).

One young man (Richard) remains close to his friends who, he related had abandoned him on the night of the RTA that caused his brain injury. He was found hours later by ‘the tow truck man’ who had been sent to clear away the car. There is no evidence of bitterness towards the two; instead he believed he is ‘lucky to be alive’.

Richard: They legged it on me, they left me in it. They got put out of the house a couple of weeks later like ... They admitted to it like. Well me myself even if I had no ‘phone like I would have gone in to someone and tell their Da

Interviewer: Did they leave you there for dead?
Richard: Oh yeah.
(Richard)

‘I don’t like company now ... too many people now, like around me it annoys me, you know, if it’s a one to one I’m ok, but I don’t know, it’s my head, I don’t know’
(Ned).

‘Now all my friends are gone now, gone to college and to work in the buildings ...’
(Sam).

Gary’s memory problems sometimes present problems in his relationships with young women. His experiences in personal relationships have left him concluding that ‘women are only a waste of time’.

I know that I’ve been to (University A) and I haven’t forgotten that I was in (University B) ah it’s gas ... it’s all about young women again. I remembered kissing some girl and it all came back to me then. See I kept a journal so it’s a bit embarrassing ’cos some women I don’t like. Yeah, and it’s funny the journal I wrote years ago was from secondary school and I went to College, and the women that were horrible back then they are the same now, still horrible. So I should have learned my lesson and I wrote one thing in one diary and I said, I should learn to live by myself ’cos women are only a waste of time, all they do is hurt me
(Gary).

My ex best friend came in to see me and apologised for not seeing me before and I said I wasn’t even thinking about you. That was weird and ... we hadn’t even seen each other since school which would have been 9 or 10 years ago. Yeah that was weird, a lot of my friends are getting married and stuff which
is nice, not my cup of tea but it's great for them (Sarah).

Four participants commented on how kind their friends were. One man said his friend had run his furniture manufacturing business, even financing it, while he was in a six week coma. In another case of a builder by occupation, friends had come together to organise the construction of the apartment in which he now lives. A participant is taken to the pub twice a week by his friends even though he has lost the ability to speak.

However, many other survivors spoke about those friends who drifted away.

'A lot of friends and that have distanced themselves from me. That's what I have found ... and they have more or less said sure I can't do anything, I am totally dependent ... they can't be looking after me' (Dan).

These findings illustrate the considerable adjustment necessary for many survivors. The important aspects of a young man's life, such as playing football, driving cars, having a girlfriend and socialising with friends, are suddenly and severely hampered, or ended. While some survivors spoke of forming new relationships and developing new interests, the sense of being left behind when others have moved on compounds their sense of loss.

Similarly, Heller et al. (2006) and Morris et al. (2005) point out that brain injury is a sudden and negative change associated with an acute sense of loss. Hill (2004) suggests that TBI forces the survivor to create a new sense of identity that includes impairment and disability. While traditional disability theorists, such as Oliver (1996) suggest that disablement is only the consequence of social oppression, Barnes and Mercer (2003) attempted to draw attention to the significance of impairment in terms of its implications and the meaning attached to its consequences. Activities of daily living may need adjustment, as well as other practical matters related to the altered body (Bury, 2005). The significance of a disorder relates to how visible it is, which part of the body is affected, and how these issues are located within a particular culture (Bury, 2005:75).

See Table 29 for a summary of the themes discussed in this section.
Table 29: Friendships

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>True Friends, Know true friends</td>
<td>‘when you get a brain injury you will know who your true friends are. I know who they are now’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Girlfriends</td>
<td>‘all the girls went. ‘Cos once you are playing football, driving around and the next thing you cannot even say hello’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Women (girlfriends) and hurt</td>
<td>‘cos women are only a waste of time, all they do is hurt me’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Girlfriends the biggest challenge</td>
<td>‘I have to say young women they are the biggest challenge’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Male friends</td>
<td>‘They’re all great’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Friends moved on</td>
<td>‘Friends have moved on ... they have their own lives’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Friends moved on</td>
<td>‘a lot of my friends are getting married and stuff which is nice, not my cup of tea but it’s great for them’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Friends moved on</td>
<td>‘Now all my friends are gone now, gone to college and to work in the buildings’.</td>
<td>Sam</td>
</tr>
<tr>
<td>Friends came back</td>
<td>‘My ex best friend came in to see me and apologised for not seeing me before’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Protecting self from hurt</td>
<td>‘and I said I wasn’t even thinking about you’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Lack of awareness/ Couldn’t accept</td>
<td>‘I was a different person and I wasn’t aware of that at the time, you see that’s part of the problem and I couldn’t accept that’.</td>
<td>Ann</td>
</tr>
<tr>
<td>New friends</td>
<td>‘I have made loads of new friends’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Good Support / lack of support</td>
<td>‘People surprise you the whole time, how good and how bad they can be’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Company social gatherings)</td>
<td>‘I don’t like company now too many people now, like around me it annoys me’.</td>
<td>Ned</td>
</tr>
<tr>
<td>annoying</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends distanced themselves</td>
<td>‘A lot of friends and that have distanced themselves from me’.</td>
<td>Dan</td>
</tr>
</tbody>
</table>

Uncertainty

Brain injury recovery is filled with uncertainty. The following is a survivor’s account of his own experience as he explains how difficult it is to predict the long-term outcome of a brain injury:

Well, the doctors over in London said I wouldn’t recover from my brain injury and if I recovered ... if I survived the coma, they gave me a 30 per cent chance of living and after that if I did live I would be in a wheelchair for the rest of my life. So that didn’t give me much hope. See brain injury for everybody is different, everybody’s brain injury is different.

(Gary).
Some of the participants in this study sought reassurance from the researcher, which reveals the lack of information available to them about their prognosis. The feeling of not having a prognosis following brain injury was again articulated by Hugh:

‘Even the best brain doctors can’t tell what’s going to happen to you when you suffer brain injury, so there is a big huge black hole’.

(Hugh).

According to Judd and Wilson (2005), because TBI is sudden and can cause so much damage, survivors find it difficult to face their often newfound restrictions and limitations. The uncertainty which follows from brain injury or any chronic illness results in a considerable change to that person’s life. This is frequently in relation to predicting long-term outcome (Locker, 2008) and can be frightening and worrisome.

A summary of this section is provided in Table 30.

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of hope</td>
<td>‘So that didn’t give me much hope’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Uniqueness of brain injury</td>
<td>‘See brain injury for everybody, everybody’s brain injury is different’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Cannot predict outcome</td>
<td>‘Even the best brain doctors can’t tell what’s going to happen to you when you suffer brain injury, so there is a big huge black hole’.</td>
<td>Hugh</td>
</tr>
</tbody>
</table>

**Isolation and Loneliness**

Themes of isolation and loneliness were evident in conversations with many survivors. A combination of reduced physical ability, unemployment and the distancing from their usual social circle were the main causes of this increased sense of isolation which marks out their present existence.

Richard describes how his friends react if he talks about his head injury:

‘See all my friends just laugh about something like that, yeah … if I said oh my head hurts like, they would laugh at that. They wouldn’t pay any attention or anything to it’

(Richard).

Physical impairments add to Dan’s problems and prevent him from participating in the taken-for-granted activities of daily living, like reading the paper and watching television. He explains his predicament here:
What I find is that because of my disability, I cannot read a newspaper, I cannot see the television screen, there's people on that that are a blur. Your face, you're sitting a couple of feet away from me there now, I cannot see your face because of the 10 per cent eye sight I have in this eye. I have none in this' (pointing to other eye) (Dan).

Another participant who has aphasia was frustrated at not being able to communicate with his children. He described the loneliness and frustration of being left behind while the children went to school and his wife to work:

John: ‘Idle. Home, oh yeah. Jesus Christ. Good Bye, see ya, good bye’
Tara (wife acting as a proxy): ‘See I work three mornings a week and the kids are gone to school so he is here on his own’
John: ‘Oh yeah. On own, on own … fed up, fed up’ (John).

A range of emotions were reported by participants. Dan lives alone and has little contact with friends or family. His remarks have resonance in the context of on-going supports:

I get depressed an awful lot because I just feel I cannot do anything, I cannot work, I cannot … This apartment that I have here, I cannot brush the floor 'cos I will fall. Even if I went in and tried to make the bed, which I have tried several, on several occasions in the last three years, I will fall.
(Dan).

‘Sometimes it’s depressing but no more than before the accident (depression) but maybe it’s just not talking to people and I keep things bottled up inside a lot’ (Rob).

But I am very disappointed with the … Health Board, because there’s times I need a psychologist at times, because I get very depressed here and … I’ve nobody to talk to or to bounce things off and because of my brain operation by Mr. … in … Hospital said I wasn’t to do any exercise either.
(Dan).

Findings in this section show that the loss of friends, jobs and previous routine had the effect of plunging survivors into isolation, loneliness and depression. See Table 31 for a summary of themes. As previous researchers (Morton and Wehman, 1995; Levin et al. 1996) have noted, depression is often a feature of TBI. Survivors talked of loss of physical capacity and changes in their social and friendship networks. These data fit with Herzlich’s
(1973) depiction of illness as a destroyer and Frank’s (1995) chaos narrative, which is a story of illness, without order or structure.

Table 31: Isolation and Loneliness

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolated/ ignored</td>
<td>‘They wouldn’t pay any attention.’</td>
<td>Richard</td>
</tr>
<tr>
<td>Friends laugh at his complaints</td>
<td>‘I cannot read a newspaper, I cannot see the television screen ... I cannot see your face’.</td>
<td>Dan</td>
</tr>
<tr>
<td>Everyday things difficult to do</td>
<td>‘Idle’.</td>
<td>John</td>
</tr>
<tr>
<td>No activities, no structure</td>
<td>‘I get depressed an awful lot because I just feel I cannot do anything, I cannot work’.</td>
<td>Dan</td>
</tr>
<tr>
<td>Depressed / cannot do things</td>
<td>‘Sometimes it’s depressing but no more than before the accident (depression) but maybe it’s just not talking to people and I keep things bottled up inside a lot’.</td>
<td>Rob</td>
</tr>
<tr>
<td>Depressed / not expressing feelings</td>
<td>‘there’s times I need a psychologist at times, because I get very depressed here and ... I’ve nobody to talk to or to bounce things off’.</td>
<td></td>
</tr>
</tbody>
</table>

5.3. Dependence/Independence Issues

The loss of independence is a subject mentioned by ten of the fifteen participants. Their examples illustrate the adaptations they were forced to make on a daily basis. References were made to not being allowed to drive which increased the survivor’s dependence on others. The young men in the study were particularly frustrated by this. Dan’s first words to the interviewer summed up how much his life has changed:

“Well, I have gone from a totally independent person to being totally dependent”

(Dan).

A female in this study worried about what would happen to her after her parents died. Her concerns were partly in relation to her access to resources:

‘I have no money, I am just managing on my little allowance, I am very good at managing money and I am living at home with Mam and Dad. I think at times Mam and Dad aren’t going to be alive for ever and ever you know’.

(Sarah).

Another who has aphasia depended mostly on his wife to communicate for him.
Interviewer: ‘Has your life changed much since the injury’
John: ‘Ah yeah it has’
Interviewer: ‘In what way?’
John: ‘In what way? I can’t talk’
(John).

Ned, a single male in his late 40’s was ‘fiercely’ independent before the injury, but the effect of the injury is a loss of independence which is articulated as a great loss:

‘I think of what I was before like you know, with the walking, I wasn’t depending on people so much. My independence is a fierce loss, independence’
(Ned).

A dependence on public transport was new to most of the participants, as verified by the stories from survivors. Their changed status and a reliance on others for lifts or dependence on public transport, for many were causes of major anxiety.

‘My independence is gone Kay. I can’t drive, when you can’t drive your independence is gone. I miss the driving. I have double vision like. Who should I go to see about driving?’
(Ned).

Rural Ireland is generally poorly served by public transport, as survivors find out first hand. Some of the narratives describe in great detail what is entailed in getting from home to hospital appointments, to and from meetings organised by the NGOs or to a course they attend. Jack gave the example of not being able to use the local train station 20 kilometres away because there is no transport to it from his town. Instead he needs to get a bus to the city and another bus to the town, a round trip of 60 kilometres, just to get to the local train station.

When I need to get the train I have to go to (Name of City). You can’t get back to (Name of Town) from here and that is a disgrace. There’s a lot of people going to hospital in (Name of Town) and you have to go to (Name of City) to get there. It is a joke like, or else you go to (Another City). It’s a joke, disgraceful.
(Jack)

Gary also has problems with mobility:

My biggest problem is walking, and I have that sorted now. My next biggest challenge is the driving, but like once I wait so long I know I must be the most patient man in Ireland ‘cos it’s gas, I met there is a guy back in (Name
of Village), he’s a goalkeeper for (Name of Village) and he got a brain hemorrhage and he told me it took him five years to recover. before he got back on the pitch, that means next year I should be back in my boots so I warned (Well-known footballer) don’t you dare retire ’cos I want to go back and hit him, he didn’t believe me of course.

(Gary)

You know we live in the back of ‘beyonds’ here ... yeah.

My mother can’t drive. There is one bus a week to town out here once a week.

I thumb. I have loads of friends going to town every day that bring me in and it’s gas whenever I have a lift home, I get home earlier when I thumb ... And like the people come here to do home help they won’t allow them to take me out in their cars, so that’s a big problem.

(Gary)

The overriding wish of most survivors is to drive again. Tuition was available at the National Rehabilitation Hospital (NRH) but many participants complained that they were not well enough at that time to avail of this. The Irish Wheelchair Association, as well as some private organisations, offer driving lessons. Gary described his disappointment at being told by a staff member of an NGO that he might never be able to drive again, and his refusal to accept this assessment:

He said to me you must realise that a lot of people with brain injuries don’t ever get to drive again and you won’t play football competitively. But I know that people with brain injuries do drive, there is a man up the road from here who had a stroke and he is driving

(Gary).

The reaction and interaction with staff on trains and buses was graphically described. Some experiences were excellent, while other survivors were puzzled by the attitude of staff to them:

I have found the ... bus drivers very good, the coach drivers very helpful.

... and I have found (train) staff in all ... in (Local Station) and in (Main Dublin station) station excellent, and very helpful. And ah, especially in (Main Dublin station) station, I wouldn’t be able to get around an awful lot, do an awful lot of things if ... only for the staff being so helpful. I find the shop assistants in the supermarket here very helpful. And as I have said the
personnel in (train) and in (bus) fantastic.
(Dan)

However, Jack’s experience was different to Dan’s. He recalled the first time he used ‘the pass’ which entitled him to free travel:

The girl selling the ticket ... I asked for the ticket at (Main Dublin station) station and then I put up the pass and she hopped off me ‘why didn’t you tell me about that first, she said’. It’s my first time using it I said. She didn’t even look at the signature, she just threw it back at me, she said in future tell me about that first. I was ashamed of my life ... I felt because she was so rude that I wasn’t entitled like.
(Jack)

Changes to material resources and access to money were of concern for a number of survivors. Dan was a self-employed businessman before the accident. He explains how careful he has to be with his allowance:

I haven’t used it (Internet on the computer) an awful lot ‘cos I cannot afford to have a line for the computer, because the amount of money I get from the disability pension I’m getting the blind persons pension. The cost of this apartment plus my ESB (electricity) bill at times is up to nearly €200 and the apartment is costing me €800 euros a. month, and my disability pension plus my blind person’s subvention isn’t enough. By the time I have the apartment, the electricity paid for, food and all that, I don’t have that much for myself. And I just can’t afford to go and have broadband or any of that.
(Dan)

Hugh articulates some of the additional pressures on him and his mother due to his dependence on a welfare pension. This statement also demonstrates the anxiety associated with dependence on welfare.

‘I got a letter there a few weeks ago saying that my allowances is up for renewal so I have to get my GP and my social worker to sign it. My mother is worried that it will be stopped and sure look I don’t have a job’
(Hugh).
Table 32: Independence to Dependence

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence to dependence</td>
<td>‘Well, I have gone from a totally independent person to being totally dependent’</td>
<td>Dan</td>
</tr>
<tr>
<td>Lack of access to resources</td>
<td>‘I have no money’</td>
<td>Sarah</td>
</tr>
<tr>
<td>Long-term worry</td>
<td>‘I think at times Mam and Dad aren’t going to be alive for ever and ever you know’</td>
<td>Sarah</td>
</tr>
<tr>
<td>Isolation/ can’t express</td>
<td>‘I can’t talk’</td>
<td>John</td>
</tr>
<tr>
<td>Dependence / loss</td>
<td>‘I wasn’t depending on people so much. My independence is a fierce loss, independence’</td>
<td>Ned</td>
</tr>
<tr>
<td>Dependence / loss</td>
<td>‘My independence is gone Kay. I can’t drive, when you can’t drive your independence is gone. I miss the driving’</td>
<td>Ned</td>
</tr>
<tr>
<td>Transport issues / dependence</td>
<td>‘You can’t get back to (Name of Town) from here and that is a disgrace’</td>
<td>Jack</td>
</tr>
<tr>
<td>Driving</td>
<td>‘My next biggest challenge is the driving’</td>
<td>Gary</td>
</tr>
<tr>
<td>Isolation / transport</td>
<td>‘You know we live in the back of ‘beyonds’ here ... yeah. My mother can’t drive. There is one bus a week to town out here once a week’</td>
<td>Gary</td>
</tr>
<tr>
<td>Don’t drive again</td>
<td>‘a lot of people with brain injuries don’t ever get to drive again and you won’t play football competitively’</td>
<td>Gary</td>
</tr>
<tr>
<td>Do drive again</td>
<td>‘But I know that people with brain injuries do drive, there is a man up the road from here who had a stroke and he is driving’</td>
<td>Gary</td>
</tr>
<tr>
<td>Ashamed to use ‘bus pass’</td>
<td>‘I was ashamed of my life ... I felt because she was so rude that I wasn’t entitled like’</td>
<td>Jack</td>
</tr>
<tr>
<td>Lack of access to resources</td>
<td>‘I cannot afford to have a line for the computer’</td>
<td>Dan</td>
</tr>
<tr>
<td>Worry about access to resources</td>
<td>‘My mother is worried that it will be stopped and sure look I don’t have a job’</td>
<td>Gary</td>
</tr>
</tbody>
</table>

Findings from this study show how difficult survivors find the changes to their financial status after TBI. For many of the survivors, this is their first experience of being dependent on social welfare and reliant on public transport. The reality of living on social welfare and being economically dependent on the state creates feelings of insecurity. To a large extent, their fears were rational, because disability is likely to increase an individual’s probability of experiencing poverty (Whelan et al., 2004). These data support Bury (1982) who argues that illness may negatively influence independence and individual identity.

5.4. Societal Barriers to Active Participation following TBI

The main category identified in this section relates to the societal barriers which impact on the survivor’s active participation following TBI. A number of sub-categories were also identified by grouping the concepts in the data analysis. The sub-categories here are as follows:
• Being 'written off'
• Lack of expertise amongst health professionals
• Paternalistic Attitudes.

Societal barriers to active participation following TBI can be identified as those which prevent, or make it more difficult, for survivors to have an active role in society. These include: (a) being 'written off', (b) a lack of expertise amongst health professionals and (c) experiences of paternalism.

The manner in which disability is treated in western society influences the process of recovery for the survivor. How others expect disabled people to conform to stereotypes (Scrambler, 2008) is reflected in many of the themes. Cultural norms attribute distinctive traits to disabled people, such as: helplessness, dependency, docility and melancholy (Scott, 1969).

The findings in this study indicate that people with brain injury have to fight to overcome an imposed dependency and powerlessness. The majority of the participants experienced a loss of role, helplessness, a shift from independence to dependence and are often overwhelmed by uncertainty. They seek out answers, particularly in relation to a prognosis. The core category of ‘recovery’ following a TBI is influenced by factors that reinforce their changed roles (negatively and positively).

5.4.1. Being 'written off'

Survivors referred to how they felt at their needs being ignored in that 'no-one' informs them of how they can work towards recovery by accessing support / resources out there. This was a common experience for many. Gary articulates this thus:

'No-one tells a brain injured person about the things that are out there'
(Gary).

This suggests that survivors are not capable of being helped towards recovery, and are therefore ignored. A recurring theme was the lack of information on brain injury, particularly in relation to supports and services, much of which are discovered through 'word of mouth'. Three of the participants in this study were completely unaware of the NGOs offering training, education and supports to brain injured individuals.

'Interviewer: Have you heard of Headway
Ned: No, I never heard of them. They are good, are they?'
(Ned).
All the participants highlighted the need for an official information site, or ‘one-stop shop’, to address their needs at varying stages of their recovery.

‘People need to know what’s out there, different home help or if they want to go to college and then there is grants ... I never knew there was so much’

(Gary).

Survivors with communication problems were particularly vulnerable to being ignored. One respondent’s efforts to communicate over a period of 30 years with expressive aphasia (see Appendix C) were revealing. He only regained his ability to speak, with the help of speech and language therapy, one year before the interview. He expressed his observation in the following extracts:

‘Written off yeah, rude but couldn’t bear ... I have to think of the words and say the words but very ... very slow but ‘tis, excuse me, frustrating ... people don’t wait. I’m happy now you know to learn the speech ... I know that’s slow but ah it’s coming written off, written off before, sad’

(Harry).

A further recurring theme was in relation to the supports participants felt they should have been getting, such as speech and language therapy (2 participants), counselling and/or psychotherapy (5 participants).

‘I have received very little help from the ... Health Board once I was discharged from [Hospital Name] after three months’

(Dan).

Gary succeeded in getting a grant, which enabled him to return to college, with the help of an acquaintance who worked in an official capacity. She advised him not to admit that he already had a degree which would have prohibited him from taking up a grant. He feels strongly that clearer information be made available regarding college places and funding options. The college grant scheme in Ireland is complicated for all applicants and has been heavily criticised for its lack of coherence, clarity and consistency (Power, 2009).

Four participants praised an approach to providing information on brain injury offered by an NGO supporting TBI survivors. This is a course run on a pilot basis. An important component of the course is information on how the brain works and what happens when the brain is injured. Some even suggested that had they been in possession of this information earlier, they would have better understood the changes in cognitive and physical terms. Ann said that she did not realise that many of the effects of her injury, such as fatigue and memory loss, were common and well documented. She expressed her thoughts in the following manner:
The brain injury management class that is just, it explains so much for me, I can’t believe and I keep thinking if I had only known what I am learning in that book like ...

all about the consequences of a brain injury and like there is something in the book and I am thinking Jesus that book could have been wrote about me. That is the best class, what I have gained from that is just brilliant ... I feel like things I know happened and I would know it was right and I’d fight and fight to the last and I’m sitting there thinking even only I had known what I got from that class things would have been so much easier ...

(Ann).

See, I never got any of that, like that’s what was missing and I feel if I had been made aware of what I learned in that brain injury management class because I would have been able to accept when people were telling me ‘no’ (Name) that didn’t happen, that wasn’t said and I would fight things to the last and I wasn’t wrong. I’m not imagining this, this is all happening and like I made problems because I wasn’t aware like that was the biggest problem for me

(Ann).

TBI survivors sense of being denied autonomy over their lives is evidenced in the findings from this study. This can be manifested in a myriad of ways, such as being denied access to information and decisions made by others on behalf of survivors, without any engagement with them. Survivors with communication problems have particular difficulty.

Data from survivors is similar to Sherry’s (2006) and Philip’s (1990) reference to brain injured people being viewed as damaged goods. Being ignored is a common experience for many TBI survivors but is compounded for those with speech and language difficulties.
Table 33: ‘Written-off’

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denied information</td>
<td>‘No-one tells a brain injured person about the things that are out there’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Need for information</td>
<td>‘People need to know what’s out there’.</td>
<td>Harry</td>
</tr>
<tr>
<td>Received little help</td>
<td>‘I have received very little help’.</td>
<td>Dan</td>
</tr>
<tr>
<td>Information on brain injury important</td>
<td>‘The brain injury management class that is just, it explains so much for me’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Information on brain injury important in understanding injury</td>
<td>‘because I would have been able to accept’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Information on brain injury important in understanding injury</td>
<td>‘I’m not imagining this, this is all happening and like I made problems because I wasn’t aware like that was the biggest problem for me’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Sad</td>
<td>‘written off’, written off before, sad’.</td>
<td>Harry</td>
</tr>
<tr>
<td>No awareness of NGOs</td>
<td>‘No, I never heard of them’.</td>
<td>Ned</td>
</tr>
</tbody>
</table>

5.4.2. Paternalistic Attitudes

The paternalistic approach adopted by others, particularly health professionals and family members, is an indication of how difficult it is for survivors to re-establish their independence. An observation made by 11 out of 16 participants in this study was that people with brain injury are judged to be less competent, and in need of protection for their own well-being and safety.

A female in her early twenties pointed out that one of the greatest difficulties she faces is attempting to persuade others, particularly her family, that she has now recovered. Further direct comments illustrate this:

Well yeah, when I got sick my sisters lived in England and one of my sisters moved back to Ireland for a year ‘cos Mam and Dad were kind of ‘molly coddling’ me, that’s what they do I suppose. But my sister knew I suppose she tried her best to and she did everything going about getting extra help and that but it was tough (Ann).

Gary, a young single man, recalled being reprimanded for kissing a girl outside the premises of the National Learning Network, where they were both attending a course. He refused to go back because he could not accept being ‘treated like a child while being expected to behave like an adult’.

Like one second the NLN is work and then it’s school, so they should make up their mind and they do … training and there’s no way I can hold a conservation with, there’s no one I can talk to or if someone is teaching me they don’t
listen. I want to go back to proper placement with proper engineers so (Gary).

Jack told how he witnessed his friend with a brain injury being spoken down to by a staff member of one of the Non-Government Organisations.

‘The girl that was there and she started talking down to him like a two year old child and to be honest with you I did not like it’ (Jack).

Sarah, a female in her twenties, was told by her GP that she should go back to living in a nursing home after she had a seizure.

‘I went out to my doctor and my doctor actually said to me I would be better off in a nursing home. And I said what age do you think I am?’ (Sarah).

Her previous nursing home experience was less than positive, as she recalled being treated like a child during her stay. She told how nursing staff were enforcing dependence by over-protecting her and not allowing her any role in decision-making:

The nursing home is a bit different, I had to kind of fight with them to explain I am not going to seizure, I am fine, you know I have my bus pass, I can get in and out and it’s not an accompanied bus pass so … I spoke to the owner, I learned that from my sales training go to the decision maker, that I wanted to go onto the course and I was going in and out here to the course just up to Christmas from the nursing home.

I had been in another nursing home and that was run as a business, but N… Was a family run one and they are completely different. And … in the other one I would still be a veg (Sarah).

She now lives in supported living accommodation at an Irish Wheelchair Association hostel, where her experience is positive; the staff understand her needs by promoting a sense of independence. However, she is worried that the funding for this project will be removed. She describes the arrangements at this facility:

They have two staff on at all times and so yeah. I have my own room en-suite and I am quite happy there as a step down, and am I got into the habit when I was in the nursing home I was just ‘veggying’ in front of the television so they am … I borrowed a TV from them and I was doing the same thing so they took it out of the room and I think it was the best thing they ever did (Sarah).
Life changes

Social life has changed for all the survivors. Some talked about being taken on social outings rather than choosing where to go. Sam, a teenager, was not impressed at being taken to a 'Charley Pride' concert by his mother. He made it clear that this was not his choice of music. Another young woman recalled in detail how an acquaintance offered to take her playing bingo. She agreed so as not to offend, but found it extraordinarily boring. She made the point that well-meaning people do not ask her what she would enjoy doing; instead she is supposed to feel grateful for being taken out. Dan was an avid rugby fan before the accident; he has only been to one match since the accident which happened two years previously because he cannot see the players.

Physical impairments prevent survivors from getting where they could socialise for leisure. The cinema was the outing of choice for the majority of participants. Some go to the pub on occasion, but two survivors stressed that their greatest problem is hearing conversation in such a noisy environment. This is understandable given the young age of most of the participants - young people mostly socialise in noisy pubs.

I go to the cinema through the outreach workers with Peter Bradley and I went to the Headway Ball and I don’t drink, maybe it’s just a glass of Chardonnay. I have seizure problems as well; it just doesn’t work so I am on medication for the seizures. And I was just on the edge of two and a half years clear of the seizures (Sarah).

In 2007, I was in a pub once, one night at closing time because I cannot stand in the pub at weekends or anything like that anymore because of my hearing. If I was ... if someone was sitting here next to me and we were having a one-to-one conversation it would be ok, but in a pub I hear about half of what that person has to say to me. The noise whether it is the other people talking or background music or a television or whatever, that noise would come in and drown that person’s conversation to me, most of it. Not knowing what that person next to me is saying, I’m not able to enjoy a drink or a social occasion (Dan).

See I find it really hard to hear if I’m in a pub or the very odd time I went to a club, it was really hard to hear. Now, if the person talking to me was standing near and if it was quite I might be able to hear but not a hope otherwise. I notice the noise in pubs now but before the accident, I couldn’t have the music up loud enough (laughs), like when I worked in pubs (Hugh).
The key finding here is the lack of capacity to engage in the normal social activities survivors enjoyed prior to injury because of impairments resulting from the injury (e.g. hearing difficulties) and the lack of autonomy experienced by TBI survivors. Similar to health professionals, acquaintances also have a stereotypical attitude towards people with disability, for example they feel they need protecting for their own good, are unable to manage their own lives and therefore need decisions to be made for them. The process of recovery following a TBI is heavily influenced by interactions with health care professionals, and others in the survivor’s social network. Based on the evidence from interviews in this study, participants found it difficult to gain a sense of independence.

These findings are similar to Goble (2004); Berry and Jones (1991) and French (1994) who found that the focus is all too often on loss and deficit. Goffman (1961) described how institutional life for residents meant isolation from society and restricted opportunities for personal development. Even though there are no longer large institutions, it is argued that smaller care homes and sheltered workshops reinforce the same practices (Townsend, 1979).

Table 34: Paternalistic attitudes

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over protecting</td>
<td>‘Mum and Dad were kind of ‘molly coddling’ me’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Not treated as an equal</td>
<td>‘The girl that was there and she started talking down to him like a two year old’.</td>
<td>Jack</td>
</tr>
<tr>
<td>Over protecting</td>
<td>‘I had to kind of fight with them to explain I am not going to seize, I am fine, you know I have my bus pass’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Not treated as an equal</td>
<td>‘there’s no way I can hold a conservation with, there’s no one I can talk to or if someone is teaching me they don’t listen’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Not treated as an equal</td>
<td>‘treated like a child while being expected to behave like an adult’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Over protecting / focus loss and deficit</td>
<td>‘my doctor actually said to me I would be better off in a nursing home’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Difficulties /limitations socialising/dependent on others for social outlets</td>
<td>‘See I find it really hard to hear if I’m in a pub or the very odd time I went to a club, it was really hard to hear’.</td>
<td>Hugh</td>
</tr>
</tbody>
</table>

5.4.3. Interactions with Health Professionals

The findings in this study show that there was a perception amongst survivors that some health professionals are inexperienced and lack knowledge on brain injury. Three participants stated that general practitioners lack the specific expertise to deal with brain injury, and found the labels used to diagnose brain injury offensive. They made the point that often the injury is described in terms of deficit and referred to as brain damage, instead of the more acceptable term brain injury.
Drawing on how survivors relate their experiences with health professionals, it is evident that there is a lack of confidence regarding their expertise on TBI. Many indicate that this lack of understanding about brain injury is also the basis for the labels they attach to people with brain injury.

‘Well they kinda say, well he’s brain damaged, they says and you know you can’t fix that, we’ll say, that’s kinda what they says I can’t know what the words they use but I read it in books is it called rewiring of the brain or something like that’ (Tara acting as a proxy for her husband, John).

One participant, Ned, recalled being upset by a doctor who was caring for him:

Up in Hospital Z this one doctor ... I never met him before in ‘me’ life. He was reading my files like you know, he was reading my files, he never even looked at me you know. I said I can breathe now since I gave up the cigarettes. It doesn’t matter he said, you are as good as you’re going to get. I’ll tell you Catherine, he brought me back down to zero. I’ll tell you something else he said to me, I was on depression tablets I didn’t like them ‘cos my memory was bad with them, and I started putting them on the fire. And he stood over me and he said ‘depression, depression isn’t it, isn’t it’, pointing at me. Catherine, he made me a lot worse, he brought me back down to zero. I never wanted to meet him again

(Ned).

This key finding from the encounter with the doctor, was to make the patient feel vulnerable and to lose hope about future recovery prospects. This encounter further impacted on Ned’s willingness to consult with a doctor:

‘I don’t go near him at all. Sure what’s the point like. I’m supposed to but I don’t. I’m sick of doctors, I’m sick of doctors, seen enough of them’

(Ned).

Brain injury is presented in a particular stereotypical manner, and may act as a factor in deciding how the individual survivor of TBI is treated in encounters with health and social care providers. It demonstrates the way in which judgements are made based on factors such as the person’s illness, and on the person’s identity and characteristics (Griffiths and Hughes, 1993). This is supported by a social judgement theory, as described by Sherif and Hovland (1961). Chamberlain (2006) similarly suggests that recovery from brain injury is often hampered by a lack of understanding by healthcare professionals as well as others in society. Pryor (2004) identified that some nurses in a brain injury rehabilitation unit lacked the necessary expertise to deal with the specific needs of their patients. This may be seen as a failure of the education and training of health professionals, which largely ignores
non-clinical aspects of brain injury - i.e. the social characteristics and consequences. Hill (2004) drew attention to the appropriateness of language or lack of it in dealing with TBI. She suggests that the individuality of a patient is overshadowed by the labels placed upon them by healthcare staff. Brain injury is usually viewed by the medical profession as a tragedy (Oliver, 1986). The emphasis on normality and social conformity comes high on the agenda of health professionals and family (Hill, 2004; Baird, 1992).

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative labels</td>
<td>'well he's brain damaged, they says and you know you can't fix that'.</td>
<td>Tara acting as proxy for her husband, John</td>
</tr>
<tr>
<td>Negative encounter with doctor.</td>
<td>'he made me a lot worse, he brought me back down to zero. I never wanted to meet him again'.</td>
<td>Ned</td>
</tr>
<tr>
<td>Negative impact on feelings related to recovery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't believe doctors can help further recovery</td>
<td>'I don't go near him at all. Sure what's the point like. I'm supposed to but I don't. I'm sick of doctors'.</td>
<td>Ned</td>
</tr>
</tbody>
</table>

5.5. Environmental Factors Influencing Recovery

The fourth main category involves the environmental factors which influence recovery after TBI. The sub-categories identified in from the data analysis are as follows:

- Lack of public awareness regarding brain injury and the reaction of others
- Invisibility of Brain Injury
- Experiences with the National Rehabilitation Hospital and Therapies
- Statutory and Voluntary Agencies; Education and training; Other supports.

Recovery from TBI and the strategies adopted are profoundly influenced by the social context in which they occur. The sub-categories in this section include: the lack of public awareness regarding brain injury and the reaction of others; the invisibility of brain injury; experiences with the National Rehabilitation Hospital and therapies; statutory and voluntary, education, training, and other supports.

Lack of public awareness regarding brain injury and the reaction of others

Some thirteen participants articulated a view that, because of a lack of awareness on brain injury in the wider community, they had negative experiences. The following examples illustrate some of the experiences survivors recalled on a daily basis, doing ordinary things:

'I would say that ordinary people, ordinary people don't realise. Like my
family there now doesn’t realise what I am going through you know. People don’t realise (crying). People say do this, do that do the other thing, they don’t realise what they are doing, how hard it is’

(Ned).

Sam, a teenager, showed how offended he was by the reaction of others who talked about him as if he did not exist. He explained his hurt by saying in a very deliberate way: ‘I have very strong feelings’.

‘People come along and talk about me and I feel like saying ‘hello, I’m here’ and I can hear and talk. One day in the supermarket a man came and asked Mam can he talk and can he feed himself?’

(Sam).

‘Well some people look at me in a strange way as if there is something wrong with me’

(Eoin).

They don’t know what to say to me, or they treat me as if I am stupid. Not all of them though. But I suppose it’s hard for them too, like everything has changed, and it’s only now I am coming back to myself … well if I will ever be the same again

(Hugh).

A young female recalled being deeply upset when she was refused entry to a nightclub. She was particularly embarrassed in front of her friends and went home alone while her friends went into the club. Her experience is articulated thus:

I have a left sided weakness in my upper body, palsy or something it is … and when I am tired it is very noticeable, so much so I have been refused to go into nightclubs and my left side staggers, and I say ‘why’ and … Yeah, they say you’ve had too much to drink. And I spent most of the day in bed, it was my friend’s birthday and I wanted to cry because.. but I couldn’t because my friends were all about me and I said look lads I am tired anyway but I wasn’t ‘cos I had the day in bed and it is hard like all your friends are going out to a disco and you know. The hardest part is not being one of the girls you know, not being able to fit in because you are tired like

(Ann).

Rob, a young man, is reluctant to go to public places because of the reaction of strangers to the scar on his throat from a tracheotomy.

The weight. I can’t do much exercise, the doctor said not to overdo it and I eat
a lot. It's funny for ages I was too skinny and they thought I would die, now I am eating far too much. There is no happy medium. Also, going out, I hate this thing in my neck [pointing to the scar left by the tracheotomy]. Will that go? (Rob).

Table 36: Lack of public awareness regarding brain injury and the reaction of others

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>People do not realise</td>
<td>‘People say do this, do that do the other thing, they don’t realise what they are doing, how hard it is’.</td>
<td>Ned</td>
</tr>
<tr>
<td>People talk about survivor in presence / ignoring</td>
<td>‘People come along and talk about me’.</td>
<td>Sam</td>
</tr>
<tr>
<td>People perceived survivor as having something wrong (i.e. not normal)</td>
<td>‘Well, some people look at me in a strange way as if there is something wrong with me’.</td>
<td>Eoin</td>
</tr>
<tr>
<td>People do not know what to say</td>
<td>‘They don’t know what to say to me, or they treat me as if I am stupid’.</td>
<td>Hugh</td>
</tr>
<tr>
<td>Refused entry to nightclub / as visible effects of injury mistaken for drunkenness</td>
<td>‘I have been refused to go into nightclubs’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Not fitting in</td>
<td>‘The hardest part is not being one of the girls you know, not being able to fit in because you are tired like’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Embarrassed by scar</td>
<td>‘Also, going out, I hate this thing in my neck. [pointing to the scar left by the tracheotomy]. Will that go?’</td>
<td>Rob</td>
</tr>
</tbody>
</table>

5.5.1. Invisibility of Brain Injury

The hidden aspect of brain injury also created problems, as identified by three-quarters of the participants. Participants revealed how these misconceptions caused them some distress. Reference was made to the burden of having an invisible injury compared to more apparent physical impairment and/or disability. Cian has a problem with memory and finds this presents a problem when he takes a taxi because he cannot remember where he wants to go:

‘Hundreds of people they don’t know like it just like … Some don’t understand. The taxis I can’t understand, like I sit in and I can’t remember’

(Cian).

‘It’s so hard to do the normal things’

(Harry).

‘Like the visual is everything and because you don’t look alright you’re considered … and a brain injury is a hidden disability and like ’cos you don’t look ok you are not accepted yeah’

(Ann).
Further misunderstandings result from others not recognising the limitation caused by the brain injury, which led some participants to conclude that they would be better off with a noticeable disability. Ned was visibly upset when describing the pressure of having to cope:

'I mean if you have only one arm people would realise you know ... People with brain injury look normal. People don't realise, people don't realise'

(Ned).

Pressure to perform to expected norms comes from friends, family and the public, particularly bus drivers, taxi drivers and shop assistants. According to Higham et al. (1996), this passing off for 'normal' by the brain injury survivor is what may well disadvantage them in their dealings with others, adding significantly to their pressures. One young man told of a negative experience his friend had with a member of An Garda Síochána (Irish Police force). The participant made the point that police training should include awareness of brain injury.

BRI, they are for brain injured people and there’s a young woman there, she’s from (Name of Town) and one day she went to a concert and she can’t use a mobile phone 'cos she just not able to and so she showed, she asked this old woman if she could phone a taxi and get a taxi. And she said ‘what’s wrong with you why can’t you do it?’. And she showed the brain card that you show to get into the games. And she showed it to a guard (a member of the Garda Síochána) and the guard said what’s wrong with you why can’t you do it. I mean even guards don’t even know and that is bad like awareness should be for everybody, but like when people like the guards ...

(Gary)

Ned also used the card (see Appendix E) supplied by the Acquired Brain Injury Association (formally Peter Bradley Foundation):

Interviewer: 'Why do you think it is necessary to carry a card like that (Peter Bradley card). Does it help?’

Ned: 'It does yeah. I showed it in a shop, it was ok then. Yeah it is good yeah. I only used it the once, I should, but I don’t’.

(Ned)

A further distinction was made by three participants in relation to people with brain injury and a physical disability. It is interesting that the two participants in this study were happy to use the card in their interactions with people in public places. It does highlight, however, the lack of understanding about brain injury amongst the wider community. Gary describes a conversation he had with a relative, who is an amputee:
Gary: 'And as well as that my cousin her husband had a disability right, his leg got amputated but he can walk around. But I said it’s gas 'cos he said to me, Gary do you hate when people say they will do things for you and you are well able to do it yourself, damn right.

Interviewer: Does that happen to you?

Gary: It can yeah, 'cos it’s gas I’m classed as a disabled ... how come a disabled guy can train with my football team. They accept me as myself. So I’m called disabled by everybody from (Place Name) or whatever and then as I said how can a disabled person train with a football team?

(Gary)

In summary, the findings show that lack of public awareness regarding brain injury and the reaction of others to disability has a profound effect on how a survivor of TBI manages everyday encounters and interaction with others. For instance, a young female’s experience of being refused entry to a club, because of effects of her injury being mistaken for drunkenness, was deeply upsetting for her. Another young man avoids going to social gatherings because he is afraid of people’s reaction to the tracheotomy scar in his throat. The pressure to appear normal is overwhelming and comes from a variety of sources, such as policemen and well-meaning family members. The invisibility of injury may present an additional problem, and some give the impression of functioning without disability (Chamberlain, 2006). However, some survivors in this study stated they would rather have a visible injury, such as broken limbs than a TBI. There was no evidence that they tried to cover up the effects of TBI. This bears out Lonardi’s (2007) and Shilling’s (2005) contention that it is essential to find a socially acceptable representation of a disease in order to remain a valued member of society.

Table 37: Invisibility of Brain Injury

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looks ‘normal’</td>
<td>‘People with brain injury look normal’.</td>
<td>Ned</td>
</tr>
<tr>
<td>Lack of understanding of TBI</td>
<td>‘I mean even guards don’t even know and that is bad like awareness should be for everybody’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Accepted by others</td>
<td>‘I’m classed as a disabled ... how come a disabled guy can train with my football team. They accept me as myself’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Lack of understanding</td>
<td>‘Some don’t understand. The taxis I can’t understand’</td>
<td>Cian</td>
</tr>
<tr>
<td>Not accepted /don’t look ‘normal’</td>
<td>‘and a brain injury is a hidden disability and like ‘cos you don’t look ok you are not accepted’</td>
<td>Ann</td>
</tr>
<tr>
<td>Trying to be ‘normal’</td>
<td>‘It’s so hard to do the normal things’.</td>
<td>Harry</td>
</tr>
</tbody>
</table>
5.5.2. Experiences with the National Rehabilitation Hospital and Therapies

Acceptance on to a rehabilitation programme at the National Rehabilitation Hospital (NRH) offered the promise and expectation of greater improvement. In many cases this did not materialise, due to the severity of the injury, and led to further disappointment and pessimism about future progress. A participant’s explained how this aspect of her husband’s recovery was upsetting for them both. He had worked as a race jockey before his injury. They told how this facility is held in such high esteem amongst the jockeys. She likened it to a place where miracles were likely, but told of feeling disappointed when the staff at the NRH were not able to offer much hope of further improvement. Both positive and negative experiences of the National Rehabilitation Hospital are articulated by some survivors:

‘It’s grand. We have loads of things to do ... Classes and physio, OT and all that. The day flies. I find the nights crawl but Mam is here most of the time’.

(Eoin)

Well, Dun Laoghaire was good ’cos they were the best for me when I was very bad like, I couldn’t even, I was just a body. I couldn’t even stand up with a crutch or whatever. In (Name) my skull was so crushed they had to raise the skull so they had to put in a titanium plate ... Speech I got up in Dun Laoghaire.. the thing is when I was over in England I couldn’t talk so they used play me CD’s; up in Dun Laoghaire they tried to get me to talk.

(Gary)

‘Dun Laoghaire never again, F... sake ... hated it, f... sake’.

(John)

‘I got to go to the rehab and I’m still going there. I love it, it’s a great laugh and the people are great.

We are laughing and joking all day. But we do some work as well’ (smiles).

(Hugh).

The survivors related a wide range and different experiences at the NRH - some positive, some negative. While many acknowledge the positive aspects of their time at this facility, others were disappointed that they did not make the progress they had expected. A number of survivors acknowledged that they were too ill to understand what was going on. This highlights the need for rehabilitation at a later stage of recovery as well as at the early point post injury. For example, in a previous section, a participant talked about the availability of driving lessons at the NRH, but at the time he was too ill to avail of them. Based on this data, it is clear that there is a communication gap between the staff and the service users. Hence, some survivors did not feel well-informed about their treatment options.
And my mother was in the room as well and she was asked by the physio, and by me answering first she wouldn’t dampen my thoughts, she just agreed with what I had said. So one of the questions was have you seen a change or an improvement good or bad in Ann in the last while and my mother said ‘no’ ‘cos she didn’t want to dishearten me

(Ann).

The mismatch between goals of the rehabilitation team and the expectations of the survivor has been documented by Watkins et al. (2001). He argues that this disparity may result in disappointment and the increased vulnerability of the client. Rehabilitation marks a disruption in a life, and is a time of uncertainty and adjustment (Hammell, 2006). Clinical evidence shows that people with TBI typically make the most significant gains in the first six months (Connor, 2002). Abberley (1995) and Johnson (1993) argue that rather than providing clients with the knowledge and tools to resist the marginal status to which social norms strive to confine them, professionals use tactics to adjust client’s expectations downwards (Hammell, 2006). This process of ‘getting real’ (Hammell, 2006: 123) is designed to enable them to ‘accept’ or ‘adapt to’ their new lowly status and its diminished opportunities and privileges (Hammell, 2006: 124). Findings from this study show survivors and families are given limited information on possible prognosis. Tara described how health professionals dealt with her when her husband was being treated by them:

‘He was sitting like this with his head down and you know a bit condescending and not giving him any chance sort of, I think he would have come out a lot better if they put more work into him’

(Tara acting as a proxy for her husband, John).

The findings here can be understood by placing in context the dominant role of biomedicine, which offers explanations founded only on the basis of impairment and limitation, and therefore has a profound effect on how disability is understood by society. While fully acknowledging the role and influence of biomedicine, Shakespeare and Erickson (2000) suggest a social model of disability should include other elements such as cultural, political and psychological dimensions. Findings of this study show that the recovery process following a TBI, is assisted by appropriate social supports and understanding of the individual survivor’s needs and concerns.
Table 38: Experiences with the National Rehabilitation Hospital and Therapies

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good experience / things to do</td>
<td>'It's grand. We have loads of things to do'</td>
<td>Eoin</td>
</tr>
<tr>
<td>Good experience / great</td>
<td>'I love it, it's a great laugh and the people are great'.</td>
<td>Hugh</td>
</tr>
<tr>
<td>Communication problems with health</td>
<td>'And my mother was in the room as well and she was asked by the physio, and by me answering first she wouldn’t dampen my thoughts, she just agreed with what I had said'.</td>
<td>Ann</td>
</tr>
<tr>
<td>professionals</td>
<td>'he was sitting like this with his head down and you know a bit condescending and not giving him any chance sort of. I think he would have come out a lot better if they put more work into him'.</td>
<td>Tara acting as proxy for her husband, John</td>
</tr>
</tbody>
</table>

5.5.3. Statutory and Voluntary Agencies; Education and training; Other Supports

The younger participants, particularly those whose education was interrupted by the injury, expressed an interest in returning to education. As Table 39 illustrates many survivors were attending training courses, while others had returned to their previous occupations. The type of training available is somewhat limited, due to a shortage of providers and a lack of government resources to fund training programmes specific to the needs of brain injured survivors. This is demonstrated in the following comments:

'I wouldn’t be able for computers; I have no interest in computers anyway. I don’t like those yokes'.
(Ned)

'Well he did try computer training down in a place and that didn’t work out ... Like it was because of the type of injury he had, he never worked a computer before ...'
(Tara acting as a proxy for her husband, John.)

'... Yes, yes, that’s it, horses ... only horses'.
(John)

'Headway, they were teaching me swimming. But I got fed up. But that’s me again I didn’t want to go swimming anymore I wanted to go to the gym, so I went to the gym, I didn’t bother going swimming'
(Jack)

Some praised voluntary bodies providing supports and services, and also offered a context to build new social relationships:

'I can’t praise Headway enough, the vocational training and the friends I’ve met equally and the key workers I must say are brilliant and they seem to
really understand and they are committed'. Sarah

I do computers in Headway. I could go to Headway five days a week if I want but ... what are they doing now tomorrow they are doing cooking, listening to music now not the kind of music you would listen to ... it's all whales and that kinda stuff. Now if I had the computer now I'd be listening to music alright but am ... What else, I do art work ... we actually built a boat in Headway. We launched it in.

(Jack)

Furthermore, Gary gave an example of duplication of supports:

'Headway were offering me counselling but then Peter Bradley offered me counselling, so Headway ... It was gas they were having a fight about what they could offer me and they were following me saying I took up the other offer. I didn't want that'.

(Gary)

More experiences on this subject are expressed thus:

'Yeah, Peter Bradley, the Peter Bradley crowd, they are very good. Well Yeah, he calls to me twice a week, you know. He comes on a Monday, we go bowling or swimming or to the gym ... or whatever'.

(Ned)

At the very, very start he used bring me to for night courses we were doing computers. So we used to go there and get out and meet all the local people and then even though he wasn't supposed to be used to bring me to the pub afterwards and it sure we used have a great craic.

Every week then, once a month there is a Peter Bradley meeting in (Name) or wherever. It's great to talk to people who have been there, done that, bought the postcard. And then there's BRI as well ... Bri see work with Peter Bradley.

(Gary)

What happens with Headway is they are more vocational and they are trying to get our skills more up to date, like we are using Office 2007 and I have a computer qualification but I would have been using Office 2003, which is completely different. my background in computing and Microsoft and do a TEFL course and take it from there.

(Sarah)
Other agencies, such as the National Council for the Blind and the Irish Wheelchair Association were also mentioned by survivors. Further details on employment/training of survivor participants interviewed are presented in Table 39 following:

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Gender</th>
<th>Age</th>
<th>Employment</th>
<th>Previous Occupation</th>
<th>Course Organiser</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td>51</td>
<td>Unemployed</td>
<td>Self employed business</td>
<td>National Council for the Blind of Ireland</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>43</td>
<td>Attending Course</td>
<td>Landscape Gardener</td>
<td>Headway, Cork</td>
</tr>
<tr>
<td>3</td>
<td>Male</td>
<td>17</td>
<td>Attending NGO centre</td>
<td>School</td>
<td>Quest, Galway</td>
</tr>
<tr>
<td>4</td>
<td>Male</td>
<td>28</td>
<td>Part-time barman</td>
<td>Plasterer</td>
<td>NRH, Dun Laoghaire</td>
</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>26</td>
<td>Unemployed</td>
<td>Bar Manager</td>
<td>Youth Reach</td>
</tr>
<tr>
<td>6</td>
<td>Male</td>
<td>17</td>
<td>Back full time at previous occupation</td>
<td>Self employed Carpentry business</td>
<td>University</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>49</td>
<td>Student</td>
<td>Undergraduate</td>
<td>Post Leaving Cert course, VEC</td>
</tr>
<tr>
<td>8</td>
<td>Male</td>
<td>30</td>
<td>Student</td>
<td>Student on a different course</td>
<td>University</td>
</tr>
<tr>
<td>9</td>
<td>Male</td>
<td>32</td>
<td>Back full time at occupation plus part time student</td>
<td>Security man</td>
<td>NRH, Dun Laoghaire</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>17</td>
<td>School</td>
<td>Security man</td>
<td>Peter Bradley Foundation</td>
</tr>
<tr>
<td>11</td>
<td>Male</td>
<td>47</td>
<td>Unemployed</td>
<td>Plasterer, Carpenter, Roofer,</td>
<td>Headway, Limerick</td>
</tr>
<tr>
<td>12</td>
<td>Female</td>
<td>27</td>
<td>Course</td>
<td>Student</td>
<td>Headway, Limerick</td>
</tr>
<tr>
<td>13</td>
<td>Female</td>
<td>28</td>
<td>Course</td>
<td>Business Development Manager</td>
<td>Peter Bradley Foundation</td>
</tr>
<tr>
<td>14</td>
<td>Male</td>
<td>40</td>
<td>FAS scheme</td>
<td>Jockey</td>
<td>Peter Bradley Foundation</td>
</tr>
<tr>
<td>15</td>
<td>Male</td>
<td>28</td>
<td>Unemployed</td>
<td>Musician</td>
<td>Headway, Limerick</td>
</tr>
<tr>
<td>16</td>
<td>Male</td>
<td>53</td>
<td>Unemployed</td>
<td>Part-time farmer</td>
<td>Headway, Limerick</td>
</tr>
</tbody>
</table>

*Other supports*

The findings revealed that the help available from the Health Services Executive (HSE) varied between geographic locations, and was often influenced by the relationship people had with a local service provider. In a few cases, the participants did not make the
connection between the HSE as an organisation, and the employees of this service. The following comments illustrate this:

No there was no support, not a bit ... (Name) is in charge of home help inside in (Name), he ... my mother kicked up a stink and said this guy is going home and that's it, Dun Laoghaire said no, that she wouldn't be able to cope, 'cos you know, I'd need 24 hour care. So (Name) said don't worry (Name) 'I'll send out people that'll be able to look after Gary'. Like he said to her don't worry we will help.

(Gary).

Jack acknowledged the financial help provided by the HSE towards the cost of transport, saying that they were 'more than generous'. While Ann was disappointed by the level of community physiotherapy she got, and the 'do it yourself' approach:

A physiotherapist used to call to the house maybe once every two weeks and then it became less frequent and my mother is 62 and she gave my mother a sheet with exercises on it and, she said look could you continue doing these. Well what does my mother know about physiotherapy, so the services just faded.

(Ann)

I have received very little help from the Health Board once I was discharged from hospital after three months ... and it's not that I don't need it, I do ... I have found the district nurse here (Name) fantastic. Ah, she got the home help organised for me, Monday to Friday for one hour. 9 o'clock in the morning I have my home help.

(Dan)

These findings clearly show that there are deficits in post-hospital rehabilitation services. The non-government agencies, Headway, Ireland, Acquired Brain Injury, Ireland (Formally Peter Bradley Foundation), BRI and Quest, have a presence in some places but not all. In some geographical locations there is an absence of any NGO support. This finding supports Payne (2000) who pointed out that eighty percent of brain injured patients discharged from the National Rehabilitation Hospital (NRH) in Dun Laoghaire, Dublin, failed to receive the treatment recommended to them. Almost one-quarter in this study received no follow up treatment at all.

Findings from interview data with survivors show the effort they make to move through stages of recovery. Many talked about having a lot of time on hands. They cannot work, go to school or college, play football or drive. While it is acknowledged that rehabilitation and post-rehabilitation is necessary after TBI, Bury (1991) argues it fails to address the
effect of stigma, cultural norms and notions of social worth for the individual. Similarly Sherry’s (2006) points out that biomedicine has had an intense effect on social policy. The ideology of normality, which Oliver (1990) considers to be the basis of rehabilitation, is questioned in the context of rehabilitation by Hammell (2006), who is also critical of the manner and the methods in which the notion of normality is promoted.

Table 40: Statutory and Voluntary Agencies; Education and training; Other supports

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training not appropriate</td>
<td>‘I have no interest in computers anyway’.</td>
<td>Ned</td>
</tr>
<tr>
<td>Training not appropriate</td>
<td>‘Well he did try computer training down in a place and that didn’t work out’.</td>
<td>Tara acting as proxy for her husband, John</td>
</tr>
<tr>
<td>Good support /training /friends</td>
<td>‘I can’t praise Headway enough, the vocational training and the friends I’ve met equally and the key workers’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Overlap of services</td>
<td>‘Headway were offering me counselling but then Peter Bradley offered me counselling’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Good support /social and leisure</td>
<td>‘the Peter Bradley crowd, they are very good, we go bowling or swimming or to the gym … or whatever’.</td>
<td>Ned</td>
</tr>
<tr>
<td>Good support /vocational training</td>
<td>‘At the very, very start he used bring me to for night courses we were doing computers’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Good support /vocational /skills</td>
<td>‘What happens with Headway is they are more vocational and they are trying to get our skills more up’.</td>
<td>Sarah</td>
</tr>
<tr>
<td></td>
<td>‘my mother kicked up a stink and said this guy is going home and that’s it, Dun Laoghaire said no, that she wouldn’t be able to cope, ‘cos you know, I’d need 24 hour care. So (Name) said don’t worry (Name) ‘I’ll send out people that’ll be able to look after Gary’. Like he said to her don’t worry we will help’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Good support / coping /care</td>
<td>‘A physiotherapist used to call to the house maybe once every two weeks and then it became less frequent’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Not enough support /time limited</td>
<td>‘I have received very little help from the Health Board once I was discharged from hospital after three months’.</td>
<td>Dan</td>
</tr>
</tbody>
</table>

5.6. Path to Recovery

The final category identified is ‘the path to recovery’, with a number of sub-categories generated from the data analysis as follows:

- Trying to change
- Recovering as far as is possible
- Taking control
• Ambition
• ‘Lucky to be alive’

The importance of advocacy

The findings from this study support the argument put forward by Bury (1982) that chronic illness can upset the individual’s social relationships and self-sufficiency. This can be frightening for the TBI survivor whose recovery goes through a number of stages. The various strategies to reconnect to life employed by survivor participants in the study included: using humour as a cover up; not getting involved in social situations because of the potential to be hurt by stares or remarks from others; finding religion as a comfort; trying to overcome feelings of depression, and dividing emotions into manageable parts. Survivors talked of viewing life differently and even appreciating eating normal food again.

5.6.1. Trying to Change

The sub-category trying to change showed the personal effort made by survivors to reclaim some of their former lives. A participant made contact two months after being interviewed to say that he had completed the Dublin marathon. This, he reminded me, was just two-and-a-half years after his mother had been told by staff at the National Rehabilitation Hospital to put him in a nursing home, because he would never be able to walk or talk again. The following is the transcript given at the time of interview:

Interview: ‘You did a lot of work yourself’
Gary: I did yeah. I had to do it. I know myself that it’s only myself that will ever get me to do a marathon, so that’s why I walk.

Interview: You are determined to do that
Gary: I will do it, I will do it.
(Gary)

‘I am trying to get out of this’.
(Ned)

Each milestone is marked out as a triumph and further evidence that recovery is possible:

‘The biggest, the biggest, the happiest day of my life was when I told my OT to take away every wheelchair that was here’.
(Gary)
However, the following quote is a reminder that each victory is the result of exceptional hard work and commitment on the part of the survivor; support, encouragement and a push to independence by close ties:

I always remember my brother and my friend they took me down to the beach and they made me walk well say ten steps that way in the .. but they pushed me in the wheelchair and I’d go ten steps and ten steps the other way, I’d be yelling and screaming at them.

(Gary)

Social relationships matter and can provide a positive environment for acceptance and encouragement. Kartalova-O’Doherty and Tedstone Doherty (2010) in a study of recovery processes from mental illness, suggest that this facilitates self-acceptance and reconnection with others over time. Different approaches were adopted by the survivors to reach their goals. These included making every effort to regain their physical strength by walking or exercising, reading poems and learning basic mathematics. Their resilience was considerable in trying to overcome the physical aspects of TBI. One survivor cut up wood planks every day to practice his skills as a carpenter.

The following quotes give a flavour of the strategies adopted:

So with that I learned to walk, then I walked to the town, when I come back I stretch and relax for some time. I was tired but I did that for a month. Then one day I just called my employer and I said I want to go to work and he said no. He said you have to go back to your GP. I work it out that if my body is ok and I keep working on building up the strength. So I went back to the GP and I said to him I’m ok but anytime I am at home I am not feeling well, and he said what do you want, I said I want you to write a letter to say I can go back to work.

(James)

Various strategies were employed to help the process of recovery. One young girl smiled when she recalled what kept her going:

I have been very lucky that I had weakness and I couldn’t walk initially, because it was a right frontal lobe injury, my left side wasn’t working for a while and red shoes fixed it. I knew I needed red shoes so I would have something interesting to look at, it’s amazing the little things that mean a lot.

(Sarah)

The survivor’s own motivation had an important role in attempting to reach set goals.
‘Well, I push myself to show improvements. Well (Name) is five miles away, right and I walked out there one day when Clare were playing against Tipperary’
(Rob).

‘Like some days I would walk 14 miles’
(Dan).

Religion is used as a coping strategy by three interviewees. One participant held strong religious beliefs before his accident, but the two others turned to religion after their injury.

I wouldn’t have been a religious man before, a man brought in Padre Pio’s glove, he’s down in (Place name), he has relics and says the prayers, I was still unconscious at this stage but he said to my two girls ‘tell him ring me in a fortnights time, I have a job for him’. I asked him afterwards how do you know and he said I actually know by the feel of the gloves. I carry a Padre Pio medal ever since around in the van with me
(Joe).

‘Life is a thing that we don’t … we don’t control our lives, it is God. If I had gone, I don’t know what would happen to them (children) now. After a year or two they would forget about it and move on with their lives’
(James).

Some have been able to fall back on a sense of humour to get them through.

Interviewer: ‘You have retained you sense of humour’
Gary: ‘Never lost it. I was always a funny lad. It depends who you talk to, some people call me funny and others call me a charmer’
(Gary).
Table 41: Trying to change

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had to do it myself</td>
<td>‘I had to do it. I know myself that it’s only myself that will ever get me to do a marathon, so that’s why I walk’.</td>
<td>Gary</td>
</tr>
<tr>
<td>I am trying</td>
<td>‘I am trying to get out of this’.</td>
<td>Ned</td>
</tr>
<tr>
<td>Religion - acceptance</td>
<td>‘Life is a thing that we don’t … we don’t control our lives, it is God’.</td>
<td>James</td>
</tr>
<tr>
<td>Religion - a new orientation</td>
<td>‘I wouldn’t have been a religious man before’.</td>
<td>Joe</td>
</tr>
<tr>
<td>Humour</td>
<td>‘I was always a funny lad’.</td>
<td>Gary</td>
</tr>
<tr>
<td>Milestone /achievable / remove</td>
<td>‘the happiest day of my life was when I told my OT to take away every wheelchair that was here’,</td>
<td>Gary</td>
</tr>
<tr>
<td>aids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Push / push</td>
<td>‘Well, I push myself to show improvements’.</td>
<td>Rob</td>
</tr>
<tr>
<td>Trying / determination</td>
<td>‘Like some days I would walk 14 miles’.</td>
<td>Dan</td>
</tr>
<tr>
<td>Motivation / keep working at it</td>
<td>‘I work it out that if my body is ok and I keep working on building up the strength’.</td>
<td>James</td>
</tr>
<tr>
<td>Motivation-little things I like</td>
<td>‘red shoes fixed it. I knew I needed red shoes so I would have something interesting to look at, it’s amazing the little things that mean a lot’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Milestone /achievement</td>
<td>‘I’d go ten steps and ten steps the other way, I’d be yelling and screaming at them’.</td>
<td>Gary</td>
</tr>
</tbody>
</table>

5.6.2. Taking control

Taking control over areas of life appears to be a resistance mechanism against powerless­ness for survivors. One way they managed their lack of power was to put order on their living spaces - the clothes they wore and the food they ate. The empowerment which comes from being able to make choices about food and clothes is apparent. Four participants made an enormous effort to show me their living arrangements. This involved being shown every room in great detail and included descriptions of clothes, shoes and very personal possessions. One man painstakingly explained the type of food he eats and how he manages to cook it. This is an example of taking back the ordinary aspects of living. It is a means of exerting control and achieving independence.

Five participants said they had gained too much weight since the injury, but there was an appreciation of being able to eat normally again. They described going through the various stages: from a high fitness level achieved through sport, to being tube fed and then losing a considerable amount of weight in the early recovery phase. Hugh talked a lot about his relationship with the staff at a local Chinese restaurant. They give him extra portions and he enjoys the banter with them. All five mentioned how great it is to be able to eat normal food again.

‘The staff at the Chinese across the road are great. They give me extra portions. I told them I was getting fat … (laughs) but I have fun chatting to them’.  
(Hugh)
As well as physical and cognitive problems, many wrestle with pain, exhaustion and confusion. However, all survivors in this study expressed hope. The recurrent theme was the notion of moving on from the illness. Sometimes these stories bear witness to the struggle by the survivor to overcome the tyranny of illness, thereby reflecting a natural desire to recover from the injury, and to persuade others that they are capable of living a full and rewarding life. A participant talked about trying to get out of it; meaning for him the burden of being dependent. Rob was adamant he would not give in to the injury:

‘But I’d be head strong, I don’t like things holding me back like ... I like to get on with things if I can, get up and do it man. That’s it’.

(Rob)

Overcoming the reaction of others was the challenge for Sam. He used humour as a coping strategy and joked a lot during the interview.

Table 42: Taking control

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Interaction</td>
<td>‘I have fun chatting to them’</td>
<td>Hugh</td>
</tr>
<tr>
<td>Taking control - get up and do it</td>
<td>‘But I’d be head strong, I don’t like things holding me back like ... I like to get on with things if I can, get up and do it man. That’s it’</td>
<td>Rob</td>
</tr>
</tbody>
</table>

These findings in relation to the themes ‘trying to change’ and ‘taking control’, illustrate the enormous effort participants make after a TBI, and the various strategies employed to cope with the changes brought about by the injury. This is in contrast to that of Hill (2004) who argues those over time people stop comparing themselves to their pre-injured selves and instead accept an image of themselves which accommodates the consequences of their injury. For many participants in this study, the effort is on-going and relentless. Findings in this study support Charmaz (1987), who notes that chronically ill people are involved in a constant struggle to lead valued lives and remain positive. As previously discussed, chaos narrative, as described by Frank (1995), is a reminder of the chaotic nature a TBI survivor finds themselves in, and the difficulty they have in putting order or telling their story. However, the present data could not be considered random or chaotic. Rather it shows how survivors work through their experiences and how various encounters along the way impact on their lives.

The quest illness narrative as described by Frank (1995), affords the ill person a voice. In the quest narrative, people accept illness and seek to use it. Findings from this study clearly show that survivors found it helpful to narrate their experiences. However, few accepted their illnesses. Instead they made and continue to make every effort to recover as quickly as possible. Williams (1996) argues that people with chronic illness must embark
on the process of narrative reconstruction, of which they are a significant part. This then becomes an important aspect of their recovery process.

5.6.3. Ambition

Some survivors in the study, particularly those who made a good recovery, had ambitions such as to do further study, as articulated by James:

‘The accident taught me to look forward. I was doing a course in law before the accident and I got a credit in it, I will go back to that’.

(James)

Others such as Eoin, Ann and Sarah had a variety of aims:

‘Ambitions … I want to get back driving. I know I have to wait but it’s hard …’. (Sarah)

I want to finish school and maybe do a course. I am working really hard to get better fast. But it is a slow …, some days good, other days bad. My memory is bad … like that needs to improve and I get tired very easily. Like now I just had a shower and that’s enough to send me to sleep for hours …

(Ann)

‘I played football, I miss that now but I’m not good enough for that yet’ (Eoin)

‘I’m going to definitely continue on with further education and take some of my background in computing and Microsoft and do a Teaching English as a Foreign Language (TEFL) course and take it from there’.

(Sarah)

I want to travel again but the only thing that might limit that is my meds and driving is a big thing because I was just two and a half years clear of the seizures, you only have to be a year clear of the seizures, I was after taking my first step with the Irish Wheelchair Association getting my licence, it’s seven years in the UK, God Almighty can you imagine. But because of the seizure that’s another year back.

(Sarah)

‘I would like to go back to school’.

(Rob)

Ann wants a job and found the work experience in a library satisfying:
'I want to get a job 'cos like the feedback they have got from the work has been really good and just to hear that has been really great, and I feel oh my God you know. I was on work experience in the library'.

(Ann)

As outlined by ten of the participants, brave attempts were being made to recover after the accident. James, a native of Africa, outlined how he hastened his recovery by walking four to five miles a day and returned to work one month after the accident.

What I believe is in as much as you believe so much in yourself, you just have to have the confidence in yourself to be there, you should not let the spirit go out of you, you have to just go out there do what you were doing before, start doing that again and before long you are back on your feet. You have to accept yourself, don’t think you have to be this and that no, no, no, be positive, just believe you can do it.

(James)

As these findings show, survivors have definite goals and aspirations. Many showed self-belief but an acceptance of limitations, while striving to improve. Investment in supports for survivors, such as training and education, would greatly enhance their quality of life. This in the long-term, would increase their independence and self-worth. The lack of priority afforded to rehabilitation for survivors of TBI gives credibility and credence to the widely held cultural notion that a life with a disability is a life not worth living and, the survivor would be better off dead than disabled (Hammell, 2006). Again, illness and disability is influenced by the discourses used in the public domain, which are based on narrow biomedical explanations (Blaxter, 2007).
Table 43: Ambition

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Look forward</td>
<td>‘The accident taught me to look forward’.</td>
<td>James</td>
</tr>
<tr>
<td>Drive again</td>
<td>‘I want to get back driving. I know I have to wait but it’s hard’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Finish school /get better fast</td>
<td>‘I want to finish school and maybe do a course. I am working really hard to get better fast’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Play football</td>
<td>‘I played football, I miss that now but I’m not good enough for that yet’.</td>
<td>Eoin</td>
</tr>
<tr>
<td>Further education</td>
<td>‘I’m going to definitely continue on with further education’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Travel</td>
<td>‘I want to travel again’.</td>
<td>Sarah</td>
</tr>
<tr>
<td>Back to education</td>
<td>‘I would like to go back to school’.</td>
<td>Rob</td>
</tr>
<tr>
<td>Get a job</td>
<td>‘I want to get a job’.</td>
<td>Ann</td>
</tr>
<tr>
<td>Confidence and self-belief</td>
<td>‘What I believe is in as much as you believe so much in yourself; you just have to have the confidence in yourself to be there, you should not let the spirit go out of you’.</td>
<td>James</td>
</tr>
</tbody>
</table>

5.6.4. ‘Lucky to be alive’

An overarching theme emerging from the data is that the participants feel lucky to have survived and be as well as they are. They compared themselves to others who had more severe deficits and made judgements that their experiences were tolerable compared to others. A prominent aspect for many participants was the strong will to survive. The following quotes illustrate this, as participants look back to the accident:

‘I am very lucky like, especially when you are going 80 or 90 mile an hour and hit into a van’.

(Richard)

In Cork my skull was so crushed they had to raise the skull so they had to put in a titanium plate so now my mates call me tin head. But then when I was in Cork when I was recovering I got two diseases which have killed a lot more braver than me, I got MRSA and Cdif. But I am very lucky to be here and doing ok.

(Gary)

I am improving though, a little bit anyway. No I suppose, if you compare me now to early on I have made major progress. When I was in (Hospital Z) I had
a trachea and all. When I got MRSA everyone thought that was the end of me. It was a struggle back after that. (Hugh)

Jack never thought he would be involved in an accident. He highlighted the reactive approach taken by statutory bodies in case of litigation, rather than taking pro-active approaches to road safety issues:

But I didn’t think it could happen to be honest, I thought it could never happen to me. 
It was off a quad bike you know just down at the end of the road. Did you see the wall across the road? When you go down now do you know where you come to a stop, well first of all the ‘STOP’ sign they put that up the next day after I had the accident. Just look straight across the road where I knocked the wall. (Jack)

Richard is convinced, after his own experience that:

‘It could happen to anybody’. (Richard)

Similar to the previous findings, the theme ‘lucky to be alive’ and findings from survivor accounts, offers an alternative argument to the often held societal belief that a TBI survivor would be better off dead. According to Hammell (2006), the systems of classification, such as DALY and QALY, which use value measurement to accord a higher value to a person without a disability than to one with a disability, do little to address the cultural notion that a life with a disability has less value than one without. In addition, while some participants accept that this type of injury could happen to anyone, they also reveal how young people, particularly young men, think accidents will never happen to them. This supports Webb (1998) argument that TBI is largely related to the male adulation of speed and cars.
<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lucky to be here and doing ok</td>
<td>‘But I am very lucky to be here and doing ok’</td>
<td>Gary</td>
</tr>
<tr>
<td>Making progress</td>
<td>‘if you compare me now to early on I have made major progress’</td>
<td>Hugh</td>
</tr>
<tr>
<td>Could never happen to me</td>
<td>‘But I didn’t think it could happen to be honest, I thought it could never happen to me’</td>
<td>Jack</td>
</tr>
<tr>
<td>Could happen to anyone</td>
<td>‘It could happen to anybody’</td>
<td>Richard</td>
</tr>
</tbody>
</table>

5.6.5. The importance of advocacy

The core category of ‘recovery’ and reconnection with life is reliant on positive supports. The NGOs have an important role to play in representing the view of survivors. For example, in this study, Sarah had much praise for the director of her local Headway organisation who accompanied her to the Irish Wheelchair Association, the organisers of her supported accommodation arrangements. As previously stated, the level of involvement and support by family and friends had an enormous influence on how recovery was experienced. Fathers, mothers, wives, brothers, sisters, sons, daughters and aunts acted as advocates in their relationships with healthcare professionals and the statutory providers to gain information and access to rehabilitation and services for their loved ones.

‘Well Mam and Dad like every day they were just come on pushing and pushing, Jane then pushing and pushing, yeah, yeah.

(Cian).

‘Jane is like a .. oh my God a block of kind hardness if you know what I mean’.

(Cian).

A young male was quite definite that it was his father who helped him most after his accident:

Interviewer: ‘What do you think helped most after the accident?

Richard: ‘Me Da … He is still helping away’.

(Richard).

Many of the survivors attributed their recovery to a loved one taking on a caring role. Mothers in particular came in for particular praise, many of whom gave up their jobs to care full time.

Hugh: I came home here. Mam gave up work to look after me. The health
board also gave us some help with people like, home help and a bed and a hoist and all that. They also paid for the downstairs bathroom and ...

Interview: If your mother had not been able to give up work, do you think it would have been different?

Hugh: Definitely. I think I would have been put in a nursing home or a hospital. She worked 24/7 for months to look after me. She never took a break, although my sisters help out as well and Da does his best, but he works so he is not as free. She minds Adam as well now, she is a mighty woman. I suppose all Ma’s are like that, do you think?

(Hugh).

‘Like my mother had to give up everything. She is always here, helping me and everything. Without her I think I would have found it much worse being down here in Dublin’

(Eoin).

Sam’s complaint that his mother ‘makes him do things’ to become more independent is significant in the context of dependence and independence issues.

‘I will have to pay her ... She’s my home help (his mother)... She makes me do things’.

(Sam).

The findings here demonstrate the loving support many survivors received from their families, especially from mothers. While others highlighted the great practical and emotional support from friends, staff of NGOs were an important source of practical support and advocacy. A distressing aspect was the lack of support from other friends within their social networks. Survivors articulated the need for people to represent and advocate for them, particularly at the early stages. The level of personal capital which family members and friends possess generally influences survivor experience. Findings from an interview with Gary show that his mother was the person who persuaded the medical team that she could take care of him, even though they thought his care needs were too demanding.

Shapiro (1993) suggests that disabled people need to quickly acquire skills of self-confidence to overcome a world of prejudice and discrimination (Hammell, 2006). Negotiating the world of clinical medicine is challenging for families with little prior knowledge of this subject. Findings from this study clearly show that survivors and families must find ways to understand the clinical aspects of brain injury. At the early stages when the survivor is unconscious, this is a particular concern for families, who may have very little prior experience of dealing with this type of event, (this is discussed in more detail in Chapter 6:
Other Voices-Family Members). A trusting and partnership type of relationship is essential between survivors and the health professionals treating them. The unequal distribution of power between these two groups creates tensions. Etzioni (1961) in an attempt to explain power and control, showed how compliance is an essential element in the relationship between those who hold power and those over whom they exercise it.

Sarah had encountered problems since moving to sheltered accommodation owned and run by an NGO. The staff insisted she got up early on Saturday morning, while she preferred to sleep on, as the weekend is her only time off. She was reluctant to complain fearing that she would be returned to the nursing home if she failed to conform. She outlined here how she felt:

You have to be very good at fighting your case if you are any way intelligent which I hope I am. I am a fairly good advocate by myself and I find Headway resources very good because if I am having a problem or if anyone is having a problem with me they can talk to me. Like (Name) went to a meeting about me in the Irish Wheelchair Association, I thought I was going to be kicked back to a nursing home and I was frightened 'cos (Name) from Peter Bradley Foundation took me out to see my Dad and am I called in to say Hi to people in the nursing home and I thought Oh My God I can’t believe I stayed here. It’s very weird.

(Sarah).

Table 45: The importance of advocacy

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quotation</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouragement from parents and</td>
<td>‘Well Mam and Dad like every day they were just come on pushing and pushing, Jane then</td>
<td>Cian</td>
</tr>
<tr>
<td>wife ... pushing</td>
<td>pushing and pushing, yeah, yeah’</td>
<td></td>
</tr>
<tr>
<td>Help from father /still helping</td>
<td>‘Me Da ... He is still helping away’.</td>
<td>Richard</td>
</tr>
<tr>
<td>Help from mother /gave up work</td>
<td>‘Mam gave up work to look after me’.</td>
<td>Hugh</td>
</tr>
<tr>
<td>Help from mother /gave up</td>
<td>‘Like my mother had to give up everything. She is always here’.</td>
<td>Eoin</td>
</tr>
<tr>
<td>everything</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help from mother /make me do</td>
<td>‘I will have to pay her ... She’s my home help (his mother)... She makes me do things’.</td>
<td>Sam</td>
</tr>
<tr>
<td>things</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Peer advocacy

Involvement with peer advocacy groups, such as BRI, was mentioned as a positive experience. Survivors found these advocacy groups provided a safe place for them to talk about their injuries, without feeling they were being judged by able-bodied people. Participants told other brain injured survivors about the advocacy groups and brought them to meetings.
I met one guy in the last two weeks. He told me three years ago he had a brain injury, he was a back seat passenger in a car and the car crashed and out he went. And he told me he’s got no contact with Peter Bradley and he’s not even a member of BRI. So the next meeting now he is going to go there (Gary).

Goffman (1954) describes ‘back room’, the informal behaviour reserved for those with shared experiences and have therefore common knowledge of circumstances and certain insider understandings of one another. The other behaviour he calls ‘front room’, where a certain decorum is observed in a formal setting. For disabled people, who have to present themselves as normal to the outside world, ‘back rooms’ in the shape of support groups, are a welcome relief. Findings from this study show the positive benefits of support organisations for survivors. The strategies used by survivors could be described as efforts to regain control. These had varying degrees of success, but were aptly described by one participant as ‘managing life in small parts’ (Rob). This was echoed by others in the study who talked of taking one day at a time, and a favourite phrase of John’s was ‘wait and see’.

Resistance to negative reaction from others appeared to be more difficult for the very young participants in the study. Ann’s experience of being refused entry to a nightclub, Rob’s embarrassment due to the scar on his throat from a tracheotomy, and Sam’s concern that people stared at him in public places, have obliged them to develop new ways of protecting themselves from hurt and embarrassment. Sam is careful never to go out on his own, while others only go to places that are familiar to them. The setting of achievable targets was a central focus for eight participants. Two talked of taking driving lessons in an effort to get a driver’s licence again. Ned told of cutting timber planks every day, so he would get the dimensions right for the time when he could return to work in the buildings. Sam is taking basic Mathematics and English lessons so he can go back to school, while Hugh and Eoin are working at improving their skills in an effort to regain some independence. Gary has set himself a goal of running a marathon and playing with his local football team.

In summary, these findings are a clear demonstration of how survivors strive for independence and are driven by a need to take back a sense of control and autonomy over their lives. The data also show the extremes they will go to achieve this. A reason for this is, as commented by Barnes and Mercer (2003), is that cognitive impairments carry negative implications. The pressure to fit in and appear normal places undue pressure on survivors. Goffman (1993) outlined the possible options available to the individual, either to hide the injury and its effects, or to disclose all information and, in doing so risk labelling and stigma. For example, two participants in this study were unable to socialise because of
the possibility of getting a seizure or of losing their balance and falling. Kelly and Field (1996) argue that essential to becoming credible in society is to give the impression of some degree of control over our bodies.

5.7. Discussion
TBI survivors related their own personal experiences and challenges during a process of recovery - but their stories of public ignorance and lack of sensitivity highlight the need to place their individual problems in a broader social context. This research has suggested that illness narratives, a common approach to recording experiences of chronic illness, must thoroughly integrate social aspects of the illness experience. Only then, will these elements of the TBI experience be fully acknowledged. By highlighting the processes of recovery for TBI survivors and their personal stories, a more balanced sociological approach has been developed. This compares well with a limited biomedical description of TBI. Health and illness are not just individual experiences - they occur in social contexts which, can be more or less, open to the needs of the person. Therefore, the theoretical framework adopted at the start, based on a top down approach, needs to be expanded to include these other aspects of the TBI experience.

The powerful stories shared by TBI survivor’s highlight the power of illness narratives. At present, the voices of TBI survivors have not been heard compared with that of healthcare providers. Foucault (1976) insists that truth is produced by people in social positions of power. Truth is produced and sustained by power and in turn truth produces and extends power. He claims knowledge and power are inseparable (McLaren, 2002). This is particularly relevant here in the context of how little information is given to the survivors and their families. It also highlights the need for self-advocacy training for survivors and their families. Kleinman (1995) acknowledges the need for patients and families to tell their stories of suffering and to share their experiences with others, in order to understand what has changed for them in their social world.

In this study, the experience of sixteen survivors of traumatic brain injury is represented. It may not be generalised to all survivors of TBI in Ireland because in qualitative research, the analyses are distinctive to the particular researcher, the participants and the perspective of the study (Morrow and Smith, 1998). However, the findings provide an important and useful insight into the experiences of TBI survivors. Nine participants referred to the benefits of talking to someone, emphasising the need for service providers, family and friends to take time to listen to stories of survival. For instance, Dan, a man who lives alone, reiterated a number of times how he would value having someone to listen to him. Most survivors remarked how helpful they found giving the interviews - telling their version of the event for the first time since the injury. Frank (1995:1) contends that ill
people have to learn to think differently: ‘they learn by hearing themselves tell their stories, absorbing others’ reactions, and experiencing their stories being shared’ (Frank, 1995:1).

It was apparent from the stories survivors told that each was experiencing different types of narrative, many going through more than one type during recovery. For example, the restitution narrative form was common in the majority of cases, particularly those who were relatively recently injured. The aim in the restitution narrative is to get better. Ann’s story is one of restitution, her challenge is to persuade others that she was sick, but is now well. Frank (1995) argues that people learn this approach ‘from institutional stories that model how illness is to be told’ (Frank, 1995:78).

Newspapers and magazines regularly run features on how well people have recovered from serious illness - they return to work or to playing sport within a short time. With this type of message comes the expectation that every ailment is curable. Little attention is given to the experience of living through treatment, recovery and perhaps major lifestyle changes resulting from illness. While restitution stories offer the promise of a happy ending, the chaos narrative is an exposure of the teller’s fragility. It has been described as ‘the pit of narrative wreckage’ (Frank, 1998:110). Dan’s story, one of the respondents in this study is one of chaos. He is seeking recognition of this chaos, a common coping strategy during illness or trauma, by trying to put order on the situation in which he now finds himself. On the other hand, Gary’s and Sarah’s story are ones that fits the quest narrative description. Their illness journeys are attempts to ‘meet illness head on’; they take on the challenge and try to use it to some advantage. For example, Sarah’s analysis of her injury is positive; it has opened up a whole new network of friends. Gary trains with his football team and is now preparing to run a marathon. The past thus becomes reintegrated into the present, and takes on an increased significance (Frank, 1995).

5.8. Other Issues: Limited Resources

Phillips (2009) stated that Ireland has only ten neurosurgeons in total, a level below other European countries. Interview data from the present study with a consultant neurosurgeon in Cork University Hospital, and a consultant neurosurgeon at Beaumont Hospital, Dublin, bear testimony to this finding. They describe being overwhelmed by the workload, and used expressions such as: ‘barely keeping my head above water’. One neurosurgeon also talked candidly about the disconnect between what he does as a surgeon and where the survivor goes after he leaves the acute setting. Even with the best intentions, it is impossible for him and his colleagues to do any more than just deal with the neurosurgical aspect of the patient’s care. The same can be said about the scarcity of resources to fund rehabilitation and the training of appropriate staff in current rehabilitative practice.
According to O’Connell (2008) only one in four people awaiting neuro-rehabilitation will succeed in gaining a place at the National Rehabilitation Hospital. This opinion was also echoed by a consultant in rehabilitation medicine whom I interviewed. He felt that the government needs to take seriously and fully resource this type of service. Funding is determined by diagnosis and ‘resources are primarily allocated for the diagnosis and specific treatment of disease’ (Wade and Halligan, 2004:1399). This narrow approach ignores the social factors which determine how well or poorly a patient responds to treatment. It also undermines the benefits of rehabilitation and post rehabilitation, or the use and provision of technology and equipment. The WHO’s ‘International classification of functioning, disability and disease’ (2001) clearly recognises that disease has consequences at different levels and must be placed in the context in which they occur (Wade and Halligan, 2004).

5.9. Conclusion

It must be stated that the fortitude displayed by the survivors in this study bear testimony to their resilience in the face of overwhelming change in their lives. The key themes identified are: loss of role, helplessness, dependence and, being overwhelmed by uncertainty. The recovery process - reconnecting with life, identified sub-categories such as: taking control, ‘lucky to be alive’, and ambition. The survivors narrated the challenges they face on a daily basis and yet almost all remained positive. This study shows the potential for improvement if survivors are facilitated and encouraged to develop their skills of adaptation after TBI. Without doubt, there is a need to integrate policy and practice of the rehabilitation sector into the wider health, education, and training and employment areas. At present, the sectors in Ireland are disjointed and services are unintentionally fragmented (Kiernan, 2004). Currently, so much remains un-recorded. The setting up of a database registry of people with traumatic brain injuries will allow an analysis of this population. From this, evaluation of service provision can be undertaken and proposals to resource service provision can be advanced.

This is one of the few instances of research documenting the perspectives of people with TBI and therefore contributes to new knowledge. Further knowledge can be gained regarding communication links and service integration and how these can be fostered between the various elements of service provision. The findings can contribute to the wider debates on the delivery of healthcare and enhance understanding of broader quality of life issues. The study findings suggest the value of a multi-disciplinary approach to researching the problem and potential solutions drawing on disciplines of sociology and clinical sciences, and in particular, the sub-field of neuro-rehabilitation. The next chapter (Chapter 6) presents the findings of the qualitative research with the data collection and analysis focused on the experiences of family members of TBI survivors.
Chapter 6
Other Voices – Family Members

6.1. Introduction

The purpose of this chapter is to present the findings from the eleven qualitative one-to-one interviews which were conducted with family members of survivors of traumatic brain injury. The research question being addressed in this chapter is: what are the experiences of family members of survivors after a traumatic brain injury?

The chapter aims to connect the macro to the micro (a top-down aim), showing that the rehabilitation and post-rehabilitation services in Ireland remain significantly under-resourced, both financially, and in terms of infrastructure. This puts pressure on carers, who generally are immediate family. I draw widely on the works of Blaxter (1976) and Bury (2005) in the analysis of the research findings, and to address the research question (a top-down approach). These suggest that the meaning of chronic illness is to be found in its symbolic and practical consequences (Locker, 2008). Analysis of the interview transcripts allowed the development of an approach to explain the surreal experiences of family members following the survivor’s injury. This was indicated by the participants who told of not believing that this was happening to them, of it being like a dream or a nightmare. Several categories, grounded in the data, were arrived at inductively, having re-read the transcripts repeatedly and referred to field notes. These categories formed a model to describe the processes from the time the respondents heard the news to the present. In terms of the core category, the process of adaptation by family members, was identified as significant. According to Roy (1988), a person reacts to internal and external stimulus which leads to a change of behaviour and adaptation to circumstances. The sub-categories identified are illustrated in Figure 3. The theoretical framework on how family members adapt to the changes brought about by a TBI, initially to the survivor’s life and then to other close family members, are illustrated in Figure 4.
Figure 3: Recurrent Sub-Categories from Interviews with Family Members of TBI Survivors.

- Getting the News
- Reality of Survivor's Life
- Response of Healthcare Professionals
- Milestones and Hopes
- Realisation of Change
- Reclaiming Own Life

Figure 4: Theoretical Framework-Family members 'Adaptation'

CONSEQUENCES/ADAPTATION
- Strategies
- Survival
- Hope
- Milestones
6.2. Getting the News - The 'Surreal' Experiences

Participants described the shock of being told the news that a family member had been in an accident. Their memories were vivid and each detail was important - how they were told, what the survivor looked like, when they were allowed to visit the hospital, the time spent there and the endless waiting for news. Some described this as a surreal experience, which was interspersed with a mixture of hope and despair, terror and fear and the uncertainty of not knowing whether their family member would survive. The following quotes illustrate their initial feelings:

Well, maybe when you get your head around ... you know he is not going to come out of that coma and get up and be ok again. When he comes out of the coma you think this is great we have turned the road, turned a bend in the road.

(Jane-Mother).

'You come through all the stages. The shock of hearing the news, then wondering and waiting ... Coming out of the coma, then more waiting and eventually getting a bed in the rehab'.

(Miriam-Mother).

Well, the first we heard of it was when the guards called and said Hugh had been in an accident. He had been shifted to [Hospital Name] at that stage. We just got in the car and went. I thought he was dead. It was the longest car journey ever. When we got to the hospital, he was in Intensive Care unit and they wouldn’t let us see him, they were doing things to him ... tracheotomy and that you know

(Sarah-Mother).

Father: They looked after him well to be fair to them; they did everything possible to give him the best chance. We stayed then in the hospital night after night. All our relations came ... sat with us. When we did get to see him after about 6 hours it was an awful shock ... I couldn’t believe it was (Hugh) ... He was all battered and black and blue.”

Mother: ‘Unrecognisable. His head was twice the size. I didn’t think he would survive ... but he did.

(Sarah and Tim-Mother and Father).

This sense of insecurity is articulated by many family participants:
‘He nearly died so many times. It was a rollercoaster of emotion. One minute we were hopeful and then it would all change … We would be called in to the hospital and we were told loads of times that he wouldn’t survive. (Alan-Father).

Noel recalls his experiences of waiting in the acute hospital where his brother was being treated:

In the three weeks he was in that ward, 12 people came out, nine were in body bags, that’s the sort of figures we were dealing with. That’s the truth, I mean there were people crying on corridors at night in the hospital, they didn’t have anywhere for you to stay, you were on couches sitting on the corridor and … but there was great spirit amongst people. I used to stay there at night, just sleep in the car in the car park and get up every three hours to go in and it was grand like that (Noel-Brother).

Table 46: Getting the News – ‘The Surreal experiences

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Illustrative Quote</th>
<th>Participants</th>
</tr>
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<tbody>
<tr>
<td>‘Waiting’ and ‘Time’</td>
<td>‘We stayed then in the hospital night after night’</td>
<td>Sarah (Mother)</td>
</tr>
<tr>
<td>‘Waiting’</td>
<td>‘You come through all the stages. The shock of hearing the news, then wondering and waiting … Coming out of the coma, then more waiting and eventually getting a bed in the rehab.’</td>
<td>Miriam (Mother)</td>
</tr>
<tr>
<td>‘Waiting’</td>
<td>‘I used to stay there at night, just sleep in the car in the car park and get up every three hours to go in’</td>
<td>Noel (Brother)</td>
</tr>
<tr>
<td>‘Disbelief’</td>
<td>‘… it was an awful shock … I couldn’t believe it was (Name) … He was all battered and black and blue’</td>
<td>Tim (Father)</td>
</tr>
<tr>
<td>‘Milestones’</td>
<td>‘When he comes out of the coma you think this is great we have turned the road, turned a bend in the road’</td>
<td>Jane (Mother)</td>
</tr>
<tr>
<td>‘Survival’ – uncertainty</td>
<td>‘I didn’t think he would survive … but he did’</td>
<td>Sarah (Mother)</td>
</tr>
<tr>
<td>‘Survival’ – looked bad / bad news</td>
<td>‘I didn’t know if he would survive, he looked so bad and the doctors were giving me bad news’</td>
<td>Elizabeth (Wife)</td>
</tr>
<tr>
<td>‘Survival’ / thought he was dead</td>
<td>‘I thought he was dead’</td>
<td>Sarah (Mother)</td>
</tr>
<tr>
<td>‘Survival’ / unlikely</td>
<td>‘We would be called in to the hospital and we were told loads of times that he wouldn’t survive’.</td>
<td>Alan (Father)</td>
</tr>
<tr>
<td>‘Time’ – hopeful</td>
<td>‘One minute we were hopeful’</td>
<td>Alan (Father)</td>
</tr>
</tbody>
</table>

The key finding is the shock and horror experienced on hearing about the accident and then hope mingled with despair in the weeks that followed. The unexpected and abrupt changes brought to the lives of family members and significant others as a result of a TBI, can only be poorly understood by them at the early stages (Jumisko et al., 2007; Duff, 2002). Close relatives are totally focused on the injured person (Engström, and Söderberg,
2004), and their time directly after the injury is taken up entirely with the injured person and their chances of survival (Bond et al., 2003 and Duff, 2002). According to Cameron (2001) predictable actions are activated during times of heightened anxiety. Families act predictably after a major disruption, such as injury to a loved one.

6.3. The Reality of Survivor’s Condition

The category ‘the reality of survivor’s condition’ is a combination of sub-categories: independence to dependence; financial burden; physical effects; embarrassing behaviour and lack of public awareness. These were derived from other themes which included: may not make a full recovery; mood swings, frustration; memory loss; physical changes; stone throwing, unwanted visits to the hospital; help from friends, community and the Police.

6.3.1. Independence to Dependence

Kaufman (1994) and Marshall et al. (1995) point out that definitions of independence differ considerably from definitions of dependence, where the emphasis on independence is on self-regulation, control and the ability or opportunity to make choices about aspects of their lives. Hence, Barnes (1991) warns that attempts by family members and care givers to over-care and over-protect, may encourage dependency. Family members described how the survivor changed from being independent, to requiring care. In some cases this was a total care requirement. Future plans and aspirations for the injured person were shattered. The adjustment necessary is articulated by the mother of a young man who now requires continuous twenty-four hour care:

Well he was a 21 year old independent which he was, we thought he was reared and he was leading his own life. He is now become totally dependent. He was doing an apprenticeship; he had two years done at car mechanics. He was car mad. From then independent, he is totally ... in need of total care, and even two years down the road he does need total care and support.

(Jane-Mother).

However, there is a presumption that the individual is dependent in all aspects of their lives. Some brain injured survivors may quickly become physically and cognitively independent and be able to perform everyday tasks but, out of concern for their own safety, are prevented from doing so. Elizabeth articulates this as she describes how her husband wanted to return to work weeks after his TBI:

‘He could not understand why he had to rest: he was walking six miles a day. He only wanted to go back to work, he hated hanging around’

(Elizabeth-Wife).
Noel found a solution which respected the TBI survivor’s efforts to be independent when his brother Ned insisted on going for walks on his own. He articulates it thus:

‘I didn’t want him walking on his own but he insisted, so what I did was I let him go and I would go up to the top of the hill with a pair of binoculars and I’d watch him and see how he was getting on’

(Noel-Brother).

The findings in this section demonstrate the effect of the shift from independence to dependence. On the one hand, it presents a dilemma for the family members and caregivers who are torn between trying to protect the survivor while encouraging a sense of independence. Various approaches and the language used, particularly by healthcare providers, may well reinforce dependency. For instance, Helen, the mother of Sam, a teenage boy, described how he found the questions the speech therapist asked a bit childish. He felt this approach undermined his confidence. The reality of the survivor’s condition is difficult for both survivor and family members to accept, particularly when is survivor is young. .

Gignac and Cott (1998) list a number of consequences which accompany loss of physical independence. Nevertheless, maintaining a sense of independence is critical because, as Giddens (1991) and Kelly and Field (1996) suggest, bodily competence is an essential part of how social interactions are maintained.

6.3.2. Financial Impact/Burden

Many of the family participants in this research described the negative impact of the accident on their financial resources. Many families experienced severe negative change to material resources and income which led to other changes in family roles. For example, one young wife and mother of four children, the youngest a baby of three months, was obliged to find a job in order to support her family after her husband’s accident.

‘I now have to work ’cos he will never be able to work again’

(Tara-Wife).

Another couple was hopeful that they will receive from the State the three million euros needed to treat their son at a special facility in the UK.

‘Well, we are hoping the HSE will pay, it will cost a couple of million, sure how else do we do it, we can’t sell the house from under us’

(Jane-Mother).

Harry, the father of a survivor explains how he and his wife are able to cope with the financial demands of caring for a dependent son because of their stage in life. He is retired and she was able to give up her part-time job because their other children are reared.
We have no mortgage and the few pound that we earn we have and we wouldn’t be too worried about … they are at the stage they are all educated. He was the youngest then as well. What you have you can do what you like with it. He is the youngest, we might not have been able to do it as good if it was otherwise, we know that. We met people and it was their eldest (Harry-Father).

A survivor with a significant brain injury can unintentionally place a financial, as well as an emotional burden, on their family (Hawley et al., 2003). McMordie and Barker (1988) point out that the financial burden placed on the family after a TBI has a significant negative effect on their quality of life. Some interviewees expressed concern about ‘cuts’ in welfare payments¹. Data from the previous chapter (Chapter 5) show that survivors find it difficult to survive on a disability allowance. For instance, one TBI survivor mentioned he could not afford the cost of broadband, while another found transport costs prohibitive. Recently the Government in Ireland cut the disabled people’s income by 4.1 percent. Further income and service cuts are expected in 2010 (Disability Federation of Ireland, 2010).

The extent to which the problems associated with chronic illness and disabilities are managed is dependent on the resources to which individuals have access (Scambler, 2008a). The level and the type of available services and supports greatly influence how well the survivor and family members cope with the consequences of brain injury. Data from TBI survivors in this study show the positive effects of the supports offered by the NGOs at locations in Ireland.

‘Peter Bradley are very good’
(Tara-Mother).

Tanya explained how difficult it would be for them to access the services of the nearest NGO:

‘But you would have Peter Bradley in (Name of City) I suppose, but we actually never went, its 90 miles away’
(Tanya-Mother).

Findings from this study also show that services provided by the HSE were often absent or inadequate, as Noel explains:

Well the services when Ned came out of Dun Laoghaire, it seemed as if people they were only going through the motions, like the occupational therapist that came here just looked around and said you need to get this, you need to get that, they just weren’t interested you knew by the body language that apathy was rampant and really and that was the situation with the community physiotherapist that came. In fairness I am being harsh because I know that
woman has 300 people to see and she is the only one doing it, I know that. But this is the way and it's not her fault but she would literally get out of the car, talk to Ned sometimes for two minutes without even getting him to ... checking him out.
(Noel-Brother).

I suppose if he was getting more one-to-one three or four times in the week for an hour it would be great. Just to get the spellings maybe and a few different things, 'cos it is all repetition and all learning and the more he does the freer it will be I suppose.
(Tara-Wife).

Scambler (2008a) suggests that there is a relationship between the individual's experience and the social and political approach to providing services specific to a person's needs, being mindful of the long-established links between disability and poverty. Strategies taken by government to facilitate treatment and support are not being implemented, or are inadequate (United Nations Economic and Social Council, 2010).

6.3.3. Physical Effects

The physical effects of brain injury manifest in different ways. Tara describes how difficult and frustrating it 'must be' for her husband who has expressive aphasia – see Appendix A. She empathises with him as he tries to manage the limitations of this physical side-effect of TBI:

'I mean he wouldn't be as patient as he was before, but I suppose that all the frustration. I know yeah (sad), it's annoying for him. It's on the tip of his tongue he just can't say it'.
(Tara-Wife).

Helen and Tanya, mothers of young survivors, described how they struggle with the tiredness and other physical problems.

'He could go somewhere now and be very tired the day after'
(Tanya-Mother).

'I didn't think he would have a long hard road ahead of him. He struggles with tiredness, trying to walk, problems with breathing and loads of other things'.
(Helen-Mother).

Alan who is the father of a young man describes the negative side-effects of TBI that have lingered on:
'But he's still madly muddled in his head like you know he didn’t know where he was, and he doesn’t remember anything, well not much about the accident anyway'
(Alan-Father).

Harry found it surprising and difficult to cope with the fact that his son has so little awareness of the effects of his injuries, even though he can hold a conversation with him. He explains this in the following way:

His insight into his injuries is one of his biggest problems. The left hand side of his body has no power whatsoever … The way he can talk like that yet he is unaware that he is incontinent, like it’s unbelievable. He would lie in bed all day there; he would never look to get up. Sure he could be wet there and he wouldn’t know. Sure that’s the way he is
(Harry-Father).

Tara describes how her husband’s activities are restricted because of his seizures and spasms:

Interviewer: How often do the spasms occur?
Tara: Could be twice a week. There is no set pattern, no warning or anything, they just happen out of the blue. That’s why it’s a bit … going off walking is difficult. Two or three minutes they last for. I asked them one time and they said it’s because his muscles are so tight. But I think a lot of stuff they don’t really know.
(Tara-Wife).

Noel demonstrates with his example how little understanding there is amongst acquaintances in social settings about the effects of brain injury, and their reaction to cognitive difficulties of the TBI survivor i.e. they are offended:

‘We found that there was some people who would take offence at the fact that he couldn’t remember them, which I thought was amazing. But 3 or 4 people would go on and say ‘surely he remembers me, what’s wrong with him?’
(Noel-Brother).

The key findings here centre on the encounters family members have with acquaintances. Rather than offering any understanding, others make judgements based on the physical effects of TBI. This is also similar to the findings from survivors who reported being ignored (or ‘written off’) because of their brain injury. Memory loss, fatigue, and lack of insight to the extent of their injury posed difficulty for family members in this study. Frustration and mood swings are also side-effects of TBI. These are clearly findings of this
research and are also consistent with findings of other researchers (Cantor et al., 2005). The findings of this research are also similar to that of Jumisko et al. (2007) who notes that close relatives are saddened by the change in personality brought on by the injury.

Families also need to learn how to deal with the new situation and the changes in the personality of the survivor:

'And the family are trying to interpret what they want and trying to speak for them and you are learning as a family I suppose because this is a different person you are dealing with, like it’s a whole different'.

(Helen-Mother).

Assumptions about disability are based on aspects that are visible to others (Sherry, 2006). This is a key issue for families caring for survivors. The disability may not be visible and the reaction and lack of understanding of others may undermine and affect feeling of self-worth of the survivor. This is borne out by Tanya, for instance, who said acquaintances do not understand the nature of the survivor’s disability, and ignore her son, presuming he does not understand:

Well I suppose in the beginning it was touch and go for such a long time and nobody, a lot of people can’t believe he can walk and talk, can do the normal things and he has feelings like everybody else. And you know they look at us and say can he talk.

(Tanya-Mother).

Goffman’s (1963) work on stigma is helpful in understanding the cultural representations of disabled people. The individual is ‘reduced in our minds from a whole and usual person to a tainted and discredited one’ (Goffman, 1963:3).

The mother of another young man tries to understand why her son is ignored by acquaintances:

‘Because a lot of people think he is worse than he actually is’

(Jane-Mother).

A prominent theme in interviews with family members about their everyday routine is the embarrassment they feel at dealing with a survivor’s difficult behaviour. This often involved impression management and creating strategies to deal with the reaction of others to the survivor’s unpredictable behaviour. Jane and Harry, the parents of a young man who is being cared for in a nursing home since the brain injury, gave some insight into their experiences:
Mother: You will get the verbal abuse, and very inappropriate
Father: He comes out with the worst things, unbelievable (deep sadness)
Mother: Oh the worst
Father: Ah the worst, worst’ (disgust)
Mother: Ah. Unbelievable and they say people with brain injuries, because of
the lack of inhibition; they go back to being primitive
Father: You couldn’t put up with him at all, no. You couldn’t take him
anywhere … He is just saying what he is thinking; it’s out of his mouth
Mother: But it’s even worse than what he is thinking
Father: Well it is worse
Mother: But it’s a level deeper than that, it’s a primitive attack like
Mother: I don’t even know if you put him in with other people who are brain
injured, how he would relate to them
Father: That is the huge problem with him is, the behavioural aspect, he needs
specialist sort of care.
(Jane and Harry-Mother and Father).
Father: Well he comes across that he means it, he would hurt you with the
insults. He would leave you sitting.
Mother: Very personal and like some people have a great ability to shrug it
off.
A fat bitch is a great one, even people who are not fat, people have weight
issues.
But you see it’s the injury and not the person. They see his bad behaviour
and they can’t see it as the injury. That’s a huge thing. A free whore, I don’t
know where he came up with that, what’s a free whore I said to him one day
(laughs), my sister said it has to be one worse than a whore (laughs). He is so
perceptive it’s unreal and yet his awareness or insight is so poor. He will tell
you ‘hooker boots’ like these are and … I do say: ‘this is your mother you
are talking to’, sorry about that he’d say, I take it back and in the next breath
it’s the same thing. But he is very racist, for a guy who would give out to you
before for saying anything like that
(Jane and Harry-Mother and Father).

Jane and Harry told their story as they searched for answers and reasons why their son could
make such inappropriate comments. It appears such strange behaviour is regarded by them
as totally out of character. Linked to that, they have a need to hear an explanation:
'whatever the injury did to him he doesn’t understand that and he has behaviour problems, then so he has another obstacle'.

(Jane-Mother).

A number of family members described the benefit of meeting others, with similar experiences, such as at the support group meetings organised by NGOs and other voluntary groups. They described feeling safe talking to people who understood their problems. Tara was willing to travel fifty miles in order to meet others in similar circumstances:

'I suppose as I said support groups 'cos I don’t know anyone at all who this has happened to so I would like to know someone else that would know what you are talking about 'cos people don’t understand what you are talking about, they haven’t a clue like so it would be nice to have someone else to know, do you know, that would be ... something. I think they might be bringing something to (Name of City). I’d travel there alright.'

(Tara -Wife).

The findings show the enormous effort made by family members to limit the effect of a survivor’s behaviour in public. They are forced to develop coping strategies to deal with the survivors’ behaviour so as not to cause offence to others. The impact of TBI on families and carers is well-documented (Brooks, 1991; Kreutzer et al., 1992). Personality changes, including irritability, anxiety, depression, volatility, impatience and frequent loss of temper, are all common after severe TBI (Lezak, 1986; Weddell et al., 1980; Brooks et al., 1987). These personality changes, and the reality that certain impairments carry negative connotations (Barnes and Mercer, 2003), impact on how families cope after a TBI.

Goffman (1959) developed the concept of dramaturgy, as the idea that life is like a never-ending play in which people are actors (Kivisto and Pittman, 2001). He distinguishes between front stages and back stages; the front stage is where we spend most of our time (meeting others, performing acts); the back stage is where we can let our guard down (no longer need to perform). Goffman (1959) used the term impression management to refer to our desire to influence others’ impressions of us. Jane and Harry relate their concerns about their son’s behaviour, particularly in relation to how others react to him. Joining a support group or finding a listening ear at one meeting hosted by NGOs, allows them to ‘let their guard down’, as Goffman (1959) described in his work on dramaturgy. However, support groups are sometimes too far away in terms of physical distance for them to attend more often.

Well support groups, I would be interested in the supports all right, but he wouldn’t go I suppose because he can’t talk, but I would have a big interest in it. The nearest one is (Name of City) it’s too far away for me to travel, I mean
there's a need for that as well.

(Tara – Wife).

‘But basically they are trying to set up a support group here in the (Name of County) for people with injuries and ... it's only at the being set up stage as yet’

(Harry-Father).

This theory relating to ‘front stage’ (impression management vis-à-vis others) and having a ‘back stage’ (where family care givers can ‘let the guard down;) is particularly relevant and can be used to interpret the social interactions of family members with different types of others (i.e. acquaintances who do not understand the situations and people with common experiences who do).

6.3.4. Lack of Public Awareness

Misconceptions about brain injury amongst the general public are a common complaint from survivors and family members, and are also outlined in Chapter 5 (Voices of Survivors).

You have a lack of awareness, and then we had a local situation with the secondary school. Kids have fired stones at him when he is passing by on his way down the road because he has a stagger and it's pretty obvious that he has a problem

(Noel-Brother).

Ten participants mentioned the positive support they received from people in the community. Noel described how local people come to his brother's house to enquire about him or 'give him cigarettes' if they met him in the street, saying:

'there you are, there's a few fags for you Ned'

(Noel-Brother).

Alan, the single father of a young survivor, lives in a working class housing estate in a large city. If he needs anything, such as having the children minded, he just calls out to the women across the road. He was surprised at how helpful the Police (An Garda Siochana) were after his son's accident:

Oh yeah the guards ... the area I live in, well the guards aren't really popular but I found them terrific and I know I'm not a gentleman by any means, but I found the guards terrific, and if anyone asks, I do say that, I'm a man that talks, I say what I think ... and if anyone says anything here I say 'ah no, hold
on a minute', you know, not everyone tells the truth around here, you have to tell it as it is, you know (Alan-Father).

This positive supportive experience contrasts with other negative experience of interactions with acquaintances after TBI. For example, there were people who went to visit the survivor in hospital in order to satisfy a morbid curiosity, as explained by Noel about his experience:

At one stage a fella got in pretending to be his brother, we were putting a very positive side to my mother 'cos we didn’t want her to know that he was so bad. He was in a coma and the guy went in, saw him and went back to (Name of Town) and told everyone that he was in a coma, he was a vegetable. And that came right back into this house here, and one of my uncles even told me Ma here that there was holes after being drilled in his head ... you know absolutely no reason for it. I had to lie to her for three weeks. (Noel-Brother).

The key findings here show while some friends and acquaintances offered understanding and help, others added to the family’s distress by their intrusive behaviour. Swift and Wilson (2001) found that there is a general lack of awareness of the physical, cognitive and behavioural problems that brain injury can cause. They suggest that others often erroneously assume the same kind of recovery trajectory for brain injury as for other physical injuries. The recovering self is without clear guidance by the medical profession, because they also lack a clear understanding of how brain injury affects each individual (Chamberlain, 2006). The concept of stigma is frequently associated with disability and the experience of this is culturally influenced. Goffman (1963) uses the term ‘normals’ to distinguish between those in society that are not visibly stigmatized or disabled. He summarises the techniques used by those with disabilities in order to manage their self-concept, it is to either hide or to accept their disability as a sort of master status (Goffman, 1963:56). Findings in this study demonstrate that the correct approach towards family members is important.
Table 47: The reality of the Survivor’s Condition

<table>
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<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
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<td>Elizabeth-Wife</td>
</tr>
<tr>
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<td>‘I didn’t want him walking on his own but he insisted’</td>
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</tr>
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<td>Tara-Wife</td>
</tr>
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<td>Jane-Mother</td>
</tr>
<tr>
<td>Annoying/ frustration</td>
<td>‘but I suppose that all the frustration. I know yeah (sad), it’s annoying for him’.</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Tired</td>
<td>‘He struggles with tiredness’</td>
<td>Helen-Mother</td>
</tr>
<tr>
<td>Muddled</td>
<td>‘But he’s still madly muddled in his head’</td>
<td>Alan-Mother</td>
</tr>
<tr>
<td>Insight</td>
<td>‘His insight into his injuries is one of his biggest problems’.</td>
<td>Harry-Father</td>
</tr>
<tr>
<td>Spasms</td>
<td>‘There is no set pattern, no warning or anything, they just happen out of the blue’.</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Different person</td>
<td>‘And the family are trying to interpret what they want and trying to speak for them and you are learning as a family I suppose because this is a different person you are dealing with, like it’s a whole different …’</td>
<td>Helen-Mother</td>
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<td></td>
<td>‘You couldn’t put up with him at all, no. You couldn’t take him anywhere … He is just saying what he is thinking; it’s out of his mouth’</td>
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<td>‘He comes out with the worst things, unbelievable (deep sadness)’</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Support from community</td>
<td>‘the guards aren’t really popular but I found them terrific’</td>
<td>Alan-Father</td>
</tr>
<tr>
<td>Lack of support from health professionals</td>
<td>‘people they were only going through the motions … they just weren’t interested you knew by the body language that apathy was rampant’</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Lack of understanding (social contact)</td>
<td>‘We found that there was some people who would take offence at the fact that he couldn’t remember them’</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Curiosity and deception/ not support</td>
<td>‘a fella got in pretending to be his brother’</td>
<td>Noel-Brother</td>
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6.4. The Response of Healthcare Professionals to the Family Member’s Anxieties and Questions

6.4.1. Lack of Information from Healthcare Professionals on Brain Injury

Similar to the themes emerging in Chapter 5 (The Voices of Survivors), the lack of information on brain injury posed problems for family members. They expressed their feelings when they were faced with a situation that was new and unfamiliar to them. Many participants only discovered vital information from other families who had been through similar experiences. A participant in this study (the mother of a TBI survivor) described feeling alone and recalled receiving advice from the relative of another patient in the hospital on how to deal with the staff. She told her ‘not to let them bully you’.

Mother: ‘We didn’t know a thing about it until we had to. I think there should be a campaign to increase knowledge about it. I thought that he would wake up and he would be fine. I didn’t think he would have a long hard road ahead of him.’

Father: ‘Yes, I agree we didn’t know enough and they (the hospitals) didn’t tell us much. I don’t think they know themselves. It’s a bit of guess work (Frank and Tanya-Father and Mother).

The first thing that happened in the NRH he was put into a ward, a lock up, he was actually locked into this ward. And now I thought that was a standard procedure before they assessed him to make sure he was capable of … Ned was walking around, I thought this was a standard procedure, after two weeks I started saying what the hell is going on here and it turns out that they just didn’t have space elsewhere and they just left him in there.

(Noel-Brother)

Tara’s view of the medical profession was coloured by her encounters with the health professionals which she articulates here:

Course the medical side don’t seem to tell you these things … they kinda say well he’s brain damaged they says and you know you can’t fix that. They kept telling me they would have to wait and see, every case is different. That’s all I ever heard.

But I read it in books. Is it called rewiring of the brain or something like that? The brain can’t go the normal way there’s a lot of other ways for it to work, it has to find another path to the job. But the medical side don’t seem to think like that. The impression I get from them is that it’s an injury and you can’t fix that

(Tara-Wife).
Sarah: They said they couldn’t tell if he would survive. When he did they couldn’t tell if he would be in a bad state for the rest of his life.

Interviewer: What do you mean a bad state?

Bill: Not able to do anything.

(Sara and Bill-Mother and Father).

Tara’s views are shared by other participants who got the impression that healthcare professionals have less interest in the survivor than the injury.

‘I think it is the medical crowd. I think they are doing all these statistics and this and that but they don’t actually see the person. They only see the injury not the person’

(Tara-Wife).

Tara articulated a common sentiment when she said the medical team were more interested in the injury than the person. Key findings from this section highlight the difficulties encountered by family members of survivors in order to get information from healthcare professionals. As previously discussed in Chapter 5, the level of personal capacity and resources families possess frequently influences the outcome. Often family members lack the expertise to be able to challenge expert knowledge and therefore risk being excluded from care. These expressions of powerlessness vis-à-vis expert health professionals may be understood within the context of parenting, as Harden (2005) found in a study of parents of children with mental illness. Harden (2005) further points out that where family members had to rely on expert advice, but when this was not forthcoming, they often felt at a loss. The findings of this research are consistent with those of Harden (2005). For instance, similar experiences were expressed by Noel regarding his brother’s initial hospitalisation:

He was so ... am for the 17 days he was so ... everything was the same every single day and I was looking at the monitor and I was asking why is this like that every single day and they had pressure centres on the screen and you are trying to figure out what does it mean, do these things improve, do the higher numbers mean more better conditions like you are trying to work it out yourself without having to ask ... I was watching for a nurse to see if I could ask her something over lunch like 'cos I felt I was pestering them

(Noel-Brother).

Findings here show families want to have an understanding of what progress or otherwise is being made but it is not always presented by health professionals in a way which shows an understanding of the person and the need on the part of family to understand
what is going on and a prognosis. The initial knowledge of family caregivers was limited but many who took part in this research showed their search for knowledge on TBI and their capacity to discuss symptoms and effects of injury. Through networking with other families in similar situations in health care settings such as hospital and in NGO support organisations, they became more familiar with the subject of TBI. Giddens (1991) argues that the formation of knowledge, such as medical knowledge, has resulted in the subordination of lay knowledge. The findings of this research supports Giddens’ view.

6.4.2. Healthcare Providers - Lack of Training

The need for specialised staff training in dealing with brain injury was stated by four of the participants. Jane and Harry were almost apologetic as they described their horrific experience when their son was admitted to a general hospital for a procedure. The staff there were not used to him and did not know how to deal with his insults and personal remarks. Harry, the father of the boy articulates this:

He had a private room and everything but staff had no understanding like, some of them are good, I have to say but they really had no understanding whatsoever and he was awful bad after surgery, the two of us had to hold him in the bed with the roars of pain. But you see if this is directed at you constant (insults) you get to a stage. I mean this was a big issue in (Hospital name). I’d say when they saw the back of us they were delighted, for a lot of them ’cos he upsets people … different personalities, some can take it others can’t (Harry-Father).

The findings here on the experiences of parents and other family members indicate the need for specialised training in dealing with people with brain injuries. This is particularly pertinent given the current under-staffing in many of the general hospitals (Thomas et al., 2008; Wren, 2003). Swift and Wilson (2001) found that many of the misconceptions attributed to society in general were also common to healthcare professionals who are not experts in the field of brain injury. These included inaccurate beliefs about time span and extent of recovery, and behavioural symptoms. The professionals mentioned in their study included hospital doctors, general practitioners, nurses, occupational therapists and physiotherapists. The lack of staff training in dealing with behavioural issues after brain injury has negative consequences for survivor recovery and family confidence (Swift and Wilson, 2001).

The findings of this research identify that family caregivers perceive that there is a lack of knowledge of TBI on the part of health professionals. Harry expressed his concern about the lack of understanding of TBI:
"The awareness of brain injury is very poor and even from the nursing point of view, people have years of nursing and their awareness is bad and with him because his behaviour is as a result of his brain injury, it’s the biggest obstacle as well”

(Harry-Father).

Other aspects and effects of TBI need to be considered, such as stigma and the individual’s sense of self-worth, following injury (Friedson, 2001; Johnson, 1972; Bury, 1991; Bury, 1982). Illness narratives, as a means of communicating with patients, are increasingly popular amongst health practitioners who recognise their value as a teaching method and as a device for creating new knowledge (Charon, 2001).

6.4.3. Rehabilitation Services

Experiences in the one and only national rehabilitation centre in Ireland were mixed. Expectations of this centre sometimes are unrealistic, as borne out by Tara. Her views are previously articulated in Chapter 5, in her role as a proxy for her husband. She explained that she was disappointed with the treatment she received there (the National Rehabilitation Hospital - NRH), having had high hopes of a positive outcome. However, she acknowledges that had her husband’s progress been better, she probably would have a different impression of the NRH. Other participants shared this view, as illustrated by the quotes below.

‘We thought, and loads of people said this to us, that the rehab would help him. We thought the rehab would cure him and we could go home ... perfect like. We didn’t realise that it would go on so long and that it would be so slow’

(Eoin-Father).

‘I had this huge image of Dun Laoghaire [rehabilitation centre] that I thought this was going to be like the place like, we are going to go in here and we are going to come out of here playing volleyball, this is the way I set myself up’

(Noel-Brother).

Noel said he felt let down by the treatment his brother Ned got in the NRH. He did not blame the staff for this, suggesting instead a minimal amount of facilities and a limited budget prevent the staff from offering a full service.

I never saw one week when Ned had all his appointments. He used have a schedule, a timetable for the week and it would be set up for the week up until 5 o’clock on a Friday evening. Now the M50 is crazy on a Friday evening, but I’d say no, we will stick with the schedule you have here. But what I found
was that in the afternoon on Friday, that although he was scheduled for gym work, it never happened. For 5 whole weeks we sat there and they never came for him. The following week it was the same thing, I lost confidence in them, they seemed to be putting up the schedule so that he could aim for that but no one else was aiming for that.

(Noel-Brother).

Tara was also disappointed with her husband’s progress at the NRH, as she articulates here:

He only had three words going in there and he had no extra word coming out and when he came home after a couple of weeks he had extra words. I think he hated it up there so much they couldn’t get another word out of him there anyway, he just hated it.

(Tara-Wife).

Noel and his brother found it difficult to comprehend why he was not allowed to use the stairs at the rehabilitation facility.

‘He used to walk up and down the stairs to get better, to strengthen his legs, he was given out to for doing that because he was blocking people from coming up and down ’cos he was too slow’.

(Noel-Brother)

Tara’s experience of insensitivity at a multi-disciplinary meeting is articulated thus:

One thing I want to say is I wasn’t happy with the rehab. See I didn’t like (Name of Doctor) because he wouldn’t tell me anything good, I suppose so I don’t like him. Well I found he can be a bit condescending. We had a family meeting and when we walked in, there was about eight or ten around this big table and John was here and his brother came with us, but they didn’t talk directly to any of us, he was sitting like this with his head down. They were all a bit condescending, and not giving him any chance sort of. I think he would have come out a lot better if they put more work into him, now maybe he wasn’t ready for it. I don’t know I suppose if he came out perfect I’d be singing their praises

(Tara-Wife).
Tara’s concern for her very ill husband demonstrates the inability of close relatives to understand and their dissatisfaction with practices applied in the delivery of health care to TBI survivors.

It was very bad the way he was treated up there, he was left there and I remember going up one day and the dinner was put out for him and he couldn’t cut up the dinner and only for I was there how was he going to manage, and what did he do for the rest of the time when I wasn’t there, you know this sort of thing and I kinda found them condescending now talking to them. He didn’t get much therapy. A small bit taken out of your day and that’s it they were left sitting there for the rest of the day. And they even left him go before the time even. They said he wasn’t making any progress, they said there was nothing more they could do for him. But there was nothing at all after that (Tara-Wife).

The father of a young male survivor recalled his experience of spending weekends in the NRH with his son:

But there wasn’t a lot going on and the weekends were terrible, some would go home and the whole place would go quiet. There were other people there and they were up from the country and they didn’t have many visitors and they were just going around in wheelchairs or that the whole long day. It wasn’t so bad for me I used to go up every weekend (Frank-Father).

In many cases, as illustrated above, in order to visit family and friends had to make the long journey to Dublin from remote parts of the country. The following quote showing the benefits of friend’s support demonstrates the importance of having localised settings which are more easily accessible:

When he went to (Name of Hospital), there was a few friends in everyday and they were great. They would be laughing and talking and even before he was able to talk at all. When we got him back from (Hospital Z), first of all in August, he couldn’t talk at all but he knew what you were saying like you know and when you would mention Liverpool he would give you the thumbs up like you know, and if you really wanted to know if he was alert you’d say Man United won at the weekend. (Frank-Father).

It is important to note that not all experiences were negative. Jane recalls how the nurses from Dun Laoghaire came home with her son on two weekends in the hope that being
in familiar surroundings would increase his awareness. She praised their kindness and dedication:

They wouldn’t do that under any other circumstances but they did it for him, they were just trying anything. They were great like that, they never did it before, he came home and the nurses stayed with us all night and they went back the next day, then they came and left him with us and came back the next day for him.

(Jane-Mother)

As such, while some participants had positive experiences at the NRH and praised the efforts of the staff, others were critical of how health professionals dealt with survivors and their families at their most vulnerable. These findings point to a lack of understanding and insensitivity by some healthcare professionals. All too often, a clinical explanation is too overwhelming for families, but they need information. One woman recalled her despair at being told at a multidisciplinary staff meeting that her husband was brain damaged and could not be helped further.

This finding again draws attention to the societal belief that discharge from hospital after a brain injury equates to a return to good health (Swift and Wilson, 2001). Springer et al. (1997) argue that inaccurate media portrayal of brain injury is partly to blame for people’s misconceptions. Discourses suggest that hospitals do not have a duty of care towards people who cannot be cured. According to Thomas (1999), the hospital is an organised way to exclude people who cannot be cured. Perrow’s (1963) analysis of hospitals suggests that these organisations have multiple goals, and recognises that these goals have the potential to create tension and conflict. Consequently, people who have chronic illness or disability are seen as not responding to treatment by doctors, and therefore do not deserve hospital care (Age Concern, 1993).

The findings related to the responses of health care professionals to the need for information and to develop an understanding of the condition and prognosis is summarized in Table 48.
Table 48: The response of healthcare professionals to the family member's anxieties and questions

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness</td>
<td>‘We didn’t know a thing about it until we had to. I think there should be a campaign to increase knowledge about it’.</td>
<td>Tanya-Mother</td>
</tr>
<tr>
<td>Did not understand brain injury</td>
<td>‘I thought that he would wake up and he would be fine’.</td>
<td>Tanya-Mother</td>
</tr>
<tr>
<td>Communication gaps between healthcare teams and family</td>
<td>‘Course the medical side don’t seem to tell you these things … they kinda say well he’s brain damaged they says and you know you can’t fix that … The impression I get from them is that it’s an injury and you can’t fix that’.</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>No way of predicting outcome</td>
<td>‘They said they couldn’t tell if he would survive’</td>
<td>Sara-Mother</td>
</tr>
<tr>
<td>Unrealistic expectations of rehab</td>
<td>‘We thought the rehab would cure him’</td>
<td>Eoin-Father</td>
</tr>
<tr>
<td>In the way</td>
<td>‘he was blocking people from coming up and down ‘cos he was too slow’.</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Unrealistic expectations of rehab</td>
<td>‘we are going to go in here and we are going to come out of here playing volleyball’</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Poor awareness of brain injury, even amongst nursing staff</td>
<td>‘The awareness of brain injury is very poor and even from the nursing point of view, people have years of nursing and their awareness is bad’</td>
<td>Harry-Father</td>
</tr>
<tr>
<td>Reassurance in ‘sameness’</td>
<td>‘everything was the same every single day and I was looking at the monitor and I was asking why is this like that’</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Poor awareness of brain injury in hospital</td>
<td>‘I have to say but they really had no understanding whatsoever and he was awful bad after surgery’</td>
<td>Harry-Father</td>
</tr>
<tr>
<td>Ignored in rehab</td>
<td>‘It was very bad the way he was treated up there, he was left there and I remember going up one day and the dinner was put out for him and he couldn’t cut up the dinner’</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Bad experience of multidisciplinary team meeting</td>
<td>‘there was about eight or ten around this big table and John was here and his brother came with us, but they didn’t talk directly to any of us, he was sitting like this with his head down’</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Doctors do not see the patient, only the condition</td>
<td>‘I think it is the medical crowd. I think they are doing all these statistics and this and that but they don’t actually see the person. They only see the injury not the person’.</td>
<td>Tara-Wife</td>
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</tbody>
</table>

6.4.4. Post-rehabilitation Services

Post-rehabilitation services in the community are fragmented and vary greatly between geographic areas (Maurer, 2008; O’Connell, 2008). Two survivors were still attending a workshop at the NRH on a post-rehabilitation programme. Their families praised the staff at the NRH. However, other family participants had mixed experiences, but were often resigned and grateful for any support. Some acknowledged that survivors would not have benefited from additional therapy at the early stages. A certain level of trust in
health professionals is necessary for the smooth functioning of the health services. Many of the family participants acknowledge the valuable work being done by the voluntary sector (NGOs), such as the Acquired Brain Injury Ireland [previously the Peter Bradley Foundation], Headway, BRI and Quest. However, in some areas of the country, these organisations do not have a presence.

The Peter Bradley crew come every week. We have gone through a few of them, and some are brilliant, and others are 'crap' to be honest with you, and it’s great to have them and some of them are very good from the beginning. The liaison nurse in the (Area of the Country) and she has been there all the time you know. When Ned had his accident she liaised with us in [Name of Hospital] and she is constantly pointing him in the right direction. She is the coordinator (Noel-Brother).

The key finding here is how fragmented the post-rehabilitation service is for survivors of TBI. People are expected to feel grateful for the level of service offered, even if it falls short of their expectations. Townsend (1998) is critical of the way rehabilitation services are organised and delivered. Social Policy Advocates for patients (such as patient action groups and NGOs) promote the notion of access to services as the embodiment of the highest standards in healthcare. However, Donabedian (1980) identify three main components of quality: structure, process and outcome. Goddard and Smith (2001) argue that, in different ways, differences in each of these aspects of quality affect patient care and patient outcomes. The concept of fair access and ease of access has been a central tenet of many of the recent policy reports. Regrettably, as Goddard and Smith (2001) have also noted, the needs basis is not clearly defined, and they urge an urgent investigation on the issues that affect supply and demand for services.

6.4.5. 'Bed Blocker'

Unquestionably, the most harrowing part of this study was listening to the stories told by family members of their experiences of being forced to remove their brain injured relatives from the acute hospital setting. Putting this in the context of a severe shortage of rehabilitation beds and waiting times of up to 12 months, it was impossible for them to comply with such demands. The father of a young survivor explained what he thought was happening in the acute hospital where his son waited for a bed in the NRH:

Sure apparently, when Thursday evening comes they have to empty out all the wards, sure there’s people going home who weren’t fit to go home, but it didn’t matter ’cos they empty the wards on a Thursday evening whether if they took them back on Friday evening, they had so many gone through
the beds anyway, you know all these things, it was pure stupid, it’s for accreditation, it’s pure stupid (Harry-Father).

Interviewer: Did you feel under pressure to move out of any of the hospitals?

Mother: All the time, we were constantly pressured in (Name of Hospital), all the time, we were in a constant battle

Father: Oh terrible pressure, the bed manager there

Mother: He is a bed blocker we were told

Interviewer: Was that term used

Mother: Yes. Yes’. Move on, move on and as time goes on you feel you are even more removed, I know they say you are a patient for life at Dun Laoghaire but … we had to go back and look for the review this time now, there is no follow-up (Jane and Harry-Mother and Father).

I had no advice on how to go about looking for a place in Dun Laoghaire. I tried every angle, they weren’t very helpful in (Name of Hospital), they just had no way of dealing with it; towards the end of his stay in (Name of Hospital) it became very stressful for us for one very simple reason they wanted him out of the hospital in (Name of Hospital). He was a ‘bed blocker’, now this term was used straight out to my face in (Name of Hospital), he was a ‘bed blocker’ and I was under the impression through contact with people if my brother had any chance of getting to Dun Laoghaire he would have had a better chance from a hospital than from home. Now that to me seems logical, I knew that if he stayed in the hospital he would get a better chance but every time I went into see him I was harassed for over a month by senior staff.

And in one case I was called in by a consultant who I thought was going to give me some information on how he was doing but he actually told me that we can do nothing for your brother, you get him out of this hospital, whatever means you have, I don’t care how you do it, he needs to be in Dun Laoghaire, how you do it is your own business.

I said to him who do I ring, who do I talk to, I don’t know, it’s nothing to do with me, we can do nothing for him. He didn’t say bed blocker but it was used in other conversations. I felt so bad I was actually going outside visiting hours ‘cos I couldn’t stand the pressure any more. In the end he was sent home one Saturday morning with a Zimmer frame and in need of a lot of care. An uncle went into see him, and they sent him home with a Zimmer frame to my mother who was in her 76th year and they didn’t even know he was coming home.
You know they just basically dumped him on the first person on a Saturday morning and sent him home.

(Noel-Brother).

Helen had a similar experience in an acute hospital in another part of the country:

Oh they wanted him out, well it was the bed manager that wanted him out and she came to me one day, and I'm sort of sorry I didn't give her an answer, she wanted, she came to me one day, the doctor the consultant never once said about moving him but she came to me one day and she said the physiotherapy down in the (Local Nursing Home) Home was much better than there and that he would do much better there

(Helen-Mother).

Noel went further on to add how dedicated and hardworking the staff were in the hospital from which he came under such pressure to move his brother. He was puzzled by the opposing positions taken by management and staff:

'There is a kind of contradiction there, the staff so good and management wanted you out of there. But they were very, very good, the staff were brilliant, it was the management I had a problem with, he was there too long for their liking'

(Noel-Brother).

The key findings in this section relate to the immense pressure on family members to move the TBI survivor from the acute hospital setting. The attitude of healthcare providers was that it was not their concern where the patient would go. Budget constraints and pressures exerted by Government agencies have placed many health care professionals in a dilemma - that of being unable to offer specialist services, such as rehabilitation services, needed by the patient and coming under pressure to free up hospital beds. According to Henwood (1992), discourses on the allocation of health resources is presented in terms of people with brain injury, and others such as older people with chronic illness, as being a burden on society.

Etzioni's (1960) model of system survival and system effectiveness explains the organisational structure of hospitals. In this, he focused attention on the goal activities of organisations as a way of measuring effectiveness. His model is an attempt to make a distinction between ideal and real goals and to draw comparisons between the two (1960:257), recognising that the official goals of organisations may differ from the actual goals being pursued. Goal attainment may be used as a measure of effectiveness, that is 'freeing up' beds. However, this approach ignores the social impact of TBI on patients and their
families. According to Chestnut et al. (1999) recovery from TBI is often influenced by ‘the resources of the community, the person’s employment or financial status, the consent of the family’ (Chesnut et al. 1999:2).

Etzioni (1961) further argues that effectiveness is a matter of absolute standards. Performance of organisations can therefore be compared, one with another, by using measurements as defined by their stated goals (health and wellbeing of all patients). The real goals may therefore be influenced by a desire to comply with directives from the Department of Health and Children, which is to keep beds free for the admission of other patients. Hospital activity is measured in the form of statistics for ‘Waiting Times’ and ‘Length of Stay’, the latter dictating the provision of resources. Hospital bed occupancy ideally means making the best use of expensive high technology equipment and facilities (Browne, 2004).

The findings in relation to family carers experiences of TBI survivors being described or considered as ‘bed-blockers’ are summarised below.

Table 49: Bed-Blockers

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was harassed</td>
<td>‘every time I went into see him I was harassed for over a</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td></td>
<td>month by senior staff’</td>
<td></td>
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<tr>
<td>they wanted him out</td>
<td>‘Oh they wanted him out, well it was the bed manager that</td>
<td>Helen-Mother</td>
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<td></td>
<td>wanted him out’</td>
<td></td>
</tr>
<tr>
<td>they wanted him out</td>
<td>‘it became very stressful for us for one very simple reason</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td></td>
<td>they wanted him out’</td>
<td></td>
</tr>
<tr>
<td>we can do nothing for him/ no way</td>
<td>‘just had no way of dealing with it … we can do nothing</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>of dealing with situation</td>
<td>for him’</td>
<td></td>
</tr>
<tr>
<td>it’s for accreditation</td>
<td>‘it was pure stupid, it’s for accreditation, it’s pure stupid’</td>
<td>Harry-Father</td>
</tr>
<tr>
<td>you get him out of this hospital / I</td>
<td>‘you get him out of this hospital, whatever means you have,</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>don’t care</td>
<td>I don’t care how you do it, he needs to be in Dun Laoghaire,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>how you do it is your own business’.</td>
<td></td>
</tr>
<tr>
<td>dumped him</td>
<td>‘they just basically dumped him on the first person on a</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td></td>
<td>Saturday morning and sent him home’.</td>
<td></td>
</tr>
<tr>
<td>couldn’t stand the pressure</td>
<td>‘I couldn’t stand the pressure any more’.</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Contradiction</td>
<td>‘There is a kind of contradiction there, the staff so good</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td></td>
<td>and management wanted you out of there’.</td>
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6.5. Milestones/Hope

Family members were slow to acknowledge that more improvement was unlikely.

Participants interviewed in this study were willing to search for ways to improve the quality of the survivor’s life. The depth of their love for the injured person was obvious
in their discussions with the researcher. Helen recalled how her injured son had suffered so much the year before his own injury because his best friend was killed in a motorbike accident.

When they were in 5th year his best friend was killed in a motorbike accident ...

He was 16, the poor lad was doing nothing wrong, he had indicated to go in to his own house, or into his friend’s house, the bike was stopped on the road and ... He was in (Name of Hospital) for a week or 10 days and that was it (Helen-Mother).

‘We go every day. We did 10 hours a day in the hospital. We lived in the hospital during the week’ (Jane-Mother).

Good humoured banter between the parents of a young survivor is as follows:

‘Frank: She spoils him ... getting this and that for him. I think she should let him do a bit more for himself.
Tanya: I don’t spoil him. I still help him with his shower but I’m afraid he will fall’
(Frank and Tanya-Father and Mother).

None of the participants described the care and support they provided for the survivor as a burden. Wives and mothers displayed their devotion by attending to basic needs of their grown-up sons. Showering, dressing, toileting and feeding routines were described with love and pride. Helen recalls how she toilet trained her teenage son before he left the NRH:

The weekend before we actually came home before Christmas, he actually wasn’t toilet trained, and of course it was up to me to toilet train him. I remember it was Friday and I took off the nappy and we got him using the toilet and we didn’t do much on Saturday ’cos we took him out, and we did it again on Sunday and on Monday the sister on the ward, the speech therapist and the occupational therapist came to the bed and said we need to talk to you. And I though God now what is it, and it was what are we going to do about toilet training. I said, sure it’s done I told you on Friday that it’s done, we have managed it and I know we are going to have accidents (Helen-Mother).

A sense of pride was evident when Jane, the mother of a teenager, told of how much her son had improved; she repeatedly used the expression ‘time is a great healer’.
When you look back things have improved a good bit. I’d say now Dun Laoghaire would like to see, and even (Name) says that to me, the Peter Bradley girl, they would be very interested in seeing him doing his cognitive work and all that, they wouldn’t believe it she says (Jane-Mother).

Noel outlined how important it was to keep a sense of hope:

The neurologist told him on his last visit that he is as good as he is going to be. Now that hit him very, very hard, now it was actually the first hospital appointment he went to on his own and he told him this. I still don’t know why he did it. Maybe he had to do it ’cos he didn’t want to give him false hope, but having said that he is improving every day, he doesn’t see it. I haven’t seen a lot of improvement lately but I went away working during the Summer for a month and when I came back, I couldn’t believe how well he was working, like his walking improved. Like some days he would walk 14 miles (Noel-Brother).

As evidenced in Chapter 5, survivors make immense efforts to return to their previous levels of physical and cognitive competence. However, Noel acknowledges that his brother is also adapting to the changes brought by the TBI.

‘Maybe he is not improving so much as adapting; if Ned can’t do something he will find some other way of doing it’ (Noel-Brother).

Again, the sense of pride is evident when close relatives talk about the small improvements they have noticed. Eoin, the father of a young man and Tara, whose husband is a survivor describes this:

‘The consultant in Dun Laoghaire was pleasantly surprised the last day I went in with him’ (Eoin-Father).

It has improved a bit yeah, a bit, he has learned to write again. I mean he can write his name and stuff now, you know. He can pick out the names of the horses on the paper. He couldn’t read a paragraph or anything, I would read it for him, but he can pick out the horses … There is a thing that you type in on the computer, but you have to be able to spell. But that won’t work ’cos he can’t spell. (Tara-Wife).
Five participants compared progress to others they had come across in either the hospital or the NRH. They all thought they were luckier than the others, giving examples, such as a man who has a wife and young family and is no longer able to provide for them, or a young woman who could not communicate because she has ‘locked in’ syndrome - see Appendix A.

'I suppose ads on TV. But I doubt they would heed anything. Like my son may have to suffer the effects of this for the rest of his life. Hopefully not but … Then he is lucky really 'cos look at all those who have lost their lives' (Diane-Mother).

'We are so lucky. He is getting along slowly’ (Tanya-Mother).

The key findings here illustrate how participants sought to keep a sense of hope. They admit that they need to be realistic as well, but a deep love and affection for the survivor compels them to keep trying and refusing to give up. A further finding is in relation to the gendering of care (Knight et al., 1998). Highly gendered role performance is evident throughout the literature, with mothers providing most of the care to brain injured sons (Knight et al., 1998). While evidence from this study suggests fathers, brothers and sons provide care, intimate care is almost always the responsibility of women, such as mothers. For example, Helen recalled toilet training her teenage son, Jane went to the hospital every day for months to help feed and shower her son. However, Alan, a single parent, cared for his young son when he sustained a TBI in a car accident. After he brought him home from hospital, he was able to call upon neighbours in the housing estate when he needed extra help providing care. These findings illustrate that, irrespective of gender, parents will assume caring roles if required for a family member. Webb (1998:552) observes that, ‘the ambivalences that mark the tussle between labour and love as the imperative to parenting are reawakened with a vengeance as what was once seen to have been finished becomes a new and unexpected moral obligation … the present and the future are collapsed in a radically revised assumptive world’.

Jumisko et al. (2007) remark that close relatives never lose hope for a better future and, struggle on only because of a goal. They go on to suggest that the natural love between the ill person and the close relative gives them the strength to continue. Similarly, the findings of Carson, (1993) and Smith and Smith (2000) show that relatives of very ill people need to feel hope and make sense of their experience. However, emotional and social distress is common in caregivers and relatives of TBI survivors (Hawley et al., 2003). In particular, mothers and wives who are usually the primary caregivers, experience greater psychological distress than other caregivers (Perlesz et al., 2000). According to Kneafsey (2004),
responsibility for caring long-term is often met by the survivor’s family. In Ireland, the notion of care has been presumed to exist in conflict-free family sites, dependent mainly on the good will of mothers, wives and daughters (Daly and Clavero, 2002). Changes in family structure and the increased involvement of women in the workforce has presented a series of challenges for policy makers eager to save money (Hayes, 2008). The traditional role of women as homemakers and as a ready unpaid workforce, willing to take on the burden of care, can no longer be presumed (Tovey and Share, 2003; Hodgins and Kelleher, 1997). Share et al. (2007) point out that women have an important role as healthcare providers, particularly in caring for others and mediating with healthcare providers. According to O’Connor (1998), women’s work, whether paid or unpaid, usually involves service (1998:101). However, findings from this study show that parents, spouses and siblings were happy to provide care for a loved one.

Table 50: Caring By Families

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit every day</td>
<td>‘We go every day’</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>In the hospital</td>
<td>‘We lived in the hospital’</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>Doing everything for him</td>
<td>‘getting this and that for him’</td>
<td>Frank-Father</td>
</tr>
<tr>
<td>Toilet train adult son</td>
<td>‘it was up to me to toilet train him’</td>
<td>Helen-Mother</td>
</tr>
<tr>
<td>Reached his potential</td>
<td>‘he is as good as he is going to be’.</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Adapting</td>
<td>‘Maybe he is not improving so much as adapting’</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Long-term effects</td>
<td>‘Like my son may have to suffer the effects of this for the rest of his life’</td>
<td>Diane-Mother</td>
</tr>
<tr>
<td>We are lucky</td>
<td>‘We are so lucky. He is getting along slowly’</td>
<td>Tanya-Mother</td>
</tr>
<tr>
<td>He is lucky</td>
<td>‘he is lucky really ‘cos look at all those who have lost their lives’</td>
<td>Diane-Mother</td>
</tr>
<tr>
<td>Looking back</td>
<td>‘When you look back things have improved a good bit’.</td>
<td>Jane-Mother</td>
</tr>
</tbody>
</table>
Table 51: The response of Healthcare Professionals to the Family Member's anxieties and questions

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of information</td>
<td>'Course the medical side don’t seem to tell you these things …'</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Lack of information</td>
<td>'They said they couldn’t tell if he would survive'</td>
<td>Sarah-Mother</td>
</tr>
<tr>
<td>Don’t see the person</td>
<td>'I think it is the medical crowd. I think they are doing all these statistics and this and that but they don’t actually see the person'</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Lack of understanding by staff</td>
<td>'staff had no understanding'</td>
<td>Harry-Father</td>
</tr>
<tr>
<td>Insensitivity</td>
<td>'he was given out to for doing that because he was blocking people from coming up and down ‘cos he was too slow'</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Pressure</td>
<td>'All the time, we were constantly pressured in (Name of Hospital), all the time, we were in a constant battle'</td>
<td>Jane and Harry-Mother and Father</td>
</tr>
<tr>
<td>Terrible - all quite</td>
<td>'the weekends were terrible, some would go home and the whole place would go quite'</td>
<td>Frank-Father</td>
</tr>
<tr>
<td>Lack of commitment</td>
<td>'it seemed as if people they were only going through the motions'</td>
<td>Noel-Brother</td>
</tr>
</tbody>
</table>

Table 52: Milestones/Hope

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking back / improvement</td>
<td>'When you look back things have improved a good bit'</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>Improvement</td>
<td>'I couldn’t believe how well he was working, like his walking improved. Like some days he would walk 14 miles'</td>
<td>Noel-Brother</td>
</tr>
<tr>
<td>Not prepared</td>
<td>'I suppose ads on TV. But I doubt they would heed anything. Like my son may have to suffer the effects of this for the rest of his life'</td>
<td>Diane-Mother</td>
</tr>
<tr>
<td>Not prepared</td>
<td>'You see it on the television … the accidents, some get killed and others are seriously injured … and people don’t realise'</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Adapting</td>
<td>'Maybe he is not improving so much as adapting'</td>
<td>Noel-Brother</td>
</tr>
</tbody>
</table>

Family members made enormous efforts to remain positive. They smiled and laughed when they remembered little idiosyncrasies that reminded them of the survivor prior to the injury.

'He could be chatty and funny … when he was in the house he could be very quiet'
(Jack-Father).

He wouldn’t have been a lad that studied now or anything (laughs) but he would know every film that was on and he … nature like, his interests are broad and you would think now that a lad that age they are all the same. But the nature programmes he would watch, great interest in dogs and cars, nature, hurling, he was a hurler and a soccer player (Jane-Mother).
Tara wanted to provide a space for a horse which she said would be therapeutic for her husband because of his love of horses:

He would like to have horses himself. He would love a horse of his own. That's the worst of it, we only have a tiny space 'cos it wouldn't cost much to get an old horse, it wouldn't have to be a race horse, and if you had the space it would be great

(Tara-Wife).

Tara reminds us how little she thought about the consequences of brain injury until it happened:

You see it on the television ... the accidents, some get killed and others are seriously injured ... and people don't realise, seriously injured and they are the hardest ones to deal with. I know death is very hard to deal with but the other one is on-going all the time it's very, very hard

(Tara-Wife).

Paul, the father of a young boy I interviewed, did not approve of his son being back again with the same crowd who left him dying in a stolen car on the night he was injured. He explained:

'Yeah, unfortunately he has the same friends ... idle hands you know. And he has gotten into some trouble 'cos I believe that he is very easily led, I do believe that now'

(Paul-Father).

The findings here are about coming to terms with the changes brought about by the TBI. Families tried to remain positive by remembering the times before the injury. Caregiver stress and depression are often reported by carers of TBI survivors (Marsh et al., 1998). This stress is aggravated by the behavioural intentions of the survivor (Mitchley et al., 1996). The belief that caregivers have, that the survivor has hostile intentions towards them, contributes further to their distress (Riley, 2007). In this study, data collected from a father who found his son's behaviour upsetting, supports this contention. He described trying to understand why his son insulted his carers:

'You couldn't put up with him at all, no, no. You couldn't take him anywhere'

(Harry-Father).

A mother talked about how she finds stories about other survivors depressing:

You look up the internet and you go into the sites and they are all American sites. Maybe and some of this is not good reading either, it's very depressing
where they end up, you read the personal stories of similar injuries and where they end up
(Tanya-Mother).

Diane worried about future care for her son:

'And our concern is we won't always be around'
(Diane-Mother).

Families and carers experience profound changes (Jumisko, 2007; McLaughlin, 1985), and are often ill-prepared to deal with behaviour issues (Rosenthal and Young, 1988). Similarly, the majority of participants in this study described their lives as 'hard' and difficult to cope with at times. There was a desire for a sense of closure. For example, Harry pointed out that if his son had suitable twenty-four care, he and his wife could move on with their own lives:

'It's worth a try. Then we could move on but there is nothing, no funding for that purpose in this country'
(Harry-Father).

All the participants made reference to feeling lucky that the survivor had lived. Many were prepared to give up part-time jobs and hobbies in order to spend more time with survivors. Acceptance while still remaining positive was how Helen described her situation:

Interviewer: Are you grieving?
Helen: Yeah, you are, but you don't give up, you have to be positive but every now and then it hits you and you say you are not going back to that, not going back to that
(Helen-Mother).
<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seriously injured</td>
<td>'some get killed and others are seriously injured ... and people don’t realise’</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Hardest to deal with</td>
<td>'they are the hardest ones to deal with’</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Couldn't take him anywhere</td>
<td>'You couldn’t put up with him at all, no, no. You couldn’t take him anywhere’</td>
<td>Harry-Father</td>
</tr>
<tr>
<td>Worry for the future</td>
<td>'where they end up’</td>
<td>Tanya-Mother</td>
</tr>
<tr>
<td>Worry for the future</td>
<td>'And our concern is we won’t always be around'</td>
<td>Diane-Mother</td>
</tr>
<tr>
<td>Depressing</td>
<td>'it’s very depressing where they end up, you read the personal stories of similar injuries and where they end up’</td>
<td>Tanya-Mother</td>
</tr>
<tr>
<td>Very hard to deal with</td>
<td>'on going all the time it’s very, very hard’</td>
<td>Tara-Wife</td>
</tr>
<tr>
<td>Don’t give up</td>
<td>'don’t give up, you have to be positive but every now and then it hits you’</td>
<td>Helen-Mother</td>
</tr>
<tr>
<td>Positive</td>
<td>'you have to be positive’</td>
<td>Helen-Mother</td>
</tr>
<tr>
<td>Hard to deal with</td>
<td>'very hard to deal with but the other one is on-going all the time it’s very, very hard’</td>
<td>Tara-Wife</td>
</tr>
</tbody>
</table>

6.6. Redefining their Lives

The mother and father of a young survivor described putting their own lives on hold. Another couple called it an obsession they find hard to let go. They offered the following account:

Mother: But where has time gone, we spent all that time ... and they tell me here sometimes if I go off for a day you are not allowed talk about that now today, because you are obsessed, and I know I am ... and we end up talking about it. We are going off now for a few days and we try not to get back, but you end up coming back and talking about it even when you try to remove yourself.

Father: Yeah. So we are kind of leaving him for the first time now, there is no one going over to him, we go every single day.

(Jane and Harry-Mother and Father).

Family members appeared to learn to accept the changes the injury brought, despite this being new and strange. Many, particularly mothers and wives, gave up full-time work, or reduced hours, to care for survivors. A father took early retirement in order to devote more time to caring for his young son.

'I can’t describe how different the whole thing is. I have got partly used to it now funny enough’

(Miriam-Mother).
Many participants were philosophical, as the following statement demonstrates:

'It's just the way life goes, it can go one way or the other just like a bump in the road, it could have gone either way for him you know'

(Jane-Mother).

Many studies have shown that close family members take on role changes and assume more responsibility than before the injury (Gill and Wells, 2000; Kneafsey and Gawthorpe, 2004). Duff (2002) also found that there is a great willingness on the part of relatives to accommodate the injured person by altering their own lives. Findings in this study relate to the enormous adjustment families/carers made in order to accommodate the TBI survivor. A number of participants in this study gave up work, as presented above, and also made personal sacrifices, such as staying in a hospital for months. In most cases this also required long distance travel. Some called this putting their own lives on hold for a while and then described their attempts at redefining their lives.

<table>
<thead>
<tr>
<th>Concept</th>
<th>Illustrative Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time gone / time spent</td>
<td>'But where has time gone, we spent all that time …'</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>Time – repetition</td>
<td>'we go every single day'</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>Talking about it</td>
<td>'we end up talking about it'</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>Different life</td>
<td>'I can’t describe how different the whole thing is'</td>
<td>Miriam-Mother</td>
</tr>
<tr>
<td>Way life goes – philosophical</td>
<td>'It’s just the way life goes, it can go one way or the other just like a bump in the road’</td>
<td>Jane-Mother</td>
</tr>
<tr>
<td>Adjustment</td>
<td>'how different … got partly used to it’</td>
<td>Miriam-Mother</td>
</tr>
<tr>
<td>Move on</td>
<td>'Then we could move on’</td>
<td>Harry-Father</td>
</tr>
</tbody>
</table>

6.7. Conclusion

This study has endeavoured to contribute to the existing literature on the context of family member’s experience of caring for a loved one with a traumatic brain injury. Based on the categories, patterns and themes which emerged from the data, the following is a summary of the key findings:

i. The news of the accident is received with shock and horror. Images of accidents shown in road safety campaigns do not prepare the family for the consequences of severe injury.

ii. The extent of the injury, and the reality of its consequences, comes after a period of hope and despair. The 'roller coaster of emotion' is described and improvement is slow; each phase takes on new meaning, for example, the survivor’s first words during the recovery phase, the first food taken, and the toilet training of adults. During this time and for a long time afterwards, lives are put on hold and, the financial and psychological burden is considerable.
iii. Health care professionals give little or no information on prognosis or further treatment beyond the acute system, and even this is seriously deficient. All respondents, except one, had problems getting information and understanding recovery or other prospects and implications.

iv. Families soon realised that they would have many challenges to overcome; getting a bed in the NRH, bed managers at the referring hospitals putting pressure on the family to move the ‘bed-blocker’ on, and staff not adequately trained to deal with brain injury. Those with high levels of personal capacity fared best. These included social resources, such as communication skills and an understanding of how healthcare services are delivered, and material resources, such as health insurance and income.

v. Public awareness about brain injury is poor; for example, a participant’s experience of children throwing stones at his brother, a survivor of TBI. The protective strategies employed by families to protect the survivor are seen as necessary to ensure safety.

vi. Family members of survivors are faced by new demands and some forced to give up work in order to devote more time to caring for the survivor. Many are at the stage of life when they should be enjoying retirement, but devote time and effort willingly to the care of the survivor.

vii. Most respondents reported that they are trying to get on with their own lives, having made adjustments and making adjustments to accommodate the needs of the survivor.

6.8. Discussion

Throughout this chapter I have argued and endeavoured to lay out evidence which demonstrates that access to services and supports, particularly rehabilitation and post-rehabilitation, affects how recovery is experienced. I argue that survivors of traumatic brain injury (on a macro level) are restricted in scope and substantially modified in practice (on a micro level) because of the unavailability or the shortage of supports. Difficulties accessing places at the NRH is perhaps the greatest obstacle and has knock-on effects throughout the acute hospital sector.

The lack of cooperation from hospital bed-managers and administrative staff overshadowed the positive aspects of care delivery in many acute settings. Findings from this study show that the respondents who had prior knowledge or experience of how the hospital systems work fared better in their interactions with healthcare professionals.

This chapter on the findings from family members illustrates that the lack of a prior knowledge and understanding of brain injury impacts on how families made sense of the changes brought about by the injury. It is noted there was a dearth of information on brain injury and treatment options, so that family members and concerned others are left searching for information and support.
There is evidence in this study that the services available for this population do not take account of factors such as geographic location, access to resources, family support and stage in life of the survivor. For example, the one and only rehabilitation hospital is located in Dublin, requiring survivors and their families to make the long journey from all parts of the country. Likewise, post-rehabilitation services differ vastly between geographic areas of Ireland. For example, the NGOs and voluntary sectors who offer the survivor a range of supports and services have little or no presence in some areas. A post-rehabilitation workshop based at the NRH, is suitable only for survivors who live in the Dublin area, because of their proximity to this facility. The Primary Care Health Strategy (2001b) proposes to address some of these issues by introducing improved health and social service needs through primary care teams. According to ‘this is to ensure a more equitable, accessible and responsive range of basic needs and personal social services for all’ (DoHC, 2001:7). Poverty is more common in families who are dependent on social welfare (Starrin, 2002; Kennedy, 2007). If the breadwinner in the family is the brain injured survivor, the whole family face uncertain futures and can find themselves in circumstances of material poverty.

In the next chapter, Chapter 7, the findings from the previous three chapters are discussed in detail. The Chapter is entitled: ‘Conclusions and Discussion’.
Chapter 7
Conclusions and Discussion

7.1. Introduction
This chapter provides a summary of the key findings from the preceding three Chapters 4, 5 and 6, and the conclusions and discussion.

The key objectives of this study were to:

- examine the common causes and effects of TBI in Ireland; (literature review and secondary data review)
- provide an approximate quantification of the problem in the Irish context – i.e. how many adults (16-64 years) in Ireland experience a TBI; (quantitative data collection and analysis)
- build on the existing body of research to offer more holistic explanations of the changed context of the lives of TBI survivors, and those of family members/ significant others (qualitative data collection and analysis).

7.2. Summary of the Quantitative Findings
The findings from two datasets of activity from the only two neurosurgical centres in Ireland show that males are more likely to sustain brain injury than females. Furthermore in terms of the age, there is a marked increase in incidence in the 16 to 23 year age group. The combined data showed that falls and road traffic accidents were responsible for the majority of all brain injury cases. Both datasets showed that alcohol was commonly involved when injuries occurred. Beaumont Hospital had double the rate of TBIs where alcohol was taken, compared with CUH. It should be noted that of these cases at Beaumont, 35 per cent sustained a severe or a very severe TBI, whereas the CUH dataset showed that only 2.4 per cent were treated for a severe TBI. The most likely reason for the higher rate of severe TBI presenting at Beaumont Hospital is because it is the National Treatment Centre for Neuroscience and, as such, it tends to get transfers of the more serious TBIs from other hospitals throughout the country. These patients are usually returned to their referring hospitals or were sent to specialist units within a short time.

From these data, it can be concluded that the typical patient admitted to CUH was male and aged between 16 and 23 years, a student or working in a manual skilled occupation.
at the time of injury. The cause of injury was usually a Road Traffic Accident (RTA), or was sports-related. The typical patient presenting at Beaumont Hospital was also male and aged between 16 and 23 years at the time of injury. The injury was likely to be severe or very severe and the probable cause was a fall or a Road Traffic Accident (RTA).

7.2.1. Usefulness of Quantitative Data on TBI

Systematic data collection on TBI is all but absent in Ireland, and this study has attempted to address, in some small way, this deficit. Phillips (2009) also emphasises that there are only a limited number of national TBI studies available within Europe. In contrast, I observed first-hand that the current situation in the USA is different and much more advanced due to the presence of Traumatic Brain Injury Model Systems (TBIMS). This is a systematic and comprehensive method of data collection and analysis on TBI, located at sixteen centres throughout North America. As already discussed, Ireland needs to adopt this type of systematic approach to data collection in the future. This was also a key issue identified in this study by health and social care providers, including NGOs providing services in this area.

7.3. Summary of Qualitative Findings – Perspectives from Survivors

7.3.1. Introduction

In the following section, summaries are presented of the key findings of the qualitative data analysis based on interviews with survivors of TBI and family members, presented in Chapters 5 and 6 of this thesis. The key research questions addressed were as follows:

iv) What are the key changes experienced in the lives of TBI survivors?

v) How have the lives of family members of TBI survivors changed?

vi) What are the perspectives of TBI survivors and their families regarding the health and social care supports and services?

iv) Based on the perspectives of TBI survivors and their families, how could health and social services be developed to respond better to their needs?

7.4 Experiences of TBI Survivors

The focus of the present study is to examine and explore changes in the lives of TBI survivors. The first core category identified is the process of recovery. The findings are discussed here under the core category of recovery and a number of sub-categories emerging from the analysis of the data. These include:
• Changed roles following TBI Requiring Adjustment
• Societal Barriers to Active Participation following TBI
• Environment influencing the development of coping strategies
• Path to Recovery.

How TBI survivors see themselves as ‘written off’ by others is discussed and other factors that influence how recovery is experienced, such as feelings of isolation and loneliness. Themes such as a lack of public awareness regarding brain injury, the reaction of others and the invisibility of injury are addressed. Finding a path to recovery gives hope for the future, realising ambition, taking control and discovering the importance of advocacy influence the process of recovery.

7.4.1. Changed Roles following TBI Requiring Adjustment

The analysis of ‘changed roles following TBI’ identified the following sub-categories:

• Changed role /Friendships
• Uncertainty
• Isolation and Loneliness
• Dependence/Independence issues.

7.4.2. Changed Role /Friendships

This research found that considerable adjustment was needed for many of the survivors of TBI. For instance, the normal social aspects of a young man’s life, such as playing football, driving cars, having a girlfriend and socialising with friends, were suddenly and severely hampered. An inability to engage, physical aspects of illness, interaction and attitudes and altered self-concept influenced how recovery was experienced. While some survivors spoke of forming new relationships and developing different interests, the sense of being left behind when others had moved on, compounded feelings of separation and loneliness. Heller et al. (2006) suggest that impairment cannot be ignored because these are the experiences that offer real challenges, and the sense of loss associated with injury or impairment is real. However, Morris et al. (2005) found in their study of people who had brain injury that some had begun to come to terms with losses and accept their new self and abilities, while others were unable to accept their losses.

This was also confirmed by my findings, which demonstrated that following TBI survivors need to develop new sources of identity to incorporate the effects of the brain injury. This may include identifying new abilities, competences and changes in physical appearance, and this is largely influenced by the type and extent of impairment. One young male
completed a marathon, even though his mobility is limited. Hill (2004) similarly suggests that it becomes necessary after a TBI to develop a new sense of self that incorporates any physical impairment and disability. This is understood in terms of the positioning of impairment, defined as restricted activity and participation in relation to disability. While traditional disability theorists, such as Oliver (1996), insist that disablement is only the consequence of social oppression, Barnes and Mercer (2003) recently attempted to draw attention to the significance of impairment in terms of its consequences and the meaning attached to its consequences (Bury, 2005). Activities of daily living may need adjustment, as well as other practical matters related to the altered body (Bury, 2005). As Bury (2005: 75) notes, significance of a disorder relates to how visible it is, which part of the body is affected, and how these issues are located within a particular culture'. My study also found that the level of impairment was significant in terms of the changes that survivors have to make to everyday life. Survivors in this study had to cope with varying degrees of memory loss, pain and other impairments. Findings showed that the level of impairment influenced how quickly and how well recovery was experienced.

7.4.3. Uncertainty

A key finding of this study was the uncertainty that entered people’s lives following TBI. The aspect that caused most uncertainty was the lack of information on brain injury. This was found to be an impediment to progress and understanding potential states of healthy recovery that could be expected. This is understood in the context of Herzlich’s (1973) framework of illness, which describes illness as a destroyer, involving loss and loneliness. Similarly, Frank’s (1995) work also usefully outlines a type of illness narrative, which he terms chaos narrative. This can be viewed as an illustration of the chaos in the teller’s life, and is pertinent to my findings. Lives after TBI can also lack sequence and order. A key finding was the feeling of fear and insecurity experienced by many survivors following TBI. Life plans had to be put on hold. The uncertainty which follows brain injury or any chronic illness results in a considerable change to that person’s life. Locker (2008) similarly confirms that uncertainty is often due to difficulties in predicting long-term outcome. This aspect is both frightening and worrisome for TBI survivors. Survivors find it difficult to face their often newfound restrictions and limitations.

7.4.4. Isolation, Loneliness and Depression

The loss of friends, jobs and previous routine was reported by survivors of TBI. Often this contributed to survivors feeling isolated and lonely. As other researchers have noted, depression is often another consequential feature of TBI (Morton and Wehman, 1995; Levin et al., 1996). Ylvisaker and Feeney (2000) highlighted the difficulty survivors have
with social integration after the injury. They furthermore note, the resistance by survivors to some of the professional services offered to them in good faith (Ylvisaker and Feeney, 2000: 408). Findings from this study support this. For example, two participants were only offered computer training which they declined, because they felt they would not benefit from this type of training.

In terms of the key changes in the lives of TBI survivors, Kleinman's (1988) usefully outlines three different representations of illness that encapsulate the changes in the lives of TBI survivors. How TBI survivors cope with these changes are further summarised in a later section. Coping strategies employed by TBI survivors include avoidance of social situations, hiding physical aspects, such as memory loss and so on (Lonardi, 2007). This was also confirmed by my research findings. For example, Rob avoided going to pubs and clubs because he was embarrassed by the scar left by the tracheotomy.

7.4.5. Dependence/Independence Issues

The majority of survivors experienced loss of role, helplessness and an immense shift from independence to dependence, which significantly impacted on their lives, and in various ways. Changes in financial status, as a result of TBI, were complex. The reality of loss of financial independence, living on social welfare and being economically dependent on the State created feelings of worthlessness. For many in this study, this marked the first time in their lives they were dependent on social welfare and reliant on public transport. To a large extent the fears of the survivors were rational, because disability is likely to increase an individual’s probability of experiencing poverty (Whelan et al., 2004). Of the population at risk of poverty, 66 per cent report having a long term illness or have a disability (CPA, 2001). Many of the survivors in this study had money worries. One man was anxious because he heard somewhere that he might lose his disability allowance. Another girl said she was only surviving on the small allowance because she lived with her parents, and she was good at managing money.

Discourse on independence and dependence is highly problematic (French, 1993; Finkelstein and Stuart, 1996; Oliver, 1993), and is influenced by the dominant perspective in society which depicts disabled people as dependent and needy (Goble, 2004; Kelly and Field, 1996). Survivors of TBI, in common with other disabled people, are continuously forced to control and monitor their bodily functions (Shilling, 2005). This is because, as Bury (2005) points out, disability threatens to upset the capacity to present an acceptable public and cultural self. For example, a survivor in this study was afraid to go out in the street in case he fell over, while another described how .... (can you give some other examples to substantiate how your findings accord with this insight from the literature)
7.5. Societal Barriers to Active Participation following TBI

The sub-categories identified here, emerging from the data analysis, are as follows:

- Being ‘written off’
- Lack of expertise amongst health professionals
- Paternalistic Attitudes
- Post-rehabilitation: an underdeveloped area.

7.5.1. TBI survivors being ‘Written Off’ by Others

Findings in this study show that TBI survivors were denied autonomy in their lives. There is evidence that people with cognitive impairment are ignored and can feel socially isolated (Sherry, 2006). This can be manifested in a myriad of ways, such as being denied access to information on aspects of living with TBI, and experiences of decisions made by others, on behalf of survivors. This is similar to what Phillips (1990) refers to when he states that a brain injured person may be viewed as damaged goods. Sherry (2006) further adds that being ‘written off’, isolated and discounted is a common experience for many TBI survivors. This study observed that survivors with communication problems are particularly vulnerable to being ignored. For instance, a male survivor who had aphasia caused by the brain injury, told of people having no patience with him. This is also acknowledged by Pound and Hewitt (2005) who identify the consequences of living with language difficulties. Language difficulties pose challenges to identity and inclusion, and like other communication disabilities, has little influence or impact within disability debates (Pound and Hewitt, 2005).

7.5.2. Lack of Expertise Amongst Health Professionals

While the previous sections focused on changes in the lives of TBI survivors, this section summarises their encounters with health professionals and includes themes, such as paternalistic attitudes, treatment by health professionals, lack of expertise amongst health professionals, communication gap between service provider and service user, and post-rehabilitation (the most underdeveloped area of service provision). This section addresses the research question relating to understanding the perspectives of TBI survivors and their families regarding the health and social care supports and services.

A poor understanding of, and a lack of expertise amongst healthcare professionals on brain injury and its consequences was the principal observation of many of the TBI survivors in this study. Some indicated that this lack of knowledge is also the basis for unhelpful and damaging labels and the use of professional language attached to people with brain injury. Chamberlain (2006) found that recovery from brain injury is often hampered by a
lack of understanding by healthcare professionals as well as others in society. Survivors in this study often actively resisted the negativity of staff towards them in order to protect their morale. For example, a young male refused to go back to a training facility after he had been reprimanded for kissing a girl in the grounds of the training facility. He made the point that he was treated like a child while being expected to behave as an adult at this facility. Many other encounters TBI survivors had with healthcare professionals are described as difficult, and continued to impact negatively on their lives. These difficulties range from being made to feel inferior, having relevant information held back and being talked down to. These findings demonstrate the way in which judgements are made, are based on factors such as deservedness and on whether the survivor is considered too cognitively impaired to justify treatment. This is particularly evident in relation to the type and duration of rehabilitation which survivors are offered. Griffiths and Hughes (1993) point out that characteristics, such as the type of illness, influences treatment options.

Brain injury is thus presented in a particular stereotypical manner and may act as a factor in deciding how the individual survivor of TBI is treated in encounters with health and social care providers, e.g. a TBI acquired through a sports injury is more acceptable than one resulting from risky behaviour, such as drink driving. This is explained by Social Judgement Theory, as advanced by Sherif and Hovland (1961). However, there is no evidence in the findings that social judgements were made by healthcare providers.

7.5.3. Paternalistic Attitudes

The lack of autonomy experienced by TBI survivors was evident from the stories they told. Rather than promoting independence, health and social care staff encouraged a sense of helplessness. Similar to health professionals, close family also had a stereotypical attitude towards people with disability, e.g. they felt they needed protection for their own safety, were unable to manage their lives and required decisions be made on their behalf. This attitude further adds to a loss of independence and a change to a dependent role, as discussed previously in Sub-section 7.4.2.4. This finding is supported by Goble (2004) who points out that people with intellectual impairment deal with a constant struggle to achieve a sense of independent control over their own lives. Young (1990) further suggests that a lack of decision making power creates a sense of powerlessness, and this was also found to be the case in the present study.

It is clear from the findings in this study that health professionals have particular ways of working and practices that negatively impact on the treatment of TBI survivors and their sense of self. Strauss et al. (1998) present a Negotiated Order Theory, associated with a communications model that conceptualises well these working practices. It involves a consideration of the labour divisions in large organisations. A multi-disciplinary team
approach to patient care is preferential to prevent tensions and misunderstandings (Barr, 1997; Epstein, 1995). However, findings from this study revealed that this method can be problematic. For example, one woman’s experience at a multidisciplinary staff meeting left her upset and disappointed. She recalled feeling that the staff talked down to her. Based on the findings, it is clear that there were communication gaps between staff and service users (TBI survivors). Hence, a number of survivors did not feel well-informed about their treatments options. This was particularly evident when they entered rehabilitation. While many survivors acknowledged the positive aspects of their experiences at the National Rehabilitation Hospital (NRH), others were disappointed that they did not make the progress they had expected.

The mismatch between goals of the rehabilitation team and expectations of survivors has been documented by Watkins et al. (2001). He argues that this disparity may result in disappointment and the increased vulnerability of the client. While some survivors pointed out that they were too ill while they were patients at the National Rehabilitation Hospital, they would have appreciated being more involved in their care options. This highlights the need for rehabilitation at a later stage of recovery, as well as at the initial stages, post-injury. For instance, a TBI survivor, Ann, was disappointed by the level of community physiotherapy she got, and the do-it-yourself approach presented to her and her care giver by service providers. The wife of a survivor expressed her regret that health professionals give up easily when dealing with brain damage, saying they cannot do anything more to correct the damage. The term damage rather than (brain) injury is also viewed by some survivors as offensive and inappropriate as it highlight the deficits. As previously discussed, the outcome measurements used by rehabilitation professionals prioritise what is achievable and measurable in terms of success, and this may be at odds with the expectations of the TBI survivor.

7.5.4. Post-Rehabilitation: An Underdeveloped Area

TBI survivors strongly held the view that post-rehabilitation supports and services in Ireland remain patchy and poorly resourced. There is clear evidence in this study that there is lack of government support in this area. Harris and Enfield (2003) found that Non-Government Organisations (NGOs) have succeeded in supplementing the State provision by running services for people with specific needs. Findings in this study regarding the lack of rehabilitation and post-rehabilitation services for survivors, must be understood from the perspective of how rehabilitation is considered and resourced. Wade and Halligan (2004) argued that funding is based on diagnosis and particular treatment of disease, and is closely linked to biomedical explanations of illness. This narrow approach ignores the social factors which determine how well or poorly a patient responds to treatment. It also undermines the benefits of rehabilitation and post-rehabilitation, or the use and provision
of technology and equipment. This again emphasises the need for more holistic services in this area.

Bury (1991) argues that while acknowledging the benefits of rehabilitation for its endeavours to address the consequences of impairment, its alliance with biomedicine allows it to ignore non-medical factors that impact on the social and cultural experience of illness. In this study, survivors complained of having nothing to do all day. Some are bored and lonely. For instance, Dan expresses this thus: ‘I suppose since the accident there is very little I can do. I can’t even go out into the street’. Further misunderstandings result from others not recognising the limitation caused by the brain injury, which led some participants to conclude that they would be better off with a noticeable disability. For instance, Ned was visibly upset when describing the pressure of having to cope: ‘I mean if you have only one arm people would realise you know … People with brain injury look normal. People don’t realise, people don’t realise’.

In relation to the research question: what are the perspectives of TBI survivors regarding health and social care supports and services, there was evidence that health professionals imposed a dependency on TBI survivors due to paternalistic attitudes. Some TBI survivors (but not all) experienced negative encounters with health professionals which further impacted on their morale. There is evidence that TBI is understood by health professionals as undeserving of further treatment and resources. There is an evident lack of expertise and awareness of the consequences of brain injury amongst health professionals. This leads to inappropriate labels being assigned to TBI survivors. Communication gaps also resulted because of this. There is a mismatch between the goals of health professionals and expectations of survivors in terms of outcomes. Finally, survivors viewed rehabilitation and post-rehabilitation as significantly underdeveloped and under-resourced relative to their needs.

7.6. Environment Influencing the Development of Coping Strategies

Factors in the environment influencing the development of coping strategies by TBI survivors identified in the data analysis were:

- Lack of public awareness, and
- the invisibility of injury.
7.6.1. Lack of Public Awareness Regarding Brain Injury and the Reaction of Others

The findings show a lack of public awareness regarding brain injury. The reaction of others to disability has a profound effect on how a survivor of TBI manages everyday encounters and social interactions. An example of this from the study was the incident recalled by a young female survivor of being refused entry to a public place because she appeared to be drunk. The pressure for TBI survivors to appear normal was overwhelming. Even professionals and well-meaning family members expected normal behaviour from them. This is further discussed in section 7.6.2.

7.6.2. The Invisibility of Injury

Some TBI survivors state they would rather have a visible injury, such as broken limbs than TBI. The invisibility of injury may present an additional problem, and many give the impression of operating without disability. This is supported by similar findings from Chamberlain (2006) and Lonardi (2007). The overarching conceptual framework of biomedicine only offers explanations on the basis of impairment and limitation, which has a profound effect on how disability is understood by society (i.e. narrowly). Shakespeare and Erickson (2000) suggest that disability should be understood in the context of the cultural, political and psychological aspects of the individual experience. Therefore, I agree that the use of a broader more holistic model would be preferable to reflect and accommodate the needs of TBI survivors.

7.7. Path to Recovery

The following sub-categories were identified under the core category of ‘path to recovery’:

- Ambition
- ‘Lucky to be alive’
- The importance of advocacy / Peer and Self Advocacy.

7.7.1. Trying to Change / Recovering as Far as is Possible

The enormous effort made by survivors after a TBI, despite experiencing pain and fatigue, was remarkable. The various strategies employed included walking fourteen miles a day and training for a marathon. These findings are a clear demonstration of how survivors strive for independence and are driven by a need to take back a sense of control and autonomy over their lives. These data show the extremes they will go to in order to
achieve this. Berry and Jones (1991) and French (1994) observed that the focus after an illness or injury is all too frequently on loss and deficit, and influenced by a public as well as professional ignorance and apathy towards disability and brain injured people.

The social model of disability pays little attention to the role and function of the body or cognitive impairment (Bury, 2005; Barnes and Mercer, 2003). For example, the social model does not consider the effects of impairment, such as chronic pain and memory loss, which are common features of TBI. Many survivors of TBI attempt to overcome disability to be socially accepted. However, as Bury (2005) rightly remarks disability threatens to upset the ability to present an acceptable social and cultural front, and leads to a sequence of doubts about executive cognitive functioning. As these data show, most TBI survivors wish to regain full control over the use of their bodies. A male survivor made reference to ‘trying to get out of this’ while another is determined to get back playing football with his local team. It is understandable why TBI survivors wish to regain control over their bodies so they can be credible in society again. Unfortunately, as these data show, it is more difficult to control the mind due to memory loss and other cognitive difficulties.

Such findings, as previously discussed, can also be understood in the context of what Goffman (1963) meant when he talked about the pressure for individuals to appear normal. For many participants in this study, the effort is on-going, with most survivors wishing to revert back to their pre-injured selves. Similar to my findings, Paterson and Staton (2009) suggest that survivors struggle with taking responsibility for gaining a new sense of self, and making adjustments to their lives after a TBI, because they experience guilt and anger about the incident that caused their injury. However, in contrast to these findings, Hill (2004) argues that over time people stop comparing themselves to their pre-injured selves. Instead they accept an image of themselves which accommodates the consequences of their injury. TBI survivors in this study reported finding it therapeutic to narrate their stories, as part of the healing process and coming to terms with their altered selves.

This finding supports Williams’ (1996), Frank’s (1995) and Charmaz’s (1987) contention that people with chronic illness must embark on the course of narrative renewal of which they are a significant part. However, the narratives in this study could not be considered examples of chaotic lives. Rather they show how survivors work through their experiences and how various encounters along the way impact on their lives and influence their story of recovery. The core category identified in this study was the process of recovery. Illness narratives are increasing in popularity amongst health practitioners who recognise their value as a teaching resource and as a device for building new knowledge. The quest narrative as described by Frank (1995), affords the ill person a voice. In this narrative people accept illness and seek to use it as a healing tool.
7.7.2. Ambition Following TBI

Survivors in this study have shown that they have definite goals and aspirations. They confront the challenges brought by TBI, despite the almost complete lack of encouragement or support from health and social care providers and the wider community. This must be placed in the context of the under-funding in Ireland of rehabilitation and post-rehabilitation. Survivors voiced a view that investment in supports for them, such as in the area of training and education, would greatly enhance their quality of life, and should in the long-term increase their independence. The lack of investment in rehabilitation for TBI is confirmed by Greenwood and McMillan (1993). They make the key point that head injury rehabilitation attracts far less in funding in comparison to acute services. Significantly, rehabilitation facilities for those with spinal cord injury (SCI) are much better developed, even though the ratio of TBI to Spinal Cord Injury is in the region of 260 to 1 (Spinal Cord Injury, 2009). This indicates that some injuries are more accepted and possibly seen to be more deserving of supports. Similar to Young (1990), and as previously discussed, findings from this study largely found that TBI resulted in discrimination, powerlessness and isolation. Again, illness and disability are influenced by the discourses used in the public domain, which are largely based on narrow biomedical explanations (Blaxter, 2007).

7.7.3. 'Lucky to be as Good'

The theme ‘lucky to be so good’ and the data collected from survivors offers an alternative argument to the notion that the individual survivor would be better off dead than brain damaged and disabled for life. The TBI survivors in my study compared themselves to others who did not do as well as them after a TBI, and considered themselves fortunate to have been given another chance at life. While some participants accepted that this type of injury could happen to anyone, findings also revealed how young people, especially young men, lack a sense of danger. This needs to be further addressed in safety campaigns, e.g. Road Safety Authority Campaigns.

This finding of survivors feeling lucky to be given another chance, is pertinent in the light of the current public debate on Physician Assisted Suicide (PAS) and Voluntary Active Euthanasia (VAE). Only last year, a young man who had sustained a spinal cord injury through rugby, had apparently planned to go to a clinic abroad to proceed with an assisted suicide. He died before his arrangements were complete. TBI survivors place great value on their lives. However, health economics systems of classification, such as DALY and QALY, use value measurements which accord a higher value to a person without a disability, than to one with a disability. This does little to address the cultural idea that a life with a disability has less value than one without a disability (Hammell, 2006).
In terms of the analytical framework, it is clear that the dominance of the biomedical model is all pervasive in the area of disability and rehabilitation. This is because it places a certain value on people, where injured and disabled are less worthy of services and supports. Societal values are strongly influenced by the biomedical model, to the detriment of people with disabilities. In answer to my research question, which is to examine key changes experienced in the lives of TBI survivors, I found the following: survivors had ambitions and hopes for their futures. Many talked of feeling lucky to be alive, offering a paradoxical view in light of their experiences of being written-off and ignored. Better off dead than living with the effects of a TBI is all too often the view of wider society. This key finding shows the constant struggle TBI survivors have in order to maintain credibility.

7.7.4. The Importance of Advocacy

This section summarises advocacy for TBI survivors and discusses its importance, as well as the concept of peer advocacy. It further addresses the research question, which is to assess how appropriate health and social services could be developed, based on the perspectives of TBI survivors.

Research findings show that despite the loving support survivors receive from their families, survivors articulate the need for people to represent and advocate for them. Families are often ill equipped, at the early stages, due to a lack of knowledge or information. Many struggle against a tide of expert opinion. I found that the level of personal resources family members possessed, in terms of knowledge and assertiveness, was significant in relation to influencing the quality of the survivor experience. Negotiating the world of clinical medicine is challenging for families with little prior knowledge of the condition (injury) and the organisation of clinical services. Shapiro (1993) and Hammell (2006) suggest that disabled people need to quickly acquire skills of self-confidence to overcome a world of prejudice and discrimination. Advocacy is a useful method of addressing power imbalances and advancing fairness, because TBI survivors do not have power on their side. Blaxter (2007) highlights that trust vested in health professionals and the vulnerability and unquestioning nature of those in receipt of treatment, make this an unequal relationship.

7.7.4.1. Peer and Self-Advocacy

Findings from the study demonstrate that one organisation, which was the peer and self-advocacy organisation - BRI, was of particular benefit to survivors of brain injury. Survivors felt that people with similar experiences were well-placed to understand and empathise with each other. Goffman (1954) gives a description of how people present themselves to the world, reserving informal behaviour for friends with shared experiences.
Findings from this study show the positive benefits of support organisations for survivors. Kleinman (1995) also acknowledges the patient and the family need to have their story of suffering heard in order to find support for their experience of illness.

In addressing the research question to assess how appropriate health and social services could be developed, based on the perspectives of TBI survivors, advocacy services are part of this. The need for advocacy is connected with power differentials and lack of knowledge. Self-advocacy groups have an important function as they provide valuable social supports for survivors.

7.8. Summary of Qualitative Findings – Family Members of TBI Survivors

7.8.1. Introduction

An additional focus of this study was to gain an understanding of the experiences of family members of TBI survivors. A summary discussion from this part of the study is presented under the following themes: i) getting the news; ii) the reality of survivors condition; iii) the response of healthcare professionals to the family member’s anxieties and questions; iv) milestones/hope for the future; v) realisation of change and vi) reclaiming own lives. These categories formed a model to describe the processes from the time the respondents heard the news to the present. The core category which was identified as significant was the process of adaptation by family members. It is noteworthy that while family members discussed a number of similar themes to TBI survivors, they had additional areas of dialogue. This section addresses the research question as to how the lives of family members of TBI survivors have changed. The perspectives of families regarding the health and social care services for TBI survivors are also addressed.

7.8.2. The Surreal Experiences

The surreal experiences for families and the reality of the survivor’s condition are further discussed under the following headings:

- Independence to dependence
- Financial impact/burden
- Lack of public awareness.

The shock and horror experienced by family members on hearing about the accident had a devastating effect. This was followed by emotional turmoil and hope mingled with despair. Some researchers have remarked on these unexpected and abrupt changes brought to the lives of family members and significant others as a result of a TBI. These can only
be poorly understood by them at the early stages (Jumisko et al., 2007; Duff, 2002). Close relatives are totally focused on the injured person (Engström, and Söderberg, 2004), and their time directly after the injury is taken up entirely with the injured and their chances of survival (Bond et al., 2003; Duff, 2002).

Family members described waiting around the hospital for news, and recalled in graphic detail their shock at seeing the survivor for the first time. Families coped with the help of extended families and their communities. They explained how they took it in turn to visit the hospital. For instance, mothers of two young survivors related how they stayed in the hospital during the week while their husbands worked. The fathers then took over in terms of waiting in the hospital at the weekends. Family systems theory advanced by Bowen (Kerr and Bowen, 1978) is valuable as an explanation to understand the coping strategies of members of the survivor’s family.

7.8.3. Independence to Dependence

While TBI survivors focused on the challenges of overcoming dependence, family members remarked on the major and shocking shift from independence to dependence of their loved one. On the one hand, this created a number of real dilemmas for the family members and caregivers, who were torn between trying to protect the survivor while encouraging a sense of independence. Survivors, on the other hand, strove for more independence and complained that others were over-protecting them. Hence, Barnes (1991) warns that attempts by family members and caregivers to over-care and over-protect, may encourage dependency. Kaufman (1994) and Marshall et al. (1995) point out that definitions of independence differ considerably from definitions of dependence, where the emphasis is on self-regulation, control and the ability, or opportunity to make choices.

In terms of the consequences of a loss of independence, there are many examples given by family members and the survivors themselves. For example, social outings were limited for many due to a loss of mobility, worries about physical appearance and being mistaken for being drunk. Survivors were no longer able to work, attend college or school and complained of feeling bored and fed up. Family members reflected on the lack of bodily competence which made survivors dependent on them. This was an unexpected and additional burden of care for many parents. Given the young age of many survivors, parents are still relatively young themselves. Their expectation was that their children would be fully independent at this stage. According to Hawley et al. (2003), a survivor with a significant brain injury can unintentionally place a financial, as well as an emotional burden, on their family.
7.8.4. Financial Resources

Many of the family caregivers experienced financial and burden implications. For example, one young wife and mother of four children, the youngest a baby of three months, was obliged to find a job in order to support her family after her husband’s accident, as he was previously the main source of family income. This finding is supported by that of McMordie and Barker (1988) who point out that the financial burden placed on the family after a TBI has a significant negative effect on their quality of life. A further example from this study is the survivor who had a successful business before his injury, and now cannot afford to install broadband, as he is dependent on social welfare.

Scambler (2008a) suggests that the management of chronic illness is highly dependent on access to resources and appropriate services. This was also true of families in this study, some of whom were waiting for accident compensation. The mother of a male survivor complained about the uncertainty related to continuity of social welfare payments. She worried that her son’s social welfare payments would be cut after he enrolled on a course of study. Bury (1988) contends that chronic illness has two levels of meaning, one is to be found in the disadvantage created by a lack of resources, and the other is the extent to which a given condition renders a person culturally incompetent (cited in Scambler, 2008b).

Brain injury can be considered as a chronic condition which has the double disadvantage of rendering the survivor culturally incompetent for a considerable time (as well as chronically ill). It quickly removes all the taken for granted props and elements of living, and frequently creates a level of dependency on others. Scambler (2008a) suggests that there is a relationship between the individual’s experience and the social and political approach to providing services, being mindful of the long established links between disability and poverty. Strategies taken by government to facilitate treatment and support are not being implemented (O’Fynn, 2008), and are far from adequate. Many of the families in the study were in lower income groups and it is essential that the Government provide the necessary supports and services to help them cope.

7.8.5. Lack of Public Awareness

While some acquaintances offered understanding and help, others added to the family’s distress by their intrusive behaviour. Similarly to data from TBI survivors, family members also had unhelpful encounters with members of the public. People made judgements based on the physical effects of TBI. Many stated that their loved ones were written off by members of the public because of their brain injuries. According to Sherry (2006) assumptions about disability are based on aspects that are visible to others. Goffman’s (1963) work on stigma is also helpful here in understanding the cultural representations of
disabled people. Swift and Wilson (2001) found that there is a general lack of awareness of the physical, cognitive and behavioural problems that brain injury can cause. They suggest that people often erroneously assume the same kind of recovery trajectory for brain injury as for other bodily injuries.

The majority of the family members interviewed in the study complained of not being given a clear indication of outcome. One woman’s explanation was that the medical profession do not know because each brain injury is different. She expresses it thus: ‘well he’s brain damaged ... and you know you can’t fix that’. Chamberlain (2006) contends that there is a lack of understanding amongst the medical profession of how brain injury affects each individual. Another family member suggests there should be a campaign to increase knowledge on brain injury. Goffman (1963) wrote extensively on the concept of stigma and the techniques used by people with disabilities in order to manage everyday encounters. Research findings in this study show survivors use techniques to hide the physical aspects of their injury in an attempt to fit in. For example Ann recounts her experiences: ‘the hardest part is not being one of the girls you know, not being able to fit in because you are tired like’.

7.8.6. Perspectives on the Physical effects of TBI
A common finding among family members was that frustration and mood swings were side effects of TBI. This is confirmed by Cantor et al. (2005). Further impacts identified by care givers included memory loss, fatigue, and lack of insight to the extent of their injury. These have also been shown in previous research studies on traumatic brain injury (Jumisko et al., 2007).

Jumisko et al. (2007) note that close relatives are saddened by the change in personality brought on by the injury. Evidence from the study supports this. For example, a mother admitted that she was grieving for her son and his situation, but added she had to remain positive. A survivor’s wife, who receives little in the way of social supports, said that the on-going nature of this type of injury is very hard to deal with. She believes that it is harder than death to deal with. Riley (2007) found in a study that high depression and stress rates are associated with less social supports and more severe behaviour. However, family members in this study remained up-beat despite the situations they found themselves in.

7.8.7. Embarrassing Behaviour
Family members acknowledged that they tried to limit the effect of a survivor’s behaviour in public. They were forced to develop coping strategies to deal with the survivor’s behaviour so as not to cause offence to others. Joining a support group or finding ‘a listening ear’ at one of the NGOs, allowed them to make sense of their lives. The impact of
TBI on families and carers is well-documented (Brooks, 1991; Kreutzer et al., 1992; Lezak, 1986; Weddell et al., 1980; Brooks et al., 1987; Barnes and Mercer, 2003). The father of a young TBI survivor told of his embarrassment at his son's inappropriate comments and language. Goffman (1959) developed the concept of dramaturgy, which is the notion that life is like a never-ending play in which people are actors (Kivisto and Pittman, 2001). Goffman used the term impression management to refer to our desire to influence others' impressions of us. This theory is particularly relevant and can be used to interpret the social interactions of family members of TBI survivors have with others.

7.9. The Response of Healthcare Professionals to the Family Member's Anxieties and Questions

The sub-categories identified here from the data analysis are as follows:

- Lack of information from healthcare professionals on brain injury
- Healthcare Providers - Lack of Training
- Post-rehabilitation services
- 'Bed Blocker'.

7.9.1. Lack of Information from Healthcare Professionals on Brain Injury

The findings build up a picture of the difficulties people experience in order to get information from healthcare professionals. They demonstrated clearly that the level of knowledge families possess, particularly in relation to treatment options and social welfare entitlements, influenced the outcome in regard to this. Often family members lacked the skills to be able to challenge expert knowledge and therefore risked being offered less adequate services than others who can successfully navigate the system. The dominant biomedical model of health and illness has led to the exclusion of lay person knowledge, and pushes out other models and approaches. One family member articulated a typical sentiment that the medical team were more interested in the injury than the person. Charon (2001) argues that practitioners, such as doctors and nurses are trained to distance themselves from their patients. Protocol demands that they practice their skills in an objective manner. Charon (2001) further suggests that the illness experience is too far removed from scientific evidence and therefore without credible foundation. However, findings from this study show that survivors found it therapeutic to recount their experiences of TBI.

The expression of helplessness due to the lack of information given to family members was an ever present part of the study. Harden (2005) found that family members felt at a loss when they had to rely on expert advice, which was not forthcoming. Giddens (1991)
argues that the formation of expert systems of knowledge, such as medical knowledge, has resulted in the deskilling of lay people. Much of the language used by medical professionals is confusing for lay people.

7.9.2. Healthcare Providers-Lack of Training

Similarly to TBI survivors, family members commented on the lack of training of healthcare providers in this area of care. For instance, a parent’s experience in a general hospital, where their son was admitted for a procedure, was described as nightmarish. They recalled having to physically hold their screaming son down to prevent him escaping, while members of staff looked on. Specialised training in dealing with people with brain injuries was a key recommendation advanced by the parents of this teenage boy. This is particularly pertinent given the current understaffing in many of the general hospitals. A variety of experiences were also reported from the National Rehabilitation Hospital. While some family members had positive experiences there, and praised the efforts of staff, others were critical of the approach used in dealing with them at their most vulnerable. These disturbing findings point to a lack of understanding by some healthcare professionals on how to deal with the sensitivities of family members. All too often, a clinical explanation is too overwhelming for them. They recommended more plain English explanations and more sensitivity and more practical advice and help. One woman recalled her despair at being told at a multidisciplinary staff meeting that her husband was brain damaged and could not be helped further and she was informed that she had to take him home.

Swift and Wilson (2001) found that many of the misconceptions attributed to members of the public were also common to healthcare professionals who were not experts in the field of brain injury. These included inaccurate beliefs about time span and extent of recovery, and behavioural symptoms. The professionals mentioned in their study included hospital doctors, general practitioners, nurses, occupational therapists and physiotherapists. Swift and Wilson (2001) point out that the lack of staff training in dealing with behavioural issues after brain injury has negative consequences for survivor recovery and family confidence. Negotiated Order Theory (Strauss et al., 1998) again draws attention to the strain created by the boundaries which have developed by the various agencies and professionals involved in the provision of health and social care. This is further compounded by the lack of training in multidisciplinary approaches to care. Medical education continues to ignore the social dimension of TBI and should be considered for inclusion in future training programmes.
7.9.3. Post-Rehabilitation Services

Findings from this study illustrated how fragmented the post-rehabilitation service is for survivors of TBI in Ireland. People are under compliment for the level of service provided, which often fell short of their expectations. These findings support Townsend’s (1998) contention that rehabilitation services are not organised to suit the recipient of care. The findings also showed how difficult it was for TBI survivors to access these services due to their disabilities, and often the services were just not available. Goddard and Smith (2001) recommend an urgent audit of healthcare services.

7.9.4. TBI Survivors Viewed as ‘Bed-Blockers’

Family members in this study recalled the immense pressure placed on them by hospital management. For example, bed managers, administrators and a consultant were involved in trying to discharge a TBI survivor from the acute hospital where they were receiving treatment and care. Their attitude was one of disregard for the availability of alternative placements. Even the derogatory term ‘bed blocker’ was used by one healthcare professional to describe a TBI survivor.

Thomas (1999b) notes that the medical profession control the discourse surrounding the purpose of hospitals, which is to cure people. In this study, Tara, the wife of a survivor recalls how the rehabilitation team gave up on her husband:

He didn’t get much therapy. A small bit taken out of your day and that’s it they were left sitting there for the rest of the day. And they even left him go before the time even. They said he wasn’t making any progress, they said there was nothing more they could do for him. But there was nothing at all after that.

Another man described a conversation he had with a medical consultant who told him to move his brother out of the acute hospital: ‘he actually told me that we can do nothing for your brother, you get him out of this hospital, whatever means you have, I don’t care how you do it, he needs to be in Dun Laoghaire, how you do it is your own business’.

Budget constraints and pressures exerted by Government agencies have placed many health care professionals in a dilemma. This dilemma is that of being unable to offer specialist services, such as rehabilitation services, needed by the patient and coming under pressure to free up hospital beds. According to Henwood (1992), the distribution of health resources is presented in terms of people with brain injury, and others with chronic illness, as being a liability. In large institutions, such as hospitals, it was difficult for family members in this study to voice their concerns. Etzioni’s (1960) explanation on the organisational structure of hospitals, draws attention to how goal attainment may be used as a measure of effectiveness and efficiency - that is the ‘freeing up’ of beds (Browne, 2004). Hospital bed
occupancy ideally means making the best use of costly highly technical equipment and facilities (Ettelt et al., 2009). The father of a young survivor explained what he thought was happening in the acute hospital where his son waited for a bed in the NRH:

Sure apparently, when Thursday evening comes they have to empty out all the wards, sure there’s people going home who weren’t fit to go home, but it didn’t matter ‘cos they empty the wards on a Thursday evening. They had so many gone through the beds anyway, you know all these things, it was pure stupid, it’s for accreditation, it’s pure stupid.

7.9.5. Milestones and Hope for the Future

It was clear from my research that the family participants needed to keep a sense of hope. They give examples of how they keep trying and that this is motivated by their refusal to give up on holding out hope that their loved one will attain a quality of life that is meaningful to them. Whilst realising that improvement may not be possible, a process of adaptation is continuing. Families admitted that while they have to be realistic, a deep love and affection for the survivor compelled them to keep trying for the sake of the survivor. Jumisko et al. (2007) found that families struggle on and never lose hope. Similarly, the findings of Carson (1993) and Smith and Smith (2000) show that relatives of very ill people need to feel hope and make sense of their experience.

7.9.6. Realisation of Change

Family members tried to remain positive by remembering the times before the injury, while coming to terms with the changes brought about by the TBI. There was evidence that family members were also struggling with grief. Caregiver stress and depression are often reported by carers of TBI survivors (Marsh et al., 1998). This stress is aggravated by what carers see as the behavioural intentions of the survivor, and their conviction that the survivor may feel hostile towards them (Mitchley et al., 1996; Riley, 2007). In this study, data collected from a father who found his son’s behaviour upsetting, supports this contention. Families and carers experience profound changes (Jumisko, 2007; McLaughlin, 1985), and are often ill-prepared to deal with difficult behaviour (Rosenthal and Young, 1988).
7.9.6.1. Caring Responsibilities

The international literature shows that mothers provide most of the care to brain injured sons (Knight et al., 1998; Kneafsey, 2004). While evidence from this study suggests fathers, brothers and sons provide care, intimate care is almost always the responsibility of mothers. Survivors talked of being showered by their mother and one woman had to toilet train her teenage son. However, a single father in this study provided total care for his teenage son after he was discharged from hospital. This finding is an indication that family members, irrespective of gender, will assume a caring role for a loved one. Payment for carers should be a priority for government because it relates to avoidance of poverty issues and, in the long-term, saves state money on healthcare and social services.

7.10. Redefining Own Lives

In this study, findings document the enormous adjustment family members made in order to accommodate the TBI survivor. Some described this as putting their own lives on hold for a while and then their attempts at restarting their lives later. Many studies have shown that close family members take on role changes and assume more responsibility than before the injury (Gill and Wells, 2000; Kneafsey and Gawthorpe, 2004). Duff (2002) also found that there is a great willingness on the part of relatives to accommodate the injured person by altering their own lives. Findings in this study clearly demonstrate the big shift which results when a close family member has a TBI. Parents not being able to retire and spouses having to become breadwinners as well as carers are unexpected changes for family members. At the same time, the findings of this study show that they focus on never losing hope.

7.11. A New Model of Care

A consultant in rehabilitation medicine, discussed his views on the hospice model of care during an interview I conducted with him for this study. He considers this an appropriate model which could be applied for TBI survivors. Hospices are described as extraordinarily consumer-friendly providers of care (Pring, 2007).

The hospice approach of integrating intensive medical and social care management and focusing on quality of life can be a new and potentially transformative source of support for individuals with serious illness. Illness has dramatic impacts across the medical, functional, psychosocial, spiritual, and financial domains (Pring, 2007:1).

This consultant shares the view that hospices have a broad understanding of wellness and treat the whole person and the issues surrounding serious illness (Pring, 2007:1).
He contends that the present approach to treating TBI survivors is limited, and could benefit from exploring and developing alternatives. The hospice model of care is highly individual but recognises the advantage of involving and supporting family members and carers. Pring (2007:1) explains that ‘hospices prioritise service in the home; have interdisciplinary team management hard-wired into their operations; integrate paid and unpaid in-home assistance and support for caregivers into their service plan; and integrate both spiritual and psychosocial issues into routine care planning’.

7.12. Conclusion

In conclusion, I have addressed the research questions on how the lives of family members of TBI survivors had changed, as well as the perspectives of families regarding the health and social care services for TBI survivors. The key changes experienced by family members were the initial emotional turmoil and shock, the burden of caring, which was largely undertaken by women, the sacrifices they made and the dilemma of trying to protect a TBI survivor over the promotion of independence. Further changes included coping with public attention and lack of understanding, as well as the family resources being under pressure.

The key perspectives of families regarding the health and social care services for TBI survivors include concern over the lack of training of healthcare professionals; the labelling of TBI survivors as ‘bed blockers’; hospital systems being designed for professionals over users; the fragmentation of post-rehabilitation services and difficulty over equity and access to services. The dominance of the biomedical model was again evident and did not take into account family’s needs and opinions. Despite the often negative experiences of engaging with health and social care services, as well members of the public, this study is a testament to the strength of the human spirit to never lose hope or give up. A summary of the key findings from the study are displayed in Tables 55 and 56.
### 7.13. Summary of Key Findings

#### Table 55: Summary of Key findings from Survivors of TBI

<table>
<thead>
<tr>
<th>Sub-category</th>
<th>Key Findings from Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Sudden Change in Roles</td>
<td>Amount of adjustment necessary for many of the survivors was considerable.</td>
</tr>
<tr>
<td>Chaos</td>
<td>The chaos and uncertainty that entered people's lives following TBI.</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>Feelings of fear and helplessness were all very real following TBI. Life plans had to be put on hold.</td>
</tr>
<tr>
<td>Dependence/Independence issues</td>
<td>Loss of role, helplessness and a colossal shift from independence to dependence and an imposed dependency. Changes to independent financial status.</td>
</tr>
<tr>
<td>Isolation, Loneliness and Depression</td>
<td>The loss of friends, jobs and previous routine. This had the further effect of plunging survivors into isolation and loneliness.</td>
</tr>
<tr>
<td>TBI survivors being &quot;written off&quot; by others</td>
<td>&quot;Written off&quot;, particularly survivors with communication problems.</td>
</tr>
<tr>
<td>Lack of public awareness regarding brain injury and the reaction of others</td>
<td>Lack of public awareness regarding brain injury and the reaction of others to disability has a profound effect on how a survivor of TBI manages everyday encounters and interaction with others.</td>
</tr>
<tr>
<td>The invisibility of injury</td>
<td>The invisibility of injury may present an additional problem. Some survivors in this study stated they would rather have a visible injury, such as broken limbs than TBI. Trying to pass off as 'normal' by the TBI survivor is what may well disadvantage them in their dealings with others, adding significantly to their pressures.</td>
</tr>
<tr>
<td>Encounters with Health Professionals</td>
<td>Rather than promoting independence, health and social care staff encouraged a sense of helplessness. Similar to health professionals, members of the public also had a stereotypical attitude towards people with disability, e.g. they felt they needed protection for their own safety and were unable to manage their own lives and required decisions be made on their behalf.</td>
</tr>
<tr>
<td>Paternalistic Attitudes</td>
<td>TBI survivor participants reported their encounters with healthcare professionals, which they described as often difficult, and continued to impact negatively on their lives after TBI. These ranged from being made to feel inferior, having relevant information held back and 'being talked down to'.</td>
</tr>
<tr>
<td>Treatment by Health Professionals</td>
<td>A poor understanding and a lack of expertise amongst healthcare professionals, on brain injury and its consequences.</td>
</tr>
<tr>
<td>Lack of Expertise amongst Health Professionals</td>
<td>Lack of knowledge is also the basis for the unhelpful and damaging labels and the use of professional language they attach to people with brain injury.</td>
</tr>
<tr>
<td>Communication gaps between service provider and service user</td>
<td>Communication gaps between the staff and the service users (TBI survivors). The mismatch between goals of the rehabilitation team and the expectations of the survivor also create misunderstandings. The outcome measurements used by rehabilitation professionals prioritise what is achievable and measurable in terms of success, and may be at odds with the expectations of the TBI survivor.</td>
</tr>
<tr>
<td>Post-rehabilitation: an underdeveloped area</td>
<td>TBI survivors strongly held the view that post-rehabilitation supports and services in Ireland remain fragmented and poorly resourced.</td>
</tr>
<tr>
<td>'Trying to Change' and 'Coping'</td>
<td>The colossal effort made by participants after a TBI, despite experiencing pain and fatigue, was remarkable. TBI survivors in my study reported finding it therapeutic to narrate their stories.</td>
</tr>
<tr>
<td>Ambitions following TBI</td>
<td>Survivors in this study have shown that they have definite goals and aspirations.</td>
</tr>
</tbody>
</table>
The theme ‘lucky to be so good’ and the data I collected from survivors offers an alternative argument to the often widely held societal belief that the individual survivor ‘would be better off dead’ than brain damaged and disabled for life. The TBI survivors in my study compared themselves to others who did not do as well as them after a TBI, and considered themselves fortunate to have been given another chance at life.

Advocacy

Survivors articulated the need for people to represent and advocate for them.

Table 56: Summary of Key findings from family members of TBI survivors

Core Category: The Process of ‘adaptation’ by Family Members.

<table>
<thead>
<tr>
<th>Sub-Category</th>
<th>Key Findings from my Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>The ‘surreal’ experiences</td>
<td>The shock and horror experienced by family members on hearing about the accident had a devastating effect. This was followed by emotional turmoil and hope mingled with despair.</td>
</tr>
<tr>
<td>Getting the News</td>
<td></td>
</tr>
<tr>
<td>Independence to dependence</td>
<td>While TBI survivors focused on the challenges of overcoming dependence, family members remarked on the major and shocking shift from independence to dependence of their loved one. This created a number of very real dilemmas for the family members and caregivers, who were torn between trying to protect the survivor while encouraging a sense of independence.</td>
</tr>
<tr>
<td>Perspectives on the Physical effects of TBI</td>
<td>Frustration and mood swings were side effects of TBI. Further impacts commented on included memory loss, fatigue, and lack of insight to the extent of their injury.</td>
</tr>
<tr>
<td>Embarrassing behaviour</td>
<td>Family members were forced to develop coping strategies to deal with the survivors’ behaviour so as not to cause offence to others.</td>
</tr>
<tr>
<td>Financial Resources</td>
<td>Many of the family participants in this study experienced changes to their finances, which were largely negative.</td>
</tr>
<tr>
<td>Lack of public awareness</td>
<td>While some members of the public offered understanding and help, others added to the family’s distress by their intrusive or abusive behaviour.</td>
</tr>
<tr>
<td>Family Encounters with Healthcare professionals and Professional Dominance</td>
<td>Difficulties people experienced in order to get information from healthcare professionals. They demonstrated clearly that the level of personal and social capital families possessed influenced the outcome in regard to this</td>
</tr>
<tr>
<td>/Power of Medical Profession</td>
<td></td>
</tr>
<tr>
<td>TBI survivors viewed as ‘bed-blockers’</td>
<td>Family members in this study recalled the immense pressure placed on them by hospital management. For example, bed managers, administrators and a consultant were involved in trying to discharge a TBI survivor from the acute hospital where they were receiving treatment and care.</td>
</tr>
<tr>
<td>Healthcare Providers-Lack of Training</td>
<td>Family members commented on the lack of training of healthcare providers in this area of care.</td>
</tr>
<tr>
<td>Post-rehabilitation services</td>
<td>Fragmented post-rehabilitation services. Survivors / family are expected to feel grateful for the level of service offered, even if it falls short of their expectations</td>
</tr>
<tr>
<td>Hope for Family Members</td>
<td>Family participants needed to keep a sense of hope. They admitted that while they have to be realistic, a deep love and affection for the survivor compelled them to keep trying for the sake of the survivor.</td>
</tr>
<tr>
<td>Realisation of change</td>
<td>Family members tried to remain positive by remembering the times before the injury, while coming to terms with the changes brought about by the TBI. There was evidence in this study that family members were also struggling with grief.</td>
</tr>
<tr>
<td>Caring responsibilities</td>
<td>While evidence from this study suggests fathers, brothers and sons provide care, intimate care is almost always the responsibility of women, such as mothers.</td>
</tr>
</tbody>
</table>
Reclaiming own lives Parents not being able to retire and spouses having to become breadwinners, as well as carers are unexpected changes for family members. Additionally, they would probably feel guilty about leaving them for a new beginning.

7.14. Recommendations

My final research question addressed how appropriate health and social services could be developed, based on the perspectives of TBI survivors and their families. My assessment is presented here in terms of the key recommendations from the study:

Macro

- The use of advocacy is not a well-developed concept in Ireland, but its role must be viewed as a positive means of ensuring that TBI survivors and their families assert their rights. It could also help empower this group to demand better services and care.

- Develop a community-wide awareness of TBI to address issues of negative attitudes, inappropriate behaviour, lack of knowledge and skills in relating to TBI survivors and families.

- There is a need to develop a ‘one-stop-shop’ approach to providing relevant information at the various stages of recovery. Greater use of electronic technology, such as email and text messaging, would ensure that people are made aware of the supports and services available.

- Neurological medical services in Ireland are poor and fall well below the general acceptable level in any other western European country (BRI, 2008). Phillips (2009) in The National Report on Traumatic Brain Injury, also highlighted that Ireland has only 10 neurosurgeons - the lowest number per head of population in Europe. Therefore, more investment in Neurosurgical and Neurological services are necessary.

- Only one in four people awaiting neuro-rehabilitation will succeed in gaining a place at the National Rehabilitation Hospital, which is the only neuro-rehabilitation facility in Ireland, (O'Connell, 2008). At any time, there are approximately 120 acquired brain injured people waiting for access to the NRH, waiting times are 3-18 months and only 40 beds are assigned to brain injury rehabilitation (Delargy, 2008). Greater commitment is required by policy makers and health and social care professionals to improving the image of rehabilitation as well as the rehabilitation services in Ireland.

- The development of a national registry/database of brain injury will enable those involved with the planning and delivery of services to identify the level of need amongst people with brain injuries. The development of such a registry is required as a matter of urgency.
The NGOs are already providing vital supports and services to TBI survivors and their families/carers. However, they are considerably under-funded and rely to some extent on charitable donations. More Government funding would allow these organisations to further develop their services.

Payment of carers relates to avoidance of poverty issues and, in the long-term, saves the State money on healthcare and social services. Adequate payment for carers is needed to enable as many TBI survivors as possible to continue to live in their communities.

Many of the families in the study were from lower income families and it is essential that the Government provide the necessary financial supports to help them cope after this sudden and unexpected type of event. A special emergency fund would address their initial financial problems.

Free or heavily subsidised telecommunications (Broadband) for brain injured survivors. This would provide a link to wider society, and is so important for communicating and not being isolated and lonely. This is as important as subsidised electricity, telephone rental etc.

Survivors had difficulty negotiating the use of public transport services. A more localised / customised transport service would address these difficulties (e.g. such as rural transport services targeted / available to some elderly people).

While some participants accepted that this type of injury 'could happen to anyone', findings also revealed how young people, especially young men, lack a sense of danger. This needs addressing in terms of safety campaigns, e.g. Road Safety Authority Campaigns.

More sophisticated approaches in dealing with the post-rehabilitation needs of survivors. Many of the current training courses on offer are of little interest to individual survivors. For example, a wider range of training and educational opportunities are essential, specifically tailored to the needs of survivors, who are mostly young and male.

Barriers to education, such as eligibility to grants, should be removed to enable survivors to return to education.

**Meso**

Medical education continues to ignore the social dimension of TBI and should be considered for inclusion in future training programmes. Specialised training in dealing with people with brain injuries was a key recommendation advanced by many of the survivors and family members. This specific training for healthcare professionals and providers should be developed as a matter of urgency.

Consider the opportunities that exist to support working in partnership through an
inter-agency approach to develop shared understanding networks, e.g. education and skills providers/employment agencies working with clinicians and therapists.

- Rehabilitation professionals need to broaden the outcome measurements, to include social and cultural dimensions, as well as the physical aspects after a TBI.
- Enhance integrated working of multi-disciplinary teams by promoting professional development and utilisation of expertise to encourage an holistic approach to service delivery, through the examination of processes and structures.
- Develop and promote more open communication between service providers and service users – i.e. listen to the voices of the powerless and the ignored.

Micro

- There is considerable evidence that the follow-up after rehabilitation is poorly developed. An urgent review of this entire area is necessary in order to provide the necessary seamless services TBI survivors need.
- Consider alternative models of care, such as the independent living model and the hospice model.
- More supports in relation to alcohol and drug abuse issues, which was a factor for many survivors before the TBI.

7.15. Retrospective View of Study

A retrospective evaluation is considered a necessary task following the completion of a research project of this nature. Wellington et al. (2005:41) points out that 'untangling and becoming aware of many aspects of learning on a doctoral programme illustrates the scale and multi-layered nature of the whole endeavour'. The approach adopted in this study worked well in most aspects. For example, the development of datasets from hospital notes and existing hospital datasets ensured the sample included all survivors during a particular time period. However, I used only admissions to two hospitals; patients who were admitted to other acute hospitals around the country and remained there for the duration of their treatment were not included in the datasets for analysis. I am of the belief that most patients with severe TBI are admitted to one of the two neurosurgical units. This may not be the case with moderate TBI. As a by-product of my research, it is obvious that a data collection system, which would include all cases of TBI, needs to be put in place.

The study would have benefited from a greater community perspective, involving General Practitioners and Public Health Nurses. This would have allowed for the creation of research relationships between hospitals and between community and other care facilities. Time constraints did not allow for this approach and it would have required a changed approach in terms of design, data collection and analysis. I choose the under 65 year age
group because anecdotal evidence suggested that there were fewer facilities for people with acquired brain injury in this age group. On reflection, I could have included all age groups in the study. TBI is also common in very young children and in older adults. However, this would have extended the boundaries of the study and thus, would have added to the time and resources needed for research design and analysis.

The initial response rate from Beaumont Hospital was very low. Perhaps, a snowball sample selection would have been productive here. In the data collection phase with survivors and family member, it might also have been useful to include follow-up interviews with survivors.

On a personal basis, I found the experiences expressed by the research participants about living with TBI harrowing on occasion. However, I was also heartened by the good humour displayed by the interviewees and their families. I have remained in contact with many of the survivors and with some family members. In conclusion, given the limitations around access to patients with moderate or severe TBI, few alternatives were available.

7.16. Future Research

My goals and research activities totally support a mission shared by many others in this area of research and service provision - i.e. to enable people with a traumatic brain injury to participate fully in their families, communities, school and at work. I wish to continue this important work beyond the boundaries and limitations of this study. Currently, so much remains un-recorded, but the setting up of a database/registry of people with traumatic brain injuries would allow greater accuracy in the quantification of the problem, characteristics of the people affected and their long-term outcomes. From this, evaluation of service provision can take place and resource proposals can be advanced. My visit to the Medical University of South Carolina, U.S.A. assisted me in identifying strategies, which I believe has further informed the type of registry/database most suitable for use in Ireland. I intend to develop this link, perhaps to create a longer-term partnership, in order to enhance more comparative work and enable further productive research on TBI in Ireland.

This is an under-researched area in the general social aspects of health and illness. The existing literature has focused on clinical concerns of people with traumatic brain injuries; a distinct shortage is evident with regard to raising awareness of their unmet needs, particularly in relation to quality of life issues. Narratives of illness and the experience of suffering after illness are at present under explored. There is scope to further develop this theme, thereby gaining a better understanding of the issues for patients and their families.
This study has a strong people-centred perspective, focusing on broader quality of life issues. Therefore, it has the capacity to inform a number of multi-disciplinary clinical and academic fields in the areas of health (neuro-rehabilitation; neuro-psychology, TBI, rehabilitation, health policy) as well as sociology. It also has a role in updating curricula of education in nursing, medicine and the allied professions. Similar studies are now required to build on this knowledge. There has been a need to integrate policy and practice of the rehabilitation sector into the wider health, education, training and employment communities. At present, the sectors are disjointed leading to the provision of fragmented services (Kiernan, 2004).

Future projects should involve the examination of current service provision in the acute and rehabilitative sectors in Ireland for the above group by engaging in collaborative research with medical centres, academic research organisations, the voluntary disability agencies and the training community. Further knowledge could be gained regarding communication links and service integration and how these could be fostered between the various elements of service provision. Analysis of the shifts and/or continuities in hospital/rehabilitation ethos, knowledge, practices and cultures would be useful, and would contribute to the wider debates on the delivery of healthcare and would focus on broader quality of life issues.


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APPENDIX A: ANATOMY

THE HEAD

BACKGROUND

Definition of head injury
Head injury is defined as, 'history of, or physical signs compatible with, a blow between the eyebrows and the occiput.' This definition is not comprehensive. Severe or often fatal head injury can occur even without any impact; for example rapid deceleration caused by motor cycle collision with a helmeted rider.

Epidemiology
One million patients with head injuries attend Emergency Departments every year. Although the majority are minor injuries, based on a normal level of consciousness at presentation, cranial trauma is also a significant cause of mortality and morbidity.

There are 5000 fatal head injuries in the UK each year. It is the commonest cause of death in children and young adults and also leads to severe disability in 1500 survivors annually.

Loss of consciousness
Most significant impacts send the head into motion. Some cranial contents move more than others, therefore shearing forces are set up between the outer surface of the brain (the cerebral cortex) and deeper structures with temporary or permanent interruption of the fibres which pass between them. Normal consciousness (alertness) depends upon function in these pathways, therefore injuries with a significant decelerational component tend to cause unconsciousness. The unconsciousness may be of variable duration and severity. In an alert patient a history of, knocked out,' may be obtained from a witness or it may be implied from a patient's inability to recall events relating to the injury.
Level of consciousness is scored using the Glasgow Coma Score or GCS. Head injuries are frequently classified by severity according to GCS. Coma is defined as a GCS less than 8.

<table>
<thead>
<tr>
<th>Glasgow Coma Scale</th>
<th>Eye Opening</th>
<th>Motor Response</th>
<th>Verbal Response</th>
<th>Verbal Response in Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>N/A</td>
<td>Obeys command</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>5</td>
<td>N/A</td>
<td>Purposeful movements</td>
<td>Orientated</td>
<td>Interacts</td>
</tr>
<tr>
<td>4</td>
<td>Spontaneous</td>
<td>Withdrawal</td>
<td>Confused</td>
<td>Consolable</td>
</tr>
<tr>
<td>3</td>
<td>To voice</td>
<td>Flexion</td>
<td>Inappropriate words</td>
<td>Moaning</td>
</tr>
<tr>
<td>2</td>
<td>To pain</td>
<td>Extension</td>
<td>Incomprehensible sounds</td>
<td>Irritable</td>
</tr>
<tr>
<td>1</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>

Sometimes the anatomical injury identified (even at post mortem) is inadequate to fully describe the severity of a head injury. In such cases it is conventional to utilise the length (or less satisfactorily) the level of unconsciousness using the Glasgow Coma Scale score. The convention used is explained on page 23 of the AIS90 dictionary.

[TARN uses only the length of unconsciousness for severity coding purposes]
The skull provides bony protection to the brain. The upper part is known as the cranial vault. It is composed mainly of a frontal bone in front, an occipital bone behind, left and right temporal bones below and laterally, and left and right parietal bones above and laterally.

The cranial floor or base of skull is made up of these bones together with the sphenoid and ethmoid bones. The base of the skull contains various perforations or ‘foramina,’ through which pass nerves and vessels, and a large hole called the foramen magnum which accommodates the brain stem and part of the brain which is in direct continuity with the spinal cord.

Outside, the skull is covered by the scalp whose layers include skin, subcutaneous tissue, (large blood vessels travel in this layer) and two layers of fibrous tissue; pericranium lining the bone and galea more superficially.

Inside, the brain is covered by a thin transparent membrane, the pia mater. The arachnoid mater is a layer of intermediate thickness which lies outside the pia. The dura mater (or dura) is a tough, fibrous layer whose deep folds separate the two cerebral hemispheres (falx) and also the cerebrum from the cerebellum (tentorium cerebelli or tent). A small depression in the midline of the skull base accommodates a spherical appendage from the diencephalon (see below), the pituitary gland.

Anatomically the brain may be considered as an upward (or cephalad) extension of the spinal cord. The narrow almost conical continuation of the cord is the brain stem (comprising the medulla, the pons and the midbrain). It is continued as the diencephalon or central neuraxis which curves forward as it gives rise to three expansions from its dorsal surface; the cerebellum below and the left and right cerebral hemispheres (cerebrum) above.

Important elements of the cerebral circulation travel along the ventral (front) surface of the brain stem and the diencephalon and this region also gives origin to the 12 pairs of cranial nerves which pass caudally (downwards) before existing through foramina in the base of the skull to gain their extracranial positions from which they provide power and sensibility to parts of the face.

The brain is bathed in the colourless cerebrospinal fluid (CSF) which not only circulates over the surface of the brain but also within cavities in the brain substance known as ventricles. The cranial contents gain their blood supply from the left and right vertebral arteries. These two systems are separate as they pass from the heart to the head, but join together once within the cranial cavity to give rise to paired branches supplying the parts of the brain suggested by their names: the anterior, middle and posterior cerebral arteries. The basiliar artery is formed by the union of the two vertebral arteries prior to the origin of these branches.

The veins draining the cerebral substance empty into large thin-walled channels called venous sinuses. These sinuses drain into the left and right internal jugular veins which return the blood to the heart.
AIS DESCRIPTORS

WHOLE AREA
An abrasion is a superficial skin wound often termed as a graze.

A contusion is the result of a blunt blow to the surface. It is a swelling, often skin coloured rather than bluish, differentiating it from a haematoma. However for the purposes of injury description the two are coded as one.

A laceration is a split wound, the result of blunt trauma or crushing. The severity will vary from trivial to life threatening. The wound caused by a sharp edge such as a knife is not a laceration but an incised wound.

The wound produced by a pointed implement is a penetrating injury.

An avulsion is the severest form of laceration whereby the skin and the subcutaneous tissues are torn off from the underlying structure by a high energy crush or mangling type of force. The terms degloving and avulsion sometimes cause confusion, not least among doctors making clinical records in the notes.

Correct terminology is as follows:
Where a mangling force off the skin and the subcutaneous tissue from the next deepest layer (the deep fascia, which is an envelope of fibrous tissue 'investing the muscle') a degloving has occurred. This degloving may be 'physiology' in the absence of an open wound. This is a clinical diagnosis whereby the skin is felt to be 'floating on a sea of haematoma' and may be mobilised in abnormal directions. There is no open wound, but the skin is devascularised and appears cold, pale and mottled. Where there is an open wound and indeed the skin is seen to be hanging off, this may be described as an anatomical degloving, a term synonymous with avulsion.

INTRACRANIAL VESSELS
There are a limited number of descriptors referable to the intracranial blood vessels:

A laceration is a tear in the wall of the vessel usually associated with substantial bleeding except where this is limited by spasm in the vessel wall. The term is also conventionally applied to wounds produced in the vessel by penetrating trauma. Although incised wound or penetrating wound may be more appropriate terms these descriptors are not available.

A thrombosis is occlusion of the lumen of a blood vessel by a clot. In the early stages after injury the usual cause is a tear in the innermost layer to the vessel wall. A chemical cascade is initiated consequent upon the exposure of the blood to deeper layers of the wall which leads to the formation of a blood clot. By convention occlusion of the lumen of the vessel due to any cause is coded as thrombosis.

An aneurysm is a pathological swelling affecting the vessel wall. As a result of direct injury to the blood vessel an area of weakness develops in the wall which bulges outwards to form the aneurysm. This lesion is dangerous because of its propensity to rupture, the risk of thrombosis
within the aneurysm and the possible pressure effects on neighbouring structures.

One unusual consequence of head injury is the development of an abnormal communication between the intracranial portion of a carotid artery and the adjacent cavernous sinus, a carotico-cavernous fistula.

CRANIAL NERVES
Isolated injuries of individual cranial nerves are rare but may occur after penetrating head trauma such as gunshot wounds or complicating fractures of the base of the skull. The lesion is diagnosed clinically and coded as contusion if partial loss of function is reported and laceration if there is complete loss, the function subserved by the injured cranial nerve.

INTERNAL ORGANS
Laceration
The term is most frequently seen in relation to the brain on post-mortem reports. The term implies a split or tearing type of wound within the substance of the brain. These wounds usually result from penetration of the head e.g by a missile. Some blunt head injuries can also give rise to cerebral lacerations. Brain tissue may be torn by impact with a hard object, usually associated with skull fracture, or by violent motion within the skull causing friction between it and the rough surface of the base of the skull.

Contusion/haematoma
These are related terms often seen on computerised tomography (CT) scan reports after closed head injury. A contusion is a localised area of swelling which appears as an area of low or normal density on the scan itself. A haematoma implies that there has been some bleeding into the injured part of the brain, it appears as a high density (white) on the scan.

Either lesion may appear directly beneath the site of the impact (coup injury) or remote from the impact site (contre coup injury).

Some haematomas are large enough to be considered for surgical removal. They may occur within the brain (intracerebral), in the space between the brain and the skull (subdural) or between the dura and the inner table of the skull (extradural haematoma). These lesions are important complications of head injury because they occupy a significant amount of space within the rigid confines of the skull. This may lead to areas of the brain becoming pushed into abnormal positions relative to the folds of the dura with resultant compression of specialised regions in the brain stem which regulate the breathing and cardiac function. Generic terms for these types of brain shifts are coning, compression or herniations.

Oedema/swelling
The brain may be subject to localised or generalised swelling. The term oedema is often used to describe increased water content within tissues—the commonest cause of swelling. This response is often seen as a consequence of brain injury. Localised oedema, appearing as a low density area surrounding a contusion or haematoma is a common feature on CT scans. More sinister is the presence of a diffuse cerebral oedema or brain swelling which tends to distort the architecture of the brain on CT scans, often causing obliteration (effacement) of the ventricles or
of the convolutions of the surface of the brain which are known as sulci and gyri.

Diffuse axonal injury
Head injuries which are caused by substantial deceleration type forces (e.g. high velocity motor vehicle accidents) lead to shearing stresses on the structures within the substance of the brain. Nerve fibres (axons) stretched in this way may be permanently damaged. Patients present in coma which may be prolonged or permanent. The usual outcome is death or persistent vegetative state. The findings on CT scan which support the clinical diagnosis are diffuse brain swelling and scattered small haemorrhages (petechiae) in many parts of the brain including the brain stem.

Infarction
This is a pathological term describing a circumscribed area of tissue death due to interruption of blood supply. When it affects the brain after trauma the possible causes are an injury to a specific artery e.g. the carotid or, more frequently, a result of blood loss from extracranial injuries in a patient with pre-existing narrowing of the cerebral arteries due to atherosclerosis.

SKELETAL
Fractures of the skull occur when the head collides with a hard object at significant velocity. If the object is broad or flat (e.g. the floor) the patient may sustain a linear fracture of the skull vault which will be visible on x-ray. A fracture of the base of the skull occurs by similar mechanisms, it may be an extension of a skull vault fracture, or it may occur in isolation. Unlike the vault fracture, basal fractures do not show up well on plain skull x-rays and their presence must often be assumed based on clinical findings such as a leakage of blood or CSF from the nose or ear.

When a linear fracture enters the joint between the two skull bones the result is a widening of the joint space (suture) known as diastasis.

Fractures and diastases are important mainly because their presence is testimony to the violence of the impact and the high risk of underlying brain injury and/or development of intracranial haematoma.

When the impacting agent is more pointed (e.g. corner of a brick) the force of the impact is more localised and the resulting fracture is likely to be depressed rather than linear. Depressed fractures may be associated with a scalp wound and are then termed compound fractures. If sufficiently depressed a fragment of bone may penetrate the dura or even the brain itself. These fractures are termed open. Open fractures result from severe violence to the head, there may be multiple fragments (comminution) or leakage of brain tissue - a complex fracture.

It is also possible to dislocate the mandible, although this is coded as, 'dislocation of the temporo-mandibular joint' This is where the mandible articulates with the temporal bone of the skull.
The maxilla is often called the upper jaw and the injuries here are usually described as Le Fort I, Le Fort II or Le Fort III. These refer to the severity of the injury, the higher the grade being the more extensive the fracture. Usually asymmetrical, the Malar complex ('middle third') may be fractured at a different level on each side. A bilateral Le Fort III fracture implies that the facial skeleton has become separated from the base of the skull. This is an unstable injury usually accompanied by severe haemorrhage and often, a significant closed head injury in addition.

Both upper and lower jaws have a bony structure that supports the teeth called the alveolar ridge. This can be fractured, but since it is intimately related to the teeth, which should not be coded separately if there is also a alveolar fracture. The malar bone (often called zygoma or cheek bone) is often fractured and may be depressed (intended).

Often the fracture is not visible on x-ray, but is diagnosed clinically with a step in the orbital rim and numbness of the cheek and upper lip. This could be coded as, 'clinical malar fracture.' The zygomatic arch is on the side of the face running from the cheekbone to the ear and is not listed in your coding book. It would have to be coded as a, 'zygoma fracture.' Fractures of the nasal bones are often diagnosed clinically and rarely have x-ray confirmation. The malar is the prominent part of the cheek and should be more accurately referred to as the malar eminence. It is made up from part of the maxilla and part of the zygoma bone. There is no malar bone just as there is no elbow bone!

OTHER FRACTURES AND AREAS OF THE FACE
The orbit is the bony structure that surrounds the eye. Fractures of the upper part of the orbit are fractures of the front bone, and are coded under, 'skull.' Fractures of the lateral, medial and inferior walls or the orbit are coded under, 'face.' The signs of an orbital fracture are subconjunctival haematoma (a red eye) and inability to look upwards with that eye (sometimes called ocular trapping) For example- 'blowout' is a fracture of the orbit following a blow to the front of the eye.

SOFT TISSUES OF THE FACE
This includes lips, which can be coded under skin or mouth. Convention dictates that teeth are described as the observer looks at them, the 2 = the patient’s upper left second tooth (lateral incisor). 5 = the patient’s lower right five. Children’s teeth are known by letters (ABC etc) rather than numbers. Teeth may be missing or fractured. The tongue may be lacerated and the gums, called gingiva, may be lacerated mildly or severely (avulsed) or contused.

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EAR
The outside ear is called the external ear and comprises of the pinna (the flappy bit) and tragus (the bit in front of the external canal). The external ear canal, auditory meatus, leads down to the tympanum (ear drum) which separates the external ear from the middle ear. The middle ear contains three small bones (ossicles) which conduct sound waves and the inner ear contains the vestibular apparatus which serves the balance mechanism. The eardrum can rupture. Blood behind the ear drum is often termed, 'haemotympanum,' and this indicates a fracture of the base of the skull (not an ear fracture).

EYE
The eye consists of the globe which is the eye in its entirety. The globe is divided by the lens into a small anterior chamber containing aqueous humor and the posterior chamber containing vitreous. The whole eye can be avulsed, often called enucleation. The white area of the eye is the sclera which can be lacerated. The clear area at the front of the eye through which we see, is the cornea and behind it is the iris (the coloured shutter).

Either the iris or the cornea can be lacerated, a cornea can also have an abrasion or a contusion or ulceration. The retina is the lining at the back of the inside of the eye that allows us to see. The retina may become detached or lacerated. From the corner of the eye (the medial corner) a very fine tube (the tear duct) leads down to the nose inside. This is called canaliculus and can be lacerated or damaged. The skin on the inside of the eyelids is called the conjunctiva and this can be lacerated, injured or swell (a condition called chemosis). The corner of the eye is also called the canthus (medial or lateral).
THE NECK

BACKGROUND

The neck extends from the jaw bone to the clavicles (collar bones) anteriorly and from the hairline to the upper part of the back posteriorly. It contains skin, subcutaneous tissues and deeper structures such as the trachea and oesophagus and certain cranial nerves passing from the brain stem to the trunk. These structures may be injured especially by penetrating trauma. The bony structures of the neck (first to seventh cervical vertebrae) which are described in the section on the spine protect the spinal cord in this region. Damage to the bony architecture can disrupt the spinal cord leading to paralysis. Such injuries are usually the result of blunt trauma to the head causing the bony spine to fracture or dislocate.

ANATOMY

The left and right common carotid arteries are major branches of the aorta near to the heart. They carry oxygenated blood towards the head dividing into internal and external carotid branches on either side. The former go on to supply the brain whilst the latter divide further into branches supplying the more superficial structures of the head and face.

The left and the right vertebral arteries take their origins from major branches of the proximal aorta known as the subclavian arteries. The vertebral arteries travel upwards on either side in a bony canal formed by, ‘holes,’ in the lateral aspects of the cervical vertebral, the foramina transversaria.

The venous channels which carry blood away from the brain empty into the internal jugular system whilst the venous drainage from the superficial structures of the head and face empty into the external jugular system. The internal jugular vein descends in the neck lying immediately lateral to the internal carotid artery before joining with the subclavian vein to form the brachio- cephalic trunk which empties into the right atrium. (Fig. 16B)

In the midline of the neck lying between these paired vascular systems are two tubes extending from the upper airway and coursing down towards the trunk; the trachea in front and the oesophagus. The pharynx is a complex cavity into which opens the nasal passages (nasopharynx) and the back of the mouth (oropharynx). It may be loosely regarded as the throat. Immediately behind the back wall of the pharynx lie the bodies of the cervical vertebrae. Bleeding into the space between them (the retropharyngeal area) is sometimes caused by neck trauma with tearing of the ligaments which normally lend stability to the front of the spine. The resulting retropharyngeal haematoma may be visible on lateral x-rays of the cervical spines frequently performed in severely injured patients. The pharynx is therefore the major component of the upper-most part of the airway. It is continuous with the inside of the nose and the mouth and therefore is covered with similar specialised cells known as a mucous membrane or mucosa. Inferiorly the pharynx opens into the larynx or voice box which contains the vocal cords whose further continuation inferiorly is the trachea or windpipe. The pharynx also opens inferiorly into the oesophagus or gullet, a softer thinner tube than the trachea and lying immediately behind it.
The oesophagus is approximately 30cm long and extends as far as the upper part of the stomach.

The neck contains two pairs of salivary glands, the parotids which are situated at the level of the ear lobes and the submandibular glands which are, as the name suggests, under the mandible approximately level with the lower canine teeth. There are a number of other salivary glands inside the mouth. The function of these glands is to produce saliva which is important in the digestion of starch.

The trachea is a tube comprising stacked cartilaginous rings whose function it is to maintain patency of the main conduit for inspired air. Attached to the front wall of the trachea at the second or third tracheal ring is a bi-lobed structure known as the thyroid gland. It produces thyroid hormones important in metabolism and it has a very rich blood supply. It may bleed profusely when injured by penetrating trauma.

The bony architecture of the neck is described under 'spine.' Nerves roots emerging from the spaces between the third to fifth cervical vertebrae on each side fuse together to form the phrenic nerve which descends along with other structures such as the blood vessels described above and the lower cranial nerves. The function of the phrenic nerve is to supply motor activity to the diaphragm which has an important function in breathing.

One small bone not described under spine is the hyoid bone which lies fairly superficially in the upper part of the front of the neck in the midline between the larynx and the point of the chin. Its only function is to increase the mechanical efficiency of certain muscles located in the floor of the mouth which participate in swallowing and speaking.
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VESSELS
When a cut section of artery is examined under the microscope it can be seen to comprise three layers. The innermost layer is the intima. Immediately outside of this layer lies the media which in turn is covered by a tough fibrous serosal layer. Injuries to the vessels are usually caused by penetrating trauma such as knife or gunshot wounds. Coding conventions require some measure of the completeness of a wound such as whether the vessel is incised or completely cut across (transected). Estimated blood loss also aids description. For example a 20% blood loss which is equivalent to 1000mls in the average adult will cause the clinical syndrome of surgical shock in most cases. The added dimension of arterial injury in the neck is that interruption of the blood flow in one of these major vessels may cause a neurological defect such as a stroke. Injuries are coded up therefore if any of these complications are manifested.

Arterial injuries are sometimes attended by obstruction due to occlusion by thrombus (clot), arterial spasm or directly due to the trauma. These are the usual mechanisms by which neurological deficit is caused.
INTERNAL ORGANS

The specialised cartilage which forms the walls of the larynx are known as the **cricoid and thyroid cartilages.** The latter are paired cartilageous plates and should not be confused with the thyroid gland itself. Injuries to the larynx may be imputed from evidence of a blow to the front of the neck associated with hoarseness. Alternatively an otolaryngologist may perform a laryngoscopy to assess the extent of the injury. Hoarseness is due to vocal cord disruption directly or indirectly. **Vocal cord** injury may only be diagnosed by a laryngoscopy. This is an injury which can be caused by unskilled endotracheal intubation. Therefore if a traumatic intubation is recorded in the notes and there is no other evidence of direct injury to the larynx the injury is conventionally not coded.
THE SPINE

The spine is formed from 36 small bones called vertebrae (singular = vertebra). These bones are joined together in a very firm but complex arrangement that allows a small amount of movement between the bones. Each vertebra has several anatomical components, any of which may be fractured. Discs separate the bones from each other and these may also be damaged. Each vertebra forms a ring structure and all the vertebrae together create a hollow tube, in which the spinal cord runs. The spinal cord contains nerves running from the brain to the rest of the body.

Damage to the nerves in the spinal cord can result in paralysis (inability to move). If this is in all four limbs, it is termed quadriplegia, if in only two limbs, hemiplegia. Hemiplegia refers to one arm and one leg. Paraplegia is another term for paralysis and usually means the lower limbs.

PARTS OF THE VERTEBRA
The body is the main part of the vertebra and sticking out behind it are the pedicles which form the anterior part of the ring structure, the posterior part being the lamina (laminae). A single structure sticking out at the back is the spinous process and two small jutting out areas of bone from the pedicles are the transverse processes. Above and below the body are the facets, the joints which hold the vertebra on to the next one above and below.

REGIONS OF THE SPINE
The spine is divided into five regions, three of which are classed in the AIS coding as spine.

These regions are:
- The neck, often referred to as cervical spine and labelled C1 to C7.
- The chest region is known as the thoracic spine labelled T1 to T12, sometimes also called dorsal spine and labelled D1 to D12.
- The lower back is referred to as the lumbar region and the five vertebrae there are labelled L1 to L5.
- The two further regions of the spine are the sacrum (which is one bone) and the coccyx (sometimes called the tail bone) but in AIS coding these are considered part of the pelvis.

NECK (CERVICAL)
The cervical spine (C1-C7) contains the spinal cord coming from the brain. The spinal cord sends out nerves through the side holes in the vertebral column.

There are eight nerves that exit and where they come out of the bony vertebrae, they are called roots. These roots are labelled C1-C8. Shortly after they emerge, they form a structure called the brachial plexus, the roots combine to form trunks, the trunks divide to form divisions, and these divisions recombine to form cords (not to be confused with the spinal cord. C1 (first cervical spine) has a special name, atlas and C2 is called axis. The C1/C2 joint is sometimes called the atlanto-axial joint. The axis (C2) has a special piece of bone sticking up called the axial peg, odontoid peg or dens. This may be fractured. A C1 fracture is sometimes called a Jefferson fracture if fractured in more than one place due to a vertical force.
The nerves, if they are damaged, can produce neurological signs. This may include decreased power, decreased or abrupt sensation, tingling (often described as paraesthesia) or weakness. Any of these descriptive terms may be interpreted as alteration of nerve function. Other descriptors (often at post-mortem) include transection or crush of the spinal cord or the nerve roots. Nerve injury may be difficult to assess in the early stages. Nerve contusion may cause loss of function which completely resolves in time. Also inexplicably, some function may be preserved for a time in a nerve which has been completely transected!

CHEST (THORACIC)
The thoracic or dorsal spine (T1-T12 or D1-D12) have similar injuries to the above. The head and neck of the ribs articulate with the body and transverse processes of the vertebrae. The nerves are labelled T1-T12, a more common injury here is compression of the vertebrae where the vertebral body is crushed and loses vertical height.

LUMBAR SPINE
The lumbar spine (L1-L5). At L1 the spinal cord has split into individual nerves and is no longer a cord structure. It is therefore called the cauda equina (horse’s tail). If the nerves are damaged as they exit the spinal canal, these are called nerve roots and the pain/injury is described as root pain or radiculopathy.

The Sacrum (five vertebrae fused to form one bone) and the Coccyx (the tail bone attached to the end of the sacrum) are all part of the vertebral column but are dealt with and coded as part of the pelvis.
THE CHEST (THORAX)

BACKGROUND

Chest injuries may disrupt the mechanism of breathing and produce severe loss of blood (hypovolaemia). These events can threaten life within a few minutes of injury, and chest injuries are a common cause of trauma deaths out of hospital. These events can also develop quite suddenly or insidiously several hours after the injury.

The majority of chest injuries are caused by blunt trauma. The more serious injuries are usually as a result of road traffic accidents. There may be direct injury to the chest wall with or without damage to the underlying organs. Chest injuries from RTAs are commonly caused by seatbelts, being thrown forward onto the steering wheel or intrusion into the vehicle. High speed accidents, including road traffic accidents and fall falls from a height, may result in the contents of the chest cavity moving relative to each other resulting in tearing of the tissues, including major blood vessels.

Penetrating chest injuries are much less common but carry a high risk of serious damage to structures inside the chest such as lungs, heart or major vessels. The majority of blunt chest injuries will be managed without surgery whereas the majority of penetrating injuries will result in surgical procedure.

ANATOMY

The thorax consists of a bony cage and its contents, which the bony cage is designed to protect. The thoracic cage is formed by the spine behind, the ribs on either side, and the sternum (breast bone) and costal cartilages in front. Above, the thoracic cavity communicates through the thoracic inlet with the root of the neck and below it is separated from the abdominal cavity by the diaphragm.

The greater part of the thoracic cage is formed by 12 pairs of ribs. Of these the first 7 are connected anteriorly by way of costal cartilages to the sternum. The 8th, 9th and 10th ribs are joined at the front with the cartilage above. The last 2 ribs are free at the front (floating ribs). The upper part of the thorax is covered by the shoulder girdle, including the clavicle (collar bone). Fractures of the upper 2 ribs are therefore unusual and, when they do occur, are often associated with serious injury particularly to the major blood vessels above the heart.

In a severe injury to the chest wall several ribs may fracture in front and behind so that a whole segment of the thoracic cage becomes torn free. With inspiration this loose flap sinks in and with each expiration it blows out causing severe disruption of the mechanism of breathing (flail chest). This is usually associated with severe injury to the underlying lung, requiring urgent treatment usually by endotracheal intubation and positive pressure ventilation. In children the chest wall is very elastic and therefore fractures of ribs in children are rare.

The sternum forms the anterior part of the thoracic cage and consists of 3 parts, the manubrium...
at the top, **body** in the middle and a small **xiphoid process** at the bottom. Between the ribs are the **intercostal** spaces. These spaces contain the intercostal muscles which move the ribs during respiration. Intercostal nerves and vessels run between the layers of the intercostal muscles.

The diaphragm is a dome shaped muscular layer dividing the thoracic from the abdominal cavity. A number of structures pass through the diaphragm from one cavity to the other, the main ones being the **aorta, oesophagus** and **inferior vena cava**. Movement of the diaphragm is important in breathing.

**PLEURAE**

The pleura is a lining over the surface of the lung. It consists of a visceral layer immediately related to the surface of the lung and a parietal layer lining the inside of the chest wall, the upper surface of the diaphragm and the sides of the **mediastinum**. Normally the two layers are in close apposition and the space between them is only a potential one. Following injury this space may have become filled with air (**pneumothorax**) from the lung or through the chest wall, or blood (**haemothorax**), or both (**haemo-pneumothorax**). This fluid or air can be drained by inserting a needle or a tube (**chest drain**) through the intercostal space. Air may spread from the pleural space through the chest wall into the skin. This is detectable by clinical examination or on a chest x-ray (**surgical emphysema**).

**TRACHEA AND BRONCHI**

The trachea takes air from the larynx which is in the neck, into the chest, where it splits to form the right and left main bronchi. Since it contains air the trachea is usually visible on a chest x-ray. Displacement of the trachea may be commonly due to collapse of the lung or pressure from a haematoma (bleeding from major vessels). The right and left main bronchi subdivide into smaller bronchi supplying air to the various parts of the lungs.

**THE LUNGS**

Each lung is conical in shape, having a blunt **apex** which reaches above the first rib and a concave base overlying the diaphragm. The lungs are divided into **lobes**. The right lung has three lobes, upper, middle and lower, and the left lung only 2 main lobes, the upper and lower and a smaller **lingula**—a division of the left upper lobe bronchus. Venous blood flows to the lungs through the **pulmonary arteries** from the right side of the heart.

**MEDIASTINUM**

The mediastinum lies in the centre of the chest within the two lungs. The main contents of the mediastinum are the heart, major vessels (arteries and veins) the oesophagus, lower trachea and bronchus.

**THE HEART**

The heart lies in the pericardium which is a fibrous layer covering the outside of the heart. Damage to the heart may result in bleeding into the pericardium. This may cause pressure on the outside of the heart, preventing the heart from filling with blood (**cardiac tamponade**). This may be suspected on the basis of clinical examination or an enlarged and rounded shape of the heart on a chest x-ray.
The presence of the fluid in the pericardium can be confirmed by echo cardiography. When cardiac tamponade occurs in a trauma patient (uncommon), it is usually of rapid onset, causing sudden collapse of the patient, and is treated on the basis of the clinical findings. Treatment is by means of draining of the fluid through a needle or cannula introduced through the skin into the pericardium (cardiocentesis or pericardiocentesis). The heart consists of 4 chambers, right and left atria and ventricles. The right atrium receives blood from the superior and inferior vena cava. Blood then passes into the right ventricle through the tricuspid valve out into the pulmonary artery through the pulmonary valve to the lung. Blood is then oxygenated in the lungs and passes back through the pulmonary veins into the left atrium through the mitral valve, into the left ventricle and out through the aortic valve into the aorta.

OESOPHAGUS
The oesophagus runs from the throat to the stomach, behind the heart and trachea. The oesophagus is not normally visible on plain x-ray but the line of the oesophagus may be seen if a gastric tube is present. Deviation of the oesophagus due to haematoma may then be visible. Radiographically the oesophagus may also be studied using contrast medium (barium or gastrograffin). Leakage of the contrast through tears into the surrounding tissues may be seen.

AIS DESCRIPTORS
WHOLE AREA
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A contusion is the result of a blunt blow to the surface. It is a swelling, often skin coloured rather than bluish, differentiating it from a haematoma. However for the purposes of injury description the two are coded as one.

A laceration is a split wound, the result of blunt trauma or crushing. The severity will vary from trivial to life threatening. The wound caused by a sharp edge such as a knife is not a laceration but an incised wound. The wound produced by a pointed implement is a penetrating injury.

An avulsion is the severest form of laceration whereby the skin and the subcutaneous tissues are torn off from the underlying structure by a high energy crush or mangle type of force. The terms degloving and avulsion sometimes cause confusion, not least among doctors making clinical records in the notes.

Correct terminology is as follows:

Where a mangle force off the skin and the subcutaneous tissue from the next deepest layer (the deep fascia, which is an envelope of fibrous tissue 'investing the muscle') a degloving has occurred. This degloving may be 'physiology' in the absence of an open wound. This is a clinical diagnosis whereby the skin is felt to be 'floating on a sea of haematoma' and may be mobilised in abnormal directions. There is no open wound, but the skin is devascularised and appears cold, pale and mottled. Where there is an open wound and indeed the skin is seen to be hanging off,
this may be described as an anatomical degloving, a term synonymous with **avulsion**.

**VESSELS**

**THORACIC AORTA**

The intima of the aorta is the innermost lining. Intimal tears are usually due to rapid deceleration injuries such as falls from a height or road traffic accidents. Blood from the lumen of the aorta leaks through the tear into the wall of the aorta where it may spread along obstructing other vessels as they branch off the aorta (**dissection**).

Uncontrolled leakage of blood through the tear is a common cause of death at the scene of an accident. If the bleeding is limited in the vessel wall then the patient will commonly reach hospital alive. If the injury is not detected and treated then the patient may die hours or days later when the damaged wall of the aorta gives way leading to uncontrolled bleeding. The bleeding into the wall of the aorta may spread to involve the aortic valve causing incompetence (leakage) of the valve. This may be detected clinically as a heart murmur. Paraplegia due to damage to the thoracic aorta is caused by the blood tracking along the wall of the aorta pressing on the vessels supplying blood to the spinal cord and obstructing them. Injuries to the thoracic aorta may be suspected clinically. There may be signs on the chest x-ray such as widening of the mediastinum which are suggestive of damage to the thoracic aorta. A definitive diagnosis is usually by an **aortogram** (x-ray examination using intravenous contrast medium injected into the aorta).

The **coronary arteries** are direct branches of the aorta. They run over the outer surface of the heart, supplying blood to the heart muscle. The **brachiocephalic (innominate)** artery is a branch of the aorta. It divides into the right **carotid artery**, supplying blood to the head and the right **subclavian artery**, supplying blood to the right arm. On the left the carotid arteries and subclavian arteries are direct branches of the aorta. Damage to these vessels is usually due to deceleration type injuries, as with the thoracic aorta, to which there may be associated injuries. A diagnosis may be suspected clinically by a lack of pulse to the area supplied or by reduced blood pressure in one arm. A definitive diagnosis is usually by an aortogram. Damage to the corresponding **veins** is usually by a similar mechanism. The effects of venous injuries are usually less drastic as bleeding is less severe due to the lower pressure of the veins.

**INTERNAL ORGANS**

**BRONCHUS/TRACHEA**

Rupture (laceration) of the main bronchi or trachea is an unusual injury. The diagnosis is often very difficult to make and is suggested by subcutaneous emphysema (air beneath the skin) or tension pneumothorax. Diagnosis may be by **bronchoscopy**. Other associated serious chest injuries are usual. Lacerations or punctures may be caused by a deceleration type of injury. Injury to the main bronchi is unusual and is often fatal unless detected and treated early. Most patients will die before reaching hospital. Blunt injuries to the trachea are subtle, penetrating trauma usually obvious and require immediate surgery. Penetrating injuries are often associated with injuries to the oesophagus, carotid arteries and jugular veins.
CORDAE TENDINAE
These structures tether the flaps of the tricuspid and mitral valves to the heart wall through two papillary muscles which are in turn attached to the wall of the ventricle. They are necessary to the normal function of these valves and if damaged result in sudden severe leakage of blood back through the valve, requiring urgent open heart surgery. Clinically the picture is of severe heart failure often associated with a loud heart murmur. This is a very uncommon injury.

DIAPHRAGM
This usually ruptures as a result of increased pressure from below due to compression of the abdomen. It is more common for the diaphragm to be ruptured on the left side when the stomach and small bowel may be pushed through the rupture into the chest cavity. This may be visible on chest x-ray but is commonly misinterpreted. The diagnosis may be confirmed by contrast x-rays or occasionally a naso gastric tube in the left chest. Rupture of the diaphragm (diaphragmatic hernia) results in disruption of the normal mechanism of breathing, usually requiring urgent surgical repair. A laceration of the diaphragm may also be due to penetrating injuries but, in these cases, the defect in the diaphragm is usually much smaller and relatively minor in comparison to the other injuries the patient has. Symptoms of diaphragmatic hernia after penetrating trauma may develop some time later (sometimes years later!).

OESOPHAGUS
Blunt injury to the oesophagus may be caused by the forceful ejection of stomach contents into the oesophagus, caused by a severe blow to the upper abdomen. Leakage from the oesophagus into the mediastinum usually results in severe infection. This injury may be associated with air in the mediastinum (pneumomediastinum). Diagnosis is by contrast x-ray or oesophagoscopy.

HEART (MYOCARDIUM)
Contusions to the heart are usually caused by blunt trauma to the anterior chest and may be associated with a fracture of the sternum and ribs. Most of these injuries are minor and may be diagnosed by changes in cardiac enzymes or abnormalities on the electrocardiogram. In severe cases the contusion will result in abnormal function of the heart producing cardiac failure. Laceration to the heart is usually due to penetrating injuries.

Intra cardiac valves are the tricuspid, pulmonary, mitral and aortic. Injury to these is rare. The intra ventricular and intra atrial septum divide the right and left ventricles and the right and left atria respectively. Laceration is usually due to penetrating injury and is rare in UK practice.

LUNG INJURY
Lung contusion is a common injury caused by a blunt trauma to the chest wall, causing a contusion of the underlying lung. Onset of symptoms and physical signs is usually gradual over a number of hours. Diagnosis is usually by chest x-ray. It is usually associated with abnormality of blood gas measurements though this on its own is not sufficient evidence for codeable injury. Severe pulmonary contusions will require admission to the Intensive Care Unit and positive pressure ventilation.
Tension pneumothorax is caused by air in the pleural cavity under pressure, and occurs when there is a one way valve air leak either from the lung (common) or through the chest wall (rare). This causes severe difficulty in breathing and obstructs the return of blood to the heart. Unless treated rapidly it is fatal. Diagnosis will often be on the basis of clinical examination. Treatment is by releasing the trapped air from the chest by passing a needle (thoracocentesis) or chest drain through the chest wall.

Lung laceration is usually diagnosed at post mortem or surgery. Pneumo-mediastinum is air in the mediastinum. This may be diagnosed on x-ray.

PERICARDIUM
Injuries to the pericardium without injury to the heart are due to penetrating injuries and are very uncommon.

PLEURA
Laceration to the pleura is very unusual as an isolated injury. It will usually be due to a penetrating injury and is commonly associated with pneumothorax.

SKELETAL
Skeletal injuries are the most common type of chest injury. Fractures of more than three ribs are commonly associated with damage to the underlying lung (pulmonary contusion) with a haemo or pneumothorax.
THE ABDOMEN

BACKGROUND

Abdominal injury may be isolated, when there is history of a direct blunt blow to the abdomen. It is also commonly associated with injuries to other body compartments. If there are injuries to the chest and lower limbs, injury to the abdomen is also likely. Common injuries are lacerations or ruptures of the spleen and liver. These organs are very vascular, and can result in severe bleeding into the abdominal cavity. Severe deceleration type injuries cause tearing type injuries, particularly where a mobile part of the abdominal contents is attached to the part which is firmly fixed.

Penetrating injuries to the abdomen, although uncommon, often result in lacerations to the abdominal contents, particularly the gastrointestinal tract. Penetrating injuries on the abdomen may extend into the chest and vice versa. Bleeding into the abdominal cavity is usually diagnosed by the procedure of peritoneal lavage, where fluid is introduced into the abdomen through a tube passed through the anterior abdominal wall. The fluid is subsequently drained back out of the abdomen and, if there is blood in the peritoneal cavity, this is immediately visible from the colour of the fluid drained.

Intra-abdominal fluid such as blood, or urine from a ruptured bladder, can also be diagnosed by an abdominal ultrasound. Injuries to the kidneys and urinary system are usually diagnosed by x-rays following the intravenous injection of contrast medium (IVP, intravenous pyelogram). Rupture or penetration of the stomach may be diagnosed by the presence of fluid and/or free gas in the abdominal cavity on x-ray. Increasingly used for the specific diagnosis of abdominal injury is the computerised tomography (CT) scan, sometimes combined with intraluminal and intravenous contrast media (double-contrast CT scan).

ANATOMY

Many of the organs in the abdomen are covered by a membrane called the peritoneum. The organs are normally packed close into the abdominal cavity. The peritoneum forms a potential cavity which may become filled with blood following injury to the organs which are covered by the peritoneal membrane. Small amounts of bleeding may be limited to one particular organ and not extend into the peritoneal cavity. Extensive bleeding in the abdomen can occur behind the peritoneal cavity (retroperitoneal haemorrhage). The retroperitoneum contains the aorta, vena cava, pancreas, kidneys, ureters and parts of the colon and duodenum.

Much of the abdominal cavity is filled with the gastrointestinal tract. The oesophagus, immediately after passing through the diaphragm, drains into the stomach. The stomach drains into the duodenum which curls around the head of the pancreas.

The duodenum is fixed firmly to the posterior abdominal wall. The duodenum then runs into the small intestine which has an average length of 20 feet. The first part of the small intestine is
called the jejunum, the second part is known as the ilium. This part of the bowel is suspended by the mesentery which is formed by layers of peritoneum and carries the blood supply to the intestine.

The small bowel drains into the large intestine. This is sub-divided for descriptive purposes into caecum, ascending colon, hepatic flexure, transverse colon, splenic flexure, descending colon, sigmoid colon, rectum and anal canal. The ascending and descending colon adhere directly to the posterior abdominal wall. The transverse colon and sigmoid colon are mobile, and completely covered in peritoneum suspended from a mesentery.

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Correct terminology is as follows:
Where a mangling force off the skin and the subcutaneous tissue from the next deepest layer (the deep fascia, which is an envelope of fibrous tissue ‘investing the muscle’) a **degloving** has occurred. This degloving may be ‘physiology’ in the absence of an open wound. This is a clinical diagnosis whereby the skin is felt to be ‘floating on a sea of haematoma’ and may be mobilised in abnormal directions. There is no open wound, but the skin is devascularised and appears cold, pale and mottled. Where there is an open wound and indeed the skin is seen to be hanging off, this may be described as an anatomical degloving, a term synonymous with **avulsion**.

**PELVIC CAVITY**
This is the lower continuation of the abdominal cavity which is protected by the pelvis.

**VESSELS**

**AORTA (ABDOMINAL) AND OTHER VESSELS** (see section on the chest)
The abdominal aorta (Fig. 33) carries blood from the thoracic aorta, supplying the intra-abdominal organs, including the gastrointestinal tract (coeliac and mesenteric arteries), liver
The aorta divides into the common iliac arteries to supply blood to the pelvis and legs. Intimal tears to the aorta in the abdomen may cause damage spreading to the chest and vice versa. The inferior vena cava carries blood returning from the legs to the right atrium of the heart. The inferior vena cava is closely related to the liver and severe injuries to the liver may involve tearing of the hepatic veins and the inferior vena cava into which they directly drain.

**INTERNAL ORGANS**

**ADRENAL GLAND (SUPRA RENAL)**
These glands sit on the upper part of the kidneys and lie against the diaphragm. Each gland only weighs a few grams. Isolated injuries are very rare. Injury may occur in association with injury to the kidney or major vascular injury.

**BLADDER**
Urine from the kidneys drains via the ureters into the bladder. The bladder drains by the urethra, (Fig. 35). Blunt injury to the abdomen may cause a rupture of the bladder if the bladder is distended at the time of injury. Penetrating injury is uncommon. Urethral injuries may occur complicating pelvic fractures.

**COLON**
This may be injured in severe deceleration type injuries where the mobile parts move relative to the fixed part of the colon. The colon may also be damaged by a penetrating injury although this is also usually accompanied by an injury to the small bowel which lies anterior to the colon. Perforation of the colon results in contamination of the peritoneal cavity with faeces. This may be detected by peritoneal lavage when the returned fluid is contaminated with faecal material. Surgical repair will be required. The patient may require a colostomy (opening from the colon to the surface of the skin to bypass the damaged section of colon).

**DUODENUM**
The duodenum is fixed and curves around the head of the pancreas and is about 8 inches long. Injury to the duodenum may be associated with injury to the pancreas.

**JEJUNUM / ILEUM (SMALL BOWEL)**
This is commonly injured in a penetrating injury as it lies anterior in the peritoneal cavity. It may also be injured by a blunt injury.

**KIDNEY**
The kidneys lie on the posterior abdominal wall just below the diaphragm on either side of the spine. Injuries to the kidneys are often associated with other injuries to the back. Injuries to the kidney often result in bleeding which is retro-peritoneal and therefore not detected on peritoneal lavage. If renal injury is suspected then usually an abdominal ultrasound or an intravenous pyelogram (IVP/contrast x-ray) would be performed.
LIVER
This is a large vascular organ which has a tendency to split when subject to a blunt injury, resulting in profuse bleeding. Although the bleeding may result in a localised haematoma, the bleeding is commonly into the peritoneal cavity and may be severe. Significant lacerations to the liver usually require surgical repair.

MESENTERY
The mesentery suspends the portions of the bowel and carries the blood supply to the bowel. The mesentery may be torn in blunt injuries or damaged by penetrating injuries. Damage to the blood vessels results in bleeding into the peritoneal cavity.

OVARY
Isolated injuries to the ovary are very uncommon as they are protected by the bones of the pelvis.

PANCREAS
The pancreas lies on the posterior abdominal wall. Injuries to the pancreas is usually as the result of a severe blunt injury to the upper abdomen, compressing the pancreas against the underlying spine. This is commonly associated with other serious injuries. Injuries to the pancreas usually result in a raised amylase level which may be detected in the peritoneal lavage fluid or the blood. Injuries to the pancreas are frequently associated with injuries to the duodenum, stomach, liver and spleen.

PENIS
See urethra and testes.

PERINEUM (Fig. 37)
The perineum is the area below the pelvis and between the legs. It consists of a diaphragm of muscles through which the rectum, urethra and, in the female, vagina pass to reach the exterior. Injuries to the perineum are commonly associated with injuries to the pelvis or may be due to a penetrating injury. The commonest mechanism is, ‘fall astride.’

PLACENTA
See uterus.

RETRO PERITONEUM
Injuries to organs at the back of the abdomen which lie behind the peritoneal membrane may cause bleeding into the retro peritoneal area, with or without bleeding into the peritoneal area. Retro peritoneal haemorrhage or haematoma may be caused by injury to the pancreas, duodenum, kidney, aorta, vena cava, mesenteric vessels. It may also be due to pelvic or vertebral fractures. Retro peritoneal haemorrhage is often diagnosed on operation when the specific cause of the bleeding may be difficult to identify.

SCROTUM
See testes.
SPLEEN
This is usually damaged by a blunt injury causing a tear or split in the substance of the spleen. The spleen is a very vascular shaped organ and this usually results in severe bleeding although bleeding may be into a localised haematoma. There is usually blood in the peritoneal cavity. Splenic injury may also occur during laparotomy for other injuries. This is a complication of surgery and should not be coded as an injury.

STOMACH
Isolated injuries to the stomach area are rare, whether due to blunt or penetrating injuries. There are usually other associated serious injuries.

TESTES
Serious injuries to the scrotum, testes and penis are unusual and are caused by direct trauma. Injuries are mostly bruises or lacerations, and in extreme circumstances, avulsion or amputation may occur.

URETER
The ureters carry urine from the kidneys to the bladder, running along the posterior abdominal wall. Isolated injuries to the ureter are rare. Injuries to the ureter are usually associated with damage to other posterior structures eg. Lumbar vertebrae in the abdomen and often damage to the kidneys.

URETHRA
The urethra carries urine from the bladder out through the perineum. The urethra may be damaged by injuries to the perineum or penis in association with injuries to the pelvis. Damage to the urethra is often suspected following bleeding at the external urethral meatus. Diagnosis of rupture of the urethra in the male is usually confirmed by a retrograde urethrogram (contrast introduced via the penis).

UTERUS
Injury to the uterus is uncommon unless pregnancy is present when a blunt injury may cause a rupture of the uterus. A blunt injury may also cause separation (abruption) of the placenta. The placenta is a vascular structure where oxygen from the mother’s bloodstream is transferred to the foetal circulation. Separation of the placenta may result in severe blood loss which will usually be apparent by bleeding per vaginum. Placental abruption may also result in death of the foetus.
UPPER AND LOWER LIMBS INCLUDING PELVIS

BACKGROUND

Skeletal trauma is almost universal after significant traffic related injury and is a common cause of disability.

ANATOMY

Each upper and lower limb is attached to the torso by the shoulder and pelvic girdles respectively. The shoulder girdle consists of a clavicle or collar bone in front and the scapula or shoulder blade behind. The two are joined together at the point of the shoulder where the acromion (a process from the scapula) articulates with the outer end of the clavicle at the acromio-clavicular or AC joint. The shoulder joint is more correctly known as the glenohumeral joint since it is formed by the articulation between the head of the humerus and the glenoid cavity of the scapula. This is an extremely mobile joint because of its anatomy and is relatively unstable, save for the fact that it is surrounded by a joint capsule and certain ligaments. The whole structure is overlain by four cuff muscles.

Each limb consists of one proximal long bone attached to two distal ones followed by a hand or foot. The bones are attached to one another by ligaments. The important ligaments lying on either side of the joint are called collateral ligaments. In the knee there are two ligaments joining the femur above to the tibia below and they are called the anterior and posterior cruciate ligaments. Also in the knee are two cartilaginous structures, the medial and lateral menisci which form the smooth articulation between the lower femur and the upper tibia. Eight small bones are packed into the space between the forearm and the hand known as the carpus. Some of the distal (lower) row of carpal bones articulate with the long thin bones of the bulk of the hand known as metacarpals which in turn articulate with the phalanges of the digits. A similar arrangement occurs in the lower limb where the space between the ankle and the foot is occupied by seven tarsal bones articulating with metatarsals at the so-called tarso-metatarsal joints.

Long bones especially the femur and sometimes divided into head, neck, shaft and condylar areas. The condyles of the femur are expansions of the lower end of the shaft which bear the articular surface of one half of the knee joint. Fractures of the lower end of the femur are known as inter-condylar or supra-condylar dependant on their relationship to the condyles. At the upper end of the femur there are bony prominences known as the greater and lesser trochanters. Common fractures (see over) of the upper end of the femur, especially in the elderly, occur through the neck of the bone or extending between the greater and lesser trochanter in which case they are termed inter-trochanteric.

The limb bones are enveloped by muscles which are attached to the bones by tendons. The muscles are supplied by nerves and all the tissues receive their blood through arteries. The blood drains back to the heart via the veins.

PELVIS

The pelvis is a bony ring comprising the sacrum behind, the ilium and the ischium laterally and the pubic bone in front and below. The head of the femur articulates with a process of the pelvis.
(taking contributions from more than one bone) known as the acetabulum. This is the hip joint. Isolated fractures of the bony pelvis are common after falls and traffic injuries. More substantial comminuted fractures, especially open injuries, may severely disrupt the rich network of blood vessels which course inside the back wall of the pelvis. The result is torrential bleeding into the retro-peritoneal space i.e., the space behind the peritoneal membrane which invests the abdominal and pelvic organs. Such injuries pose a significant threat to life.

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VESSELS

In common with arterial injuries elsewhere, injuries to the major arteries of the extremities are classified as intimal tears or lacerations which may be minor or major. A laceration of the skin is generally caused by blunt trauma causing a split in the skin. However a tear in the wall of a blood vessel is coded as a laceration whether caused by a blunt or penetrating trauma. The innermost layer of an artery is the intima. An intimal tear does not therefore fully breach the vessel wall but the torn piece of tissue may block the vessel resulting in reduced or no blood flow. If this occurs the blood supply to the rest of the limb may be impaired resulting in lack of oxygen supply known as ischaemia.

A laceration of the vessel wall is coded as major if it is completely cut across or a length of vessel has been obliterated. If there has been significant blood loss of greater than 20%
(manifest as an estimated blood loss exceeding 1000mls in the average adult or clinical evidence of surgical shock) then this too is coded as major. All other vessel injuries are coded as minor.

NERVES
The upper limb is ultimately supplied by the brachial plexus whose origin is the nerve roots exiting from between the vertebrae of the lower cervical and upper thoracic spine (see spine). The hand is supplied by three named nerves which are formed by the fusion of certain branches of the brachial plexus around the elbow. The named nerves are the **radial nerve** which supplies the back of the hand on the thumb side, the **ulnar nerve** which supplies motor and sensory function to the hand on the little finger side both front and back, and the **median nerve** which subserves both motor and sensory function in the remainder of the hand. Small branches from the ulnar and median nerve travel in pairs up the sides of each digit including the thumb and these are known as the **digital nerves**. Individual nerves may be injured by blunt or penetrating trauma. A contusion is a blunt injury to the nerve without division which may be recorded in clinical notes as **neuropraxia**. Complete division of a nerve is coded as **laceration**. It may be recorded in clinical notes as **neurotmesis**.

In the lower limb most of the back of the leg and foot as supplied by the **sciatic nerve** (whose thickness is similar to that of an adult male index finger) and its divisions. Some of the front of the leg is supplied by the slightly smaller and flatter **femoral nerve**. There are digital nerves which supply sensation to the toes analogous to those in the fingers.

MUSCLES, TENDONS, LIGAMENTS
The deep soft tissues of the upper and lower limb consist mainly of muscles, tendons and ligaments. Ligaments lend stability to the joints and are aided in this function by a fibrous envelope in continuity with the ligaments known as the joint capsule. When the muscle contracts this movement is conducted along relatively inelastic cord-like structures known as tendons which pull on a bone causing movement at a joint. Muscle injuries tend to be coded as lacerations when caused by penetrating injury. The more massive destruction caused by mangled type forces pose a more significant threat to life and are coded under, ‘whole area.’ Tendons may be injured by cutting type forces or may be torn by over stretching when a joint moves in an abnormal plane due to blunt injury. In the lower limb two thick and very tough tendons which may occasionally be injured are the **patellar tendon** which extends from the knee cap to a bony prominence in the upper tibia and the **achilles tendon** which is in continuity with the calf muscles and inserts into the back of the calcaneum, also known as the **os calcis or heel bone**.

SKELETAL—BONES AND JOINTS
The commonest bone injury is a fracture. This implies that there is an interruption of the continuity of a bone. However there is a whole spectrum of severity from a small kink or crease in the outer layer (or cortex) of a bone which is known variously as a **buckle fracture** or a **greenstick** injury which is slightly more severe. At the other end of the spectrum is the more severe injury causing complete separation of the bone ends which may remain in line (undisplaced) or alternatively may be **angulated** or **displaced**. Shattering of a bone into several pieces is known as comminution. Other terms referable to fractures are **open** (or **compound**) and
closed. If the overlying skin is intact then the fracture is closed. However, if there is a skin wound which may potentially communicate with the fracture site the fracture is said to be open or compound. Some fractures have specific names such as Colles fracture for those of the distal radius commonly seen in the elderly. The fracture of the base of the thumb metacarpal may be called a Bennetts fracture. An old classification of ankle fractures was Pott’s fracture classification, a term you may still come across.

Dislocation of a joint occurs most commonly as a result of an abnormal load causing a joint to be stressed in a direction or to an extent which is unphysiological. The soft tissues which lend stability to the joint are inevitably severely disrupted and sometimes there is an associated fracture of one of the bones contributing to the joint. Lesser stresses where the integrity of the joint surfaces remain intact may be known as contusion or, more commonly, sprain.
EXTERNAL, BURNS, OTHER TRAUMA
SKIN AND SUBCUTANEOUS TISSUES

BACKGROUND

The coding convention for external injuries dictates that an isolated skin wound is coded under this section providing that it is not associated with deep tissue injury. Where this is an associated muscle, nerve, tendon or vascular injury then the skin wound is coded under 'whole area' within the specific body area. These injuries are marked by an asterisk in the Dictionary.

ANATOMY

The external body layer consists of skin and a fatty subcutaneous tissue through which pass blood vessels, nerves and tendons. Skin is specialised in certain areas for example the eye (conjunctiva) and the mouth (mucosa). There is a variable layer of tough material (keratin) lying outside the skin. Beneath the keratin are two distinct layers which are visible under the microscope in cross section. The epidermis consists of stacked cells known as epithelium which migrate towards the surface during maturation. Eventually they are shed and replaced from a germinal or basal layer which demarcates the epidermis above from the dermis below. The dermis contains nerve endings, hair follicles and sweat glands. The latter two structures are essentially tubular down-growths from the epidermis. The fact that they contain elements from the epidermis is important in the repair process following wounds and burns as they are the source of epithelial cells which must cover the defect in the process of healing by, 'skinning over.'

AIS DESCRIPTORS

WHOLE AREA
An abrasion is a superficial skin wound often termed as a graze.

A contusion is the result of a blunt blow to the surface. It is a swelling, often skin coloured rather than bluish, differentiating it from a haematoma. However for the purposes of injury description the two are coded as one.

A laceration is a split wound, the result of blunt trauma or crushing. The severity will vary from trivial to life threatening. The wound caused by a sharp edge such as a knife is not a laceration but an incised wound.
The wound produced by a pointed implement is a penetrating injury.

An avulsion is the severest form of laceration whereby the skin and the subcutaneous tissues are torn off from the underlying structure by a high energy crush or mangling type of force. The terms degloving and avulsion sometimes cause confusion, not least among doctors making clinical records in the notes.
Correct terminology is as follows:
Where a mangling force off the skin and the subcutaneous tissue from the next deepest layer (the deep fascia, which is an envelope of fibrous tissue 'investing the muscle') a degloving has occurred. This degloving may be 'physiology' in the absence of an open wound. This is a clinical diagnosis whereby the skin is felt to be 'floating on a sea of haematoma' and may be mobilised in abnormal directions. There is no open wound, but the skin is devascularised and appears cold, pale and mottled. Where there is an open wound and indeed the skin is seen to be hanging off, this may be described as an anatomical degloving, a term synonymous with avulsion.

**BURNS**

Burn injury can be caused by hot liquids (scalds), hot objects and flames. Less frequently it can be caused by chemicals (acids/alkalis) and, paradoxically by intense or prolonged cold. In the context of significant burn injury, the most likely cause will be the house fire or a severe scald. Secondary (eg. Skeletal) injuries may be sustained while escaping from a fire. House fires are often complicated by lung injury caused by inhaling hot or poisonous gases. Other toxic products of incomplete combustion may also be released in house fires including cyanide and carbon monoxide. The latter is readily measured and high levels are associated with cardiac and neurological impairment and a significant risk of death.

The severity of the burn is determined by the area (percentage of total body surface) and the depth of the burn. A common formula for estimating the body surface area burned is depicted in the AIS90 dictionary on pg65 and is known as the rule of nines. Depth of burn is assessed by experienced clinicians. A burn wound may be described as erythema only which implies redness of the skin. It is generally not recognised in the calculation of body surface area burn. Some people would describe this as a first degree burn. The second degree or partial thickness burn implies that the burn wound extends to an intermediate depth. UK surgeons further differentiate this type of burn into superficial dermal (with destruction of the layers as far deep as just beneath the epidermis) and deep dermal where epithelial elements are more scarce and skinning over takes longer with poorer cosmetic results. A full thickness burn implies destruction of all the layers of the skin both epidermis and dermis. Such burns may extend into subcutaneous fat, to muscle or even to bone. High voltage electricity typically induces a full-thickness cutaneous burn.

North American burns surgeons describe full thickness burns as third degree burns.

**OTHER TRAUMA**

Injuries due to heat and cold are often associated with a severe whole body insult posing a significant threat to life. Examples are, 'burn shock,' which is the cardiovascular collapse on-setting 24-48 hours after a large burn and the aforementioned inhalation injury. High voltage electrical injury may also cause cardiac arrest if the current traverses the heart causing disruption of the membranes of the cardiac cells. Cold injury, in addition to causing skin lesions, is often associated with a fall in the core temperature of the body below a critical level. This is known as hypothermia. Trauma victims with prolonged exposure are particularly at risk of this condition if their intrinsic thermo-regulation is impaired by old age, drugs or alcohol. A severe drop in core temperature below 28° is commonly followed by death.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Meaning</th>
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<td>intracranial pressure</td>
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<td>i.e.</td>
<td>that is</td>
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<td>intra peritoneal</td>
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<td>intensive therapy unit</td>
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<td>intelligence quotient</td>
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<td>knee jerk</td>
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<td>KUB</td>
<td>kidney, ureter, bladder</td>
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<td>L(n)</td>
<td>lumbar vertebrae</td>
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<tr>
<td>L</td>
<td>liver</td>
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<tr>
<td>L</td>
<td>left</td>
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<td>LA</td>
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<td>LB</td>
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<tr>
<td>LBBB</td>
<td>left bundle branch block</td>
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<td>Description</td>
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<tr>
<td>LL</td>
<td>lower lobe of lung</td>
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<tr>
<td>LLL</td>
<td>left lower lobe of lung</td>
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<td>LIF</td>
<td>left iliac fossa</td>
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<td>loss of consciousness</td>
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<td>LSK</td>
<td>liver, spleen, kidney</td>
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<td>LS</td>
<td>lumbo sacral</td>
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<td>left upper lobe of lung</td>
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<td>LUQ</td>
<td>left upper quadrant</td>
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<td>M.m</td>
<td>murmur</td>
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<td>MAIS</td>
<td>maximum AIS</td>
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<td>N</td>
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<td>no abnormality detected</td>
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<td>non-accidental injury</td>
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<td>normal</td>
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<td>NoF</td>
<td>neck of femur</td>
</tr>
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<td>not otherwise specified</td>
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<td>Description</td>
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<td>NSU</td>
<td>non surgical unit</td>
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<td>nausea and vomiting</td>
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<td>OBG</td>
<td>obstetrics/gynaecology</td>
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<td>O/E</td>
<td>on examination</td>
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<tr>
<td>O+G</td>
<td>obstetrics/gynaecology</td>
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<tr>
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<td>observations</td>
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<td>O.M.V.</td>
<td>occipito mental view</td>
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<td>out patient department</td>
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<td>Ophth</td>
<td>ophthalmology</td>
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<td>OPG</td>
<td>orthopantomogram</td>
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<td>OR</td>
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<td>pulse</td>
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<td>Path</td>
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<td>PC</td>
<td>presenting complaint</td>
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<tr>
<td>Per</td>
<td>through or by</td>
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<td>PERLA</td>
<td>pupils equal react to light and accommodation</td>
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<td>P/F Joint</td>
<td>patello-femoral joint</td>
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<tr>
<td>PH</td>
<td>past history</td>
</tr>
<tr>
<td>PIP</td>
<td>proximal interphalangeal</td>
</tr>
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</table>
PM  petit mal
PM  post mortem
PM  afternoon
PMH past medical history
POP plaster of paris
post posterior
post-op post operative
PR per rectum
pre-op pre operative
pm according to circumstances
prog prognosis
pt patient
PTA post traumatic amnesia
PV per vaginum
qds four times daily
q.i.d. four times daily
R respiration
R right
RA retrograde amnesia
RBBB right bundle branch block
Reg registrar
RIF right iliac fossa
RLL right lower lobe of lung
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>RMO</td>
<td>resident medical officer</td>
</tr>
<tr>
<td>ROM</td>
<td>range of movement</td>
</tr>
<tr>
<td>ROP</td>
<td>removal of plaster</td>
</tr>
<tr>
<td>ROS</td>
<td>removal of sutures</td>
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<tr>
<td>RS</td>
<td>respiratory system</td>
</tr>
<tr>
<td>RSO</td>
<td>resident surgical officer</td>
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<tr>
<td>RR</td>
<td>respiratory rate</td>
</tr>
<tr>
<td>RTA</td>
<td>road traffic accident</td>
</tr>
<tr>
<td>RUL</td>
<td>right upper lobe of lung</td>
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<tr>
<td>RUQ</td>
<td>right upper quadrant</td>
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<tr>
<td>Rx</td>
<td>treatment, prescription</td>
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<tr>
<td>S</td>
<td>spleen</td>
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<td>SAH</td>
<td>subarachnoidhaemorrhage</td>
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<tr>
<td>SB</td>
<td>small bowel</td>
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<td>S.C.</td>
<td>subcutaneous</td>
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<td>SDH</td>
<td>subdural haematoma</td>
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<tr>
<td>SE</td>
<td>systematic enquiry</td>
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<td>semi</td>
<td>half</td>
</tr>
<tr>
<td>SH</td>
<td>social history</td>
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<td>SHO</td>
<td>senior house officer</td>
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<td>SOB</td>
<td>shortness of breath</td>
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<td>SOS</td>
<td>if needed</td>
</tr>
<tr>
<td>spont</td>
<td>spontaneous</td>
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<tr>
<td>Abbreviation</td>
<td>Description</td>
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</tr>
<tr>
<td>SR</td>
<td>senior registrar</td>
</tr>
<tr>
<td>STD</td>
<td>special treatment department</td>
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<tr>
<td>stat</td>
<td>at once</td>
</tr>
<tr>
<td>SXR</td>
<td>skull x-ray</td>
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<tr>
<td>subcut</td>
<td>subcutaneous</td>
</tr>
<tr>
<td>T(n)</td>
<td>thoracic vertebrae</td>
</tr>
<tr>
<td>T(temp)</td>
<td>temperature</td>
</tr>
<tr>
<td>tid</td>
<td>three times daily</td>
</tr>
<tr>
<td>TIA</td>
<td>transient ischaemic attacks</td>
</tr>
<tr>
<td>TLC</td>
<td>tender loving care</td>
</tr>
<tr>
<td>TLC</td>
<td>total lung capacity</td>
</tr>
<tr>
<td>TM</td>
<td>tympanic membrane</td>
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<tr>
<td>TMJ</td>
<td>temporomandibular joint</td>
</tr>
<tr>
<td>TPR</td>
<td>temperature, pulse, respiration</td>
</tr>
<tr>
<td>TRISS</td>
<td>trauma score, ISS</td>
</tr>
<tr>
<td>TS</td>
<td>trauma score</td>
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<tr>
<td>Tx</td>
<td>treatment</td>
</tr>
<tr>
<td>UC</td>
<td>unconscious</td>
</tr>
<tr>
<td>UE</td>
<td>upper extremity</td>
</tr>
<tr>
<td>URTI</td>
<td>upper respiratory tract infection</td>
</tr>
<tr>
<td>UTI</td>
<td>urinary tract infection</td>
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<tr>
<td>VA</td>
<td>visual acuity</td>
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<tr>
<td>Acronym</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>------------------------</td>
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<tr>
<td>VD</td>
<td>venereal disease</td>
</tr>
<tr>
<td>VF</td>
<td>ventricular fibrillation</td>
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<tr>
<td>VT</td>
<td>ventricular tachycardia</td>
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# Hospital Abbreviations and Symbols

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>Abd</td>
<td>abdomen, abdominal</td>
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<tr>
<td>ABG</td>
<td>arterial blood gases</td>
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<tr>
<td>ACLS</td>
<td>advanced cardiac life support</td>
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<tr>
<td>ADL</td>
<td>activities of daily living</td>
</tr>
<tr>
<td>Ad.lib</td>
<td>at liberty</td>
</tr>
<tr>
<td>Adm</td>
<td>admit</td>
</tr>
<tr>
<td>A &amp; E</td>
<td>Accident and Emergency</td>
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<tr>
<td>AE</td>
<td>atrial fibrillation</td>
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<tr>
<td>AED</td>
<td>Accident and Emergency Department</td>
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<td>AIS</td>
<td>abbreviated injury scale</td>
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<tr>
<td>AJ</td>
<td>ankle jerk</td>
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<tr>
<td>AK</td>
<td>above knee</td>
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<tr>
<td>AM/am</td>
<td>before noon</td>
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<td>ante</td>
<td>before</td>
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<td>ant</td>
<td>anterior</td>
</tr>
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<td>antero-posterior</td>
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<td>AP</td>
<td>arterial pressure</td>
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<td>alimentary system</td>
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<td>ASIS</td>
<td>anterior superior iliac spine</td>
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<td>ATLS</td>
<td>advanced trauma life support</td>
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<td>AV</td>
<td>atrioventricular</td>
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<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>B</td>
<td>bladder</td>
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<td>BAC</td>
<td>blood alcohol concentration</td>
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<td>BE</td>
<td>below elbow</td>
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<tr>
<td>Bab/</td>
<td>Babinski/Plantar response</td>
</tr>
<tr>
<td>BK</td>
<td>below knee</td>
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<td>brought in dead</td>
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<tr>
<td>BLS</td>
<td>basic life support</td>
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<td>basal metabolic rate</td>
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<td>blood pressure</td>
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<td>bowel/breath sounds</td>
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<td>C$_2$H$_5$OH</td>
<td>alcohol</td>
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<td>c</td>
<td>with</td>
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<td>C(n)</td>
<td>cervical vertebrae</td>
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<td>c/c</td>
<td>vision with correction</td>
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<td>CCU</td>
<td>coronary care unit</td>
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<tr>
<td>chr</td>
<td>chronic</td>
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<td>CNS</td>
<td>central nervous system</td>
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<td>COAD</td>
<td>chronic obstructive airways disease</td>
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<td>complains of</td>
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<td>consultant</td>
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<td>cerebrospinal fluid</td>
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<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>CVA</td>
<td>cardiovascular accident</td>
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<td>CXR</td>
<td>chest x-ray</td>
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<td>CVS</td>
<td>cardiovascular system</td>
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<td>CT(scan)</td>
<td>computerised tomography</td>
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<td>diffuse brain injury</td>
</tr>
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<td>D&amp;C</td>
<td>dilation and curettage</td>
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<td>DDA Δ</td>
<td>differential diagnosis</td>
</tr>
<tr>
<td>DID</td>
<td>died in department</td>
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<tr>
<td>DIP</td>
<td>distal interphalangeal</td>
</tr>
<tr>
<td>DNA</td>
<td>did not attend</td>
</tr>
<tr>
<td>DOA</td>
<td>dead on arrival</td>
</tr>
<tr>
<td>DOB</td>
<td>date of birth</td>
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<td>DT</td>
<td>delerium tremens</td>
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<td>D&amp;V</td>
<td>diarrhoea and vomiting</td>
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<td>Dx</td>
<td>diagnosis</td>
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<td>ED</td>
<td>emergency department</td>
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<td>EDH</td>
<td>extradural haematoma</td>
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<td>ENT</td>
<td>ears, nose and throat</td>
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<td>Example</td>
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<td>electromyograph</td>
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<td>EOM</td>
<td>extraocular movement</td>
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<td>ETOH</td>
<td>alcohol</td>
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<td>exam</td>
<td>examination</td>
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<td>FB</td>
<td>foreign body</td>
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<td>Abbreviation</td>
<td>Full Description</td>
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<tr>
<td>FBC</td>
<td>full blood count</td>
</tr>
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<td>FE</td>
<td>functional enquiry</td>
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<td>FH</td>
<td>family history</td>
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<td>fetal heart sound</td>
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<td>general anaesthetic</td>
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<td>gall bladder</td>
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<td>GCS</td>
<td>Glasgow Coma Score</td>
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<td>gastrointestinal</td>
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<td>gastrointestinal tract</td>
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<td>grand mal</td>
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<td>GSW</td>
<td>gunshot wound</td>
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<td>gt</td>
<td>great</td>
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<td>genito-urinary</td>
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<td>gynaecology</td>
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<td>Hct</td>
<td>haematocrit</td>
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<td>HO</td>
<td>house officer</td>
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<td>Hosp</td>
<td>hospital</td>
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<td>HP</td>
<td>house physician</td>
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<tr>
<td>HPI</td>
<td>history of present illness</td>
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<td>HPC</td>
<td>history of present condition</td>
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<tr>
<td>HR</td>
<td>heart rate</td>
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<tr>
<td>HS</td>
<td>heart sounds</td>
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</table>
Non-Government Organisations – Brain Injury

Since 1985 Headway Ireland, has provided support to those with acquired brain injury and their carers through a range of community based services tailored to individual needs. Centres are located in Dublin, Cork, Kerry and Limerick along with an Information and Education service in the South East. Their stated aim is to provide range of support services to help people live more independent lives after a brain injury.

Founded in March 1999 following a public meeting held at the National Rehabilitation Hospital, Dun Laoghaire for those affected by acquired brain injury. BRI is dedicated to supporting and advocating for all those affected by acquired brain injury. They work to achieve change in terms of service provision, public awareness and prevention.
Established in 2000, Acquired Brain Injury Ireland [formerly The Peter Bradley Foundation] is Ireland’s leading provider of flexible and tailor-made services for people with an Acquired Brain Injury (ABI).

Their stated mission is to enable people with an acquired brain injury to live an independent life within the community, by providing and maintaining a supportive living environment. Their approach is to provide a custom-made rehabilitation and care programme specific to the individual needs of each client. Acquired Brain Injury Ireland is the first organisation in Ireland to receive internationally recognised CARF accreditation as a provider of quality services for people with an ABI.

QUEST and the Galway Head Injury Support Group provide support, training, information and counselling for families of people with Brain Injury. They highlight the special needs of families where there is a Brain Injury, and advocate for recognition of these needs to government bodies and health care professionals.
APPENDIX C

Activities of daily living (ADLs):

The things we normally do in daily living including any daily activity we perform for self-care (such as feeding ourselves, bathing, dressing, grooming), work, homemaking, and leisure. The ability or inability to perform ADLs can be used as a very practical measure of ability/disability in many disorders.

Craniotomy:

Craniotomy is any bony opening that is cut into the skull. A section of skull, called a bone flap, is removed to access the brain underneath. There are many types of craniotomies, which are named according to the area of skull to be removed. Typically the bone flap is replaced. If the bone flap is not replaced, the procedure is called a craniectomy.

Craniotomies are also named according to their size and complexity. Small dime-sized craniotomies are called burr holes or keyhole craniotomies. Sometimes stereotactic frames, image-guided computer systems, or endoscopes are used to precisely direct instruments through these small holes. Burr holes or keyhole craniotomies are used for minimally invasive.


CT Scan

CT scanning—sometimes called CAT scanning—is a noninvasive medical test used to diagnose and treat medical conditions.

CT scanning combines special x-ray equipment with sophisticated computers to produce multiple images or pictures of the inside of the body. These cross-sectional images of the area being studied can then be examined on a computer monitor, printed or transferred to a CD.

CT scans of internal organs, bones, soft tissue and blood vessels provide greater clarity and reveal more details than regular x-ray exams.

Expressive Aphasia

Aphasia is a disorder that results from damage to the parts of the brain that contain language. Aphasia causes problems with any or all of the following: speaking, listening, reading, and writing.
Damage to the left side of the brain causes aphasia for most right-handers and about half of left-handers. Individuals who experience damage to the right side of the brain may have additional difficulties beyond speech and language.

Characteristics of Expressive Aphasia
- Speaks only in single words (e.g., names of objects)
- Speaks in short, fragmented phrases
- Omits smaller words like "the," "of," and "and" (so message sounds like a telegram)
- Puts words in wrong order
- Switches sounds and/or words (e.g., bed is called table or dishwasher a "wish dasher")
- Makes up words (e.g., jargon)
- Strings together nonsense words and real words fluently but makes no sense.

(HTTPS://WWW.ASHA.ORG/PUBLIC/SPEECH/DISORDERS/APHASIA.HTM)

Accessed 1/6/2010

**Glasgow Outcome Scale (GOS):**

The Glasgow Coma Outcome is a scale that assesses the outcome of serious cranio-cerebral injuries, based on the level of regained social functioning:

- Dead (Score 1)
- Vegetative (Score 2)
- Severely disabled (Score 3): able to follow commands/ unable to live independently
- Moderately disabled (Score 4): able to live independently/ unable to return to work or school
- Good Recovery (Score 5): able to return to work or school (Jennett and Bond, 1975)

A more accurate assessment tool known as the Disability Rating Scale (DRS) has now replaced the GCO scale in some places (max. 29 extreme vegetative state to zero no disability). An extended version of the scale divides each of the latter three categories in two, making eight categories (http://www.tbims.org/combi/gos/index.html) Accessed 1/6/2010

**QNHS: Quarterly National Household Survey**

HIPE: Hospital In-Patient Enquiry Scheme is a computer-based discharge abstracting system designed to collect demographic, clinical and administrative data on discharges and deaths from acute general hospitals nationally.

TBI: Traumatic Brain Injury
APPENDIX D

Card issued by the Acquired Brain Injury Association Ireland (previously Peter Bradley Foundation)

(Credit card size)
APPENDIX E

The Abbreviated Injury Scale (AIS):

This scale was produced by the Association for the Advancement of Automotive Medicine (AAAM) based in Illinois, U.S.A. It was developed in 1971 to aid vehicle crash investigators, and was extended in 1990 to be more relevant to medical audit and research.

The AIS is defined as an anatomically based consensus derived global severity scoring system that classifies each injury in every body region according to its relative importance on a six point ordinal scale.

The 6 point ordinal AIS (Post dot) severity scale:

1 = minor
2 = moderate
3 = serious
4 = severe
5 = critical
6 = maximum (Currently untreatable).

The AIS severity score indicates the relative risk of “threat to life” in an average person who sustains the coded injury as his or her only injury (www.tam.ac.uk). Accessed 1/6/2010
APPENDIX F:
Recruitment Poster, Consent and Assent Forms

Poster 1:

Have you had a traumatic brain injury in the past 3 years? Are you aged between 16 and 64 years?

IF SO, THIS STUDY IS OF PARTICULAR IMPORTANCE TO YOU.

What is in it for you?

People who participate in the research will have helped me to identify any unmet needs that may exist in different health and social environments and how these might be prevented in the future.
In addition, I am hoping that taking part in this research will benefit you by giving you an opportunity to share your experiences as a person with a traumatic brain injury. Your participation would be very valuable to the study and very much appreciated.

FIND OUT MORE OR TO GET INVOLVED CONTACT ME:

Catherine Browne, Department of Sociology, Foundation Building, University of Limerick, Limerick. E-mail: catherine.browne@ul. Phone: (087) 0523129

Poster 2:

Provision of acute and rehabilitative care in Ireland for people aged 16 to 64 years with traumatic brain injuries.

Would you like to take part in this research project?

What is the study about?

Brain injury is a leading cause of death and disability worldwide. Every year in Ireland, approximately 10,000 people sustain a traumatic brain injury. Road traffic accidents, assaults, falls and sporting injuries are the main causes; eighty percent of victims are male and 7 out of 10 are aged less than 25 years at the time of injury. However, at present it is not known how many people are living in Ireland with the disabling effects of this type of injury.

What is the goal of the study?

I want to investigate if there are unmet service needs for people with traumatic brain injury in the 16 to 64 year age group. These services and supports may be around access to therapies (such as physiotherapy, speech and language etc), education / training, jobs, housing, healthcare or social activities.

We would like to include you as one of several people to be involved in this study.

Who is undertaking the study?

My name is Catherine Browne, R.G.N., R.M., M.A., and I am currently pursuing a Ph.D. doctorate degree in the Department of Sociology at the University of Limerick.

Who can participate in the research?

Anyone between the ages of 16 and 64 years who has had a traumatic brain injury in the past 3 years and is no longer a hospital in-patient.

What you have to do?

You will be interviewed by me in a location that best suits you. In total, the interview will take 1 hour and you may want to bring a friend or a family member with you. You do not have to answer any of the interview questions, if you so wish. You can stop the interview at any time. With your permission, the interview will be tape-recorded.

The questions will be around:
What does a brain injury mean to you? Have you noticed any changes to your life since the injury happened? Do other people now treat you differently? Tell me some of the good and bad things about the care and supports you received since your injury? Have your needs changed since your injury? Do you feel you needed more services or supports than you were able to get after your injury? Can you tell me about these? Are there things, like work or study or involvement in sport that you believe would help you?

What about confidentiality?
All the information that I obtain is kept strictly confidential. Nothing reported from the study, in print, or lecture will permit identification of the participants.

Is my participation voluntary?
Yes, it is voluntary, and it does not compromise any future care. You can participate, refuse to participate or withdraw at any time. Further information or answers to your questions about the study, your participation in the study and your rights, may be obtained from the principle researcher: Catherine Browne (contact details below).
Date:

Dear,

I am doing a study on traumatic brain injuries as a part of my doctoral studies in the Department of Sociology, University of Limerick. It will centre on the question of the adequacy of current provision of neurosurgical and rehabilitation services in Ireland for people in the 16 to 64 year age group with moderate or severe traumatic brain injury. The research will particularly examine the social context in which patients and their families are expected to function following this often-sudden life-changing episode. The enclosed abstract and proposal will give you a better idea of the aims, objectives and the methodology of the study.

Beaumont Hospital is just one of the locations being used in the study and ............... has kindly agreed to co-investigate the research there.

The other sites are Cork University Hospital, National Rehabilitation Hospital and various locations in the community.

The chosen methodology involves the examination of about 800 medical records (500 in Beaumont and 300 in CUH) as well as other secondary data sources.

From this sample, I intend to select 20 people who have been treated for a TBI. These people will be invited to participate in a one-to-one qualitative interview. Twelve carers and/or family members will also be invited to give interviews.

A further ten qualitative interviews will be conducted with health professionals and service providers. This sample will be drawn from people working in Beaumont, Cork University, National Rehabilitation Hospitals, as well as Headway, Peter Bradley Foundation, Brí, and those in community care, such as GP's and Public Health Nurses.

I intend interviewing only one person from Beaumont Hospital. As the nurse co-coordinator with responsibility for traumatic brain injuries, your experiences would greatly enhance this study. Your participation would be voluntary and would only involve being interviewed by me for approximately one hour at a location, which best suits you. With your permission, the interview will be tape recorded to facilitate collection of information. Themes that will be addressed
include views on public policy, staff development and health and social care funding. Additional questions will be around the transfer of patients with TBI to other care facilities and services, and if there is uniformity with regard to provision.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at 087 0523129 or by email at catherine.browne@ul.ie. You can also contact my supervisor, Dr. Brendan Halpin at 061 213147 or by email at brendan.halpin@ul.ie or ......................... at Beaumont Hospital.

I am in the process of making an application to the Ethics Committee at Beaumont Hospital for ethical approval. Approval has been granted by Cork University Hospital.

I hope that the results of my study will be of benefit to those organisations directly involved in the study, patients and their carers, other voluntary organisations not directly involved in the study, as well as to the broader research community.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours sincerely,
Catherine Browne
PhD researcher
Telephone 087 0523129
061213061
Email: Catherine.browne@ul.ie
Health Professional CONSENT FORM

Title: Provision of Acute and Rehabilitative Care for People aged 16 to 64 years with Traumatic Brain Injury: the case of Ireland.

Please tick the appropriate answer.

I confirm that I have read and understood the Information Leaflet dated ____________ attached, and that I have had ample opportunity to ask questions all of which have been satisfactorily answered.

☐ Yes
☐ No

I understand that my participation in this study is entirely voluntary and that I may withdraw at any time, without giving reason, and without this decision affecting me in any negative manner.

☐ Yes
☐ No

I understand that my identity will remain confidential at all times, but anonymous quotes may be used in the final report.

☐ Yes
☐ No

I am aware that the interview will be tape recorded and that only Catherine Browne will have access to the tapes.

☐ Yes
☐ No

I have been given a copy of the Information Leaflet and this Consent form for my records.

☐ Yes
☐ No
FUTURE USE OF ANONYMOUS DATA:
I agree that I will not restrict the use to which the results of this study may be put. I give my approval that unidentifiable data concerning my person may be stored or electronically processed for the purpose of scientific research and may be used in related or other studies in the future.

PARTICIPANT

__________________________

Signature and dated        Name in block capitals
Title: Provision of Acute and Rehabilitative Care for People aged 16 to 64 years with Traumatic Brain Injury (TBI): the case of Ireland

Principal Investigator's Name: Catherine Browne
Principal Investigator's Title: PhD researcher at University of Limerick.
Telephone No. of Principal Investigator: 061 213061

Co-Investigator:
Co-Investigator's Title:
Telephone No. of Co-Investigator:

You are being invited to take part in a research study carried out at ................. Hospital. Before you decide whether or not you wish to take part, you should read the information provided below carefully and if you wish, discuss it with your family and friends. Take time to ask questions - do not feel rushed or under any obligation to make a hasty judgement. You should clearly understand the risks and benefits of participating in this study so that you can make a decision that is right for you - this process is known as Informed Consent.

You may change your mind at any time (before the start of the study or even after the study has begun) for whatever reason and without having to say why.

WHY IS THIS STUDY BEING DONE?

We want to investigate if there are unmet service needs for people with traumatic brain injury in
the 16 to 64 year age group. These services and supports may be around access to therapies (such as physiotherapy, speech and language, occupational therapy etc), education / training, jobs, housing, healthcare or social activities.

We would like to include you as a 'Family Member or a Significant other' of a person with a traumatic brain injury.

WHO IS ORGANISING THIS STUDY?

Catherine Browne is organising the study for the purpose of obtaining a doctorate at University of Limerick. The study in Beaumont Hospital is being supervised by ......................... Consultant Neurosurgeon at the hospital.

HOW WILL IT BE CARRIED OUT?

As a start around 500 medical records will be examined at Beaumont Hospital and 300 records at Cork university Hospital. The second part will involve doing one-to-one interviews with 20 people who have had a traumatic brain injury within the previous 24 months. This will only include people who have been discharged from either, Beaumont Hospital or Cork University Hospital and are aged between 16 and 64 years. Other parts of the study will involve interviews with healthcare and other service providers, such as doctors, nurses and representatives from a number of voluntary organisations like Headway, Ireland.

Further to this, a number of Family members / Significant others of people with traumatic brain injury will be interviewed by the principal investigator (Catherine Browne). This study has been running since January 2007 and is due to end in December 2009.

WHAT IS INVOLVED?

You will be interviewed by Catherine in a location that best suits you. In total, the interview will take 1 hour and you may want a friend or a family member with you. You do not have to answer any of the interview questions, if you so wish. You can stop the interview at any time. With your permission, the interview will be tape-recorded to facilitate the collection of information. Shortly after the interview has been completed, Catherine will get in touch with you. This will give you a chance to change the information or to add to it.

The questions will be around:
The changes you have experienced since your family member or significant other had a brain injury.
Do you feel the services and supports are adequate for their/your needs? Are there areas that could be improved?
All information collected in this research is strictly anonymous and confidential.

Anonymous means that your name, your address or other personal details will not appear in any report. However, with your permission anonymous quotations (things you say) may be used in the final report.

Your identity (name, address and personal details) will be known only to the principal investigator (Catherine Browne), who thereafter, will use a code to further protect your identity. The coded data will be held securely for up to ten years and will then be shredded. The tapes used at the interviews will be destroyed as soon they are transcribed or 'typed up' (approximately one month after the interview).

Confidential means anything you tell or discuss with the researcher will not be shared with anyone else.

BENEFITS:

People who take part in the research will have helped us identify any unmet needs for people with brain injury. In addition, I am hoping that taking part in this research will benefit you by giving you an opportunity to share your experiences. Your participation would be very valuable to the study and very much appreciated.

RISKS:

It may be upsetting to talk about this subject. If so, you can stop the interview at any time.

WHAT DO I DO NOW?

A STAMPED ADDRESSED ENVELOPE and a RETURN FORM is enclosed.

Please place an X in the box which says YES, if you wish to take part in the study.

If you do NOT wish to be involved, please place an X in the ‘NO’ box.

Use the stamped addressed envelope to post this form back to us.
IF YOU REQUIRE FURTHER INFORMATION:

If you have any further questions about getting involved in the research or any other issues about it, please contact either me, Catherine Browne at 087 0523129 or by email at catherine.browne@ul.ie

If you have any comments or concerns about this study and wish to contact someone independent please appeal to The Chairman of the Beaumont Hospital Research Ethics (Medical Research) Committee, c/o Ms. Gillian Vale, Administrator Ethics (Medical Research) Committee, Beaumont Hospital, Dublin 9. Telephone: 01-809 2680

I very much look forward to speaking with you and thank you in advance for your assistance with this research study.

FAMILY MEMBER/SIGNIFICANT OTHER PARTICIPANT
CONSENT FORM

Title: Provision of Acute and Rehabilitative Care for People aged 16 to 64 years with Traumatic Brain Injury (TBI): the case of Ireland

Please tick the appropriate answer.

I confirm that I have read and understood the attached Information Leaflet dated ___________, and that I was given enough opportunity to ask questions, all of which have been satisfactorily answered.

☐ Yes
☐ No
I understand that my participation in this study is entirely voluntary and that I may withdraw at any time, without giving reason, and without this decision affecting my future relationships with health or social care providers.

☐ Yes
☐ No

I understand why I am being asked questions.

☐ Yes
☐ No

I understand that only the people asking the questions will know the answers I give and that my identity will remain confidential at all times. I have been made fully aware that this means, my name, age or address will not appear in any report or publication or that people could know who I am.

☐ Yes
☐ No

I understand that anonymous quotations may be used in the final report.

☐ Yes
☐ No

I am aware that the interview will be tape recorded and that only the study staff will have access to the tapes.

☐ Yes
☐ No

I am aware that talking about the injury may upset me.

☐ Yes
☐ No

If I need to, I know how to contact the research team. Their contact details are provided on the attached information sheet.

☐ Yes
☐ No
I have been given a copy of the Information Leaflet and this Consent form for my records.

☐ Yes
☐ No

FUTURE USE OF ANONYMOUS DATA:

I agree that I will not restrict the use to which the results of this study may be put. I give my approval that unidentifiable data concerning my person may be stored or electronically processed for a maximum of ten years and may be used in related or other studies in the future.

☐ Yes
☐ No

Participant ____________________________

Signature and dated ____________________________ Name in block capitals

To be completed by the Principal Investigator.

I, the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that he/she could understand. I have explained the risks involved, as well as the possible benefits and have invited him/her to ask questions on any aspect of the study that concerns them.

Signature: ____________________________ Name in Block Capitals: ____________________________

Qualification: ____________________________

Date: ____________________________

This information letter is for survivors of TBI who have been PATIENTS at Beaumont or Cork University Hospital

(Cork University Hospital /Beaumont headed paper used)
Participant Information Leaflet

Title: Provision of Acute and Rehabilitative Care for People aged 16 to 64 years with Traumatic Brain Injury (TBI): the case of Ireland

Principal Investigator's Name: Catherine Browne
Principal Investigator's Title: PhD researcher at University of Limerick.

Telephone No. of Principal Investigator: 061 213061

Co-Investigator:
Co-Investigator's Title:
Telephone No. of Co-Investigator:

You are being invited to take part in a research study being carried out at Beaumont Hospital/Cork University Hospital. Before you decide whether or not you wish to take part, you should read the information provided below carefully and if you wish, discuss it with your family, friends or GP. Take time to ask questions - do not feel rushed or under any pressure to make a quick decision. You should clearly understand the risks and benefits of participating in this study so that you can make a decision that is right for you - this process is known as Informed Consent.

You may change your mind at any time (before the start of the study or even after the study has begun) for whatever reason, without having to say why. You can also be assured that your decision will not affect the future care you receive from medical, nursing or other staff.

WHY IS THIS STUDY BEING DONE?

We want to investigate if there are unmet service needs for people with traumatic brain injury in the 16 to 64 year age group. These services and supports may be around access to therapies (such as physiotherapy, speech and language, occupational therapy etc), education/training, jobs, housing, healthcare or social activities. We would like to include you as one of several people to be involved in this study.

WHO IS ORGANISING THIS STUDY?
Catherine Browne is organising the study for the purpose of obtaining a post graduate degree at University of Limerick. The study in Hospital is being supervised by Consultant Neurosurgeon at the hospital.

WHAT IS INVOLVED?

You will be interviewed by Catherine in a location that best suits you. In total, the interview will take 1 hour and you may want to have a friend or a family member with you. You do not have to answer any of the interview questions, if you so wish. You can stop the interview at any time. With your permission, the interview will be tape-recorded to help in the collection of information. Shortly after the interview has been completed, Catherine will get in touch with you. This will give you a chance to change any of the information or to add something to it.

The questions will be around:

What does a brain injury mean to you? Have you noticed any changes to your life since the injury happened? Do other people now treat you differently? Tell me some of the good and bad things about the care and supports you received since your injury? Have your needs changed since your injury? Do you feel you needed more services or supports than you were able to get after your injury? Can you tell me about these? Are there things, like work or study or involvement in sport that you believe would help you?

All information collected in this research is strictly anonymous and confidential.

Anonymous means that your name, your address or other personal details will not appear in any report. However, with your permission anonymous quotations (things you say) may be used in the final report.

Your identity (name, address and personal details) will be known only to the principal investigator, Catherine Browne. The data will be held securely for up to ten years and will then be shredded. The tapes used at the interviews will be destroyed as soon they are transcribed or ‘typed up’ (approximately one month after the interview).

Confidential means anything you tell or discuss with the researcher will not be shared with anyone else.

BENEFITS:

People who take part in the research will help us to identify any unmet needs and inform how best to tackle any shortfalls in future. In addition, taking part in this research may
benefit you by giving you an opportunity to share your experiences. Your participation would be very valuable to the study and very much appreciated.

RISKS:

It may be upsetting to talk about your injury. If so, you can stop the interview at any time. You may also want to talk to your doctor.

IF YOU REQUIRE FURTHER INFORMATION:

If you have any further questions about getting involved in the research or any other issues about it, please contact Catherine Browne at 087 0523129 or by email at catherine.browne@ul.ie
If you have any comments or concerns about this study and wish to contact someone independent, please appeal to The Chairman of the Beaumont Hospital Research Ethics (Medical Research) Committee, c/o Ms. Gillian Vale, Administrator Ethics (Medical Research) Committee, Beaumont Hospital, Dublin 9. Telephone: 01 -809 2680

WHAT DO YOU DO NEXT?

A STAMPED ADDRESSED ENVELOPE and a RETURN FORM is enclosed.

Please place an X in the box which says YES, if you wish to take part in the study. If you do NOT wish to be involved, please place an X in the ‘NO’ box.

Use the stamped addressed envelope to post this form back to us.

We very much look forward to speaking with you and thank you in advance for your assistance with this research study.
Consent form for survivors of TBI who have been PATIENTS at Beaumont Hospital or Cork University Hospital

Re: Study on the Provision of Acute and Rehabilitative care for people in the 16 to 64 year age group with Traumatic Brain injury: the case of Ireland

Consent Form for Participants

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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<tbody>
<tr>
<td>I understand the information (ATTACHED) on the above study</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I understand that taking part is voluntary and that I don’t have to take part if I don’t want to</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I understand why I am being asked questions</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I agree to answer questions about how I feel about my health and living in my community</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I understand that only the people asking the questions will know the answers I give</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I agree to have the interview tape recorded</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I am aware that talking about the injury may upset me.</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I understand that some of the things I talk about may be used in the report, but my name, address or other details will not be used in any way.</td>
<td>☐ ☐</td>
</tr>
<tr>
<td>I know how to contact the research team if I need to. Details are provided on the information sheet</td>
<td>☐ ☐</td>
</tr>
</tbody>
</table>
Participant
Signature: ________________________________

Print name: ______________________________

Date: _________________________________

Witness - Signature: ______________________________

Printed Name: ______________________________

To be completed by the Principal Investigator.

I, the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that he/she could understand. I have explained the risks involved, as well as the possible benefits and have invited him/her to ask questions on any aspect of the study that concerns them.

Signature: ________________________________ Name in Block Capitals: ________________________________

Qualification: ________________________________

Date: ________________________________
Study title: Provision of Acute and Rehabilitative Care for people aged 16 to 64 years with Traumatic Brain Injury: the case of Ireland

Study Staff: Ms. Catherine Browne and ...................................................... (hospital consultant)

Why you are being contacted at this time?

We want to tell you about a study about people with traumatic brain injury. We want to see if you would like to be in this study. This form explains about the study and if you have questions at the end we will try to answer them. If there is anything you still do not understand, you could ask your family doctor, your family or a friend.

Why are we doing this study?

We want to learn how life is for people after a brain injury and if there are services and supports available which meet they need. These services may be therapies (such as physiotherapy, speech and language, occupational therapy), education / training, jobs, housing, healthcare or social activities. The study will last about 36 months in total. Beaumont Hospital and Cork University Hospital are involved and the plan also involves holding interviews with people who have been injured, as well as family members. Catherine Browne is doing the study as part of a further study degree at University of Limerick and ................................. a doctor at Beaumont / Cork University Hospital, is supervising the work she is doing here.

What will happen to you?

If you want to be in the study these things will happen:

1. You will be asked to give an interview (or a chat) for one hour. This interview will take place in a location that best suits you – this may be in your own home. You may want to have someone there with you, such as a family member or friend. A tape recorder will be used to record the information.
2. After the interview the researcher (Catherine) will check that the information is correct. This will also give you a chance to add or to change anything.

Will the study hurt?

It may be upsetting for you to talk about your injury. If so, you can stop at any time. After that you may want to chat to your doctor.

Will you get better if you are in the study?

This study may not make you feel better or get well. But the study staff might find out something that will help other people later.

What if you have any questions?

You can ask questions any time, now or later. You can talk to the doctors, your family or someone you trust.

Who will know what you did in the study?

Any information you give to the study staff will be kept private (or secret). Your name will not be on any study paper and no one but the study staff will know that it was you who was in the study.

Do you have to be in the study?

You do not have to be in the study. No one will be mad at you if you don't want to do this. If you don't want to be in this study, just say so. Even if your family wants you to be in the study you can still say no. The doctors and nurses will still take care of you when you need them. Even if you say yes now you can change your mind later. It's up to you.

Do you have any questions?

What questions do you have?
Assent

I want to take part in this study. I know I can change my mind at any time.

________________________

Verbal assent given  Yes [ ]

Print name of Participant.................................................................

[If verbal assent obtained the process must be clearly documented in the research file]

Written assent if the participant chooses to sign the assent.

________________________   ________________________
Signature of Participant          Date

I confirm that I have explained the study to the participant to the extent compatible with the participants understanding, and that the participant has agreed to be in the study.

________________________   ________________________
Printed name of .............................. .
Signature of..............................................

Date

Person obtaining assent (1)..........................................

Person obtaining assent (2)..........................................

I was present when .............................................. read this form and gave his/her verbal assent

Printed Name of Witness...........................................

Signature of Witness..............................................

Date..............................................
RETURN SLIP for Survivors of TBI

CODE..................

‘Provision of Acute and Rehabilitative Care for People aged 16 to 64 years with Traumatic Brain Injury: the case of Ireland’

I wish to take part in this study     YES

I do not wish to take part in this study     NO

Please place an X in the first box which says YES, if you wish to take part in the study.

If you do NOT wish to be involved, please place an X in the box which says NO.

Use the STAMPED ADDRESSED ENVELOPE to post this form back to us.
RETURN SLIP for Family Members/Significant Others

CODE..............

‘Provision of Acute and Rehabilitative Care for People aged 16 to 64 years with Traumatic Brain Injury: the case of Ireland’

<table>
<thead>
<tr>
<th>I wish to take part in this study</th>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not wish to take part in this study</td>
<td>NO</td>
</tr>
</tbody>
</table>

Please place an X in the first box which says YES, if you wish to take part in the study.

If you do NOT wish to be involved, please place an X in the box which says NO.

Use the STAMPED ADDRESSED ENVELOPE to post this form back to us.
13th February 2007

Dr Brendan Halpin
Department of Sociology
University of Limerick
Limerick

Re: ULREC No. 07/07 Title: Provision of Acute Hospital and Rehabilitative Care for the Young (Age Group 16 to 64 Years) with Acquired Brain Injuries: The Case of Ireland

Dear Dr Halpin

The above application was considered by the University of Limerick Research Ethics Committee, at its meeting on 8th February 2007.

The Committee agreed the following:

* The application must be approved by the Hospital Ethics Committee, ie. Beaumont or Cork University Hospital.

Yours sincerely

K. Kelleher
Dr Kevin Kelleher
Chairman
University of Limerick Research Ethics Committee
Ethics (Medical Research) Committee - Beaumont Hospital
Notification of ERC/IRB Approval

Investigator: Catherine Browne (University of Limerick)

Protocol No.: 07/97

Protocol Title: Provision of Acute and Rehabilitative Care for people aged 16 to 64 years with Traumatic Brain Injury: the case of Ireland

Ethics Committee Meeting date: 7th December 2007

Final Approval Date: 28th March 2008

From: Ethics (Medical Research) Committee - Beaumont Hospital, Beaumont, Dublin 9

Documents Reviewed

<table>
<thead>
<tr>
<th>Document and Date</th>
<th>Date Reviewed</th>
<th>Approved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application Form, V2, 16/3/08</td>
<td>28/3/08</td>
<td>Yes</td>
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<tr>
<td>Protocol, no version number</td>
<td>28/3/08</td>
<td>Yes</td>
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<tr>
<td>Poster, V3, 16/03/08</td>
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PEOPLE WITH TBI:

- Letter of Invitation, V1, 16/03/08 28/3/08 Yes
- Return Slip, V1 16/3/08 4/4/08 Yes
19th September 2007

Mr Charles Marks
Consultant Neurosurgeon
Cork University Hospital
Wilton
Cork

Re: Provision of acute and rehabilitative care for people in the 18 to 64 year age group with traumatic brain injury: the case of Ireland.

Dear Mr Marks

Expedited Approval is granted to carry out the above study at the following sites:

- Cork University Hospital

We note the following co-investigator will be involved:

- Catherine Browne, Dept of Sociology, Foundation Building, University of Limerick

Yours sincerely

Dr Michael Hyland
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals
## APPENDIX H

Patients presenting at Beaumont Hospital by Diagnosis.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Count</th>
<th>Percent</th>
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</thead>
<tbody>
<tr>
<td>Cerebrum contusion, single/ -multiple NFS</td>
<td>12</td>
<td>9.0</td>
</tr>
<tr>
<td>Cerebrum haematoma, intracerebral, extradural, NFS</td>
<td>39</td>
<td>29.1</td>
</tr>
<tr>
<td>Cerebrum haematoma, subdural, small or moderate NFS</td>
<td>23</td>
<td>17.2</td>
</tr>
<tr>
<td>Skull vault fracture, NFS</td>
<td>12</td>
<td>9.0</td>
</tr>
<tr>
<td>Face penetrating injury superficial / Face laceration</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Skull vault fracture,compound/depressed/displaced/ Skull vault fracture, closed</td>
<td>10</td>
<td>7.5</td>
</tr>
<tr>
<td>Cerebrum injury, subarachnoid haemorrhage</td>
<td>11</td>
<td>8.2</td>
</tr>
<tr>
<td>Cerebrum diffuse axonal injury</td>
<td>5</td>
<td>3.7</td>
</tr>
<tr>
<td>Cerebrum injury, brain swelling, mild/severe</td>
<td>6</td>
<td>4.5</td>
</tr>
<tr>
<td>Scalp laceration, NFS</td>
<td>1</td>
<td>.7</td>
</tr>
<tr>
<td>Calcaneus fracture</td>
<td>1</td>
<td>.7</td>
</tr>
<tr>
<td>Cerebrum injury, pneumocephalus</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Maxilla fracture, LeFort III</td>
<td>1</td>
<td>.7</td>
</tr>
<tr>
<td>Radius fracture with or without styloid process including Colles, complex fractured humerus/ Clavicle fracture</td>
<td>7</td>
<td>5.2</td>
</tr>
<tr>
<td>Brainstem compression</td>
<td>1</td>
<td>.7</td>
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<tr>
<td><strong>Total</strong></td>
<td>134</td>
<td><strong>100</strong></td>
</tr>
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</table>