Anxiety and Information Use in Family Members of Brain Injured Clients.

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Johannesburg,

2013
Declaration

I, Deborah Elizabeth Barrie, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature: ________________________________

Date: ________________________________
Presentations Arising from the Research Report


- Paper presentation of research at the South African Neurological Rehabilitation association (SANRA) August 2013, Johannesburg.
Abstract

Whilst patients are in hospital, their families are expected to understand and remember complex information from the medical team. Previous studies have shown that high levels of anxiety impair a person’s ability to interpret complex information and memory recall. It is unknown if family members experience anxiety whilst the patient is in rehabilitation. The study aimed to determine if family members experienced anxiety, and whether there was a significant correlation between anxiety and the length of time the client was admitted to the rehabilitation facility; length of time since the client’s injury; the FIM measurement of the patient; as well as the perception of received information by the treating team. A family representative participated by completing the Hospital Anxiety and Depression Scale (HADS) and an Information Checklist on three separate occasions during the patient’s stay in a rehabilitation hospital. Family members were found to be anxious throughout the period of rehabilitation, with a decreasing trend in the average scores of the HADS assessment. An increasing trend was noted in the satisfaction of information offered by the treating team. No significant correlation could be found between the family members’ anxiety and the motor or cognitive improvement in the patient – thus indicating that a strong possibility exists that the factors influencing the family members’ anxiety are wide spread and diverse.
Acknowledgements

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# Table of Contents

Declaration

Presentations arising from the Research Report

Abstract

Acknowledgements

Table of Contents:

List of Figures

List of Tables

Definition of Terms

Abbreviations

CHAPTER 1

INTRODUCTION

1.1. Introduction

1.2. Statement of the Problem

1.3. Purpose of the Study

1.4. Aim of the Study

1.4.1. Objectives of the study

1.5. Justification of the Study

CHAPTER 2

LITERATURE REVIEW

2.1. Brain Injury

2.1.1. Traumatic brain injury (TBI)

2.1.2. Cerebrovascular accident (CVA)

2.1.3. Other causes of brain injury

2.1.4. Burden of brain injury

2.2. Outcomes of brain injury that affect the need for care

2.2.1. Severity of the Brain injury

2.2.2. Recovery after a Brain injury
2.3. Emotional response of family members of clients with brain injuries________ 14

2.4. The role of rehabilitation with client’s with brain injury and their family members

2.4.1. The role of the occupational therapist with client’s with brain injury and their family members________ 15

2.4.2. Discharge planning________________________ 18

2.4.3. Family education for clients with brain injuries______________ 18

2.5. Anxiety and Education of Family Members____________________ 20

2.5.1. Measurement of Anxiety______________________________ 21

CHAPTER 3 _____________________________________________ 23
RESEARCH METHODOLOGY____________________________________ 23

3.1. Study Design___________________________________________ 23

3.2. Study Population________________________________________ 23

3.3. Sample and Selection Size________________________________ 23

3.4. Data Collection Instruments________________________________ 24

3.4.1. Family Member Participants___________________________ 24

3.4.1.1. Demographic Information Sheet (Appendix A)___________ 25

3.4.1.2. Information Checklist (Appendix B)___________________ 25

3.4.1.3. The Hospital Anxiety and Depression Scale (Appendix C)____ 26

3.4.1.4. Information regarding the Use of Anxiety Medication (Appendix D)________________________________________________________________________ 27

3.4.2. Clients with Brain Injury_________________________________ 27

3.4.2.1. Demographic Information Sheet______________________ 28

3.4.2.2. The Functional Independence Measure (FIM) and the Functional Assessment Measure (FAM) (Appendix E)__________________________ 28

3.5. Research Procedure and Data Collection______________________ 29

3.6. Ethical Considerations____________________________________ 31

3.7. Data Analysis____________________________________________ 32

CHAPTER 4 _____________________________________________ 34

RESULTS__________________________________________________ 34
4.1. Demographics

4.1.1. Demographics of the family members

4.1.1.1. Age and relationship to the client

4.1.1.2. Employment status and income

4.1.1.3. Education level

4.1.1.4. Medication taken for anxiety by participants

4.1.2. Demographics of the client with brain injury

4.1.2.1. Position in the family

4.1.2.2. Time since onset of injury

4.2. Anxiety level of the family member participants

4.3. Information processing of family member participants

4.4. Relationship between family member anxiety and information processing

4.5. Functional Independence Measure and Functional Assessment Measure (FIM/FAM)

4.6. Relationship between family member anxiety and the Functional Independence Measure and Functional Assessment Measure (FIM/FAM)

4.7. Summary of Results

CHAPTER 5

DISCUSSION

5.1. Demographic information

5.2. Anxiety in family members with clients with brain injuries in inpatient rehabilitation

5.3. Information transfer to participants

5.4. Relationship between the client’s functional level and family member anxiety

5.5. Limitations of this study

CHAPTER 6

CONCLUSION

6.1. Recommendations

Appendices

APPENDIX A  Demographic Information Sheet

APPENDIX B  Information Checklist
APPENDIX C  The Hospital Anxiety and Depression Scale___________69
APPENDIX D  Information Regarding use of Anxiety Medication_______72
APPENDIX E  The Functional Independence Measure and the Functional Assessment Measure (FIM/FAM) score sheet_________73
APPENDIX F  Information Sheet and Informed Consent Form_______74
APPENDIX G  Ethical Clearance Certificate_________________________76
APPENDIX H  Permission letter from Life Riverfield Lodge Rehabilitation Hospital ________________________________77
APPENDIX I  Permission document from Life New Kensington Clinic Rehabilitation Hospital__________________________78
References________________________________________________________________________________________80
List of Figures

Figure 1: Monthly income of participants (n=32)........................................................37
Figure 2: Level of education amongst participants (n=34).............................................38
Figure 3: Time in days since injury or onset of illness (n=34).......................................39
Figure 4: Mean scores on the anxiety scales of the HADS-A assessment.....................40
Figure 5: Individual HADS-A anxiety scores per assessment (n=25)..............................41
Figure 6: Information assessment................................................................................42
Figure 7: Individual Information scores per assessment (n=25).....................................43
Figure 8. Linear relationship between the decrease in anxiety and increase in
information processing in family members from Assessment 1 to Assessment 3............45
Figure 9: Improvement in clients measured by FIM/FAM.............................................46
Figure 10: Individual Information scores per assessment (n=25).................................47
Figure 11: The mean scores of the motor subscale, cognitive subscale and total score
of the FIM/FAM assessment during the first assessment.............................................48
List of Tables

Table 1: Classification of head injury based on Post-Traumatic Amnesia..............12
Table 2: Explanation of mild, moderate and severe head injuries.........................13
Table 3: Core Areas of Occupational Therapy Assessment .....................................17
Table 4: The various times for the different assessments........................................30
Table 5: Drop out Figures......................................................................................35
Table 6: Relationship of the participants to the clients with brain injury.................36
Table 7: Employment status of participants .............................................................36
Table 8: Correlation between the HADS-A Anxiety Scale Assessment Scores and the Information Processing Scores .................................................................44
Table 9: Correlation between the HADS-A Anxiety Scale Assessment Scores and the Functional Independence Measure Scores..................................................49
Definition of Terms

- **Client:** The term ‘client’ refers to the individual or client who has suffered a stroke or sustained a brain injury; and who is currently admitted as an inpatient at either Life Riverfield Lodge Rehabilitation Hospital or Life New Kensington Rehabilitation Hospital.

- **Family member of the brain injured client:** The term ‘family member of the brain injured client’ refers to the individual completing the questionnaires and checklist; and whose family member is currently admitted as an inpatient at either Life Riverfield Lodge Rehabilitation Hospital or Life New Kensington Rehabilitation Hospital.

- **Brain injury:** The term ‘brain injury’ is defined as damage to the brain which occurs after birth and is not related to a congenital disorder, a developmental disability or a process which progressively damages the brain (i.e. Alzheimer’s disease or Multiple sclerosis).

- **Anxiety:** “A state of uneasiness and apprehension about future uncertainties”\(^2\)
Abbreviations

- ADL’s = activities of daily living
- CVA = Cerebrovascular accident
- CNS = central nervous system
- FAM = Functional Assessment Measure
- FIM = Functional Independence Measure
- FNQ = The Family Needs Questionnaire
- GCS = Glasgow Coma Scale
- HADS = Hospital Anxiety and Depression Scale
- HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale
- HADS-D = Hospital Anxiety and Depression Scale – Depression subscale
- LOC = loss of consciousness
- PTA = post-traumatic amnesia
- UK = United Kingdom
- US = United States of America.
CHAPTER 1

INTRODUCTION

1.1. Introduction

A brain injury is described as any injury to the brain resultant from either a vascular, traumatic, medical or surgical cause.\(^3\) For the purposes of this study, a brain injury is defined as damage to the brain which occurs after birth and is not related to a congenital disorder, a developmental disability or a process which progressively damages the brain (i.e. Alzheimer’s disease or Multiple sclerosis).\(^1\)

Occupational therapists play a vital role in the treatment of clients with brain injuries.\(^3\) They address functional independence in all aspects of activities of daily living (ADL’s), facilitate return of functional movement in the body but more especially in the upper limb and hand, assess and treat visual perceptual skills, as well as prescribe assistive devices for the home environment.\(^3\)

Since occupational therapists consider all aspects of a client’s life one aspect of the treatment offered by the occupational therapists is the education and training of the family members and primary, identified caregiver who will be assisting the client in self-care tasks and other activities once they are discharged. This is an important aspect of treatment as clients still often require care or assistance at home on discharge from the hospital\(^4\) due to their residual deficits, be they physical, cognitive or both.\(^3\) The training and education of the family members or the caregiver assists them by providing information about the prognosis of the client, future expectations in terms of recovery and how they should be managed currently.\(^1\) This allows for the family or caregiver to provide assistance that is effective and efficient at home.

It is however important that family members understand and apply the information provided to them. This may be affected by the stress that the medical intervention and hospitalization as well as the life changing injury and the future responsibility of caring for a brain injured individual places on them.\(^4\) This stress can result in high levels of anxiety for both family members and as well as for the client. The effect of
this anxiety on the ability to understand and appreciate information given to them about the condition and its management has been researched in the acute setting. There is however little information available about the presence of anxiety and the effect it has on the family’s ability to process essential information about the management of clients with brain injuries in the rehabilitation setting. It is also unclear from the literature as to whether the caregivers or family members experience anxiety during the rehabilitation process, and whether the level of anxiety changes during the rehabilitation process.

1.2. Statement of the Problem

Research has shown that family members of clients with brain injuries experience anxiety for numerous reasons whilst their family member is in an acute medical facility. Research has also shown a link between high levels of anxiety and memory as well as the inability to process complex information. Very few published studies could be found which related to the anxiety levels of family members of clients with brain injury involved in the rehabilitation process. It is therefore not clear in the rehabilitation setting how anxiety affects the family members’ ability to process information given to them regarding the client’s prognosis, care needed by the client at home and implications of the client’s condition for the family or other caregivers they involve in the client’s care.

Whilst there is research on how to give the information the family need, there is no indication of when in the rehabilitation process this should be done. Therefore, the question remains as to when would be the most appropriate time to give the family member’s complex information regarding their family member’s condition and prognosis.

The literature also does not specify which factors associated with rehabilitation could alter the family members’ level of anxiety. There is a paucity of information about the variations in the anxiety levels of these family members and what affect the information given to family members by occupational therapists regarding their family member’s progress or current level of functioning has on their levels of anxiety.
The time since injury also needs to be considered on their understanding of the information given to them.

1.3. Purpose of the Study

Since there is little information on the effectiveness of appropriate methods in occupational therapy for giving information to family members of clients with brain injury this study aimed to determine the relationship between information given to the family members and their anxiety levels. The purpose of this study was also to consider that effect of time since injury and the functional level of the client with brain damage on the family member anxiety levels.

1.4. Aim of the Study

To determine if a relationship exists between anxiety and information understood in family members of a client with brain damage in a rehabilitation setting, and what effect timing of information delivery, the functional level of independence client with brain damage as well as the their length of stay at a rehabilitation facility has on these factors

1.4.1. Objectives of the study

- To determine if family members of clients with the brain injury in a rehabilitation setting suffer from anxiety
- To determine if there is an association between family member’s levels of anxiety and the amount of information they perceive they have processed.
- To determine if there is a change in anxiety levels of family members and their ability to process information given about the client with brain injury during the period the client has inpatient rehabilitation.
- To determine if a relationship exists between the length of time since the client’s injury/accident and the anxiety levels of the family members of clients with the brain injury.
• To determine if a relationship exists between the brain injured client’s level of independence in occupational performance measured with the Functional Independence Measure and Functional Assessment Measure and the anxiety level of the family of clients with the brain injury.

1.5. Justification for the Study

It is important for occupational therapists to be aware of the factors that affect the understanding and acceptance of information given to family members of clients with brain damage about their functional prognosis and care. Knowledge about factors which affect the time best suited to giving family members complex information concerning the client’s condition and for discussing complex discharge plans will assist in making the education and training process more effective.

This study should provide some answers in relation to the anxiety levels of family members of clients with brain damage and how factors like time since injury, the client’s functional level of independence and understanding of information may affect this.
CHAPTER 2

LITERATURE REVIEW

This literature review covers information on brain injury, the burden of brain injury in South Africa as well as the outcomes that affect family members and anxiety in relation to these aspects and others like functional ability and length of time since injury. The role of rehabilitation and occupational therapy in brain injury emphasising discharge planning and the education of as well as the responsibilities of family members and caregivers of clients with brain injury are considered. The assessment of anxiety and the effect anxiety may have on information processing and understanding information is also included.

2.1. Brain Injury

An acquired brain injury refers to the rapid onset of damage to the brain caused by one of the following: trauma, vascular accident, cerebral anoxia, infection, and other toxic or metabolic insults. Thus the causes of a brain injury are varied, and the symptoms displayed by a client with a brain injury vary as well. The symptoms of the brain injury will depend on both the area of the brain that has been affected and the severity of the injury.

2.1.1. Traumatic brain injury (TBI)

A traumatic brain injury results from damage to the brain caused by external forces acting on the head. The injury may result from the initial injury (known as the primary lesion), or from secondary effects (known as the secondary lesion). There are three types of primary lesions which result in a traumatic brain injury. These are fronto-temporal contusions, diffuse axonal injuries, and coup-contrecoup injury.

Fronto-temporal contusions are cuts and bruises on the brain resulting from the soft brain tissues moving across the rough inner surfaces of the skull. Diffuse axonal injuries results from nerve fibres and small vessels tearing due to forces through the
brain as it moves and rotates in the skull during the injury. The mild form of this is often referred to as a ‘concussion’. The damage to the brain in a coup-contrecoup injury results from the brain bouncing off the opposite sides of the skull (usually the front and back of the skull). The damage is noted at the site of injury, as well as at the opposite side of the brain.

Besides the damage that is caused at the time of injury, there may be secondary damage following a brain injury. Secondary damage can include intracranial or subdural bleeding, swelling or seizures. Bleeding can occur from the damaged vessels in the brain (intracranial), or between the brain and the skull (subdural or subarachnoid). The incidence of extradural haematoma’s (bleeding) makes up 27% of the clients presenting with a head injury in the United States of America (US).\(^7\) The incidence of intradural haematoma’s is 26% for pure subdural haematomas, intracerebral plus subdural haematoma is 38%, and the incidence for an extradural plus intradural haematoma is 8%\(^7\).

Swelling or oedema of the brain can occur and has the same effect as raising the pressure inside the skull. The swelling may occur with or without a focal injury to the brain. It results from either an increase in intra- or extracellular fluid or vascular engorgement.\(^{15}\) This may cause the brain to become further compressed, which may result in further damage to the brain tissue by decreasing the perfusion to various areas of the brain.\(^{15}\)

A certain percentage of people with a brain injury develop epilepsy. Early epilepsy (a seizure occurring within the first week since injury) occurs in 5% of the patients admitted with a non-missile injury.\(^7\) Of these clients, 10% have status epilepticus seizures. Although, any seizures could further damage the brain, status epilepticus seizures significantly increase the risk of cerebral anoxia, which could lead to further brain damage.\(^7\) Tonic-clonic seizures (with a loss of consciousness) or temporal lobe seizures\(^6\) are more associated with late epilepsy (a seizure occurring after one week since injury). Clients with a head injury are often placed on prophylactic anticonvulsants as a precaution, although some discrepancy exists regarding the effectiveness of this treatment method.\(^7\)
2.1.2. Cerebrovascular accident (CVA)

This is commonly known as a ‘stroke’. The vascular system delivers oxygen-rich blood to the cells of the body and the brain to feed the cellular function. A CVA occurs when the blood supply to a portion of the brain is interrupted, resulting in damage of the brain cells which would have been supplied by that vessel. Another definition of a stroke is “a brain disease that occurs secondary to a pathological disorder of blood vessels (usually arteries) or blood supply”.

Cerebral vascular disease is associated with certain risk factors. These include hypertension, cardiac disease, diabetes, hypercholesterolemia, obesity (or diet), race, history or smoking, hyperlipidaemia, certain oral contraceptives and hereditary factors.

There are two major types of CVA’s, namely ischaemic and haemorrhagic. Ischaemic CVA’s can be caused by a thrombosis in the brain that has blocked off the blood supply to the remaining areas of the brain or through a narrowing (or stenosing) of one of the arteries in the brain. A thrombosis which originates in the brain, or an embolus which forms elsewhere in the body and travels through the vascular system to the brain, affects a specific area of the brain which suffers from a lack of oxygen supply, hence the name ‘ischaemia’. Seventy five percent of CVA’s are ischaemic of origin. Haemorrhagic strokes are due to a rupture of a blood vessel in the brain. Blood flows from the vessel and causes pressure on the brain tissue. This increased pressure results in the death of cells in the affected area of the brain.

The typical presentation of a CVA depends greatly on which side and area of the brain has been affected. Damage to the left hemisphere of the brain may result more commonly in aphasia, dysarthria, dysphagia, hemiparesis of the right side, right sided sensory loss, right visual field defect, difficulty with reading and writing, difficulty in calculating, memory difficulties, and behavioural abnormalities including impulsivity. Damage to the brain in the right hemisphere may result more commonly in dysarthria, dysphagia, left sided hemiparesis, left sided sensory loss, left visual field defect, spatial disorientation, memory difficulties, behavioural abnormalities, and a neglect or inattention to the entire left side of the body and visual field.
2.1.3. Other causes of brain injuries

The brain can be damaged through other causes such as intracranial space occupying lesions, infections, metabolic conditions, anoxic or hypoxic injuries and toxicity.

Intracranial space occupying lesions may result from a variety of causes. All space occupying lesions, no matter the origin or cause, share one common characteristic, which is that they cause the expansion in volume of the intracranial contents and the swelling that is caused can result in devastating consequences. This swelling can either be focal or diffuse and can result in a raised intracranial pressure, intracranial shift and herniation, epilepsy, hydrocephalus, and systemic effects. A tumour, or space occupying lesion, may infiltrate widely throughout the brain tissue which may hamper the removal of it. It may also occupy a critical site, and therefore affect the patient’s functioning. The majority (80 – 85%) of space occupying lesions in adults occur supratentorially.

Infections of the central nervous system (CNS) can include bacterial, viral and fungal infections. Examples of bacterial infections are bacterial meningitis, cerebral abscesses, syphilis and tuberculosis. While these infections can have no permanent damage to the CNS if treated promptly and correctly, they can have devastating effects if left untreated. Complications of bacterial meningitis include hydrocephalus, cerebral thrombophlebitis and cerebral abscesses. Cerebral abscesses and the tubercle of TB act as space occupying lesions and have similar effects as mentioned above.

Metabolic conditions are also referred to as nutritional disorders and result from dietary deficiency or absorption disorders. An example of a metabolic condition caused by a deficiency in Thiamine is Wernicke’s Korsakoff Syndrome. In the acute phase (referred to as Wernicke’s syndrome) the client will experience abnormal eye movements, ataxia and confusion. In the chronic phase of the disease (referred to as Korsakoff’s psychosis) the client experiences impairment in their short-term memory.

Hypoxic injuries are caused by a decreased in or ‘lack of’ oxygen. Anoxic injuries are caused by a complete absence of oxygen. These injuries are caused by a lack of oxygen intake, or poor perfusion to the area of the brain involved.
The incorrect use of or exposure to toxins and/or overdose of drugs commonly affect the neurological system, with varying signs and symptoms. Most of these are reversible with the withdrawal of the causing agent. The clinical picture differs greatly, depending on the drug or toxin involved and the amount used. Some common neurological signs and symptoms associated are with drugs and toxins include headache, seizures, confusion, delirium, peripheral neuropathy, retinopathy, visual disturbances, movement disorders, ataxia, muscle pain and weakness.

2.1.4. Burden of brain injury

According to the National Institute for Occupational Health in South Africa, each year 5% of the global population as well as the South African population suffer a form of serious brain injury. The most common causes of a brain injury are traumatic brain injury and cerebrovascular accident (CVA). Both are regarded globally, as some of the most significant problems to face the public health system. In developing countries research suggests that the incidence of traumatic brain injury might be 1.5 and 3.5 times higher than the accepted incidence of 200/100 000 per annum. Reliable statistics are not available although it is reported that an estimated 89 000 new cases of head injury occur each year in South Africa. The three most common causes of traumatic brain injuries in South Africa are motor vehicle accidents (including bicycle and vehicle-pedestrian accidents), falls and violence. Vehicle accidents account for 50% of the injuries, whilst falls account for 25% and violence 20%. Depending on the severity of these symptoms, these individuals may never return to their previous level of functioning, or to their previous employment. These clients often require further ongoing medical and therapeutic interventions to aid in their recovery process.

Milder brain injuries are frequently not reported as part of the statistic as people with this type of injury often do not seek medical attention. Eighty percent of those who suffered a mild head injury will be symptom free within 6 months, according to the national guidelines of the United Kingdom (UK). However, the remaining 20% may suffer with symptoms such as headaches, dizziness, fatigue, memory problems, mood changes and irritability permanently.
The crude prevalence for CVA is estimated at 300/100 000 in South Africa and while this is lower than that for some developing countries, it places an added economic burden on the country as the severity and subsequent loss of function is higher in the South African population. In a study done in South Africa by the Medical Research Council in 2000, it was found that a CVA was the 8th highest cause of death amongst South Africans. Approximately one-third of all cerebral vascular accidents worldwide are fatal. Factors that influence the outcome of a stroke, are the age of the patient, the anatomical size of the lesion, the degree of deficit and the underlying cause of the CVA. The incidence of other causes of brain injury like space occupying lesions and infections is a small with primary brain tumours occur in approximately 6 people per 100 000 a year in the United states of America.

South Africa like the rest of the world has a greater number of people surviving severe trauma and brain injury than a decade ago, with the advent of newer and better medical procedures. This has resulted in a population of clients in need of rehabilitation and long-term care beyond hospitalisation. Services to deal with clients with brain injury and their families depend on each country’s policies and in South Africa, there is generally a lack of such facilities with specialised rehabilitation centres provided mainly in the private sector only.

Even when hospital care and rehabilitation are available they are expensive and as a result fewer clients are remaining in permanent institutionalisation. Therefore, more clients are potentially being discharged to the care of their families in their home. The intensity and need for care for clients with brain injury depends on the type and severity of brain injuries and this also affects the outcomes for each client. The greatest burden however may be on the families that have to provide care and support to clients with brain injury. Families therefore face caring for a person who has changed and this can be overwhelmingly and exhausting. Caregivers can experience anxiety as well as practical problems.

2.2. Outcomes of brain injury that affect the need for care

Outcomes of brain injury are diverse and range from a vegetative state to the resumption of aspects of occupational performance. Thus there can be devastating
consequences after brain injury for the client and their family members with various demands being placed on the family and their resources.\textsuperscript{14}

This is because clients often require assistance or care at home. Assistance can take the form of cognitive assistance, physical assistance or both.\textsuperscript{3} Research has estimated that between seven and 25\% of those that have survived a stroke, require care and that this care is usually performed by a family member or a caregiver appointed by them.\textsuperscript{15}

Other factors that cause stress in families are: the financial burden, lack of support, poor available resources, severity of impairment of the patient as well as the characteristics and coping strategies of the carer.\textsuperscript{16} The care that families provide may need to be extensive, including assistance with ADLs, advocacy, medication monitoring, service co-ordination and cognitive rehabilitation.\textsuperscript{17}

The need for this care is associated with certain outcome factors related to the brain injury including the severity of the injury, independence regained in Occupational Performance and the recovery that occurs.

2.2.1. Severity of the Brain Injury

The severity of a brain injury will have an effect on the expected prognosis and the care the client may require in the future. The severity is determined in the acute stages of the injury and has been associated with later occupational performance deficits.\textsuperscript{17} Although there is no single official method of determining the severity of head injury, the most generally accepted as universal classification tools are the Glasgow Coma Scale (GCS) and the duration of post traumatic amnesia.\textsuperscript{18}

The GCS can be used to classify the severity of traumatic brain injury as mild, moderate, or severe and it is used to determine all post-traumatic states of altered consciousness, from the mild confusion to coma. It measures the best response of the patient in terms of the best ocular response, best speech, and best movement/response to pain, each on an ordinal scale of 1 – 5. The best possible score a client could score is a total of 15 and the lowest score is a total of 3. A total GCS score of 13 – 15 within 48 hours of the head injury indicates a mild head injury\textsuperscript{18}. A moderate head
injury is indicated by a total GCS score of 8 – 12 within 48 hours of the head injury with a total GCS score of less than 7 after 48 hours indicating a severe head injury.

Post-traumatic amnesia (PTA) is the interval for which the client presents with confusion or impaired memory. It begins at the time of injury, and typically lasts approximately four times as long as the coma and loss of speech.\textsuperscript{1,18} Assessment of PTA consists of a memory, orientation and basic concept assessment. This information is then used to determine whether or not the client is still in post-traumatic amnesia period. Table 1 indicates the duration of PTA in terms of the classification of the severity of a head injury:

<table>
<thead>
<tr>
<th>Post-Traumatic Amnesia Duration</th>
<th>Severity of Head Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 5 minutes</td>
<td>Very mild</td>
</tr>
<tr>
<td>5 – 60 Minutes</td>
<td>Mild</td>
</tr>
<tr>
<td>1 – 24 hours</td>
<td>Moderate</td>
</tr>
<tr>
<td>1 – 7 Days</td>
<td>Severe</td>
</tr>
<tr>
<td>1 – 4 weeks</td>
<td>Very severe</td>
</tr>
<tr>
<td>&gt; 4 weeks</td>
<td>Extremely severe</td>
</tr>
</tbody>
</table>

The American Department of Defence has produced a summary table which combines the GCS and PTA with the time that consciousness was lost. Their interpretation of PTA does not extend to “very and extremely” severe and differs slightly in terms of the levels in the GCS as can be seen in Table 2\textsuperscript{19}:
Table 2: Explanation of mild, moderate and severe head injuries.

<table>
<thead>
<tr>
<th>Severity of Head Injury</th>
<th>Glasgow Coma Scale</th>
<th>Post-Traumatic Amnesia Duration</th>
<th>Loss of Consciousness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>13 - 15</td>
<td>&lt; 1 day</td>
<td>0 – 30 minutes</td>
</tr>
<tr>
<td>Moderate</td>
<td>9 - 12</td>
<td>&gt; 1 and &lt; 7 days</td>
<td>&gt; 30 min to &lt; 24 hrs</td>
</tr>
<tr>
<td>Severe</td>
<td>3 - 8</td>
<td>&gt; 7 days</td>
<td>&gt; 24 hours</td>
</tr>
</tbody>
</table>

Although the scales described to determine the severity of head injury are useful, as occupational therapists it is important that the level of functional ability of the client with a brain injury be assessed so occupation based therapy can be appropriately prescribed.

The actual functional ability of clients with a brain injury varies greatly depending on the severity of the brain injury as well as the time since the injury. The Ranchos Los Amigos Scale is used to assess the level of activity on which the client with a brain injury is functioning cognitively in relation to their occupational performance.

2.2.2. Recovery after a brain injury

The brain’s ability to recover and learn is individualized, depending on many different factors – both internal and external. Internal factors include the patient’s age, gender, handedness, premorbid personality characteristics, neuropathological diagnosis, and the severity of the injury. Each individual’s speed of recovery, as well as the extent of recovery varies based on the decrease of pressure and swelling in the brain, as well as neuroplasticity or functional connectivity which is restored.

These are the concepts used to understand brain functioning and the effects of brain injury. The brain is assumed to be a complex network of dynamical systems with local areas in the cerebral cortex and cerebellum having a large number of interactions with other remote areas in the brain. This provides plasticity in the cerebral cortex for learning and recovery in response to brain lesions and the effects of a brain injury on a client’s functional abilities and occupational performance. Research indicates that baseline functioning in occupational performance cannot be easily
predicted after brain injury as recovery is a unique process and even increased rehabilitation cannot achieve recovery past a ceiling effect, which is dictated by the amount of improvement possible for each client.

External factors which affect recovery from brain injury include a stimulating environment and access and management in terms of rehabilitation, the demands of the environment for performance as well as family support.

Improvement can occur for up to seven years post injury, with most recovery taking place within the first 12 to 24 months after injury. The rate of recovery varies over time, and it is reported that of the clients that survive the initial impact of a head injury and remain in a coma for 6 hours, approximately 40% will die within 6 months. Residual deficits in the remaining 60% of the head injured population included both cognitive (impaired intellect, memory, and behavioural difficulties) and physical (hemiparesis and dysphasia). The family’s perceptions for recovery and resolution of these deficits are often unrealistic and they expect ongoing recovery in the client with brain injury which affects their expectations in terms of care that will be needed. Recovery from cognitive and physical deficits has been associated with independent occupational performance and a reduction in the amount of care needed.

2.3. Emotional response of family members of clients with brain injury

Clients with brain injury and their family members are reported to experience a “rollercoaster of emotions” throughout the period of her injury and discharge preparation. Holbrook (1982) and Riley (2007) described the social and emotional adjustment to the stroke by both clients with brain injury and their families.

The Bereavement Model described by Holbrook presented a first stage as crisis, characterized by shock, confusion and high anxiety. Research has documented family members reporting high rates of psychological distress particularly anxiety and depression in both this acute phase. The sub acute or treatment phase is the stage in which survivors and families develop high expectations of recovery, denial that disability is permanent and periods of grieving also marked by anxiety and depression.
It is known that the family’s emotional state in these phases has an important influence on their ability to process and accurately recall the information given.

The third stage involves the realization of the real level of disability with associated feeling of despair, frustration, anger, rejection and depression with the final stage being acceptance of and adjustment to the new reality of the disabled person. It is at this third stage in the bereavement process, according to Carnes and Quinn\(^\text{32}\) when it is usually time for the client to be discharged from hospital or rehabilitation facility.

2.4. The role of rehabilitation with client’s with brain injury and their family members

The role of the rehabilitation unit in brain injury is to provide a setting for intensive specialist rehabilitation.\(^\text{37}\) The rehabilitation unit accommodates clients that are not ready or safe to go home yet. It further provides a structured daily rehabilitation programme to allow for a successful transition between the hospital and the community.\(^\text{34}\)

Evidence suggests that rehabilitation is best delivered by a well co-ordinated team of professionals representing the relevant disciplines\(^\text{33}\). Although the research and clinical shift to involving the families of client with brain in rehabilitation started in the 1970’s\(^\text{35}\), there is still is no cohesive, well-researched framework to guide family intervention for families dealing with the emotion and bereavement in relation to clients with brain injuries. Suggested treatment deals with addressing the family belief systems and in assisting them to manage the stress and anxiety in the situation, revising attachments, and discovering hope.\(^\text{36}\)

2.4.1. The role of the occupational therapist with client’s with brain injury and their family members

Occupational therapy deals with both the deficits in client factors and performance skills identified in the client with a brain injury as well as how they will function in their environment which includes their family, possibly a caregiver and their community.\(^\text{38}\)
In terms of the individual, occupational therapy aims at assisting the client in improving aspects like sensory skills, motor skills, positioning during acute coma phases, self-care tasks, cognitive tasks, work related tasks and assistive devices to aid independence in tasks.

The occupational therapist addresses aspects of independence in daily tasks, such as dressing, cooking, shopping and housework which will assist the clients in developing the skills that are required to complete these tasks, such as budgeting, planning, problem-solving and visual perceptual skills. Occupational therapists supply specialist equipment and assistive devices to make the home environment easier and safer for those caring for people with disabilities.

Table 3 shows the core areas of assessment for clients with brain injury in occupational therapy within the framework of the International Classification of Functioning, Disability and Health (ICF) model.
The incorporation of a collaborative family into the occupational therapy and rehabilitation programme for clients with brain injury has been described in the acute, rehabilitation, discharge and home-based phases of intervention for this condition. In the acute and rehabilitation phases the family may become directly involved in care giving and therapy and assist with giving input and determining goals. This type of collaboration can result in a shorter hospital stay and was shown to significantly reduce anxiety for both the client and the family. The emphasis is placed on collaborative partnerships that should include family in all aspects of therapy but it requires intensive input from the occupational therapist and requires education, training, and good interpersonal skills if outcomes are to be maximised.

Occupational therapists and the rehabilitation team are therefore constantly in contact with family members and are required to give information to family members regarding their treatment and prognosis in terms of the client’s occupational

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**Table 3: Core Areas of Occupational Therapy Assessment**

<table>
<thead>
<tr>
<th>ICF Dimension</th>
<th>Body Function And Structure</th>
<th>Activity</th>
<th>Participation</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapy</td>
<td>Occupational performance components</td>
<td>Occupational Performance</td>
<td>Occupational Performance</td>
<td>Environment and contexts</td>
</tr>
<tr>
<td>Assessment Terminology</td>
<td>Vision</td>
<td>Upper limb function</td>
<td>Roles</td>
<td>Physical (e.g. home, work)</td>
</tr>
<tr>
<td></td>
<td>Visual perception</td>
<td>Personal self-care tasks</td>
<td>Occupational roles</td>
<td>Social</td>
</tr>
<tr>
<td></td>
<td>Memory</td>
<td>Domestic or instrumental activities of daily living</td>
<td>Community integration</td>
<td>Cultural</td>
</tr>
<tr>
<td></td>
<td>Cognition</td>
<td>Leisure activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Executive Function</td>
<td>Driving</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sensory Motor Changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychological adjustment</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
performance. An essential time for accurate information exchange is during discharge planning from the hospital.

2.4.2 Discharge Planning

Discharge planning and information given to the families addresses the client’s need for care or supervision, as well as practical ideas and suggestions to aid the client to fit into his previous environment and roles (where possible). The role of discharge planning is to assist in decreasing anxiety of the family regarding care for their family member at home, as well as decreasing the risk of re-admission to hospital. Effective discharge planning will also put the client and his/her family in touch with resources and therapists in their own community if necessary for support and follow-up. Most discharge planning and discussion around the client’s needs should be collaboratively in meetings in the hospital setting.

2.4.3 Family education for clients with brain injuries

It is the responsibility of the rehabilitation team including occupational therapists to provide clear and adequate information, as family members often feel that they do not receive sufficient information and that the information that they do receive is often insufficient and imprecise. This was confirmed in a study with a sound methodological design by Lefebvre and Levert (2006) where they interviewed clients diagnosed with moderate-to-severe TBI’s two years after injury, their family members and health professionals from different disciplines.

Information given should be about the medical prognosis, their functional prognosis, future expectations and what should be done currently. As well as detailed specifics of the assistance the client will require at home. Therefore one of the roles of an occupational therapist during the rehabilitation and discharge phase is to supply information to the family members about the client’s recovery in terms of their functional prognosis or the person’s ability to return to their pre-morbid functional tasks. As well as teaching them about and assisting them in enforcing the desired behaviour from the client/patient. Thus part of the education provided to the family
members relates to modelling the correct behaviour and interaction with the client. The family should be able to observe how the occupational therapist handles situations with the client, and therefore understand and learn how to handle their own family member.\textsuperscript{17}

Since the majority of those who will care for clients with brain injury are family members or untrained caregivers, it is important that they are given not only information but some training on how to assist the client. A study, completed 2004, concluded that a lack of information and hands on training lead to increased caregiver burden. The study acknowledged that caregiver’s needs were often low on the priority in the management of clients with a stroke and that further research is required to determine whether or not specific skills training in daily functional tasks will decrease the caregiver’s burden of care.\textsuperscript{15}

However according to McGuire (1996) between 40% to 80% of all medical information given to clients and family members is forgotten immediately after giving the information.\textsuperscript{45} It was also found that the greater the amount of information given at one time, the less information would be accurately recalled. Research by Anderson et al (1979) further showed that half of the information given by medical personal is remembered incorrectly.\textsuperscript{46} Since it can therefore be assumed that the majority of information given to the family members or clients is not being recalled correctly emphasis must be placed on giving small amounts of simplistic accurate information to ensure that as much information is recalled as possible.

Although studies with families of children with long term illnesses\textsuperscript{5,47}, found that families wanted as much information as possible initially this needs to be clear and accurate, and not too overwhelming or too complicated. The information was found to be most helpful when it was given at the correct time, and when all involved healthcare providers gave similar information and agreed on the client’s future goals\textsuperscript{3,5} as when team members disagreed, this was found to increase the families’ anxiety.\textsuperscript{3,5}

Providing honest information about the survivor’s status and prognosis, emotional support, community resources, financial support, and practical advice was ranked highly in meeting the needs of families of brain injured clients in a study by Murray et al.\textsuperscript{48} The Family Needs Questionnaire (FNQ) was completed by a small sample of 66
also confirmed that respondents felt that they did not get enough information. Thus not only is the content of the information given to family members important, but the form in which it is given is vital as well. In most everyday instances, medical information is given to client’s and family members verbally. This has been shown to be the least effective method of conveying information. Written information is remembered better than spoken information, if family members’ level of education allows them to deal with information in this format.

Families of clients with brain injury found that a lack of information caused them to experience anxiety of some form or another. This is supported by a large body of research on family’s of clients with brain injury indicate the need for information and emotional support as a priority. There is evidence however that anxiety is reduced when information given to family members about the client’s condition. It was found that a common factor in alleviating family member stress and anxiety was the provision of accurate and realistic information.

2.5. Anxiety and Education of family members

Anxiety is described as being ‘a state of uneasiness and apprehension about future uncertainties’ and although it is a very distressing human emotion is an important survival mechanism which warns of danger and encourages the use of necessary defence mechanisms. Anxiety is response to a threat and occurs in reaction to a variety of daily occurrences, like their health, social relationships, the environment, political happenings, or careers and is not necessarily pathological. It however, can become abnormal with the anxiety response is no longer proportionate to the threat.

Anxiety has been shown to impact a person’s daily functioning on various levels and in family members of the patients in hospital it was reported to have restricted their ability to absorb the information, making their experience more difficult. In this study by Blinder et al (2001) physicians and professionals that took part in the same study agreed that the family members’ inability to absorb information was closely linked to the state of shock that the family were experiencing.
For this reason, it is important for professionals to take anxiety into account and when communicating with the family to repeat the information wherever possible, and in as many ways as possible including the use of written information. This has been found to be successful\textsuperscript{57} as it allows the family members opportunity to absorb the information again at their own pace.

These findings are supported by a study completed by Ley (1990)\textsuperscript{58}, where a relationship between the families’ level of anxiety and their ability to process the information was shown. Family members with high levels of anxiety were found to show poor ability to process information accurately and this was found to be true for clients in stressful clinical situations. Studies in dentistry have found that patients are less able to understand, remember and process the information before undergoing dental treatment which is considered a more highly stressful situation than undergoing less stressful suture removal.\textsuperscript{59}

Throughout the literature, the importance of giving accurate information to the family members of brain injured clients, to assist in easing their anxiety is emphasised. However, due to the anxiety that they may be experiencing, it may be difficult for them to process complex information, as well as accurately recall this information. It is therefore clear that professionals need to be aware that when providing information to clients and their family members, anxiety may interfere with the message being given due to the ability to recall the information. This could therefore possibly lead to a further increase in anxiety, which would lead to further stress and anxiety on the family member’s part.

\textbf{2.5.1. Measurement of Anxiety}

There are various measurements for anxiety, usually paired with scales for depression in the clinical and non-clinical setting. Two of these scales that are the Irritability Depression and Anxiety Scale and two subscales of the General Health Questionnaire, one relating to the concept of depression and the other relating to the concept of anxiety.\textsuperscript{60}

A literature review showed that the Hospital Anxiety and Depression Scale (HADS) is one of the top three scales used to measure anxiety worldwide in the field of research.
It has been used to measure anxiety in somatic patients, psychiatric patients, primary care patients and the generalized population\textsuperscript{61}. The Hospital Anxiety and Depression Scale was developed to be a rapid and separate measure to assess the possibility of anxiety and depression of clients in non-psychiatric hospitals.\textsuperscript{60} It is divided into two subscales HADS-D for depression and HADS-A anxiety, with components that are inter-mingled. It was designed to measure depression and generalized anxiety in the hospital setting, out-patient and community setting.\textsuperscript{61}

The aim of the HADS-A is to measure the presence and or severity of the anxiety in the person being assessed, and not to differentiate between different types of anxiety.\textsuperscript{60} To prevent confusion between somatic symptoms and the physical symptoms of anxiety disorders, the authors did not include the physical symptoms of anxiety in the measure.\textsuperscript{60,62}
CHAPTER 3

RESEARCH METHODOLOGY

3.1. Study Design

A quantitative, prospective, longitudinal analytic survey study design was used. A quantitative research makes use of scientific methods, instruments of measurements, manipulation of variables and the analysing of data to form the basis of theories or models. A prospective study aims at investigating the changes in the phenomenon over a period of time. In this study, the strength of association between variables was investigated, by measuring the correlation between them. This included the association between anxiety, perceived information processed, time since injury, length of rehabilitation and the client’s independence in occupational performance.

The difference in anxiety levels and perceived levels of information processed by family members was established at three different times during the client’s with head injuries rehabilitation process.

3.2. Study Population

The study population were family members of the clients with a brain injury admitted for rehabilitation at either Life Riverfield Lodge Rehabilitation Hospital or Life New Kensington Clinic Rehabilitation Hospital, Johannesburg, South Africa. These are both private health care facilities.

3.3. Sample and Selection Size

The sample selected consisted of 36 family members who represented each of the clients identified for inclusion in the study. These were the clients receiving rehabilitation for brain injury for at least six weeks at Life Riverfield Lodge Rehabilitation Hospital or Life New Kensington Clinic Rehabilitation Hospital during the period in which data was collected for this study. The family members selected
were those who met the inclusion criteria, and who were willing to participate in the study.

**Inclusion Criteria:**

Family members of clients were included if the

- brain injured client would receive at least six weeks of rehabilitation.
- family member was able to speak, read or understand the questionnaires and complete them independently.
- family member was able to complete repeat questionnaires forms.
- family member was over the age of 18 years.

**Exclusion Criteria:**

Family members were excluded

- if there had been a previous admission and treatment of the client for the same condition at a rehabilitation hospital in the past month.
- if there was early discharge from the facility due to deterioration of condition or due to depletion of medical aid funds (length of stay less than six weeks).

**3.4. Data Collection Instruments**

**3.4.1. Family Member Participants**

Three data collection instrument tools were used with the family members of the clients with brain damage. These included a demographic questionnaire, a checklist to determine how much information they had received and processed and the HADS-A (Hospital Anxiety and Depression Scale - Anxiety Sub-scale).
3.4.1.1. Demographic Information Sheet (Appendix A)

The Demographic Information Sheet included the following information about the respondent: age, gender, employment status, highest level of education, socio-economic status, relationship to the client in hospital. The Demographic Information Sheet was only completed on the initial visit and was fitted with a file number to relate the information to the rest of the data collected, whilst maintaining confidentiality. The file number used in the research was a reference number for the researcher, and not the patient’s hospital file number as used by the hospital.

3.4.1.2. Information Checklist (Appendix B)

The Information Checklist was compiled by the researcher based on the written and verbal information given to all family members routinely during the first family meeting, held during the first week of admission to either Life Riverfield Lodge Rehabilitation Hospital or Life New Kensington Clinic Rehabilitation Hospital, as is standard policy at all Life Rehabilitation Hospitals. The information given is in the form of a written information pack, as well as verbal information provided at a meeting with the team members treating the client. The headings of the information checklist were taken directly and verbatim from the information pack given to each family member as standard procedure at Life rehabilitation hospitals.

The Information Checklist contains the headings of the information in the written pack, with columns to comment on and indicate on a scale if the family member felt that

a. sufficient information had been given
b. insufficient information given
c. if information had been given but more would be required.

The Information Checklist was completed by the respondent at each of the three occasions (initial, second and third assessment), to evaluate their perceived amount of information obtained throughout the rehabilitation process.
Scoring of the Information Checklist was completed as follows. A score of 5 points was given to each topic marked in the column “Received Sufficient Information”; a score of 3 points was given to each topic marked in the column “Received information, but not sufficient”; and a score of 1 point was given to each topic marked in the column “Did not receive sufficient information”. A total score of 70 points was possible.

3.4.1.3. The Hospital Anxiety and Depression Scale (Appendix C)

The Hospital Anxiety and Depression Scale is a 14-item self-reporting assessment of anxiety and depression that was developed by Zigmond and Snaith in 1983. The HADS was completed by the respondent at each of the three occasions (initial assessment, second assessment, and third assessment) to evaluate the anxiety levels amongst the respondents. The entire Hospital Anxiety and Depression Scale was administered and calculated. However, only the anxiety subscale scores were considered. The anxiety subscale and the depression subscale are scored separately. They are independent of each other and therefore can be used in isolation.

The HADS-A was designed to measure anxiety in a client who may be experiencing physical symptoms as a result of an unrelated medical condition taking into account that physical symptoms similar to anxiety that are most likely to be caused by the medical condition, for example an increased heart rate, sweating and feelings of nausea, are largely eliminated in this scale. The HADS-A could therefore be used in relation to family anxiety in this study as the HADS-A has been used in other studies to measure anxiety and depression in healthy subjects (that being subjects who do not suffer from an anxiety disorder). This was possible as the scale was designed to detect relatively mild levels of a mood disorder likely to be present in the hospital setting and it has been used extensively in research throughout the world and with many different groups of people including family caregivers of ill people. It was found to be the third most commonly used self-rating scale worldwide in medical research.

The HADS has good psychometric value and general population norms. The test shows a good correlation in re-test reliability and is stable enough to handle
When a number of studies on the validity and reliability of the HADS were reviewed, the HADS, and the subscales HADS-A and HADS-D demonstrated a good two-factor solution in all studies, clearly measuring one construct or the other. The correlations between the two scales vary from 0.40 to 0.74 and the internal consistency for the HADS-A measured using Cronbach's alpha varies from 0.68 to 0.93. An optimal balance between sensitivity and specificity has been achieved in most studies with a score of eight or above on the HADS-A indicating a problem. Convergent correlations between the HADS-A and other anxiety scales were in the range 0.49 to 0.83. The HADS-A performs well in assessing the symptom severity and the presence of anxiety disorder in the general population, patients and caregivers.

The HADS was scored according to the manual. Each item is scored from 0 to 3 and, therefore the total scores range from 0 to 21, for the anxiety and depression subscale. The scores were then interpreted according to the HADS manual. The scores were classified as the following, according to the manual:

- Normal for scores 0 to 7
- Mild anxiety for scores 8 – 10
- Moderate anxiety for scores 11 – 14
- Severe anxiety for scores 15 – 21

### 3.4.1.4. Information regarding the Use of Anxiety Medication (Appendix D)

During the last visit, the family member or respondent was asked to complete the Medication Information Sheet. This information sheet was used to ascertain if the respondent made use of any prescription or herbal medication to decrease their anxiety, whilst being a part of the study. This information was used and taken into account during the analysis of the data.

### 3.4.2. Clients with Brain Injury

Three tools were used to collect data on the clients with brain injury so this data could be collated with the anxiety levels of their family members. These tools included
demographic information, medical information and the scores of the Functional Independence Measure (FIM) and the Functional Assessment Measure (FAM) for each client. As the family members were the main participants in this study, patients with brain injuries were included in data collection on condition that their family members had met the inclusion criteria.

Patients were excluded

- If there had a previous admission and treatment of the client for the same condition at a rehabilitation hospital in the past month.
- If there was early discharge from the facility due to deterioration of condition or due to depletion of medical aid funds (length of stay less than six weeks).
- If their brain injury was not acute in nature – for example, patient’s were excluded if they had a degenerative or progressive brain injury.

3.4.2.1 Demographic Information Sheet (Appendix A)

This information was included in the same questionnaire that family members filled in and included the date of incident of the client, and whether the client was the bread winner of the family or not. This information was completed by the family member, as the patient was mostly not capable of accurately relaying that information.

3.4.2.2. The Functional Independence Measure (FIM) and the Functional Assessment Measure (FAM) (Appendix E)

The Functional Independence Measure (FIM) and the Functional Assessment Measure (FAM) are two separate measures used in conjunction with each other to rate a client’s level of independence and burden of care. The Functional Independence Measure was developed in 1983 as part of the Uniform Data System for Medical Rehabilitation. The FIM measures both physical and cognitive aspects. There are 18 items with two subscales: motor and socio-cognitive. Each item is scored on a 7 point
ordinal scale from 1 (total assistance) to 7 (independence). The Functional Assessment Measure (FAM) was developed by clinicians working in the field of rehabilitation to be used in conjunction with the Functional Independence Measure (FIM) as it expanded areas for assessment that were less emphasized in the FIM. These areas include cognitive, behavioural, communication and community functioning measures. The FAM consists of 12 items each scored on a 7 point ordinal scale from 1 (total assistance) to 7 (independence). The FAM is not designed to be a standalone measure, but was designed to be used with the FIM to make a combined 30 point scoring system.\footnote{69}

The FIM/FAM scores were not completed by the family members but by the therapists treating the client as part of the rehabilitation process for all clients at both Life Riverfield Lodge Rehabilitation Hospital and Life New Kensington Clinic Rehabilitation Hospital. At the time of data collection, both hospitals were accredited to use the FIM system.

\subsection*{3.5. Research Procedure and Data Collection}

Data was collected from the 1\textsuperscript{st} of March 2011 till the 31\textsuperscript{st} of August 2011.

Prior to the commencement of data collection, the researcher informed the therapy staff of Life Riverfield Lodge Rehabilitation Hospital and Life New Kensington Clinic regarding the purpose of the study, and the data collection techniques. The researcher felt that family members might be prompted to think about and feel the need to ask questions regarding some of the topics in the data collection. The researcher informed the therapy staff of the possibility that family members may have more questions regarding specific topics, and that they should be aware of this, and to answer these questions as best they could - as is the normal practice.

The researcher had a specific meeting with the psychology department of Life Riverfield Lodge Rehabilitation Hospital to inform them of her use of the Hospital Anxiety and Depression scale, and that this might elicit terminology or insight into the feelings that the family members are experiencing. The researcher confirmed with the psychology department that they should assist the family members through this
process, on a needs basis, in line with the normal practice. A similar meeting was held between the therapist and psychologist from Life New Kensington Clinic Rehabilitation Hospital.

As suitable clients with brain injury were admitted to the hospital, family members were approached by the researcher whilst at the hospital. The purpose of the study was explained to them in detail, and they were invited to participate in the study. If the family member agreed to participate, written informed consent was obtained. The researcher gave the participant written information regarding the purpose of the study, as well as what will be expected from them (Appendix F). The information pack included contact details of the researcher, should the family member feel the need to get in contact with the researcher.

The researcher explained the data collection process, as well as the forms that would need to be completed. The researcher allowed the family member to complete the forms in private. The forms contained only the assigned file numbers, and no personal information. The family members were instructed to place the questionnaires in an envelope and seal it before handing it to the researcher. The forms were given to the family members at three times during the admission of the clients with brain injury. The information in the envelopes was collected from the family member in the same week. (Table 4)

<table>
<thead>
<tr>
<th>Table 4: The various times for the different assessments.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st week of admission</td>
</tr>
<tr>
<td>Demographic Information Sheet</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>Information Checklist</td>
</tr>
</tbody>
</table>
The Functional Independence Measure and Functional Assessment Measure data was collected from the therapists treating the individual client on a weekly basis (as this is the normal practice at the rehabilitation units). A valid accreditation is required to use the FIM scale. Both rehabilitation hospitals were accredited to use the FIM during the period of data collection.

The researcher made use of a calendar to mark in which weeks the participants would need to be approached for further data collection. The researcher would approach the family member in the weeks that followed for the 2\textsuperscript{nd} and 3\textsuperscript{rd} data collection intervention. Each time the forms were handed to the family member with the assigned file number on the form. Each time the procedure for filling out the forms was explained, and the participant was allowed to complete the forms in private. The forms were always placed and sealed in an envelope before being handed back to the researcher.

Once an envelope was handed to the researcher it was marked with the date, the assigned file number and the week since admission. The envelopes remained unopened by the researcher until the client was discharged from the facility, whereupon the envelopes were opened and the data was analyzed. Data was sealed in the envelope to prevent bias from the researcher, as the researcher was an active member of the therapy team. This was done to ensure that no information that the researcher received from the data collection could influence her treatment of the client and family, thereby influencing the accuracy of subsequent data collection.

3.6. Ethical Considerations

Ethical clearance to complete the study was granted by the Human Research Ethics Committee of the University of the Witwatersrand prior to the commencement of data collection. [Certificate No: M10M101104 (Appendix G)] Written permission was granted by both Life Riverfield Lodge Rehabilitation Hospital and Life New Kensington Clinic Rehabilitation Hospital to the researcher, to collect data on the premises (Appendix H and I). Information sheets which explained the study were given to each family member who was selected to participate in the study and written informed consent was obtained from each prior to data collection (Appendix F).
Participant’s details were kept confidential by assigning a file number to each participant. The file number was used on all forms, and not the participant’s name. The researcher was the only person with access to the file numbers and the corresponding participant’s details.

As the researcher was an active member of the therapy team responsible for the treatment of many of the clients, all information contained in the checklists and questionnaires remained in sealed envelopes until the client was discharged and had left the facility. This was done to ensure that the researcher could not influence the amount and type of information given to the family member of the client with brain injury based on their responses to the researcher’s questionnaires.

Family members were instructed to complete the questionnaires and checklists in private, and not in the presence of the researcher. This was done to ensure that the family member would complete the information as honestly as possible, with no external pressure or influence from the researcher.

3.7. Data Analysis

Data was captured in an Excel spreadsheet and analysed using the Data Analysis functions. More advanced tests were carried out using the Data Analysis Plus 5.0 for Excel add-ons. Other non-parametric tests were conducted on ordinal data using EpiInfo statistical package using the Chi-Squared test and calculation of Relative Risk.

A one sample matched-pair t-test was used to establish the difference between the Anxiety Scale of the HADS for the participants on the three difference occasions over the length of the client’s stay in rehabilitation.

The Spearman rank correlation coefficient was calculated, as the sample size was too small for the parametric equivalent, on the variable “days since injury” and HADS levels, information processing and FIM/FAM scores. Similarly, correlation was
measured between HADS and information processing as well as HADS and FIM/FAM scores.
CHAPTER 4

RESULTS

The results of this study consider the analysis of data collected from participants who were family members of clients with brain injury being treated in the Life Health Care Rehabilitation Centres.

Unfortunately, not all the assessments were completed by all the participants, which meant that the data from some individuals could not be used in the analyses below. A defined total sample of clients with brain injury \( n = 34 \) was identified and data was gathered from family members on the HADS Anxiety Score and Information Checklist. Data from the initial Information Checklist was gathered for \( n = 25 \) participants. Due to the longitudinal nature of the study follow up was achieved for \( n = 17 \) participants for final data collection for the HADS Anxiety Scale and Information Checklist in the final or 3\textsuperscript{rd} assessment. Thus there was a drop out rate of 50\%. Due to the nature of the patients, unfortunately the medical condition of many deteriorated and they were transferred to acute hospitals. Three patients passed away during the study and others were discharged from rehabilitation for various reasons before the 6\textsuperscript{th} week. The researcher was not able to control those member’s who had to drop out due to deterioration in medical condition and their subsequent transfer to an acute medical facility. Family members of the remaining patients were not always available to complete all three assessments. The researcher made every effort to contact the family to remind them about their participation in the research project. Arrangements were made to meet the family members at the hospital, as well as arranging the family members to complete forms over the weekend when it was more convenient for the families to visit. In some cases however, families were not able to complete the forms and therefore the first and third assessments were used for analysis in these extreme circumstances.
Table 5: Drop out figures during data collection

<table>
<thead>
<tr>
<th></th>
<th>Total number of Participants</th>
<th>Drop out rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Assessment</td>
<td>34</td>
<td>0%</td>
</tr>
<tr>
<td>Second Assessment</td>
<td>12</td>
<td>64.71%</td>
</tr>
<tr>
<td>Third Assessment</td>
<td>17</td>
<td>50%</td>
</tr>
</tbody>
</table>

The results are considered in terms of demographics of the family member participants as well as the clients with brain injury in rehabilitation settings as well as the anxiety level of the family member participants and their information processing.

Association was established between the family member participants’ anxiety and their information processing as well as other factors like the clients independence measured by the FIM/FAM, their length of stay.

4.1. Demographics

4.1.1. Demographics of the family members

4.1.1.1. Age and relationship to the client

The mean age of the family members’ respondents or study participants was 46.85 years with the oldest respondent 77 years old and the youngest 22 years. Sixty one point seven percent (61.7%) of the participants were female (21 out of a total of 34 participants) and the rest were male. The relationship between the family member or participant completing the questionnaires and the client with brain injury is represented in Table 6.
Table 6: Relationship of the participants to the clients with brain injury.

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>15</td>
<td>44.0%</td>
</tr>
<tr>
<td>Mother</td>
<td>5</td>
<td>14.7%</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Sibling</td>
<td>2</td>
<td>5.8%</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>32.0%</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

The participant completing the demographic questionnaire was the main identified family member who would be responsible for the care of the client receiving treatment. The largest group of participants (44%) of the total respondents were spouses, with 32% selecting the group entitled ‘other’. Participants who were children of the clients were placed in this category.

4.1.1.2. Employment Status and income

The employment status of the participants varied with half of them being formally employed in the formal working sector. One participant refused to complete this information. These wishes were respected by the researcher. Therefore the total number of participants for employment status is 33. See Table 7.

Table 7: Employment status of participants

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>17</td>
<td>51.5%</td>
</tr>
<tr>
<td>Self-employed</td>
<td>10</td>
<td>30.3%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>9.1%</td>
</tr>
<tr>
<td>Retired</td>
<td>3</td>
<td>9.1%</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
Of the remaining 50%, 29.4% were self-employed, 11.7% were unemployed and 8.8% were retired.

In terms of the socio-economic status of the participants in the study the largest percentage of participants in a single income bracket is 31.2% in the bracket R10,000 – R19,999’ gross income per month (Figure 1).

![Figure 1: Monthly income of participants (n=32)](image)

Twenty eight percent of the clients were in the income bracket of < R10,000 which in South Africa means their income classifies them in a ‘low income’ bracket.53 A similar percentage (28%) had an income of R 20,000 – R 40,000 a month with only 12.5% of the participants having an income of >R 40,000 a month.

Two participants refused to indicate their socio-economic status due to personal reasons and therefore the income of 32 participants was analysed.

### 4.1.1.3. Education level

Forty seven percent (47%) of the participants’ highest level of education was a grade 12 certificate
Twenty six point five percent (26.5%) of the participants had completed a diploma certificate after completing schooling (Figure 2). Fourteen point seven percent (14.7%) of the participants completed a bachelor’s degree. Eight point eight percent (8.8%) of the participants completed grade 10 or less, and 2.9% completed some form of post-graduate studies. There was no association between the participants’ education level and their socioeconomic status as measured using the Chi-Squared test.

Figure 2: Level of education amongst participants (n=34)

4.1.1.4. Medication taken for anxiety by participants

Only eleven participants complete the Medication Information Form. Four participants were taking medication for anxiety - four of them were taking prescribed medication from a medical doctor and one was taking herbal medication in addition to the prescribed medication. No significant association was found between medication and the anxiety of the participants using the Chi-squared test.
4.1.2. Demographics of the clients with brain injury

4.1.2.1. Position in family

Fifty percent (50%) of the clients receiving rehabilitation were the breadwinners of the family.

4.1.2.2 Time since onset of injury

Figure 3 illustrates the days since the onset of the illness or the injury and the time of the first week assessment in the research study.

Clients were transferred to the rehabilitation facility from the acute facility on mean 33 days after the onset of the illness or injury.

![Figure 3: Time in days since injury or onset of illness (n=34)](image)

The longest period of time between onset of injury and admission to the rehabilitation facility was 76 days, whilst the shortest period of time was 11 days. The mean was 32.84 days and the standard deviation was 15.81.

Analysis using Spearman Rank Correlation coefficients indicated that the days since injury did not correlate with any other variables assessed in this study. There is no
association between days since injury, family member anxiety, information processing and the clients’ FIM/FAM score.

4.2. Anxiety level of the family member participants

Only the Anxiety Scale of the HADS (the HADS-A assessment) was analysed for the family member participants at three times.

The mean (and standard deviation) of the first HADS-A assessment was 12.16 (4.55) which is interpreted as a moderate level of anxiety. The mean of the second HADS-A assessment was a score of 10.5 (4.50) which is interpreted as a mild level of anxiety. The mean of the third assessment of the HADS-A was score of 8.9 (5.64) which is also interpreted as a mild level of anxiety.

Thus, it can be seen that there was a general decreasing trend in the mean anxiety scores of the HADS-A assessment over the weeks of the client’s stay in the rehabilitation units. A statistically significant difference was demonstrated between the first and second anxiety scale on the HADS-A assessment (p=0.01), and between the first and third anxiety scale on the HADS-A assessment (p=0.02) using the one-sample t test for the differences. (Figure 4)

![Figure 4: Mean scores on the anxiety scales of the HADS-A assessment.](image)

Figure 4: Mean scores on the anxiety scales of the HADS-A assessment. [For Assessment 1 n=33; for Assessment 2 n=12; for Assessment 3 n=17]
Some participants did become more anxious over the time from the first to the third assessment with the greatest increase in anxiety on the HADS-A scale being 91% (Figure 5). The greatest individual improvement on the HADS-A score was a 75% decrease in anxiety.

![Figure 5: Individual HADS-A anxiety scores per assessment (n=25)](attachment:image)

Figure 5 shows a generalized decreasing trend in HADS-A scores at each assessment, especially from the first to the second assessment, but there is some variation to this pattern by some of the subjects, particularly with an increase at 6-9 weeks which was just before discharge for some clients with brain injury.

There was no association between the gender of the family members and HADS-A anxiety Scale for any of the assessments using the Chi-squared test.

### 4.3. Information processing of family member participants

From Figure 6 it is clear that the mean information processing score from the first information assessment (Info 1) where the score of 37 (SD = 17.54) out of a possible score of 70, increased over the time the client was in the rehabilitation unit.
mean of the second information assessment is (Info 2 in Figure 6) a score of 57.3 (SD= 14.11) out of a possible score of 70. The mean of the third information assessment is (Info 3 in Figure 6) a score of 59.5 (SD = 11.09) out of a possible score of 70.

![Figure 6: Information assessment. [For Assessment 1 n=31; for Assessment 2 n=10; For Assessment 3 n=14.]](image)

It can be seen that there is a general increasing trend in the family member’s perception of how much information was given to them. Using the one sample t-test for the differences, a statistically significant difference was demonstrated between the first and third Info assessment (p=0.01).

It is noted that there are fewer participants who completed the Information checklist compared to the Hospital Anxiety and Depression Scale, although these two forms were handed out together. It was noted that people completed the Information Checklist incorrectly thereby not enabling the researcher to include their participation.

It was noted that the two consistently lowest scoring questions in the Information Checklist were questions surrounding the client’s prognosis in terms of their potential...
to return to normal home circumstances and to return to their previous work environment.

There was a moderate but not statistically significant correlation between the participants' level of education and their ability to process information on the first assessment of information checklist (r= 0.46).

Figure 7 illustrates the actual Information scores of each subject at each assessment.

Figure 7 shows a general increasing trend in Information Scores at each assessment but that there is some variation to this pattern by some of the participants.

Some of the comments left by the family members in the Information Checklist comments section of what information they would like, included:

- “Daily updates on improvement and what I can expect; Weekly updates from the doctor.”
- “Exactly what is happening to my dad all the time (during the day)”
• “To know if he will be the same person he was before all this happened, or will he regain his memory and function just like a normal person.”

• “Recovery process - what to look for, how long, what to expect. Activities that can be undertaken”

• “Information on her progress and what likelihood is there of a meaningful recovery”

• “If my husband will be discharged being able to do his old household chores or walking without aid or support”

• “Nothing - thank you for all your patience and support”

4.4. Relationship between family member anxiety and information processing

The Spearman Rank correlation coefficient was calculated to compare the percentage change in HADS-A Anxiety Scale and the percentage change in the Information Processing checklist.

Table 8. Correlation between the HADS-A Anxiety Scale Assessment Scores and the Information Processing Scores

<table>
<thead>
<tr>
<th></th>
<th>Information Processing Assessment 1</th>
<th>Information Processing Assessment 3</th>
<th>Percentage change in Information Processing Scores from Assessment 1 to Assessment 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS-A Scale Assessment 1</td>
<td>r</td>
<td>r</td>
<td></td>
</tr>
<tr>
<td>HADS-A Scale Assessment 3</td>
<td></td>
<td>0.13</td>
<td></td>
</tr>
</tbody>
</table>
| Percentage change in HADS-A Scale from Assessment 1 to Assessment 3 |                                       |                                       | 0.44                                                                             

There was no statistically significant correlation between the HADS-A scores and information processing change at assessment 1 and 3 (Table 8).
Figure 8. Linear relationship between the decrease in anxiety and increase in information processing in family members from Assessment 1 to Assessment 3.

The correlation coefficient ($r$) was 0.44 when the percentage change in the HADS-A Scale scores between assessment 1 and 3 were correlated with the percentage change in Information Processing Scores for Assessment 1 to 3.

Although this was not statistically significant, it is does however show that some association does exist between these two variables as can be seen in Figure 8. This implies that information processing increases as anxiety levels decrease.
4.5. Functional Independence Measure and Functional Assessment Measure (FIM/FAM)

Figure 9 shows the improvement obtained by the clients as recorded using the FIM/FAM assessment measure.

In Figure 9, a general increasing trend is noted in the mean score of the total FIM/FAM score across the data collection period. The mean total score of the first FIM/FAM assessment was a score of 76 out of a possible 210 points. The second assessment of the FIM/FAM scores produced a mean of 94.3 out of the possible 210 points. The mean total score of the third FIM/FAM measurement was a score of 117.7 out of a possible 210 points. Using the one sample t-test for the differences, a statistically significant difference was demonstrated between the first and second (p=0.0002), second and third (p<0.0001) as well as first and third assessments (p<0.0001).

![Figure 9: Improvement in clients measured by FIM/FAM. [For Assessment 1 n=32; Assessment 2 n=18; Assessment 3 n=27.]](image)

Figure 10 illustrates the actual FIMS scores of each subject at each assessment.

There was a general increasing trend in FIM/FAM scores at each assessment, similar the changes in the mean scores seen in Fig. 9, but that there is again some variation to this pattern by some of the subjects.
Figure 10: Individual FIM/FAM scores per assessment (n =25)

Figure 11 shows the mean scores of the percentage FIM/FAM subscales and total scores for the first, second and third assessment.

The mean motor subscale for the first FIM/FAM assessment was a score of 40.81 (SD = 25.12) out of a possible 112 points (36.44%). The mean of the cognitive subscale for the first FIM/FAM assessment was a score of 35.26 (SD = 14.19) out of a possible 98 points (35.98%). This is then combined to form a total score of 75.74 (SD = 35.02) out of a possible 210 (36.07%).

The mean score of the motor subscale for the second FIM/FAM measurement is a score of 51.61 (SD = 24.30%) out of a possible 112 points (46.08%). The mean score of the cognitive subscale for the second FIM/FAM measurement is a score of 42.67 (SD = 16.57) out of a possible 98 points (43.54%). This is then combined to form a total score of 94.28 (SD = 36.59%) out of a possible 210 points (44.90%).
Figure 11: The mean scores of the motor subscale, cognitive subscale and total score of the FIM/FAM assessment during the first, second and third assessment. 
[For Assessment 1 n=32; Assessment 2 n=18; Assessment 3 n=27.]

The mean score of the motor subscale for the third FIM/FAM measurement is a score of 67.44 (SD = 29.26) out of a possible 112 points (60.21%). The mean score of the cognitive subscale for the third FIM/FAM measurement is a score of 50.28 (SD = 18.14) out of a possible 98 points (51.31%). This is then combined to form a total score of 117.72 (SD = 44.19) out of a possible 210 points (56.06%).

The most amount of improvement in the FIM/FAM score of a client was a 213% increase over the period in the rehabilitation hospital. The least amount of improvement was a 2% increase over the period of rehabilitation. None of the subjects showed deterioration in their FIM/FAM scores. It can be seen that the FIM motor scores improved more that the FIM cognitive scores (Figure 11).

4.6. Relationship between family member anxiety and the Functional Independence Measure and Functional Assessment Measure (FIM/FAM)

The percentage change in the FIM/FAM scores were correlated with the percentage change in the anxiety levels of the family members of the clients with brain injury but no association between these variables was noted (Table 9).
The change in the motor and cognitive FIM/FAM scores were also correlated separately against the changes in the anxiety scores but similar results were found with all the correlation being at the low or no correlation levels.52

Table 9. Correlation between the HADS-A Anxiety Scale Assessment Scores and the Functional Independence Measure Scores

<table>
<thead>
<tr>
<th></th>
<th>HADS-A Score Assessment 1</th>
<th>HADS–A Score Assessment 3</th>
<th>Percentage change in HADS-A Scale from Assessment 1 to Assessment 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIM/FAM Assessment 1 Total Score</td>
<td>r</td>
<td>r</td>
<td></td>
</tr>
<tr>
<td>FIM/FAM Assessment 3 Total</td>
<td>0.07</td>
<td>-0.10</td>
<td></td>
</tr>
<tr>
<td>FIM/FAM Scores percentage change in score from Assessment 1 to 3</td>
<td>0.08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM/FAM Motor Scores percentage change in score from Assessment 1 to 3</td>
<td>0.19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM/FAM Cognitive Scores percentage change in score from Assessment 1 to 3</td>
<td>-0.21</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.7. Summary of Results

Through the description of these results, an overall decrease in anxiety can be seen throughout the period of their family members in rehabilitation. An overall increase in information scores was also noted. A moderate correlation was noted between in the decrease of anxiety and the increase of information use.

Throughout the period of rehabilitation, FIM/FAM scores showed an improvement, with significant difference between initial and final scores. However, no correlation could be found between the increase in FIM/FAM scores and the decrease in anxiety.
CHAPTER 5

DISCUSSION

The discussion will be structured under the following headings: demographic information, FIM/FAM, HADS-A Anxiety Scale, and information processing and will consider both the levels of anxiety and importation processing of family members of clients with brain injury as well as the association between the changes in factors during the client’s stay in inpatient rehabilitation. The association between FIM/FAM scores and the change in these over the period of inpatient rehabilitation will also be considered in terms of family member anxiety.

Due to the longitudinal nature of this study and the inclusion criteria for the clients with brain injury the sample was relatively small for a descriptive study. Over the 6-9 week duration of the study a number of factors resulted in only 15 of the family members completing the questionnaires on all three occasions. The results and discussion must be viewed in the light of this small sample size. There were trends seen however that can add value to the way in which information is given to the families of clients with brain injury in a rehabilitation setting.

5.1. Demographic information

Demographic information was collected on the participant of the study i.e. the family member completing the questionnaires. From this study, it is interesting to note that a wide variety of age and family members’ roles were identified. The majority of the participants were spouses and children, with the majority of nearly half the participants in the study being the client’s spouse. This indicates that the person in charge of most of the client’s well being is their spouse which is in line with other studies that found that the majority of caregivers of clients with brain injuries were their spouses.

One plausible explanation for this phenomenon is that once a person is married, their spouse is the person responsible for decisions about their well-being or care. As most
of victims of head injuries or strokes are adults\textsuperscript{72,73}, it is presumed that the majority of the clients were married, and that their spouse will be responsible. In the study, 17.6\% of the participants were the parents of the client. These clients were either single or divorced. In no instances in this study did the parent of the client complete the form whilst a spouse was available to complete it.

The second largest group identified participants were the category entitled ‘other’. Nearly two thirds of these participants were the children of the clients. Strokes in particular are often associated with the elderly, and while this picture is changing, many stroke sufferers are over the age of 60 years.\textsuperscript{72} The mean age of the patients in this study was 47 years. According to the American Stroke Association “the chance of having a stroke approximately doubles for each decade of life after age 55.”\textsuperscript{72} Therefore, many stroke sufferers have children that are responsible for their care, as their spouse has passed away. In this study, no child of a client completed the questionnaires if the patient’s spouse was still available and capable of completing the questionnaires.

The clients in this study were admitted to two private healthcare rehabilitation hospitals within the Johannesburg area in South Africa. It is a common thought amongst the people of South Africa, that private healthcare is only available to the wealthy in the country, and that the poor can only make use of the government healthcare services. Part of the admission criteria to a private healthcare facility is valid medical aid or a cash deposit upfront.\textsuperscript{74} No evidence could be found in the literature of the mean income of families or clients admitted to a private healthcare facility (as this is not a requirement on the admission forms of hospitals). The researcher found it interesting to note that the majority of the family member’s completing the questionnaires were from the lower – middle income bracket\textsuperscript{75} and that very few of participants were from the high income bracket. This indicates that the general perception that only wealthy patients are encountered in the private rehabilitation sector is incorrect. A possible reason for a lower income bracket service user, is that many employers are now contributing financially to a medical aid for their clients.

A second possible reason for this would be that companies are required by law to contribute to the Workman’s Compensation Commissioner, under the Compensation
for Occupational Injuries and Diseases Act of 1993. This requires the commissioner to pay for any employee should they be injured during their work duty. These employees are treated at private hospitals and receive private rehabilitation, should they require it. This would also therefore lead to more people from various socioeconomic backgrounds being admitted to private healthcare facilities. No separation was made in this study between clients on a medical aid and clients admitted through the workman’s compensation commission.

Whilst the actual income of a family member or client is not important to a therapist, the patient’s likes, dislikes and exposure to different stimuli is important. Unfortunately, this is often determined by the person’s disposable income, and therefore not their actual income. Although information about the respondent’s socioeconomic status was collected in this study, no information was collected regarding the respondents disposable income. While the Practice Framework II shows the importance of taking socio-economic status into account in order for therapists to evaluate whether their choice of activities and the structure of the rehabilitation programme is applicable, they should have knowledge of the client’s and their family’s disposable income. This is more useful to ensure that the therapy programme is adjusted to meet the needs of all the clients within their likes, dislikes, and previous experiences.

Not unexpectedly, education level of the participants correlated significantly with their socioeconomic status. Studies have shown that years of schooling are associated with higher earning ability the quality of that education. Therefore another demographic factor of concern to occupational therapists is the client’s and the client’s family members level of education. This affects a person’s competency to read and write which is determined by their scholastic achievements and this impacts on their interests and needs in rehabilitation. Studies have concluded that people with a low level of education are unable to understand abstract concepts. This is not an indication of their intellectual ability, but simply their ability to understand abstract ideas.

Knowledge of the level of education of the family members of a client with brain injury is important to the occupational therapist and rehabilitation team. This is because family members are those who need to be educated about the client’s
condition and home programme as often the client does not have the cognitive ability to understand these aspects.

According to a household survey conducted by Stats SA in 2011, it showed that 18.1% of South Africans over the age of 20 years are functionally illiterate.\textsuperscript{77} The levels of illiteracy of the family members in this study were therefore better than the national average as only 8.8% of the participants had not achieved a Grade 8 level of formal education. They were, therefore, considered to have low level of education which in South Africa is set at a level below Grade 7 according to the General Household Survey.\textsuperscript{77} These participants might therefore be described as being functionally illiterate which will affect the format in which information should be given to them. Another factor that is known to affect how information should be given to family members if they are to be able to comprehend it and retain the knowledge needed to care for a client with brain injury, is their emotional status at the time the information is given.

5.2. Anxiety in family members of clients with brain injuries in inpatient rehabilitation

The results of this study indicate that the emotional status of family members of clients with brain injury is affected by the anxiety they experience during the clients’ entire rehabilitation process. Initial assessments of anxiety in this study found that family members suffered on average from ‘moderate’ levels of anxiety according to the HADS-A Anxiety Scale.

Follow up assessments at 4 weeks and 6-9 weeks of the family members’ anxiety levels indicated that the mean anxiety scores were at the ‘mild’ levels of anxiety. Although on average the HADS-A scores fell into the moderate or minimal levels of anxiety, there was a great variation in the individual participants. Some participants scored within ‘severe’ as well as ‘normal’ ranges.

These results could not be compared to other research as no published studies measuring anxiety levels of family members at various times during the rehabilitation process could not be found in the literature. All other studies on family member anxiety have all been completed whilst the client was in ICU or in the acute
Those studies found that family members were anxious after the clients’ initial injury, thus indicating that life threatening injury and hospitalization is an anxiety provoking event. These studies however, did not measure anxiety levels over the period of hospital admission or during rehabilitation. Therefore it is unknown if their levels of anxiety decreased over a period of time or not.

However, since very few studies have been completed in rehabilitation hospitals, the factors related to anxiety needed to be investigated further. These findings needed to be carefully evaluated as there are possibly different factors at play in different settings and not one specific, isolated factor - it is rather a specific combination of factors, specific and individualised to the participant, according to what they regard as important in life.

In this study a significant decrease was seen in the mean level of anxiety of family members over the time that the clients with brain injury were inpatients at the rehabilitation units. The mean anxiety of the participants decreased during the entire period of rehabilitation with the family experiencing the most severe anxiety in the initial stages of rehabilitation process. No significant correlation could be found between the variables measured in this study and the decreasing anxiety levels. This may be because, according to the literature, the reduction in anxiety could be attributed to a number of factors, including gaining of insight into the client’s condition, improvements noted in the client and coping mechanisms of the family members. It is possible that the initial shock of the injury had abated, according to the coping phase the family may be in during the inpatient rehabilitation of the client with brain injury, and anxiety about the client’s survival had decreased. Family members may have also become less anxious as they moved to the second stage of coping - denial and unrealistic expectations with regard to the client’s recovery.

This is related to old saying that: “time heals all wounds” and the researcher therefore also speculated that another factor responsible for the general decrease in the anxiety levels of the participants was the period of time since the injury. The researcher felt, through personal experience, that this could indeed be a factor. Although no correlation was found in the current study, it is possible that the small sample size affected this result.
Research has shown that professional support assists family members with developing effective coping mechanisms over time and that as family members learn to deal with the situation they may become less anxious and stressed. Thus the overall reduction of anxiety found in this study may have been due to the professional support provided to the family members of the clients. This was supported by comments on the Information Checklist.

Not all participants maintained a lower level of anxiety over the three assessments. For 26% of participants their anxiety levels increased on the 3rd assessment after 6 -9 weeks relative to their anxiety at 4 weeks on the 2nd assessment. This finding was also not unexpected as the researcher had speculated that the average levels of anxiety may initially decrease, but then increase towards the time of discharge of the clients the reality of the situation became more apparent. This is also supported by research that indicates that families may experience severe anxiety before clients with brain injury are discharged. Family members often are therefore unable to give attention to what the rehabilitation team is teaching them just prior to the client’s discharge.

Other factors reported in the literature which appear to affect family members’ anxiety include gender and the medication they have been prescribed for anxiety. On initial assessment higher anxiety was associated with the family members’ gender with a significant correlation between higher anxiety and female family members. This finding is supported by the work of Linn et al. 1994 who also found a difference between genders in the needs, and also with regard to depression and anxiety of family members dealing with a client with brain injury. Women always scored higher on the scales for these aspects. However, in this study, no such association could be demonstrated, possibly due to the relatively small sample size.

In this study medication prescribed for anxiety was not associated with lower scores on the HADS-A Anxiety Scale for the participants taking the medication. This may be due to only 4 participants reporting taking such medication.
5.3. Information transfer to participants

The main objective of this study, other than to determine the anxiety levels of family members of clients with brain injury in inpatient rehabilitation facilities, was to establish the relationship between the family members’ anxiety levels and their ability to process the information they received from the rehabilitation team.

Results indicate that this relationship does exist as the percentage change for reducing anxiety on the HADS-A Anxiety Scale was shown to correlate moderately with a percentage increase in the processing of information by family member participants in this study. The lack of significance of the association between the percentage change of the two variables may have been affected by a small sample size, and the high information scores some participants had on first assessment which could not be greatly improved resulting in a ceiling effect in the Information Checklist. This finding is supported by literature which indicates that people show poor memory recall and information processing during periods when they are experiencing anxiety with a link been shown between poor information processing and memory recall when anxiety is high.

The information processing reported by participants however showed significant improvement over the period their family members were in inpatient rehabilitation. Since this was associated with a decrease in anxiety it is therefore recommended that members of the treating team should discuss complex aspects of treatment and discharge planning at a time when the family’s anxiety is decreasing or at its lowest. This will allow the family members to best participate in the discussions and remember the information given and the interactions around this information.

From the results of this study, there was a decrease in anxiety occurring around 4 – 6 weeks into the family members’ admission to the inpatient rehabilitation facility for the majority of the participants. The suggested time for conveying complex information would therefore be towards the middle to end of the length of stay. Research indicates, however, that some families do in fact want information as soon as possible as this helps reduce their anxiety, but others do not. Therefore the rehabilitation team should be sensitive to both the timing of when information is given as well as the level at which it is presented.
At present it is the policy of the private healthcare rehabilitation facilities that participated in the study to conduct the only official meeting with the family within the first week of admission. During this meeting, all discharge planning and recommendations were to be finalised. The findings of this study indicate that this practice may disadvantage the client and the planning for the future as family members are not able to process the information adequately due to amongst other reasons their anxiety.

Literature on family education in acute settings indicates that the majority of information given to patients and their families is forgotten immediately after being said

Therefore, a recommendation is to include written information with verbal information when complex information is given. By including both verbal and written information the aim is to improve the family’s ability to remember as much information as possible. Verbal information will be given during the meeting and discussed to ensure the family can best understand the information. Specific written information should then be given to the family for them to read at their leisure.

In the two hospitals involved in the study, both verbal and written information was given to the family – as per company regulations. Presently the written information given to the families is generic, and usually about the patient’s diagnosis and general guidelines about prognosis. Specific information about the client was given to the family verbally. It is clear from this study that the aim of the written information should also be to repeat the majority of the specific verbal information given to the family. This would allow them to access the information that they may have forgotten or not heard initially at a later date. This could possibly prevent the therapists from having to repeat information already given to the family a few times, as the family is able to read it at their leisure and as many times as they feel they would need to. They could then ask questions about aspects they do not understand.

While written information is described as being more easily remembered amongst family members, this may not be true for people of a low-level of education. While the majority of the participants in the study had a high enough-level of education to be literate and could use written information effectively alternative arrangements would need to be made with family members with a low-level of education. Therapists must ensure that they are presenting the information given to family members at the level
that the family members can best understand. This would include ensuring that the important content is either given verbally or through simple pictures; and any abstract ideas should be linked with concrete examples.

The participants in this study came from a variety of socioeconomic circumstances and presented with varying education levels defined as functionally illiterate to tertiary degrees. The variation in the background of the participants may also have been a factor in their ability to process the information provided.

The 8.8% of the study sample with a low level of education, could potentially have a difficulty in understanding written or abstract concepts initially. It is therefore important to evaluate the type of information and concepts that the family members are expected to understand during the education process. Many physical difficulties that clients struggle with after a stroke or head injury are visible to the family and are therefore concrete in nature, such as weakness in a limb, poor balance or poor coordination. These are therefore more easily understandable than cognitive difficulties, as these are abstract in nature. Cognitive difficulties include processes such as problem solving, planning, thought processing, and visual perceptual difficulties. These difficulties cannot be seen concretely in a client and are far more abstract. Although these concepts are abstract, their presentation in activities and tasks is concrete.

The anxiety levels of the family member participants may also have an effect on their ability to remember other decisions and instructions they are required to carry out in relation to the client with a brain injury. These aspects are essential for the clients care and impact on their therapy and recovery. This involves complex decisions family members are required to make regarding the patient’s care during rehabilitation, for example signing consent for procedures, or making decisions regarding a care facility, or finding a caregiver. It may however also be simple instructions given during family meetings families to bring essential items from home for use with the client in therapy – for example, reading glasses, music for therapeutic listening, clothes.

Since family members need to comply and assist with these aspects, a recommendation would be to give a written action plan to the family members highlighting who would be responsible for which actions as well as an estimated time
frame for this to be completed in. The effectiveness of the action plan suggestion could be further investigated in further studies.

It was clear from comments made on the information checklist listed on page 42 that family members feel the need for further information about the progress of their family member. Family members described all aspects of information that they may require, for example: information regarding daily therapy, progress, prognosis and expected length of rehabilitation time. Some even felt that they would like daily feedback about their family member’s progress. This is however often not possible due to the slow nature of neurological rehabilitation, where progress can only be realistically measured on a weekly basis. Therefore accurate feedback cannot be given to the family on a daily basis. However, this need for further information should be recognised and acknowledged by the treating therapists. If at all possible, this should be addressed through the explanation of the nature of progress of neurological disorders.

5.4. Relationship between the clients’ functional level and family member anxiety

The final objective of the study was to consider the relationship between family member anxiety and the functional independence of the client with brain injury. A statistically significant improvement was found in the mean total scores of the FIM/FAM over the period of rehabilitation. This study can therefore confirm that client’s receiving inpatient rehabilitation show an improvement in their functional abilities over their rehabilitation period. There was a slightly better improvement in the physical scores than the cognitive scores over the assessment period of 6-9 weeks.

Since the FIM/FAM measure has been proven to accurately measure the functional independence or burden of care of a client, it was expected that perhaps family members of clients with higher FIM/FAM scores would be less anxious as they could see an improvement in functional independence of the client.

No significant correlation was found between the HADS Anxiety Scale and the patient’s improvement. The patient’s cognitive, motor and total improvement on the FIM/FAM was compared with the improvement on the HADS Anxiety Scale, but
only weak correlations were found. Although this may have been affected by the small sample size, it indicates that the family member’s anxiety was not associated with the functional independence of the client brain injury and that is associated with other various factors which are not reflected in the client’s improvement as measured by the FIM/FAM assessment score.

This may be as the factors in functional independence measured by the FIM/FAM, which are a comprehensive analysis of improvement in a client in both motor and cognitive spheres, have some limitations. For example, although language abilities are measured as part of the FIM/FAM, pragmatics and social appropriateness is not measured. Therefore, no information is available to indicate whether the client was behaving appropriately in various social situations, or if they were embarrassing their family member through inappropriate conversations and behaviours. The investigation of factors related to this aspect should still be considered in relation to family member anxiety.

Family members may also prioritize abilities of the clients differently. Since the effects of brain injury is different for each client the recovery expected or valued as important to their family member may vary between achieving physical independence or previous cognitive and language abilities. As this is based on individual factors, it is not possible to attribute emotional response to recovery to one generalized outcome measure like the FIM/FAM. Further investigation into the specific relationship of prioritized expectations of recovery amongst family members should be analysed in a separate qualitative study.

### 5.5. Limitations of this Study

Unfortunately, the study had a small sample with a large drop-out rate of 40% from the 36 participants recruited initially, which occurred for a number of reasons. Due to the nature of the patients, unfortunately the medical condition of many deteriorated and they were transferred to acute hospitals. Three patients passed away during the study and others were discharged from rehabilitation for various reasons before the 6th week. The drop-out rate was therefore beyond the control of the researcher. The
study could not be extended past its original completion date, as the researcher left the employment of the facility.

Family members of the remaining patients were not always available to complete all three assessments and therefore the first and third assessments were used for analysis.

To accommodate the small sample size nonparametric statistics were used and the small sample size may account for the lack of significant association between factors although a trend was seen of decreasing anxiety being related to an increase in information processing. This means that the results of this study cannot be automatically generalised to other situations as this sample is not representative of the population.

It should also be noted that, sometimes, due to the severity of the brain damage, some patients do not show any improvement at all, despite the best efforts of the rehabilitation team. Measurement of change on the FIM/FAM, or lack thereof, in various tests in these cases should be interpreted with caution.
CHAPTER 6

CONCLUSION

The aim of this study was to determine if there was an association between the change in anxiety levels of family members of clients with brain injury and their ability to process information, during the period the client has inpatient rehabilitation.

In order to achieve this aim the level of anxiety experienced and the information processed by these family members needed to be established. In this study, it has been found that family members of clients suffering from brain injuries do indeed experience anxiety whilst their family member participates in inpatient rehabilitation. While this overall anxiety was moderate when the client was admitted to rehabilitation for the family member participants in the sample in this study, the anxiety was reduced to mild over a 6-9 week period before the client was discharged. During this time the participants perceived that the amount of information they processed was greater.

Thus the significant decrease in the participant’s anxiety levels was accompanied by a significant increase in their perception of processed information. Although the moderate correlation between anxiety and the family member participants’ perception of information processed was not statistically significant, the moderate correlation indicated an association between these two variables was identified for this sample. This association is supported by research which indicates that anxiety impedes the ability to understand and appreciate information.

Based on these results, it is recommended that the rehabilitation team recognize this association and adjust their presentation of information to family members of clients with brain injury in inpatient rehabilitation facilities, accordingly. They should consider using family meetings not only to give information but to assess the family members understanding of the information, they should regularly seek the family's understanding of the individual's condition, care, and future needs.

The third and fourth objectives of the study were to determine if a relationship existed between the anxiety levels of the family members of clients with the brain injury and
the length of time since the client’s injury as well as the client’s level of independence in occupational performance.

No relationship could be identified between the family member’s level of anxiety and these variables even though there was a decrease in anxiety and an increase in the FIM/FAM score over the period of the research. The length of stay varied for clients and was affected by outside factors like deterioration in the condition and the financial constraints of some medical aids.

6.1. Recommendations

From the results of this study, it is recommended that:

When presenting information to family members of client with brain injury in inpatient rehabilitation facilities that

1. Although family members want and need information early and preferably daily in the clients rehabilitation, complex information about the patient’s care and discharge planning should be discussed with the family towards the middle and end of the client’s length of stay once their initial levels of anxiety have decreased.

2. A written action plan should be given to families during any interaction in which all plans are to be written down. This will assist in reminding the various parties what information was discussed and what plans were drawn up. This is suggested to combat the difficulties that the family experiences in remembering information.

3. Coping and anxiety reduction should also be considered as part of the programme offered to family members in the rehabilitation facility. This can be done through the counsellors or social workers that are employed at the rehabilitation facility. If this is not possible, then the team should strongly recommend that the family source support on their own.

For future research in this field

4. It is recommended that this study be replicated with a larger sample size and across various rehabilitation centres.
5. For a further study, it is suggested that a qualitative research study be conducted to ascertain the factors that caused them to experience anxiety during the process such as: financial burdens, lack of support, poor available resources, severity of impairment of the patient, as well as the characteristics and coping strategies of the carer\textsuperscript{7,16}.

Throughout this research study one recurring theme has been highlighted. This is that the client is not the only person affected by their illness or injury, but that the family members are affected as well. Special care therefore needs to be given to family members during this difficult time.
APPENDIX A

File Number: ______

Demographic Information Sheet

Information about Respondent:

Age: __________________________

Gender: __________________________

Relationship to the patient: Spouse    Mother    Father    Sibling

Other: __________________________

Employment: Employed    Self-employed    Unemployed    Retired

Socio-Economic Status: On average, indicate how much you earn in a month:

< R10 000    R10 000 – R20 000    R20 000 – R40 000    > R40 000

Highest Level of Education: __________________________

Information about the Patient:

Date of accident or incident: __________________________

Is the patient the bread winner of the family? __________________________
Information Checklist

Please indicate with an (X) which statement at the top of the column you feel best suits each statement at the side in the following table. It refers to information you have received on your family member’s condition and current functioning. It is important to remember that not all of the topics listed below are necessarily relevant to your family member’s current condition.

Please note: This information will only be interpreted once your family member has been discharged from the rehabilitation facility. If you would like further information or have any questions regarding any of the topics listed below, please contact the relevant therapist who is treating your family member.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Received sufficient information</th>
<th>Received information, but not sufficient</th>
<th>Did not receive information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Cause of the brain injury.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 General functioning of the brain, such as what areas are responsible for what tasks.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Risk factors for further vascular disease, such as age, cigarette</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Topic</td>
<td>Received sufficient information</td>
<td>Received information, but not sufficient</td>
<td>Did not receive information</td>
</tr>
<tr>
<td>-------</td>
<td>---------------------------------</td>
<td>------------------------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>1. smoking, increased cholesterol, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Possible complications, such as deep vein thrombosis, seizures, depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Specific physical difficulties with the body, such as difficulty moving the arm or the leg.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Specific cognitive deficits, such as problems with memory, concentration and thinking skills.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Specific Visual perceptual deficits, such as understanding what their eyes are seeing, being able to judge distances.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Specific language deficits, such as a difficulty in understanding language or a difficulty in speaking.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Specific emotional deficits, such as depression, not interested in favourite things, child-like, aggression.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Current mobility. Are they walking, and with how much help? Will they need a wheelchair</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Topic</td>
<td>Received sufficient information</td>
<td>Received information, but not sufficient</td>
<td>Did not receive information</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td>------------------------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>or not?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Current personal care functioning. How much help do they need to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>do basic tasks of eating, washing and dressing?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Treatment goals from all of the difficulties they are experiencing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Returning to home. Will they need care at home? How much care will</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>they need?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Returning to work. Will they be able to go back to their old job?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will they need a new job? Will they be able to work again?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other information you require: _______________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________
Hospital Anxiety and Depression Scale

[Date]

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':
- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:
- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)
HOSPITAL ANXIETY AND DEPRESSION SCALE

I can laugh and see the funny side of things:
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind:
A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

I feel cheerful:
Not at all
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed:
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down:
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:
Not at all
Occasionally
Quite often
Very often

(continued overleaf)
HOSPITAL ANXIETY AND DEPRESSION SCALE

I have lost interest in my appearance:
   Definitely
   I don't take as much care as I should
   I may not take quite as much care
   I take just as much care as ever

I feel restless as if I have to be on the move:
   Very much indeed
   Quite a lot
   Not very much
   Not at all

I look forward with enjoyment to things:
   As much as ever I did
   Rather less than I used to
   Definitely less than I used to
   Hardly at all

I get sudden feelings of panic:
   Very often indeed
   Quite often
   Not very often
   Not at all

I can enjoy a good book or radio or TV programme:
   Often
   Sometimes
   Not often
   Very seldom

Now check that you have answered all the questions

For office use only:
D : [ ] Borderline 8–10
A : [ ] Borderline 8–10

© Zigmond and Smith, 1983. From ‘The Hospital Anxiety and Depression Scale,’ Acta Psychiatrica Scandinavica 67, 361–70. Reproduced by kind permission of Munksgaard International Publishers Ltd, Copenhagen. This measure is part of Measures in Health Psychology: A User’s Portfolio, written and compiled by Professor Marie Johnston, Dr Stephen Wright and Professor John Weinman. Once the invoice has been paid, it may be photocopied for use within the purchasing institution only. Published by The NFEB-NELSON Publishing Company Ltd, Danville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DS, UK
Information Regarding use of Anxiety Medication

The aim of these questions is to determine if there were any medical factors that could have influenced your handling of the rehabilitation process. (This information will remain strictly confidential.)

Did you take any prescribed medication for stress or anxiety whilst your family member was at Riverfield Lodge? Yes/No

If so, what date did you start this medication?__________________________

Are you currently taking any prescribed medication for stress or anxiety? Yes/No

Did you take any herbal medication for stress or anxiety whilst your family member was at Riverfield Lodge? Yes/No

If so, what date did you start this medication?__________________________

Are you currently taking any herbal medication for stress or anxiety? Yes/No
Good day

I, Debbie Barrie, am a Master’s Student in Occupational Therapy from Wits University. I would like to invite you to participate in my research study entitled “Anxiety and Information use in Family Members of Brain Injured Clients” and would be most grateful if you would consider it. I am investigating the anxiety levels in family members of clients with brain injuries during rehabilitation.

Why am I doing this?

Research has shown that people struggle to process information and remember complex information when they are anxious and experiencing stress. I would like to investigate how much anxiety people experience while their family member is in rehabilitation.

What do I expect from you, the participant?

I will be asking you to complete three forms during three visits during the time of your family members stay at New Kensington Clinic or Riverfield Lodge. The forms take approximately 30 minutes to complete in total. The forms will ask questions about how you are feeling, as well as how much information you have received on your family member’s condition. The questionnaires include a personal information form, the Hospital Anxiety and Depression Scale, and an information checklist. We will arrange times to see each other at your convenience, while you are visiting your family member.

I will also require your permission to collect the Functional Independence Measure and Functional Assessment Measure scores of your family member’s progress. (This is a weekly scoring system used by all the therapists to record your family member’s progress)

What about confidentiality?

Confidentiality will be maintained by the use of a file number instead of your name to identify you on all the forms. Only I will have access to your name and personal information.

I will also supply an envelope in which you will seal you completed questionnaires after each visit. I will only evaluate your questionnaires once your family member has been discharged (therefore, if you have any questions about your family member’s progress that arise from the questionnaires, please address these to the therapists that are working with your family member.)

May I withdraw from the study?

Certainly, you may withdraw at any time, without giving a reason. This study is completely voluntary and withdrawing does not carry any penalty for you or your family member’s treatment. All personal information collected till the point of withdrawal will still remain confidential irrespective of the situation.

What if I don’t want to participate in the study?

It remains your choice if you would like to participate in this study or not. I would like to assure you, that your decision to participate or not will not affect the treatment that your family member will receive at New Kensington Clinic or Riverfield Lodge. Your family member will receive the same treatment regardless of whether they participate in the study or not.

If you have any queries regarding the study, please feel free to contact me on 082 840 5938.

If you agree to participate in the study by volunteering, please sign the attached consent form.

Thank you.

Debbie Barrie

082 840 5938
I, ____________________________ (full name) hereby consent to be a participant in the study entitled “Anxiety and Information use in Family Members of Brain Injured Clients”

I consent to the researcher:

- Viewing my family member’s medical records
- Giving me questionnaires to complete
- Analysing the questionnaires
- Using the results found in the study (excluding my name)

I am aware that I may withdraw from the study at any time, and that my participation in the study is voluntary.

Signed: ____________________________

Witness: ____________________________

Date: ____________________________ Place: ____________________________
UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49  Miss Deborah E Barrie

CLEARANCE CERTIFICATE M10M10104
PROJECT Anxiety and Information Use in Family Members of Brain Injured Clients

INVESTIGATORS Miss Deborah E Barrie.
DEPARTMENT Department of Occupational Therapy
DATE CONSIDERED 26/11/2010
DECISION OF THE COMMITTEE* Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 02/02/2011

Chairperson ________________________
(Professor PE Cleaton-Jones)

*Guidelines for written ‘informed consent’ attached where applicable
cc: Supervisor: K Gradidge

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and ONE COPY returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with those conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...
Appendix H

Deborah Barrie
24 January 2011

Re: Request for consent to gather information in support of a Master’s Research Project

Dear Deborah,

Thank you for the outline of your proposed research to fulfill the requirement for a Master’s Degree in Occupational Therapy at the University of the Witwatersrand.

Life Rehabilitation is committed to the furthering of knowledge regarding rehabilitation and will support research efforts where possible. I am pleased to grant you permission to access files of patients admitted to Life Riverfield Lodge who suffered severe traumatic brain injury and to approach family members of brain injured clients to invite them to participate in the study.

Please note that the permission is granted under the following conditions:

1) A copy of the approval of this project by the Ethics/Research committee – University of the Witwatersrand
2) Patient files accessed to be listed and communicated with the Therapy Manager, Judy Wiseels,
3) Patient confidentiality to be respected at all times.
4) Information will be gathered from interviews with participants, who are a close relative of an individual who suffered severe traumatic brain injury. Participants will be provided with an information letter in which the study is explained. The participant will grant written informed consent before the interview commences.
5) I also make reference to the guidelines and principles as prescribed by the Promotion of Access to Information Act, 2000 (Act 2 of 2000), as well as to the National Health, Act 61 of 2003. The National Health Act provides for research purposes – see Section 16(6) 2
   1) A Health worker or any health care provider that has access to the health records of a user may disclose such personal information to any other person, health care provider or health establishment as is necessary for any legitimate purpose within the ordinary course and scope of his or her duties where such access or disclosure is in the interests of the user
   2) For the purpose of this section “personal information” means personal information as defined in section 1 of the Promotion of Access to Information Act, 2000 (Act No. 2 of 2000).
3) Access to health records by health care provider
4) A health care provider may examine a user's health records for the purpose of
   a) treatment with the authorisation of the user and
   b) Study, teaching or research with the authorisation of the user, head of the health establishment concerned and the relevant health research ethics committee
5) If the study, teaching or research contemplated in subsection (1) (b) reflects or obtains no information as to the identity of the user concerned, it is not necessary to obtain the authorisations contemplated in that subsection.

I am looking forward to your feedback on the research project, as well as whether you require any further assistance. Please note that access is only granted to patient files at Life Riverfield Lodge.

I wish you all the best

Regards

Dr Marinda Overbeek
Clinic Manager
FW:

Permission letter from New Kensington

Debbie Barrie
Occupational Therapist

Tel: + 27 860 748 373
Fax: + 27 86 674 3981
Mobile: + 27 82 840 5938
Email: deborah.barrie@lifehealthcare.co.za
Website: www.lifehealthcare.co.za

-----Original Message-----

From: Joelson,Danny
Sent: Tuesday, July 05, 2011 3:25 PM
To: Barrie,Deborah
Subject: RE: Permission letter from Riverfield

Dear Debbie,

We will accept on the weight of the permission letter from Riverfield. It certainly is a very involved document.
Sorry to confirm so late, but you are welcome.

Regards

Danny Joelson
Therapy Unit Manager

Tel: + 27 11 614 7125
Fax: + 27 11 614 3037
Email: danny.joelson@lifehealthcare.co.za
Website: www.newkensingtonclinic.co.za
Morning Danny

I have attached the permission letter from Dr M Overbeeck to conduct the research at Riverfield Lodge.

Thank you so much for your quick response and for permission to conduct my research at your facility.

Would you be able to formally give me permission in writing to conduct the research, for my records.

I will be in contact with Bronwyn about arranging a time to meet her to discuss this further.

Once again, thank you for your assistance.

Kind regards,

Debbie Barrie
Occupational Therapist

Tel: + 27 860 748 373
Fax: + 27 86 674 3981
Mobile: + 27 82 840 5938
Email: deborah.barrie@lifehealthcare.co.za
Website: www.lifehealthcare.co.za

-----Original Message-----
From: scanner@lifehealthcare.co.za
Sent: Wednesday, January 26, 2011 10:08 AM
To: Barrie, Deborah
Subject: This E-mail was sent from "RNPA8472D" (Aficio 1515).

Scan Date: 26.01.2011 09:08:26 (+0100)
Queries to: scanner@lifehealthcare.co.za

Life Healthcare Group (Pty) Ltd
Registration number: 2003/024367/07
This message and any attachments are confidential and intended solely for the addressee. The following link will display the full disclaimer: http://www.lifehealthcare.co.za/disclaimer/
The following link displays the list of Directors: http://www.lifehealthcare.co.za/IR/directors.aspx
References:


74. Netcare Admissions Policy Document


82. Smith MS, Testani-Dufour L. Who’s Teaching Whom? A Study of Family Education in Brain Injury. Rehabilitation Nursing, 2002;27(6)