

School of Occupational Therapy and Social Work

**The Journey Through Rehabilitation: A Study of People with Acquired
Brain Injury in Western Australia**

Annalise Marie O'Callaghan

**This thesis is presented for the Degree of
Master of Philosophy (Occupational Therapy)
of
Curtin University**

December 2017

AUTHOR'S DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007)-updated March 2014. The proposed research study received human research ethics approval from Curtin University Human Research Ethics Committee (EC00262), Approval Number HR144/2012.

Signature: 

Date: 11/12/2017

ABSTRACT

Background

Acquired brain injury (ABI) is a complex, individualised condition that causes lifelong disabilities impacting on the person's physical, cognitive, and emotional functioning. The prevalence of ABI is increasing with 432,700 people living with ABI in Australia, of which approximately 21,000 live in Western Australia. An ABI does not only affect the person who sustains the injury. Due to the nature of ABI and the impact it has on the person's functioning, the injury also changes the lives of the person's family as they manage their emotions regarding the person not being the same as they were before the injury and their need for support in completing everyday tasks. Brightwater Oats Street is the only provider of post-acute residential rehabilitation for people with acquired brain injuries in Western Australia. Post-acute rehabilitation is an important stage following acute treatment of the injury. Currently, there is a lack of literature on the experiences of people with ABI and their families as they journey through the rehabilitation process from acute to post-acute services and beyond. This research project aimed to understand the experiences of people with ABI living in Western Australia as they journey through rehabilitation, from the perspectives of the person with ABI, their family, and health professionals providing care in post-acute rehabilitation. There were four objectives to address this aim: (i) to identify gaps in our current knowledge about experiences from the perspectives of people with ABI; (ii) to describe the journey through rehabilitation for people with ABI living in Western Australia; (iii) to identify the barriers and enablers experienced by people with ABI and their families during the rehabilitation journey; and (iv) to identify the current needs of people with ABI and their families to assist in the development and delivery of future rehabilitation.

Methods

A three phase approach was used to achieve the objectives of this research project. In Phase 1, a scoping review was completed to identify gaps in the existing knowledge about ABI from the perspectives of people with ABI (Objective 1). The findings of this review were used to guide the next two phases. Phase 2 aimed to understand the perspectives of people with ABI and their families (Objective 2). Semi-structured interviews of 10 people with ABI at different stages of their journey were completed on two occasions, six months apart. Fourteen family members, including at least one family member for each

person with ABI, were interviewed after each interview with the people with ABI. Phase 3 of the study involved semi-structured interviews with 11 health professionals and the program manager involved in the care of the people with ABI at Brightwater Oats St (Objective 2). Data were collected during the interviews with people with ABI and their families about the perceived barriers and enablers to the rehabilitation journey (Objective 3) and areas they identified for improvement in rehabilitation service provision (Objective 4). Thematic analysis was used in each phase of the research project to identify the main themes that developed from each data set.

Results

The scoping review included 20 publications. Thematic analysis identified four common themes relating to gaps in the current understanding of ABI from the perspectives of people with ABI: (1) loss of self: acceptance of the injury; (2) responses of significant others towards the person with ABI; (3) relationships with family and rehabilitation team; and (4) occupational engagement and performance. The semi-structured in-depth interviews with the people with ABI revealed two main themes for people with ABI: Theme 1 - 'Services don't appropriately meet the needs of people with ABI', with the three -sub-themes (i) *We need services to help us engage in work and leisure*, (ii) *We need ongoing and consistent informal and formal support*, and (iii) *We feel lost trying to find services*; and Theme 2 - 'Person-centred services are valued'. The interviews with family members identified one main theme - 'Families have to support each other' with two sub-themes (i) *Our lives have changed forever*, and (ii) *There is limited psychological support for us*. The semi-structured interviews with the health professionals resulted in five themes on barriers and enablers to the rehabilitation journey - (1) Person factors; (2) Relationships with others; (3) Employment opportunities; (4) Community awareness; and (5) Creating the best environment for rehabilitation. The study in Phase 2 found that the services available to people with ABI and their families after discharge from post-acute rehabilitation did not meet their needs, and the services had a poor understanding of the impact of ABI on the person. Families expressed the desire for more psychological supports that were flexible and personalised, and which could be accessed as needed. Health professionals recognised that engagement in community activities, employment in particular, was an area of intervention requiring further work, and the interprofessional team working within a 24/7 rehabilitation approach was a key to the success of post-acute rehabilitation.

Conclusion

This research project has shown the value of listening to the perspectives of people with ABI, their families, and health professionals to develop future rehabilitation services. People with ABI valued opportunities to engage in meaningful community activities and employment; however, the lack of understanding of ABI and flexibility among community services available to assist the person upon discharge from post-acute rehabilitation to the community, is a concern. Families felt that the available psychological supports were not adequate and believed that flexible and personalised psychological support should be offered as needed to ensure that families can deal with the many challenges and changes they experience following the ABI. Health professionals agreed that post-discharge services for people with ABI needed to improve and the psychological supports available for families needed to be more flexible to better meet their unique needs. The health professionals provided qualitative evidence in support of an interprofessional team approach and the use of the 24/7 rehabilitation approach that included support workers who were sufficiently trained in their role within the rehabilitation process.

ACKNOWLEDGEMENTS

There are many people who I would like to thank for their support and assistance during the completion of this Masters study. Firstly, I would like to thank Professor Errol Cocks for introducing me to research, particularly in the area of acquired brain injury. The idea for this study evolved through discussions with you and for this I am very grateful.

Professor Bev McNamara, my co-supervisor at the beginning of the Masters journey, thank you for teaching me about the research process and how to complete qualitative research. You taught me how to think like a researcher and to question everything. You provided valuable support and assistance particularly in the design of the study. I am very thankful for your knowledge and support.

Associate Professor Marina Ciccarelli, this project wouldn't be finished without you. I appreciate all the hard work and encouragement you have given me over the many years we have worked together, especially over the last 12 months when you have dedicated so much of your time to helping me finish. Your knowledge, encouragement, positivity, and amazing proof reading and writing skills are greatly valued, and I will be forever indebted for everything I have learned from you.

To Associate Professors Annette Joosten and Courtenay Harris, two great minds of the occupational therapy world, I am so appreciative to have been able to work so closely with two wonderful mentors whose knowledge and enthusiasm for occupational therapy and research is something I can only hope to have one day. I have learned so much about "thinking outside the box" through working with both of you and I thank you so much for all your support, encouragement, and understanding during this journey.

To the people with acquired brain injuries, their families, and the staff at Brightwater Oats Street, I thank you for giving up your time to share your experiences, thoughts and feelings in order to improve the experiences for people with ABI in Western Australia. By being so welcoming in sharing your experiences, you will potentially make a big difference to the lives of many.

Finally, to my family and friends. Thanks for always checking to see how I was going with my study! Thanks for all your love, support, and consideration over the years to assist me to complete my study. I thank you for everything.

GLOSSARY OF TERMS

24/7 rehabilitation approach

Brightwater Oats Street service use the term 24/7 rehabilitation approach to describe the framework they use to provide rehabilitation. This approach occurs when all activities the person with ABI completes during their day are working towards their rehabilitation goals e.g. the support workers continue to help the person with ABI achieve their goals by engaging the person in activities that are working towards their goals outside their specific therapy sessions

Acquired brain injury

An acquired brain injury (ABI) is an individualised condition caused by damage to the brain after birth (Headway, 2012). Acquired brain injuries are classified according to severity divided into mild, moderate, and severe with mild the most common type of injury (Katz, Cohen & Alexander, 2015).

Acute care

Health services that provide rapid, frequent, and time-sensitive interventions to improve health (Hirshon et al., 2013). This type of care is usually individually-orientated, diagnostic, and curative, and used to treat sudden, urgent illnesses and injuries (Hirshon et al., 2013)

Rehabilitation

Rehabilitation is individualised care to assist someone to recover from a serious injury or illness (Department of Health Western Australia, 2017). It usually involves care from a team of health professionals.

Post-acute rehabilitation

Rehabilitation that is provided after a person has received acute care and when he/she are considered medically stable but requires further treatment to improve his or her health. This care may include residential programs that provide cognitive, emotional, and behavioural management; and social, leisure, and vocational treatment planning (Braunling-McMorrow, Dollinger, Gould, Neumann, & Heiligenthal, 2010).

Brightwater Oats Street

Brightwater Care Group is one of Western Australia's largest providers of residential rehabilitation care for people with disabilities (Brightwater, 2017). The Oats Street rehabilitation program is focused on providing functional rehabilitation for people aged 18-65 years with an acquired brain injury (Brightwater, 2017).

Interprofessional Team

Health professions from more than one discipline who work together to provide a patient-centred, team-based approach to health care delivery by utilising the strengths and skills of each discipline to provide quality care (Hoffman, Rosenfield, Gilbert, & Oandasan, 2008).

ABBREVIATIONS AND ACRONYMS

ABI	Acquired Brain Injury
OT	Occupational Therapy
TBI	Traumatic Brain Injury

TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	v
GLOSSARY OF TERMS.....	vi
ABBREVIATIONS AND ACRONYMS.....	vii
CHAPTER 1	1
Introduction	2
1.1 Acquired Brain Injury in Western Australia	2
1.2 Importance of Perspectives	3
1.3 Rationale for the Study	5
1.4 My Experience.....	5
1.5 Objectives.....	6
1.6 Research Design	7
1.7 Structure of Thesis	8
1.8 Conference Presentations.....	9
1.9 References	11
CHAPTER 2	14
2.0 Literature Review Scoping Review	15
2.1 Introduction	15
2.2 Method	17
2.2.1 Identifying the research question.....	18
2.2.2 Identifying Relevant Studies	18
2.2.3 Selecting relevant studies.....	18
2.2.4 Charting data	19
2.2.5 Collating, summarizing, and reporting the results	19
2.3 Results.....	19
2.3.1 Types of research studies	19
2.3.2 Location of research and publication of findings	19
2.3.3 Participants	20
2.3.4 Thematic analysis.....	28
2.4 Discussion.....	31
2.5 Conclusion.....	35
2.6 References	37
CHAPTER 3	43

3.0 The journey from the perspective of people with Acquired Brain Injury.....	44
3.1 Introduction	44
3.2 Method	46
3.2.1 Study design.....	46
3.2.2 Participants	46
3.2.3 Data Collection.....	47
3.2.4 Data Analysis.....	48
3.3 Results.....	51
3.3.1 Participants	51
3.3.2 Themes – Barriers and enablers for the person with ABI.....	51
3.3.3 Themes- Barriers and enablers for family members	58
3.4 Discussion.....	60
3.5 Conclusion.....	64
3.6 References	65
CHAPTER 4	68
4.0 The journey from the perspective of the health professionals working with the person with Acquired Brain Injury	69
4.1 Introduction	69
4.2 Context of this study	70
4.3 Method	71
4.3.1 Participants	71
4.3.2 Procedure.....	72
4.3.3 Data analysis	73
4.4 Results.....	75
4.4.1 Person factors	75
4.4.2 Relationships with others	77
4.4.3 Employment opportunities.....	80
4.4.4 Community awareness	81
4.4.5 Creating the best rehabilitation environment.....	82
4.5 Discussion.....	84
4.6 Conclusion.....	88
4.7 References	90
CHAPTER 5	94
5.0 Discussion and Conclusion.....	95
5.1 Summary of studies and findings.....	95
5.2 Implications for people with acquired brain injuries and their families.....	97

5.3 Clinical Implications.....	100
5.3.1 Recommendations for health professionals.....	100
5.3.2 Contribution to service delivery.....	102
5.4 Recommendations for further research.....	104
5.5 Strengths and limitations.....	105
5.6 Conclusion.....	106
5.7 References.....	108
CHAPTER 6	111
6.0 Bibliography	112
APPENDICES	126
APPENDIX A: Interview Guide-Person with ABI	127
APPENDIX B: Ethics Approval.....	130
APPENDIX C: Information Sheet-Person with ABI and family members.....	131
APPENDIX D: Information Sheet-Health Professionals.....	133
APPENDIX E: Consent Forms.....	135

CHAPTER 1

1.0 Introduction

1.1 Acquired brain injury in Western Australia

An acquired brain injury (ABI) is an individualised condition resulting from any damage caused to the brain after birth (Headway, 2012). Acquired brain injuries are classified according to severity as mild, moderate and severe; with mild being the most common (Katz, Cohen, & Alexander, 2015). Classification is based on the duration of loss of consciousness, level of post-traumatic amnesia, and impairment to the person's functioning (Katz et al., 2015). An ABI is complex in that it affects the person's physical, cognitive, and emotional functioning (Headway, 2012). The impact of the injury includes physical impairments to movement and motor control causing impaired mobility, hand function, fine motor skills, and communication, including speech. These physical impairments require skills retraining, which can take many years and with residual deficits remaining after the retraining. The injury can also have a lifelong impact on the person's ability to express, feel, and regulate emotions; and their cognitive abilities, such as short-term memory and organisational skills (Kat, 2010; Hoofien, 2001). Although ABI does cause cognitive impairments, it is important to note it does not affect the person's intelligence (Kat, 2010).

Acquired brain injury affects thousands of Australians; however, the exact incidence is unknown due to underreporting by health services (Doig, Fleming, Kuipers, & Cornwell, 2010). Global prevalence rates are difficult to determine due to the difference in high-quality reporting of ABI; however, the current prevalence rate is predicted to be one in 500 people (Bryan-Hancock & Harrison, 2010; Roozenbeek et al., 2013). There are an estimated 432,700 people living with ABI in Australia, with the most common cause being a stroke or accident/trauma (Australian Institute of Health and Welfare, 2007). There are estimates of approximately 21,000 people living with ABI in Western Australia (WA) (Australian Institute of Health and Welfare, 2007; Fortune & Wen, 1999), though these numbers are dated. With 1.05% of the population having an ABI, there are broad considerations of the impacts of this condition because it has lifelong effects on the person's and possibly their family's living situation, employment, finances, and relationships with others (Australian Institute of Health and Welfare, 2007; Parvaneh & Cocks, 2012).

Brightwater Care Group is a not-for-profit disability service provider that offers the only post-acute residential rehabilitation service for people with ABI living in WA. The process in WA after sustaining an ABI is that the person first receives acute care from a local hospital emergency department. From there they are transferred to an intensive care ward, and then receive in-patient services on a general ward. They may then be transferred to the State Head Injury Unit at Fiona Stanley Hospital in metropolitan Perth for short-term in-patient rehabilitation, lasting approximately six months. Upon discharge from the State Head Injury Unit, the person with ABI may receive services from one of a range of community rehabilitation service providers, including Brightwater Care Group's residential services, or they may be discharged home with community supports. Brightwater Care Group's Oats Street post-acute rehabilitation facility is a 43 bed service that focuses on supporting clients to regain independence for living within the community by restoring their physical, emotional, and cognitive skills (ACIL Tasman, 2010). The post-acute rehabilitation program at Brightwater Oats St includes an interprofessional team comprised of occupational therapists, physiotherapists, speech pathologists, nurses, and care workers. The interprofessional team provide rehabilitation interventions similar to those described in the literature to facilitate people with ABI to return home, develop independence, and participate in community activities (Cope, 1995; Griesbach, Kreber, Harrington, & Ashley, 2015; Kim & Colantonio, 2010). An important focus of interventions at Brightwater Oats St is engagement of clients in purposeful activities of their choice; such as self-care, productive activities (e.g. developing independent living and employment skills), and leisure activities (e.g. art, music, sport). This is part of the 24/7 rehabilitation approach whereby interventions are embedded in daily activities in a naturalistic environment, with support from health professionals and family (ACIL Tasman, 2010). Involvement in activities that are purposeful and meaningful to the person is recommended to achieve their rehabilitation outcomes (Johnston, Goverover, & Dijkers); and is supported by the findings of Andelic et al. (2010), who reported that better health outcomes for people with ABI are achieved when fewer limitations to activities are encountered..

1.2 Importance of Perspectives

Most of the literature on ABI report on the outcomes of rehabilitation such as functional improvements the person has made during rehabilitation (Turner-Stokes, Pick, Nair, Disler, & Wade, 2015), but there is a paucity of literature about the lived experiences

of people with ABI as they transition through stages of rehabilitation to living independently in the community. One study that investigated the perspectives of people with ABI via focus groups with stakeholders found that there is an “uncertain pathway of longer term rehabilitation” for people with ABI (Parvaneh & Cocks, 2012, p. 136). Another study explored the lived experience of two people with ABI in rural Australia and concluded that engaging in meaningful occupations and using social support systems was essential in their rehabilitation journey (Parsons & Stanley, 2008). The journey through rehabilitation from the perspectives of people with ABI in Australia, particularly people who are no longer engaged in post-acute rehabilitation, is not adequately understood. Further research is therefore required to understand the lived experiences of people with ABI in order to improve post-acute ABI care and rehabilitation experiences for this population.

It is important that research in the field of ABI includes the perspectives of nominated carers, typically a family member or close friend, in the same way a health professional would involve family and social networks in their interventions with the person with ABI (McGlynn, 2005). A common consequence of ABI is social isolation and the loss of relationships. People with ABI experience changes in their social relationships and breakdown of relationships, which may occur because of the person’s loss of sensitivity and empathy following their ABI (Jones, Mandy, & Partridge, 2008). Family members need support to cope with changes to the person’s physical functioning and the person’s emotional changes including the ability to manage feelings (Murray, Maslany, & Jeffery, 2006). Thus, it is beneficial for researchers to gain the perspectives of family members and explore psychosocial factors, such as changes in social and personal relationships, which affect people with ABI and their families; determine the level of support received by the person and their family; and identify opportunities for new services (Rosenthal, Christensen, & Ross, 1998).

It is also important to understand the perspectives of the health professionals providing services and support to the person with ABI and their family during the rehabilitation process. Therapists who have a better understanding of the experiences of the person with ABI are better able to provide services that meet the physical and emotional needs of the person (Parsons & Stanley, 2008). A systematic review by Kim and Colantonio (2010) concluded that the perspectives of health professionals, in particular occupational

therapists, regarding the rehabilitation journey of people with ABI require further investigation.

This study aimed to explore the perspectives of people with ABI, their families, and health professionals regarding the rehabilitation journey. It is expected that the findings of this study will provide a better understanding of the levels of support received by the person with ABI and their family, and what forms of support they need. Documenting the experiences of people with ABI, their families, and health professionals may inform strategies to improve future services (Kwan, 2007).

1.3 Rationale for the Study

This research contributes to the understanding of the complex needs of people with ABI, their families, and how health professionals can support them. The rehabilitation journey for a person with ABI involves not only the person, but also their family and health professionals involved in their care. There is a need to understand the perspectives of each stakeholder through the rehabilitation journey as they work together to help the person with ABI achieve their rehabilitation goals. Interviewing participants twice over a six-month period created an opportunity to document the experiences of people with ABI and their families as they progressed through and beyond post-acute rehabilitation, and to identify the barriers and enablers to successful rehabilitation outcomes that they experienced over time. This information was used to highlight the gaps in current services for people with ABI, and the findings of this research can inform improvements to the current interventions provided to people with ABI and their families in WA. Recommendations for future research to build on these findings are provided.

1.4 My Experience

Prior to becoming an occupational therapy educator, I worked as an occupational therapist in a private mental health service. I remember one particular client for whom the treatment team faced a dilemma about treatment options. The treating psychiatrist said to me, "Annalise, I don't know what to do with him, do whatever you think will work and let me know how it goes". This client, an 18 year old man, named Rob had been referred as an in-patient with possible psychosis (and a history of impulsive behaviours). Rob had experienced a brain injury from a skateboarding accident in the 12 months prior to his

admission. Rob was a friendly young man with whom it was easy to build rapport. I had one individual session with Rob, where I tried to understand his current mental health status. I was aware he had a brain injury that caused his lack of insight, impulsivity and poor memory, which when combined with his early symptoms of psychosis were complicating his treatment options as an in-patient, and more importantly, the options available on discharge. Rob only stayed in the hospital for one week before he was referred on to another service. I always felt that I had missed an opportunity to assist Rob on his recovery, in part due to my and the team's lack of knowledge on brain injuries.

When I started as an academic in the School of Occupational Therapy and Social Work at Curtin University, I was given the opportunity to work on a study investigating the experiences of people with a dual diagnosis of ABI and mental illness. I enjoyed working in the research team and hearing about the lived experiences of people with a dual diagnosis through my roles in qualitative data collection and analysis. I saw this as my opportunity to learn more about brain injuries. As I became more involved in this project, I started to realise that the voice of people with ABI is one that is not often heard. The complexity of ABI means that no two experiences are the same, and the needs of each person are very different. I decided I wanted to help people with ABI and their families to be heard and to help improve or streamline the health and social care services they receive. The impetus for this study came from my belief that it is important to fill the gap in the knowledge base about how best to help people with ABI and their families.

1.5 Objectives – bend over pool table

The aim of this study was to understand the rehabilitation journey experiences of people with ABI living in Western Australia, from the perspectives of the person with ABI, their family, and health professionals involved in their care. The objectives guiding this study were:

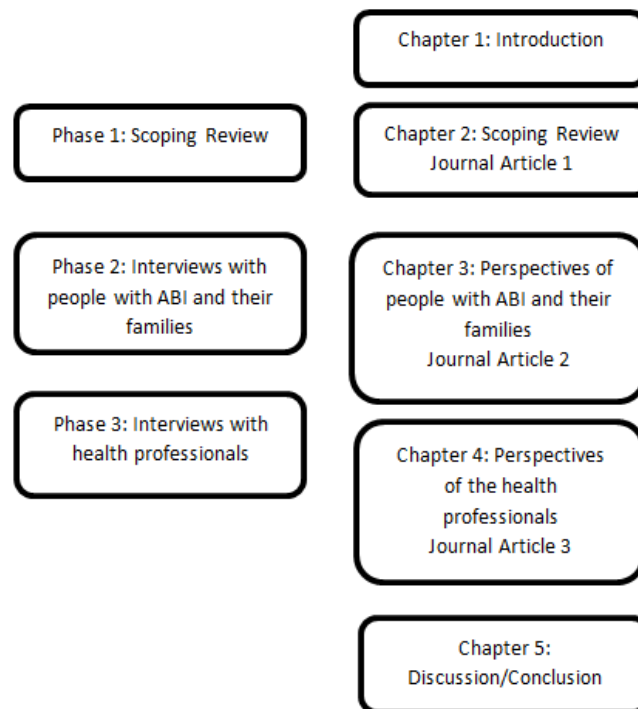
1. Examine the extent, range, and nature of existing literature on the subjective experiences of people with ABI during post-acute rehabilitation in order to identify gaps in current knowledge;
2. Describe the journey through rehabilitation for people with ABI in Western Australia;
3. Identify the barriers and enablers experienced during the rehabilitation journey by people with ABI and their families;
4. Identify the current needs of people with ABI and their families from the perspectives of the person, the families and health professionals involved in

rehabilitation to contribute to our understanding of interventions used in rehabilitation and recognise opportunities for future interventions.

1.6 Research Design

In order to document the journey of people with ABI and their families through rehabilitation, this study was completed in three phases, as shown in Figure 1.1.

Figure 1.1: Phases of the study



Phase 1: This phase identified the gaps in the current knowledge about ABI from the perspectives of people with ABI. A scoping review of the literature over the past 25 years was completed. Five databases identified 20 articles meeting the criteria for inclusion in the review. The research objective addressed in this phase was:

Objective 1: Examine the extent, range, and nature of existing literature on the subjective experiences of people with ABI during post-acute rehabilitation, and identify gaps in current knowledge about the experiences as reported by people with ABI.

Phase 2: This phase was a qualitative study to understand the perspectives of the person with ABI and their families on the journey through rehabilitation. People with ABI were interviewed using semi-structured interviews on two occasions six months apart. At

least one family member for each person was interviewed following the first interview with the person with ABI. The second phase addressed the following objectives.

Objective 2: Describe the journey through rehabilitation for people with ABI in Western Australia;

Objective 3: Identify the barriers and enablers experienced during the rehabilitation journey by people with ABI and their families;

Phase 3: The final phase of the study involved completing semi-structured interviews with the health professionals involved in the care of the people with ABI in Phase 2. This was completed by presenting the results, including the themes from Phase 2, for comment to the participating health professionals at Brightwater Oats Street via semi-structured interviews. The health professionals were from a range of disciplines involved in the post-acute care of people with ABI. The health professionals were also asked to identify what they thought was working well and what was needed to improve in the journey through rehabilitation for people with ABI and their families. The research objective connected with this phase was:

Objective 4: Identify the current needs of people with ABI and their families from the perspectives of the person, the families and health professionals involved in rehabilitation to contribute to our understanding of interventions used in rehabilitation and recognise opportunities for future interventions.

1.7 Structure of Thesis

This thesis is presented as five chapters. Chapter 1 provides background to the topic, the rationale for the study, and an overview of the research process. Chapter 2 reports on the findings of a scoping review of the literature. The scoping review was used to examine the extent, range, and nature of existing literature on the subjective experiences of people with ABI and to identify gaps in the current knowledge base on these experiences.

Chapter 3 presents the findings of interviews with people with ABI and their families. This chapter discusses the experiences that the people with ABI and their families have had during the rehabilitation journey, and highlights the barriers and enablers

throughout their journey. This study identified that people with ABI valued person-centred care and there was a lack of appropriate supports for family members. There were few services that met the ongoing long-term needs of people with ABI, and they required support to engage in leisure and productive occupations.

Chapter 4 reports on the rehabilitation experiences of people with ABI and their families from the perspectives of health professionals. This chapter identifies the current needs of people with ABI and their families in order to contribute to our understanding of the interventions and identify future opportunities for interventions. The health professionals reported the benefits of the interprofessional team and 24/7 rehabilitation approach used at Brightwater Oats Street, and identified the other factors that affect recovery, such as motivation and family and health professional support. The health professionals recognised the levels of support available for family members were not adequate.

Chapter 5 presents the conclusions drawn from this study and the implications of the findings for people with ABI, their families, and health professionals. The contribution of these findings to inform service delivery are also discussed. The limitations of the study and recommendations for future research are provided.

Finally, the appendices contain documents that were essential to the research process: (A) interview guides for the person with ABI, the family members, and health professionals; (B) ethics approval; (C) information sheet for the person with ABI and family members, (D) information sheet for the health professionals, and (E) consent forms.

1.8 Conference Presentations

The findings from this study were presented at national and international conferences.

O’Callaghan, A.M., McNamara, B., & Cocks, E. (2014, March). “What am I supposed to do? Cartwheels down the passage way? “Perspectives on the rehabilitation journey from people with ABI. Poster presented at the 10th World Congress on Brain Injury 2014, San Francisco, United States of America.

O’Callaghan, A.M., McNamara, B., & Cocks, E. (2014, May). Beyond the door of services: Perspectives of people with acquired brain injury. Paper presented at the 37th Annual Brain

Impairment Conference, Australasian Society for Study of Brain Impairment 2014, Perth, Western Australia.

O'Callaghan, A.M., McNamara, B., & Cocks, E. (2014, May). "You meet some sensational people" Perspectives of people with an acquired brain injury and their families. Paper presented at the Occupational Therapy Australia Western Australia Conference 2014, Perth, Western Australia.

1.9 References

- ACIL Tasman. (2010). *Oats Street facility redevelopment: A social cost-benefit analysis*. Victoria: ACIL Tasman Pty Ltd.
- Andelic, N., Sigurdardottir, S., Schanke, A.K., Dandvik, L., Sveen, U. & Roe, C. (2010). Disability, physical health and mental health one year after traumatic brain injury. *Disability and Rehabilitation*, 32(13), 1122-1131. Retrieved from doi:10.3109/09638280903410722
- Australian Institute of Health and Welfare. (2007). *Disability in Australia: Acquired brain injury*. Canberra: AIHW Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453666>.
- Bryan-Hancock, C., & Harrison, J. (2010). The global burden of disease project 2005: Methods utilised by the injury expert group for estimating world-wide incidence and prevalence rates. *Injury Prevention*, 16(Suppl 1), A99-A99. doi:10.1136/ip.2010.029215.356
- Cope, D. N. (1995). The effectiveness of traumatic brain injury rehabilitation: A review. *Brain Injury*, 9(7), 649-670. doi:10.3109/02699059509008224
- Doig, E., Fleming, J., Kuipers, P., & Cornwell, P. L. (2010). Comparison of rehabilitation outcomes in day hospital and home settings for people with acquired brain injury - a systematic review. *Disability and Rehabilitation*, 32(25), 2061-2077. doi:10.3109/09638281003797356
- Fortune, N., & Wen, X. (1999). *The definition, incidence and prevalence of acquired brain injury in Australia*. Canberra: AIHW Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442467114>.
- Griesbach, G. S., Kreber, L. A., Harrington, D., & Ashley, M. J. (2015). Post-acute traumatic brain injury rehabilitation: Effects on outcome measures and life care costs. *Journal of Neurotrauma*, 32(10), 704-711. doi:10.1089/neu.2014.3754

- Headway. (2012). The silent epidemic of acquired brain injury. Retrieved from <http://www.headway.ie/information/abi/the-silent-epidemic-of-acquired-brain-injury/>
- Hoofien, D., Gilboa, A., Vakil, E., & Donovick, P. J. (2001). Traumatic brain injury (TBI) 10?20 years later: A comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury, 15*(3), 189-209. doi:10.1080/026990501300005659
- Johnston, M. V., Goverover, Y., & Dijkers, M. Community activities and individuals 2019; satisfaction with them: Quality of life in the first year after traumatic brain injury. *Archives of Physical Medicine Rehabilitation, 86*(4), 735-745. doi:10.1016/j.apmr.2004.10.031
- Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: A perspective based on personal experience. *Disability and Rehabilitation, 30*(7), 507-516. doi:10.1080/09638280701355561
- Kat, L., Schipper, K., Knibbe, J., & Abma, T. A. (2010). A patients journey: Acquired brain injury. *British Medical Journal, 340*, c808. doi:10.1136/bmj.c808
- Katz, D., Cohen, S, Alexander, M. (2015). Mild traumatic brain injury. *Handbook Clinical Neurology, 127*, 131-156. doi:10.1016/B978-D-444-52892-6.00009-
- Kim, H., & Colantonio, A. (2010). Effectiveness of rehabilitation in enhancing community integration after acute traumatic brain injury: A systematic review. *American Journal of Occupational Therapy, 64*(5), 709-719. Retrieved from <http://search.proquest.com/>
- Kwan, J. (2007). Care pathways for acute stroke care and stroke rehabilitation: From theory to evidence. *Journal of Clinical Neuroscience, 14*, 189-200. doi:10.1016/j.jocn.2006.01.026.
- McGlynn, C. (2005). The triple whammy of acquired brain injury and concurrent disorders. *Cross Currents, 9*(1), 8-9. Retrieved from <http://search.proquest.com/>
- Murray, H. M., Maslany, G. W., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury, 20*(6), 575-585. doi:10.1080/02699050600664590

- Parsons, L., & Stanley, M. (2008). The lived experience of occupational adaptation following acquired brain injury for people living in a rural area. *Australian Occupational Therapy Journal*, 55(4), 231-238. doi:10.1111/j.1440-1630.2008.00753.x
- Parvaneh, S., & Cocks, E. (2012). Framework for describing community integration for people with acquired brain injury. *Australian Occupational Therapy Journal*, 59(2), 131-137. doi:10.1111/j.1440-1630.2012.01001.x
- Roozenbeek, B., Maas, A. I. R., & Menon, D. K. (2013). Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*, 9(4), 231-236. doi:10.1038/nrneurol.2013.22
- Rosenthal, M., Christensen, B. K., & Ross, T. P. (1998). Depression following traumatic brain injury. *Archives of Physical Medicine Rehabilitation*, 79(1), 90-103. doi:10.1016/S0003-9993(98)90215-5
- Turner-Stokes, L., Pick, A., Nair, A., Disler, P., & Wade, D. (2015). Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. *Cochrane Database of Systematic Reviews*, 12(Art. No.: CD004170), 691-701. doi:10.1002/14651858.CD004170.pub3

CHAPTER 2

2.0 Scoping Review: Identifying gaps in understanding of the personal experiences of people with acquired brain injury

2.1 Introduction

Acquired brain injury (ABI) is any injury to the brain that occurs after birth (Australian Institute of Health and Welfare, 2007). Most ABIs are the result of a mechanical force to the head including being struck, hit in a fall, an interruption in blood or oxygen supply, or through a degenerative neurological disease (Dimancescu, 2007). The term ABI includes traumatic brain injuries (TBI) that predominantly occur from a vehicle accident, fall, violence, or sporting injuries (Granacher, 2003). Once acquired, an ABI is a lifelong disability and with rising incidence rates of ABI, experts predict it will become the major cause of death and disability worldwide by 2020 (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007; Roozenbeek, Maas, & Menon, 2013). Differences between countries in hospital admission statistics, variability in the definition of ABI, and a lack of high-quality monitoring of data make it difficult to identify the global incidence rate of ABI (Roozenbeek et al., 2013). However, the global incidence rate is estimated to be 200 per 100 000 people (Bryan-Hancock & Harrison, 2010; Roozenbeek et al., 2013). In Australia between 1999 and 2005, the estimated incidence rate of TBI based on hospital admission statistics remained steady at around 107-108 per 100 000 (Australian Institute of Health and Welfare, 2007). The incidence rate for ABI in Western Australia according to hospital admission statistics has risen from 57 per 100 000 during 1988-1992 to 86 per 100, 000 during 2003-2008 (Fortune & Wen, 1999; Moorin, Miller, & Hendrie, 2014). The increasing incidence of ABI places more demand on services, and better models of service delivery are required to meet the needs of people living with ABI.

One in 45 people with ABI were estimated to be living with activity limitations and participation restrictions due to the disability caused by the injury (Australian Institute of Health and Welfare, 2007). People with ABI have different needs to people with other disabilities because they may experience a range of deficits, including cognitive deficits in memory, concentration, and decision making (Kat, Schipper, Knibbe, & Abma, 2010); general slowing of psychomotor functions, slower reaction times (Hoofien, Gilboa, Vakil, & Donovick, 2001), and motor control problems. People with ABI experience communication deficits and a decrease in social skills resulting in difficulties socialising and interacting with others (Kat et al., 2010), and limited social networks post-injury (Hoofien et al., 2001).

Psychiatric symptoms of depression and anxiety can also occur in people with ABI, as well as episodes of hostility and poor self-control (Hoofien et al., 2001). There are discrepancies in the reporting of symptoms, with family members often reporting that the person with ABI has more cognitive and physical symptoms, and less motivation and energy than reported by the person (Holm, Schonberger, Poulsen, & Caetano, 2009). Adapting to these lifelong changes can be challenging.

Following the acute stage of treatment, a person with ABI is engaged in a post-acute rehabilitation journey to manage and adapt to the ongoing deficits and return or find new meaningful occupations in the community. People with ABI can find this experience stressful and challenging, caused by problems with transport, finances, and employment, their living situation, and the loss of independence in completing daily tasks (Yates, 2003). The journey for people living with ABI in Western Australia begins with an intensive rehabilitation period of six to 12 months, followed by post-acute rehabilitation in a residential setting for approximately two years. Post-acute rehabilitation is based on goal setting, task analysis, and social reinforcement with a focus on improving skills resulted in improved engagement and motivation (Parish & Oddy, 2007). People with ABI who participated in post-acute rehabilitation may continue to regain skills many years post-injury (Parish & Oddy, 2007).

The perspectives of health professionals during the post-acute rehabilitation process were investigated and focused on three specific areas (Keightley et al., 2009; King & Curtin, 2014; Stergiou-Kita, Yantzi, & Wan, 2010). King and Curtin (2014) interviewed six occupational therapists working in brain injury rehabilitation in Australia to explore how occupational therapists used advocacy for their clients. All participants felt they had a role in advocating for people with brain injuries and their families, and the authors concluded that occupational therapists were well placed to fulfil this role due to the holistic and client-centred approach they use with their clients. Advocacy is important in assisting community integration; however, health professionals believed more training in advocacy skills was needed (King & Curtin, 2014). Occupational therapists' perceptions of the factors important to work readiness for people with ABI were explored by Stergiou-Kita et al. (2010). The findings of interviews with 10 occupational therapists highlighted that return to work for clients with ABI was dependent on the use of compensatory strategies and workplace factors such as employer support, accommodations made by the work environment, and communication with the employer (Stergiou-Kita et al., 2010). Health professionals placed

an emphasis on understanding the client's motivation to return to work as part of the rehabilitation process (Stergiou-Kita et al., 2010).

There are few longitudinal studies that have focused on the perspectives of people with ABI during post-acute rehabilitation. This has resulted in gaps in the knowledge base about what people with ABI believe best meet their needs over time. Understanding the perspectives of people with ABI in their journey through post-acute rehabilitation and beyond could assist in improving post-acute rehabilitation services and the person's ability to manage and adapt to changes they experience as a result of the injury. Rehabilitation services were more likely to be effective when the person was permitted to choose and meet their own individualised goals with the support of health professionals and their families (Bergquist et al., 2012; Doig et al., 2009).

A scoping review of the existing literature was undertaken to identify what is currently known, and to identify the gaps in rehabilitation services, from the perspectives of people with ABI. It is likely that there are elements of the rehabilitation experience that, when fully understood, could be used to inform changes to existing services that may improve the experiences and outcomes for people living with ABI.

2.2 Method

A scoping review was chosen to examine the extent, range, and nature of existing literature on the subjective experiences of people with ABI during post-acute rehabilitation, and to identify gaps in current knowledge about the experiences reported from the perspectives of people with ABI. Unlike, systematic reviews where a well-defined question and appropriate study design are identified in advance, a scoping review is used when the topic is not extensively reported and different study designs are relevant and included (Arksey & O'Malley, 2005).

Scoping reviews can include quantitative and/or qualitative research, and evaluation of the quality of the evidence is not essential (Rumrill, Fitzgerald, & Merchant, 2010). A scoping review can give meaning to complex and developmental topics (Davis, Drey, & Gould, 2009), and because ABI has been described as being a very complex experience (Australian Institute of Health and Welfare, 2007), a scoping review was considered an appropriate framework for this study. The methodological framework chosen for this scoping review was that described by Arksey and O'Malley (2005). This framework identifies five stages in conducting a scoping review: (i) identifying the research question;

(ii) identifying relevant studies; (iii) selecting studies; (iv) charting the data; and (v) summarising and reporting the data.

2.2.1 Identifying the research question

The focus of this scoping review was to collate and summarise the peer reviewed published research on the perspectives of people with ABI on their journey through post-acute rehabilitation. The research question guiding this study was 'What is known from the published, peer-reviewed literature about the experiences of people with ABI in post-acute rehabilitation services from their perspective?'

2.2.2 Identifying relevant studies

Relevant studies were identified for review using electronic searches of publications in the last 25 years in Scopus, PsychINFO, Science Direct, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and Web of Science databases. Search terms used included acquired brain injury, traumatic brain injury, experiences, rehabilitation, post-acute, community, and adults. The search terms were truncated, expanded, and adjusted to match the databases being searched. Inclusion criteria were studies with participants with ABI aged over 18 years; published in English language in peer-reviewed literature from 1990–2015; and used a qualitative methodology to describe the perspectives of people with ABI. Studies not done within the context of post-acute community based rehabilitation were excluded.

2.2.3 Selecting relevant studies

The electronic search located 36 articles from Science Direct, 11 from Scopus, five from PsychINFO, five from CINAHL, and four from Web of Science, for a total of 61 potential studies. A manual search of reference lists from relevant papers was completed to ensure any relevant peer-reviewed published literature was not excluded. The first author and a second researcher independently reviewed abstracts generated from the search strategy. The researchers met throughout the review process and discussed which abstracts met the criteria for full article review until agreement was reached on studies to include. If it was unclear from the abstract that the article met the inclusion criteria, then the full article was read.

2.2.4 Charting data

This process resulted in the inclusion of 20 articles published over 20 years (1993-2013) and a variety of geographical locations. Fifteen articles were published between 2003 and 2013.

A data extraction form was created and the information from the included articles was charted using the following criteria: citation, purpose of study, study design, context, recruitment method, sample characteristics, and the main findings. Consistent with a scoping review, the articles were not critically appraised using a critical appraisal tool (Arksey & O'Malley, 2005); however, reported actions that improved methodological rigour were summarised in the data extraction table. This charting process allowed for themes in the articles to be identified, grouped, and interpreted using thematic analysis.

2.2.5 Collating, summarizing, and reporting the results

Data about authors, publication, location and context, participants, methodology, rigour, and findings of the 20 included studies were collated to summarise the available evidence and are presented in Table 2.1.

2.3 Results

2.3.1 Types of research studies

The research studies were all of a qualitative design with a variety of approaches including phenomenology, mixed methods, qualitative design using interpretative interactionism, naturalistic paradigm, heuristic perspective, reflexive and dialogic approach, relative interactionist perspective, and grounded theory. All studies used structured, semi-structured or unstructured interviews as part of the data collection process.

2.3.2 Location of research and publication of findings

The studies were completed in six countries including the United Kingdom (UK; n=7), Australia (n=4), Sweden (n=4), Canada (n=3), Japan (n=1), and Denmark (n=1). The articles were published in a range of journals with the majority published in Brain Injury.

2.3.3 Participants

There were 268 participants in the reviewed studies. A majority were male (64%) and aged between 17 and 77 years. Time since ABI ranged from six months to 15 years and most participants were living at home and attending out-patient rehabilitation services at the time of the study.

Table 2.1. Summary of studies review in scoping review

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
Chamberlain (2006) The Journal of Advanced Nursing	Mixed methods design; only qualitative part discussed in the article; unstructured, in-depth interviews at 1 year post-injury. Qualitative content analysis.	Australian hospitals; TBI based on the Extended Glasgow Outcome Score.	60 people (40 males) who were admitted to ICU of participating hospitals between September 2001 and March 2002.	Analysis discussed between the author and the nurse researcher to ensure reliability. Agreement of >95% coding occurred.	Five main themes -: (1) grief and regret, (2) insensitivity, (3) invisibility, (4) stranded self, and (5) recovering self.
Conneeley (2003) British Journal of Occupational Therapy	Qualitative phenomenological approach, semi-structured interviews at discharge, 6 months, and 12 months post-discharge.	Hospital in United Kingdom (UK). Post-discharge from neurological rehabilitation ward.	People with ABI (n=18, 13 males; aged 17-60 years) and their significant others. Recruited at time of discharge from hospital if they met the inclusion criteria.	Member checking to improve credibility of findings. Information was reiterated periodically during the interview to ensure the meaning was correctly understood.	Four themes that influenced subjective perception of quality of life -: (1) wellbeing, (2) functional status,(3) personal autonomy, and (4) the acceptance of disability.
Crisp (1993) Disability, Handicap and Society	Qualitative, multiple interviews with participants over a 12 month period.	Completed in Australia. Author identified a need for further research on the experience of living with a TBI and to explore psychosocial responses.	Ten participants (6 males; aged 22-50 years) were recruited from a state-wide self-help organization and rehabilitation health professionals.	Themes revised and verified by the author after re-checking the transcribed interview data. Member checking with participants.	Findings about interpersonal relationships suggest a need for rehabilitation services to focus on issues in the social environment. The respondents' diverse perceptions concerning self, disability and handicap highlight the need for greater flexibility in interpreting or diagnosing psychosocial adjustment to disability

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
Gill, Wall, & Simpson (2012) Brain Injury	Qualitative design, participants interviewed once using semi-structured interviews.	Completed at a rehabilitation service in the UK, service selected due to their holistic and person-centred approach to care.	Seven participants (6 males) aged 26-50 y., living in a rehabilitation unit (n=4) and in the community (n=3).	Each stage of the analysis was reviewed by a different member of the research team to minimise researcher bias	Four main themes-:(1) I can live a normal life—Rebuilding self-belief; (2)It all boils down to each individual - Recognition of personal identity; (3)Things are different—Acceptance and Change; (4) It's like having our own tribe—Sense of community atmosphere
Haggstrom & Lund(2008) Journal Rehabilitation Medicine	Qualitative design. Interviews using an interview guide of 20 open-ended questions to allow participants to express their experience of participation in everyday life.	Rehabilitation service in Northern Sweden.	11 participants (5 males) aged 38 - 63 y. who were at least three years post - injury to ensure they had enough time to experience a variety of situations. Medical secretary selected participants.	Codes and categories were continuously compared against the data; every step of analysis by one author was reviewed by another author. Peer review completed by colleagues with experience in content analysis.	Five themes -: (1) Performing tasks; (2) Making decisions and exerting influence; (3) Being engaged in meaningful activities; (4) Doing things for others; and (5) Belonging. A variety of strategies were used to enhance participation.
Howes, Benton, & Edwards (2005) Psychology and Health	Qualitative design using interpretative interactionism. Semi-structured interviews using five broad questions.	Participants were living in the UK. Women who had a TBI at least 6 months prior to the interviews. Data collected at the hospital.	Six women aged 30-51 y.; three were injured ≤17 months prior and three ≤15 years prior. Referred from a district hospital by clinical neuropsychologist.	Independent rater reviewed the texts and created a table of themes. Discussion occurred until consensus on themes was reached.	Four themes -: (1) awareness of change, (2) emotional reaction, (3) the struggle to make sense, (4) adaptation and acceptance
Jones, Mandy, & Partridge (2008) Disability and Rehabilitation	Qualitative phenomenological approach. In depth interviewing using three questions as prompts.	An acute stroke unit and intermediary care team in the UK. The study sought to include people with diverse experiences in rehabilitation and varying social experiences.	Ten participants (6 males) aged 29-75 y. Purposive sampling to select participants at different times post-stroke. Registers of the acute stroke unit and intermediary care team were screened for suitable participants.	Two independent researchers with experience of stroke and qualitative research reviewed the interviews using the same process as the researchers.	Two themes with sub-categories (1)Personal or internal influences on recovery included personal strength and control over recovery, generalised optimism/hope and perceived dependence following stroke; (2)External influences included markers of independence and therapeutic interactions

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
Jumisko, Lexell, & Soderberg (2007) Disability and Rehabilitation	Qualitative inquiry using naturalistic paradigm to understand how people construct reality within their context. The participants with TBI were interviewed twice	Participants were from two different hospitals in Sweden and the patients' association. The study was within the naturalistic paradigm.	12 people with TBI (10 males) aged 23-50 y. and 8 close relatives. Recruited via a patients' association, and a psychologist and a nurse working at two hospitals in Northern Sweden.	The third author reviewed the categorisation by the first author. Reviews were performed repeatedly throughout the process.	Two themes and six categories -: (1) Being excluded: 'Being avoided', 'Searching for answers', and 'Being ruled by the authorities' (2) Missing confirmation: 'Being misjudged', 'Meeting distrustfulness', and 'Longing for right kind of help'
Klinger (2005) Journal of Occupational Science	Qualitative research approach using heuristic perspective. In-depth semi-structured interviews were completed.	Study done in Canada. Participants were from the local clubhouse and brain injury association	Seven participants (6 males) aged 29-47 y. were referred to the researcher from the directors of the local clubhouse and brain injury association. One participant was recruited through the researcher's clinical work.	The researcher kept a journal of personal impressions and reflections for truthfulness. Researchers met to clarify categories and themes. The themes were clarified through member-checking by participants.	Five themes-: (1) I am who I am, but I am not who I was before; (2) Who I am is intimately and completely intertwined with what I do and how I do it; (3) Adapting means accepting the new me; (4) I am different, thus I must change my doing; and (5) I am different, thus I must change the environment in which I do things.
Lefebvre, Pelchat, Swaine, Gelinat, & Levert (2005). Brain Injury	Qualitative design, reflexive and dialogic approach. Semi-structured interviews were used to explore different aspects of the participants' experiences.	The study was completed in the Greater Montreal area in Canada, to show the necessity of working in partnership with an individual who has a TBI and to establish appropriate skills and aptitudes.	Eight people with moderate to severe TBI aged 18-49 y., 8 family members, 22 health professionals and nine physicians. All participants recruited by key people from a tertiary trauma care centre, two rehabilitation centres, a paramedical organisation and association for people with TBI. All participants spoke French.	Internal validity of categorisation confirmed by two researchers from Family Intervention Research Team. To ensure continuity and credibility of the content of each category, units of meaning were verified in the context of emergent themes. Inter-rater reliability calculated from the categorisation of the three researchers.	Five themes -: (1) Information: communication and sharing of information; (2) Uncertainty experienced by all during the care process; (3) Relationships between the actors, and the relationship between the individual with TBI and care team, family members and care team and inter-disciplinary team; (4) Continuity of care and services; and (5) Adaptation process of the persons with TBI and their family.

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
Lewinter & Mikkelsen (1995) Disability and Rehabilitation	Qualitative design. In-depth interviews with 19 of the 21 participants, using a semi-structured interview schedule covering two topics, the patient's current situation, and their experience in rehabilitation.	Study completed in an experimental stroke unit in Denmark. A large number of studies involve physicians' perspectives, so the authors completed a study evaluating the program from the patients' perspectives.	Twenty-one participants, (11 males) aged 36 and 77 y. All patients in the unit were recruited into the study. The unit physician examined potential patients prior to their referral to the clinic.	Triangulation of interview data with other data sources (primarily medical chart data) and interviews with other participants (the participants all knew each other so it was "easy to corroborate many bits of information").	Results were grouped into four categories: (1) Being in a stroke unit; (2) Amount of rehabilitation; (3) Non-physical factors; and (4) Benefit of rehabilitation. Sub themes were generated from each of these categories.
Mansson Lexell, Alkhed, & Olsson (2013) Brain Injury	Qualitative design using semi-structured interviews. Interviews were completed using an interview guide and open-ended questions.	The study was completed in Sweden to address the lack of knowledge regarding how people with an ABI experience their rehabilitation and how the program can contribute to their everyday lives.	Eleven people (5 males) aged 25-62 y. participated. Recruited from those who participated in a group rehabilitation program run from 2004-2006.	The preliminary set of codes, sub-categories and theme were validated by the first author who read all the interviews and scrutinized the results of the analysis. All findings were discussed by all three authors until a consensus was obtained.	The group rehabilitation gave participants knowledge and tools to change everyday life:- (1) Learning to plan activities and to have a new routine in life; (2) Learning to use and accept support in daily life; (3) Knowledge facilitates adaptation in everyday life; and (4) Understanding the importance of adapting the social network to one's ability.
McColl, Carlson, Johnston, Minnes, Shue, Davies, & Karlovits (1998) Brain Injury	Qualitative methodology using intensive interviewing with each participant eight times during their first year in the community post injury to uncover the ideas and words used by people with brain injuries to define and describe community integration.	The study was completed in the United States of America (USA) and Canada. Part of a larger study on outcomes and processes of community integration for people with ABI that had rehabilitation.	Eighteen participants (15 males) aged 19-58 y. with moderate to severe injuries. Recruited from 14 community re-entry programs in Ontario.	Participation of all investigators and research staff in the coding and interpretation of data was an attempt to triangulate the findings and minimise bias.	Nine themes emerged in defining community integration: (1) Conformity; (2) Acceptance; (3) Orientation; (4) Close relationships; (5) Diffuse relationships; (6) Productivity; (7) leisure; (8) Independence; and (9) Living situation.

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
Murray & Harrison (2004) Disability and Rehabilitation	Qualitative design with the view that a person with a stroke is an expert in their own experience. Data collected via face-to-face and email interviews. Used interpretative phenomenological analysis.	Completed in the UK and No specific information on site and location given.	Ten people (4 males) aged 38 -55 y. who had a stroke, recruited through the National Stroke Network.	Emergent themes were presented and supported by the participants' actual discourse so the reader can assess the trustworthiness of the interpretations.	Four themes -: (1) Disrupted embodiment and loss of self; (2) Invisibility of emotional difficulties; (3) Gender, romance and sexuality; and (4) Social interaction.
Nochi (1998) Social Science and Medicine	Qualitative design (grounded theory) using semi-structured interviews to develop a deeper understanding of the sense of self experienced by people with TBI.	The study was completed in the USA by a Japanese researcher and used a narrative focus to help the person to understand themselves and gain a "universal truth". More information on the site of the study is needed.	Ten people with TBI (6 males) aged 24 - 49 y. Participants chosen as to whether they had insight into "loss of self experiences" related to TBI, so the researcher could obtain useful information for "theory building". Some participants were recruited from the TBI support list which contained email details and was available to the author. Other participants were recruited from a local TBI support group.	Checked by the researcher writing analytical memos, which were checked by a senior researcher. The researcher also made a presentation of the findings to the TBI support group and the participants agreed with the findings.	Three themes -: (1) Loss of clear self-knowledge; (2) Loss of self by comparison; and (3) Loss of self in the eyes of others.

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
O'Callaghan, Powell & Oyeboode (2006) Neuropsychological Rehabilitation	Interpretative phenomenological analysis of semi-structured interviews on how they had changed since the TBI, how they learned they had changed, what it felt like to learn they had changed, how they coped with learning about the changes	The study was completed in the UK. There are few studies around awareness of deficits, therefore the researchers decided to investigate awareness of deficits after TBI.	Ten people with moderate to severe TBI (7 males), aged 21 - 60 y. Participants attended an out-patient, post-acute rehabilitation service; they were invited to participate by their key worker or a therapist.	Triangulation occurred through a second researcher analysing a selection of transcripts. The final master themes and sub-themes were decided through discussions by the co-researchers	Eight master themes -: (1) People's reactions when things went wrong; (2) Personal discovery; (3) Explanations; (4) Obstacles to becoming aware; (5) Fear and loss; (6) Denial; (7) Accepting my changes; and (8) Me as I am now. From these, 16 sub themes were developed.
Parsons & Stanley (2008) Australian Occupational Therapy Journal	Phenomenological approach. In-depth interviews focused on the participants' descriptions of their experiences of occupational adaptation.	Study completed in rural Australia due to sparse attention being given to the perspective of people in rural areas.	Two male participants aged between 30 and 45 y. participated. Recruited from the Brain Injury Rehabilitation Services South Australia. No further detail about this process was given.	One participant reviewed the themes and a peer-review to finalise the themes occurred. Bracketing preconceptions occurred and these were documented in a journal.	Three main themes -: (1) Things are different now; (2) Acceptance; and (3) Just another chapter
Shotton, Simpson & Smith (2007). Brain Injury	Qualitative using interpretative phenomenological analysis. Flexible semi-structured interviews were developed through reviewing the literature. The Dysexecutive Questionnaire was used to compare the person's insights with the reports from their carers or family.	Completed in the United Kingdom. Little research has explored appraisal of TBI and there is conflicting evidence on coping, therefore this study will further explore coping.	Nine participants (7 men) aged between 21 and 59 y. were identified through the service user database. Participants were people with ABI who had accessed a neuropsychological rehabilitation service in north west England.	Ensured themes were supported through the data (dependability); multiple analyst consensus with the co-researchers reviewing three transcripts to validate the principal researcher's analysis (confirmability); and two participants reviewed themes (credibility).	Four interconnected themes-: (1) Waking up: understanding TBI; (2) I keep going: coping after TBI, (3) I knew I'd get better: beliefs about TBI; and (4) The benefits have far outweighed the consequences: searching for positives.

Citation	Study design and methodology	Context described	Sample and recruitment	Methodological rigour	Findings
Strandberg (2009) Social Work in Health Care	Relative interactionist perspective -the critical interpretation perspective. This involved seeking and interpreting the content of the everyday life and lived experience from a hermeneutic theory of science. Interviews used an interview guide covering six areas of interest: consequences of TBI, family and social networks, working life and occupation, life changes, support from society, and daily life.	The study was conducted at the University hospital of Orebro, Sweden. Previous studies raised questions about a person with a brain injury's life situation, rehabilitation and recovery process.	Fifteen people with TBI (10 males), aged 19 - 53 y. Varied cases sampling was used. Recruited with support from the outreach team at the University Hospital of Orebro, Sweden.	Analysis performed using many steps and another researcher worked through the process with the main researcher. The main researcher acknowledged the risk of bias in the results.	Six themes -: (1) The meaning of care - a question of formal and/or informal support; (2) The meaning of action - a question of activity versus inactivity; (3) Autonomy - a question of dependence versus independence; (4) Social interaction -a question of encounter and/or treatment; (5) The theme of changes - a question of process versus stagnation; and (6) Emotions, an oscillation between hope versus hopelessness.
Turner, Fleming, Cornwell, Worrall, Ownsworth, Haines, Kendall & Chenoweth (2007) Brain Injury	Phenomenological approach using in-depth semi-structured interviews that followed a set of six questions. Prompts were given to allow for elaboration of responses.	The study was completed in Australia. It was recognised that further research was needed to gain an in-depth understanding of the lived transition experiences of people with an ABI and their family caregivers. The study was completed in Australia.	Thirteen participants with ABI (6 males), aged 19–53 y. recruited from a hospital-based ABI out-patient service and a community-based ABI case management service. Participants were screened for eligibility by a health professional using the inclusion criteria.	Consensus coding between two researchers was used. Member checks performed by a member of the research team discussing a summary document with each participant for comment and feedback. A high level of support was identified for the key themes in this member checking process.	Eight categories -: (1) The hospital experience; (2) The transition process; (3) The role of families/caregivers; (4) Post-discharge services; (5) Friendships, networks, and community involvement; (6) Meaningful activities and time management; (7) Physical and psychological wellbeing; and (8) Barriers and facilitators.

2.3.4 Thematic analysis

The main findings of all articles were summarised using thematic analysis (Braun & Clarke, 2006) and recurrent themes identified. Twenty emergent themes were grouped into eight broad themes using a card sort process. The first author met with another member of the research team to discuss and reach consensus on four recurrent themes: (1) loss of self; acceptance of the injury; (2) responses of significant others towards the person with ABI; (3) relationships with family and rehabilitation team; and (4) occupational engagement and performance.

Loss of self: Acceptance of the injury

Many of the included studies reported that people with ABI undergoing rehabilitation experienced psychological changes that affected their rehabilitation experience. In particular, grief for the loss of *the person they were* prior to the injury (Chamberlain, 2006; Klinger, 2005; Nochi, 1998) and *feeling changed as social beings* (Howes, Benton, & Edwards, 2005) were reported as significant impacts that affected the rehabilitation outcomes of people with ABI.

People with ABI reported that in order to deal with the psychological changes there was a need to rebuild their self-belief and accept that although life was different now, they could lead a normal life (Gill, Wall, & Simpson, 2012; Parsons & Stanley, 2008). O'Callaghan and colleagues described this as the need for a journey of personal discovery (O'Callaghan, Powell, & Oyebode, 2006), and another study reported that acceptance of the ABI, which could be facilitated by acceptance and commitment therapy, was important during the rehabilitation journey (Gill et al., 2012). People with ABI reported feelings of anxiety and anger as they became aware of their physical and/or psychological losses post-injury, but they were able to make sense of the situation through the guidance received from health professionals (Howes et al., 2005). Integration of the person's physical and psychological limitations into developing their concept of self throughout their rehabilitation journey was important in achieving an acceptable quality of life (Conneeley, 2003).

Accepting and adapting to changes were made easier for the person with ABI when unexpected benefits of the ABI were identified; for example, positive changes to the family relationships or lifestyles (Shotton, Simpson, & Smith, 2007). By accepting their loss and developing a new identity, the person developed the ability to 'value life in a different, more meaningful way' (Howes et al., 2005, p. 136).

Responses of significant others towards the person with ABI

The psychological impact of ABI was related not only to the person's own thoughts and feelings about themselves, but also the impact of the attitudes and responses of other people. People with ABI reported experiencing 'invisibility', and insensitivity from others, and their need for more recognition by their significant others of their new personal identity (Chamberlain, 2006; Howes et al., 2005; Murray & Harrison, 2004). The lack of recognition from others and a need to encourage greater flexibility in the interpretation and diagnosis of the psychological impact of ABI that includes an awareness of the effect of other peoples' behaviours on the person has been highlighted (Crisp, 1993). This lack of recognition and insensitivity was referred to as a 'loss of self in the eyes of others' (Nochi, 1998).

People with ABI reported that people, including those who knew them before their injury, were afraid to talk to them (Jumisko, Lexell, & Söderberg, 2007). Friends of the person and their families found it difficult to accept how the person had changed and so it was easier to avoid the person and the family (Jumisko et al., 2007); consequently people with ABI felt alone and dehumanised throughout the journey (Chamberlain, 2006). Not everyone had the same experience and receiving rehabilitation in their own cultural context limited the impact of social isolation (Gill et al., 2012).

Relationships with family and the rehabilitation team

Relationships with other people including family and the care team were recognised as important during the rehabilitation journey (Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005). Resumption of social relationships with family and others were important when the person returned home (McColl et al., 1998), even though relationships between the person with ABI and their family had to adapt and change as the journey through rehabilitation progressed (Lefebvre et al., 2005; Turner et al., 2007). People with ABI valued meeting new people throughout the rehabilitation journey and those with close friendship networks were more likely to engage in social activities than those without these networks (Turner et al., 2007).

Regular and consistent communication and sharing of information among the person, family, and the interprofessional care team were required to ensure successful rehabilitation outcomes (Lefebvre et al., 2005; McColl et al., 1998). Having an optimistic, honest, and encouraging therapist improved the person's confidence in their recovery

(Jones et al., 2008), although some people with ABI felt inequality and insensitivity in the relationship with their therapist (Chamberlain, 2006; Jones et al., 2008). The care team needed to build trust also with the family because as the person with ABI became more independent, the family needed to know they were safe (McColl et al., 1998). Families' expectations about the outcomes of rehabilitation had an impact on whether the experience through rehabilitation was positive for the person; for example, knowing that physical injuries may have healed but understanding that emotional and cognitive difficulties may remain (McColl et al., 1998; O'Callaghan et al., 2006).

Involving people with ABI in social relationships with others beyond their family and care staff was important for successful rehabilitation (McColl et al., 1998). There is limited evidence reported about the changes in the relationship of the person with ABI and their family and friends (Lefebvre et al., 2005; Turner et al., 2007), and less about how interactions change between a person with ABI and their friends, and how they make new friends post-injury (McColl et al., 1998). People with ABI had different social experiences and had fewer social contexts following injury (Crisp, 1993; Haggstrom & Lund, 2008). Changes to social relationships resulted in a loss of previous friendships; for example, many friends lacked the courage to talk to the person with ABI post-injury (Jumisko et al., 2007), and fewer new relationships with people outside the family (Crisp, 1993; Jumisko et al., 2007).

Occupational engagement and performance

Rehabilitation is a long term process for a person with ABI post-injury that required perseverance and motivation (Lexell, Alkhed, & Olsson, 2013). There were no clear conclusions in the literature about what internal and external factors motivated people with ABI to achieve their rehabilitation goals. Personal strength, hope, perceived dependence, and interaction with health professionals were identified as factors that could motivate the person towards successful rehabilitation (Jones et al., 2008). Engagement in meaningful occupations was also connected with maintaining motivation for rehabilitation (Strandberg, 2009). Gill et al. (2012) reported the person with ABI believing 'I can live a normal life' was important for them to rebuild self-belief; particularly as the rehabilitation journey continued over the long term. People with ABI hoped that everything would return to its previous state; however, this hope for a return to a normal life diminished as their rehabilitation progressed over time (Shotton et al., 2007). People with individualised goals aimed at increasing their engagement in vocational activities, such as paid or voluntary

work, and leisure occupations were likely to have a positive experience throughout the rehabilitation journey (Turner et al., 2007).

Experiencing a sense of community during rehabilitation was likely to result in the person's successful engagement in meaningful occupations on their return home; however, ongoing contact from the rehabilitation team via telephone calls and home visits was required after discharge (Gill et al., 2012). The experience of having a sense of community was supported by Lexell et al. (2013) who identified that group rehabilitation was beneficial in acquiring the knowledge and skills to perform everyday occupations

Rehabilitation services that focused on the person's social environment created a community atmosphere that allowed for improved engagement and performance in meaningful occupations (Crisp, 1993; Gill et al., 2012). A range of strategies can enhance a person's experience in engaging in activities (Haggstrom & Lund, 2008), including learning how to plan activities, develop new routines, accept supports, and understand the importance of adapting their social environment (Lexell et al., 2013). Successful engagement and interaction in meaningful occupations required the person to prioritise activities that gave them a sense of belonging; avoid environments that restricted their participation and performance; and plan tasks in new ways to enhance their engagement in the activities (Haggstrom & Lund, 2008). This is a process of the person working from dependence to autonomy in their performance of meaningful occupations (Strandberg, 2009; Turner et al., 2007).

The research literature did not provide a comprehensive understanding of how prejudices towards people with ABI affected their engagement in the community during their rehabilitation journey. People with ABI reported they felt insensitivity and a lack of recognition from those around them (Crisp, 1993; Nochi, 1998). Involvement in meaningful community activities was restricted by community prejudices towards people with ABI (Haggstrom & Lund, 2008) and rehabilitation was more successful when there were fewer restrictions to involvement in the community (Andelic, 2010).

2.4 Discussion

The psychological impacts of the 'changed-self' and the attitudes and responses of others were reported as important factors affecting the rehabilitation journey. People with ABI have a need for more psychological support to assist them to accept their injury and deal with the changes to their physical abilities and emotions caused by the injury.

Psychological supports were needed to assist in building self-belief and were of particular importance when the person's insight into their injury was developing and they realised for the first time that they were very different to the person they were before the injury. These findings highlight the importance of psychological support for people with ABI at this time because improved self-belief, acceptance of who they are, and assistance in identifying positives were linked in several studies to improvement in motivation during post-acute rehabilitation and in more efficient and effective achievement of rehabilitation goals (Howes, Benton, & Edwards, 2005; Gill, Wall, & Simpson, 2012; Klinger, 2005; McColl et al., 1998; O'Callaghan et al., 2006; Parsons & Stanley, 2008; Shotton et al., 2007). Psychological interventions, such as Cognitive Behavioural Therapy and counselling for acceptance of the injury and managing emotions that are delivered individually or to groups, have been shown to be effective in the treatment of depressive symptoms and to assist with developing a new sense of self (Stalder-Luthy et al., 2013).

This scoping review has highlighted the importance of psychological supports to assist family members to accept the person post-injury and to improve their understanding of how the injury had and would continue to affect the person. Research findings that family and familiar others did not know how to interact and support the person with ABI after injury highlights families' need for education about how to interact and manage their relationships. Families also needed psychological support to adjust to the physical, cognitive, and emotional changes in the person, and to deal with the increased social isolation that the person with ABI and their family often experienced. Effective emotional support from family and friends to assist the person to meet their individualised social and occupational goals is important throughout the rehabilitation process (Sander, Maestas, Sherer, Malec, & Nakase-Richardson, 2012). When the relationships between the person with ABI and their family and friends can be enhanced through psychological assistance, positive post-acute rehabilitation outcomes are likely for the person with the ABI with associated benefits to their family (Dillahunt-Aspillaga et al., 2013).

This review has shown there is evidence that more interventions are needed that focus on developing and maintaining relationships, in particular with family and friends (Murray & Harrison, 2004; Nochi, 1998; McColl et al., 1998; Mansson et al., 2013; Lefebvre et al., 2005; Crisp, 1993). Health professional teams should develop effective rapport and relationships with the person and their family because such relationships enable the transfer of information about the injury and the person's rehabilitation to the family;

ensure the family has appropriate expectations of the person and their rehabilitation; and facilitate the development of family relationships when many changes have occurred to the person following their injury. Further research is recommended to address the changes in relationships between people with ABI and their old and new friends, as well as changes to the social contexts in which they engage. Service providers should consider changes in the person's relationships as important in the rehabilitation process in order to improve rehabilitation outcomes.

Education and awareness programs are needed to develop community understanding of ABI and to provide more opportunities for people with ABI to be involved in the community, including paid or volunteer work and community-based leisure activities that enable them to engage in occupational roles they previously held or new roles that contribute to their overall health and well-being. Work as a meaningful activity was shown to be an important part of rehabilitation as it helped establish a daily structure for people with ABI (Johansson & Tham, 2006). The findings of the current scoping review has confirmed that the involvement of people with ABI in meaningful work activities could help reduce community prejudices and negativity towards people with ABI (McLellan, Bishop, & McKinlay, 2010). The opportunity for community participation would also potentially have a significant impact on people with ABI as it would provide them with opportunities to develop friendships outside of their family and other people with ABI. Improved community awareness and understanding of ABI may provide opportunities for participation that help people with ABI to have better self-belief and independence (Linden, Hanna, & Redpath, 2007).

This scoping review has identified that opportunities exist for consumer-orientated research in the area of ABI, where the consumer, in this case the person with ABI, is actively involved in the research. People with ABI can identify and discuss their experiences providing valuable information for the development of future services. Seeking the views of health consumers regarding health research is recognised as important for accessing valuable knowledge and essential in good research practice (Payne et al., 2011; Saunders, Crossing, Girgis, Butow, & Penman, 2007). Participation in research including identifying the research needs, creating the hypothesis, and disseminating research findings was valued by people with ABI and had a positive impact on their experiences by increasing their motivation, self-belief, and independence (Saunders et al., 2007).

Achievement of goals in post-acute ABI rehabilitation can progress slowly (Parish & Oddy, 2007). This scoping review found that the intrinsic and extrinsic motivations for achieving goals in post-acute rehabilitation are not fully understood, but the motivation of people with ABI during the post-acute rehabilitation period may improve if they receive psychological support and interventions to facilitate and maintain their relationships with family and friends, and if there is better community awareness of ABI.

Directions for future research

Only seven of the 20 studies reviewed were longitudinal in design, so in many cases information was missing about the experiences of people with ABI at various time points throughout their rehabilitation. The literature focused on people in the first two years post-injury with very little information available on how people were managing 10-15 years post-injury and how their rehabilitation needs changed over time. This evidence can be used to inform service providers on how to more effectively predict the outcomes of their rehabilitation practices, and appropriately target their interventions to assist the person to manage the challenges they face after discharge from post-acute rehabilitation.

Only one study reported on the positive experiences of people after sustaining an ABI. Shotton et al. (2007) noted that people with ABI reported beneficial changes in their lifestyles and positive experiences of self-discovery. If more studies reported some of the unexpected positive outcomes that occur from the changes people experience after an ABI; for example, improved relationships with family, meeting inspiring people, and experiences of self-discovery, this would provide an evidence base for providing encouragement to people with ABI as they progress through their rehabilitation.

There is an urgent need for research regarding the benefits of returning to existing occupations and developing new meaningful occupations in a community-context, and their relationship with re-establishing a new identity following ABI. This research is needed to help health professionals to develop rehabilitation programs with goals that focus on improving the person's health and wellbeing and sense of identity. Returning to existing occupations, developing new occupations within the community, and regaining a sense of identity may improve the rehabilitation experiences and rehabilitation outcomes for people with ABI (Maher, 2001)

The advice provided to people with ABI depended largely on the culture of the individuals' societies. All studies reviewed were conducted in a western culture, but given

that Australia has a large multicultural population it is important to have an understanding of the influence of each person's culture in order to better understand their ABI experience. This review highlighted the limitations of the available information from the perspectives of people with ABI, their families, health professionals, and the community. There is a need to learn more about the external and internal factors that motivate people with ABI to achieve their long term rehabilitation goals, and a need for an efficient and targeted approach to rehabilitation. Research is needed to provide the evidence on how to best individualise goals and design interventions that were adapted and appropriate throughout the rehabilitation journey, including after the person returns home. The need for support on the return home was highlighted as an area for future focus of interventions and support (Lefebvre et al., 2005; McColl et al., 1998; Turner et al., 2007).

Limitations

The methodological framework used for this scoping review aimed to identify all the available literature in the area of study. The included articles were limited to qualitative studies because the focus was on understanding perspectives and experiences. In order to manage the large quantity of data, inclusion criteria were developed to identify studies suitable for the purpose of this review. While the use of qualitative methodologies were appropriate to address the phenomena of interest and the intentions were not to generalise findings rather to gain a better understanding of the findings, any interpretations in the studies were dependent on whether the studies' authors achieved saturation of their data, how saturation was determined, and how biases in the respective study samples were managed. The studies selected for this scoping review were purposively sampled to ensure the studies reported on the experiences of people with ABI. Studies published in languages other than English were not included in this scoping review, which may have excluded important and relevant studies.

2.5 Conclusion

The gaps identified in the literature revealed the need for more reporting and better understanding of the perspectives of people with ABI at different times throughout their post-acute rehabilitation journey. Few studies reported on the positive experiences that people with ABI have post-injury. This review found evidence that interventions to improve self-belief, increase community acceptance, develop relationships with others, reduce prejudices, and increase engagement in meaningful activities were important for people

with ABI during their post-acute rehabilitation journey. More psychological supports for people with ABI and their families are needed to assist in motivating the person to achieve their rehabilitation goals. Further research from the perspectives of people with ABI and involving them in the research process may result in improved rehabilitation outcomes and services in the future.

2.6 References

- Andelic, N., Sigurdardottir, S., Schanke, A.K., Dandvik, L., Sveen, U. & Roe, C. (2010). Disability, physical health and mental health one year after traumatic brain injury. *Disability and Rehabilitation*, 32(13), 1122-1131. doi:10.3109/09638280903410722
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32. doi:10.1080/1364557032000119616
- Australian Institute of Health and Welfare. (2007). *Disability in Australia: Acquired brain injury*. Canberra: AIHW. Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453666>.
- Bergquist, T. F., Micklewright, J. L., Yutsis, M., Smigielski, J. S., Gehl, C., & Brown, A. W. (2012). Achievement of client-centred goals by persons with acquired brain injury in comprehensive day treatment is associated with improved functional outcomes. *Brain Injury*, 26(11), 1307-1314. doi:10.3109/02699052.2012.706355
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi:10.1191/1478088706qp063oa
- Bryan-Hancock, C., & Harrison, J. (2010). The global burden of disease project 2005: Methods utilised by the injury expert group for estimating world-wide incidence and prevalence rates. *Injury Prevention*, 16(Suppl 1), A99-A99. doi:10.1136/ip.2010.029215.356
- Chamberlain, D. J. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing*, 54(4), 407-417. doi:10.1111/j.1365-2648.2006.03840.x
- Conneeley, A. L. (2003). Quality of life and traumatic brain injury: A one-year longitudinal qualitative study. *British Journal of Occupational Therapy*, 66(10), 440-446. doi:10.1177/030802260306601002
- Crisp, R. (1993). Personal responses to traumatic brain injury: A qualitative study. *Disability, Handicap & Society*, 8(4), 393-404. doi:10.1080/02674649366780371

- Davis, K., Drey, N., & Gould, D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies*, 46(10), 1386-1400. doi:10.1016/j.ijnurstu.2009.02.010
- Dillahunt-Aspillaga, C., Jorgensen-Smith, T., Ehlke, S., Sosinski, M., Monroe, D., & Thor, J. (2013). Traumatic brain injury: Unmet support needs of caregivers and families in Florida. *PLOS ONE*, 8(12), e82896. doi:10.1371/journal.pone.0082896
- Dimancescu, M. D. (2007). Neurosurgery and acquired brain injury: An educational primer. In J. Elbaum & D. Benson (Eds.), *Acquired brain injury: An integrative neuro-rehabilitation approach* (pp. 4-17). New York: Springer.
- Doig, E., Fleming, J., Cornwell, P. L., & Kuipers, P. (2009). Qualitative exploration of a client-centered, goal-directed approach to community-based occupational therapy for adults with traumatic brain injury. *American Journal of Occupational Therapy*, 63(5), 559-568. doi:10.5014/ajot.63.5.559
- Fortune, N., & Wen, X. (1999). *The definition, incidence and prevalence of acquired brain injury in Australia*. Canberra: AIHW Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442467114>.
- Gill, I. J., Wall, G., & Simpson, J. (2012). Clients' perspectives of rehabilitation in one acquired brain injury residential rehabilitation unit: A thematic analysis. *Brain Injury*, 26(7-8), 909-920. doi:10.3109/02699052.2012.661118
- Granacher, R. P. (2003). *Traumatic brain injury: Methods for clinical and neuropsychiatric assessment*. London: CRC Press.
- Haggstrom, A., & Lund, M. L. (2008). The complexity of participation in daily life: A qualitative study of the experiences of persons with acquired brain injury. *Journal of Rehabilitation Medicine*, 40(2), 89-95. doi:10.2340/16501977-0138
- Holm, S., Schonberger, M., Poulsen, I., & Caetano, C. (2009). Patients' and relatives' experience of difficulties following severe traumatic brain injury: the sub-acute stage. *Neuropsychological Rehabilitation*, 19(3), 444-460. doi:10.1080/09602010802296402
- Hoofien, D., Gilboa, A., Vakil, E., & Donovan, P. J. (2001). Traumatic brain injury (TBI) 10?20 years later: A comprehensive outcome study of psychiatric symptomatology,

cognitive abilities and psychosocial functioning. *Brain Injury*, 15(3), 189-209.
doi:10.1080/026990501300005659

Howes, H., Benton, D., & Edwards, S. (2005). Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology & Health*, 20(1), 129-142.
doi:10.1080/0887044042000272903

Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007). The impact of traumatic brain injuries: A global perspective. *NeuroRehabilitation*, 22(5), 341-353. Retrieved from <https://search.ebscohost.com>

Johansson, U., & Tham, K. (2006). The meaning of work after acquired brain injury. *American Journal of Occupational Therapy*, 60(1), 60-69. doi:10.5014/ajot.60.1.60

Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: A perspective based on personal experience. *Disability and Rehabilitation*, 30(7), 507-516.
doi:10.1080/09638280701355561

Jumisko, E., Lexell, J., & Söderberg, S. (2007). The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives. *Disability and Rehabilitation*, 29(19), 1535-1543.
doi:10.1080/09638280601055816

Kat, L., Schipper, K., Knibbe, J., & Abma, T. A. (2010). A patients journey: Acquired brain injury. *British Medical Journal*, 340,c808. doi:10.1136/bmj.c808

Keightley, M. L., Ratnayake, R., Minore, B., Katt, M., Cameron, A., White, R., . . . Colantonio, A. (2009). Rehabilitation challenges for Aboriginal clients recovering from brain injury: A qualitative study engaging health care practitioners. *Brain Injury*, 23(3), 250-261. doi:10.1080/02699050902748331

King, D., & Curtin, M. (2014). Occupational therapists' use of advocacy in brain injury rehabilitation settings. *Australian Occupational Therapy Journal*, 61(6), 446-457.
doi:10.1111/1440-1630.12149

Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science*, 12(1), 9-16.
doi:10.1080/14427591.2005.9686543

- Lefebvre, H., Pelchat, D., Swaine, B., Gélinas, I., & Levert, M. J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury, 19*(8), 585-597. doi:10.1080/02699050400025026
- Lexell, E. M., Alkhed, A.-K., & Olsson, K. (2013). The group rehabilitation helped me adjust to a new life: Experiences shared by persons with an acquired brain injury. *Brain Injury, 27*(5), 529-537. doi:10.3109/02699052.2013.765598
- Lewinter, M., & Mikkelsen, S. (1995). Patients' experience of rehabilitation after stroke. *Disability and Rehabilitation, 17*(1), 3-9. doi:10.3109/09638289509166621
- Linden, M. A., Hanna, D., & Redpath, S. J. (2007). The influence of aetiology and blame on prejudice towards survivors of brain injury. *Archives of Clinical Neuropsychology, 22*(5), 665-673. doi:10.1016/j.acn.2007.04.009
- Mahar, C., & Fraser, K. (2001). Strategies to facilitate successful community reintegration following acquired brain injury. *International Journal of Disability Management Research, 6*(1), 68. doi:10.375/jdmr.6.1.68
- McColl, M. A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The definition of community integration: Perspectives of people with brain injuries. *Brain Injury, 12*(1), 15-30. doi:10.1080/026990598122827
- McLellan, T., Bishop, A., & McKinlay, A. (2010). Community attitudes toward individuals with traumatic brain injury. *Journal of International Neuropsychological Society, 16*(4), 705-710. doi:10.1017/s1355617710000524
- Moorin, R., Miller, T. R., & Hendrie, D. (2014). Population-based incidence and 5-year survival for hospital-admitted traumatic brain and spinal cord injury, Western Australia, 2003-2008. *Journal of Neurology, 261*(9), 1726-1734. doi:10.1007/s00415-014-7411-y
- Murray, C. D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretative phenomenological analysis. *Disability and Rehabilitation, 26*(13), 808-816. doi:10.1080/09638280410001696746

- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine*, 46(7), 869-878. doi: 10.1016/S0277-9536(97)00211-6
- O'Callaghan, C., Powell, T., & Oyeboode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychological Rehabilitation*, 16(5), 579-593. doi:10.1080/09602010500368834
- Parish, L., & Oddy, M. (2007). Efficacy of rehabilitation for functional skills more than 10 years after extremely severe brain injury. *Neuropsychological Rehabilitation*, 17(2), 230-243. doi:10.1080/09602010600750675
- Parsons, L., & Stanley, M. (2008). The lived experience of occupational adaptation following acquired brain injury for people living in a rural area. *Australian Occupational Therapy Journal*, 55(4), 231-238. doi:10.1111/j.1440-1630.2008.00753.x
- Payne, J. M., D'Antoine, H. A., France, K. E., McKenzie, A. E., Henley, N., Bartu, A. E., . . . Bower, C. (2011). Collaborating with consumer and community representatives in health and medical research in Australia: Results from an evaluation. *Health Research Policy and Systems*, 9(1), 1-14. doi:10.1186/1478-4505-9-18
- Roozenbeek, B., Maas, A. I. R., & Menon, D. K. (2013). Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*, 9(4), 231-236. doi:10.1038/nrneurol.2013.22
- Rumrill, P. D., Fitzgerald, S. M., & Merchant, W. R. (2010). Using scoping literature reviews as a means of understanding and interpreting existing literature. *Work*, 35(3), 399-404. doi:10.3233/wor-2010-0998
- Sander, A. M., Maestas, K. L., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2012). Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: A multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, 93(5), 842-848. doi:10.1016/j.apmr.2011.11.031
- Saunders, C., Crossing, S., Girgis, A., Butow, P., & Penman, A. (2007). Operationalising a model framework for consumer and community participation in health and medical

research. *Australia and New Zealand Health Policy*, 4(1), 1-6. doi:10.1186/1743-8462-4-13

Shotton, L., Simpson, J., & Smith, M. (2007). The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: A qualitative investigation. *Brain Injury*, 21(8), 857-869. doi:10.1080/02699050701481621

Stalder-Luthy, F., Messerli-Burgy, N., Hofer, H., Frischknecht, E., Znoj, H., & Barth, J. (2013). Effect of psychological interventions on depressive symptoms in long-term rehabilitation after an acquired brain injury: a systematic review and meta-analysis. *Archives of Physical Medicine & Rehabilitation*, 94(7), 1386-1397. doi:10.1016/j.apmr.2013.02.013

Stergiou-Kita, M., Yantzi, A., & Wan, J. (2010). The personal and workplace factors relevant to work readiness evaluation following acquired brain injury: occupational therapists' perceptions. *Brain Injury*, 24(7-8), 948-958. doi:10.3109/02699052.2010.491495

Strandberg, T. (2009). Adults with acquired traumatic brain injury: Experiences of a changeover process and consequences in everyday life. *Social Work in Health Care*, 48(3), 276-297. doi:10.1080/00981380802599240

Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., . . . Chenoweth, L. (2007). A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury*, 21(11), 1119-1130. doi:10.1080/02699050701651678

Yates, P. J. (2003). Psychological adjustment, social enablement and community integration following acquired brain injury. *Neuropsychological Rehabilitation*, 13(1-2), 291-306. doi:10.1080/09602010244000408

CHAPTER 3

3.0 The journey from the perspective of people with Acquired Brain Injury and their Families

3.1 Introduction

An acquired brain injury (ABI) is an injury to the brain after birth due to an accident or trauma, infection of the brain, disease, stroke, or drug and alcohol misuse (Head West Brain Injury Association of Western Australia, 2014). An ABI can cause enduring impairments including physical and cognitive changes such as memory loss, concentration and decision making difficulties, and changes to motor function and communication skills (Australian Institute of Health and Welfare, 2007; Kat et al., 2010). An estimated 432,700 people live with ABI in Australia, with approximately one in 45 people with ABI experiencing activity limitations and participation restrictions due to disability caused by the injury (Australian Bureau of Statistics, 2009).

In the acute stage of ABI, hospital admission is commonly required to medically treat physical and cognitive impairments. Medical treatments can include surgery to manage physical injuries, neurological assessments such as the Glasgow Coma Scale to monitor cognitive function, and medication to manage a range of symptoms such as headaches, fatigue, nausea and dizziness (Wittstatt & Valadka, 2017). Treatment strategies and the length of stay in acute care varies depending on the severity of the brain injury. Once the person is assessed as medically stable they undergo post-acute rehabilitation to help them regain skills and learn ways that they and their family can cope with the changes related to the injury (Parish & Oddy, 2007). This post-acute rehabilitation may last for many years (Parish & Oddy, 2007), depending on the rate and extent of recovery. A person with ABI living in Western Australia may be referred by the discharging hospital to a residential rehabilitation service for post-acute rehabilitation that is usually for a period of two to three years (Kreutzer et al., 2001). Post-acute rehabilitation consists of intensive therapy that is provided by an interprofessional care team including nursing, occupational therapy, physiotherapy, psychology, social work, and community support workers (Kreutzer et al., 2001). The aim of post-acute rehabilitation is to develop the person's physical, cognitive, and social skills so they can be discharged to an appropriate living environment, such as living independently in the community, with family, in shared supported accommodation, or residential aged care (De Koning, Spikman, Coers, Schonherr, & Van Der Naalt, 2015).

The scoping review of literature reporting on the perspectives of people with ABI identified gaps in the evidence on the interventions available to assist people with ABI to maintain relationships with their families and friends (see Chapter 2). The recommendations based on the findings of the scoping review included the need for more research on the impact of ABI on a person's existing friendships, the development of new friendships, changes to relationships with family members, and the social contexts in which the person with ABI engages. The scoping review identified the importance of engaging in community activities such as paid or unpaid work to assist people with ABI develop opportunities to widen their social networks and form new relationships.

The scoping review also highlighted the lack of available information about ABI and its impacts from the perspectives of people with ABI, their families, health professionals, and the community. This identifies the opportunities for people with ABI to share their experiences through participation in research. Consumer-orientated research where people with ABI use their experiences to inform the focus and design of future studies and dissemination of the findings would be valuable. Consumer-oriented research involves consumers, community members, and researchers working together for the duration of the project on research priorities, policies, and practices that are important to the consumers and the researchers (McKenzie & Hanley, 2014). This research approach can include high level involvement and co-production such as consumers initiating the research, deciding on the research question, and study methodology, to lower level involvement such as asking the opinions of the consumers during the research process (McKenzie & Hanley, 2007). When done well, involving consumers allows for better research practice and helps empower consumers which can be beneficial to the motivation and independence of people with ABI (Saunders, Crossing, Girgis, Butow, & Penman, 2007). The scoping review in Chapter 2 noted more work is needed to identify the external and internal factors that motivate achievement of long term goals and the need for a targeted and efficient approach to rehabilitation for people with ABI.

The aim of this study was to report on the perspectives of people with ABI, and their families, about their rehabilitation journey at a Western Australian post-acute rehabilitation service. In particular, the study focused on identifying the enablers and barriers to successful post-acute rehabilitation from the perspectives and lived experiences of people with ABI and their families, in order to inform service providers and to assist with improving the existing services.

3.2 Method

3.2.1 Study design

Qualitative research methods can be used to make sense of complex situations (Wills, 2007). This study used a qualitative phenomenological approach to guide the study design, data collection, and data analyses to deepen our understanding of the complex experience of ABIs. Phenomenology “describes the common meaning for several individuals of their lived experience” (Creswell, 2013, p.76) and is best used when studying the meaning of a person’s experience (Richards & Morse, 2007). Phenomenology focuses on understanding from the perspective of the persons being studied, thus, phenomenological research methods attempt to identify the perceptions of the participants (Willis, 2007). Using this approach gave the study participants opportunities to describe their common experiences and perspectives of ABI as they moved through the rehabilitation journey over a 12-month period, these data were subsequently analysed to develop a description of the essence and meaning of the lived experiences of people with ABI. Data were collected using in-depth semi-structured interviews to explore the important features of the participants' lived experiences (Liamputtong, 2013)

3.2.2 Participants

Study participants were recruited from the Brightwater Oats Street residential post-acute rehabilitation facility in metropolitan Perth, Western Australia. Purposive sampling of participants ensured the in-depth experiences of people with ABI in post-acute rehabilitation were explored (Liamputtong, 2013). The inclusion criteria were (i) adults with ABI resulting from a traumatic brain injury, stroke, or infection of the brain; (ii) who had received services from Brightwater Oats Street in the past 12 months; (iii) able to nominate a family member also willing to participate in the study; and (iv) able to provide informed consent to participate in the study.

Case managers at the facility assisted with recruitment of participants by identifying suitable participants who met the inclusion criteria and were willing to participate. Case managers who worked intensively with the participants were able to assess whether the person had the cognitive ability to provide informed consent. Case managers discussed the study with potential participants who were then contacted by the

researchers if they agreed to hear more about the study. Eleven people with ABI were nominated and 10 of these agreed to participate in the study.

Ethics approval for this study was granted by the Curtin University Human Research Ethics Committee (HR 144/2012). All participants provided informed consent prior to data collection.

3.2.3 Data Collection

The researcher conducted all interviews using an interview schedule (see Figure 3.1). Interviews ranged in duration from 30 to 105 minutes with an average time of 45 minutes and were audio-recorded with the participants' consent. The interviewer made field notes and recorded relevant observations during the interviews.

Questions for the person with ABI - Interview 1
<p>Tell me about yourself? <i>-Prompts:</i> previous employment, previous activities you enjoyed, current work situation, current social activities, leisure interests</p> <p>What is your relationship like with your family? <i>-Prompts:</i> who are you close to? How would you describe your relationship with your family members? How often do you see your family? What activities do you do when you see your family?</p> <p>Tell me about how you acquired a brain injury?</p> <p>What have been some significant events or experiences you have had during your rehabilitation?</p>
Questions for the person with ABI - Interview 2
<p>What is happening for you with your rehabilitation at the moment?</p> <p>Where do you see yourself in six months? 12 months? 5-10 years?</p> <p>What have been the main challenges you have experienced throughout your rehabilitation journey?</p>
Questions for family members
<p>How would you describe the experience through rehabilitation for (person with ABI)?</p> <p>What has been helpful? What has been challenging?</p> <p>How has your life changed since the ABI?</p> <p>Thinking about the future, what are your plans? What would you like to see happen?</p> <p>What changes would you like to see occur in the rehabilitation of people with an ABI?</p>

Figure 3.1. Sample questions used in the semi-structured interviews

Participants with ABI were interviewed at two time points, with the second interview occurring six months after the first interview in order to explore the impact of time on their experiences. The first interview with each participant was preceded by a discussion to provide them with more information about the study and to obtain their informed consent. During the first interview, the interviewer asked participants with ABI about the cause of their injury; their occupations; family situation; leisure interests prior to the injury; how their life had since changed; and significant events and experiences throughout their time in rehabilitation. The interviewer facilitated discussion about the participants' current work, social and leisure activities, and relationships with family and friends.

In the second interview, participants with ABI were asked about any changes since the first interview, in their work and leisure activities, and their relationships with family and friends. The interviewer clarified and further explored the information obtained in the first interview. The participants were also asked about their plans for the future.

Each family member was interviewed only once and at a time close to the first interview with the participant with ABI. They were asked to describe their perspectives on how the person with ABI had changed since the injury. Families provided additional information and their data were used by the interviewer to confirm the experiences of the person with ABI.

The family members were asked about the nature of their relationship with the person with ABI, their description of what happened at the time of the injury, and how they felt their life had changed since the injury. They were asked to share their perspectives on the barriers and enablers to the person achieving their goals during their rehabilitation journey.

3.2.4 Data Analysis

All audio-recorded interviews were transcribed verbatim. The researcher used principles of the constant comparison analysis approach (Strauss & Corbin, 1990), and read and re read the transcripts to become familiar with the data prior to coding. The data from the people with ABI and their family members were analysed using a card sort method.

The first interviews of the people with ABI were analysed prior to the second interviews. This enabled the researcher to use the second interview to clarify information

and explore further the ideas expressed in the first interview. The participants reviewed and confirmed the information during the second interview. The interviews with the respective family members were analysed after analysing the data from the two interviews with each person with ABI.

Twelve broad themes were developed and discussed with two research supervisors who had each read a selection of transcripts to determine the validity of the themes in relation to the data set. This process led to the development of two main themes and three sub- themes about the experiences of people with ABI, and one main theme and two sub-theme about the experiences of the family members. Refer to Figure 3.2 for the data analysis process and Figures 3.3 and 3.4 for the development of themes.

Strategies were employed throughout the study to ensure the trustworthiness of data collection and analysis. The researcher documented the interactions between herself and the participants using field notes, and the interviews were transcribed verbatim and checked for accuracy by listening to the recorded interviews. To improve credibility, the researcher discussed the data collection and analysis with a research supervisor. The researcher and two research supervisors reviewed the data and linked the data to the research question and identifying themes. The study participants and the research officer at Brightwater Oats Street who was not involved the data collection and analysis, reviewed the themes to improve the confirmability of the findings.

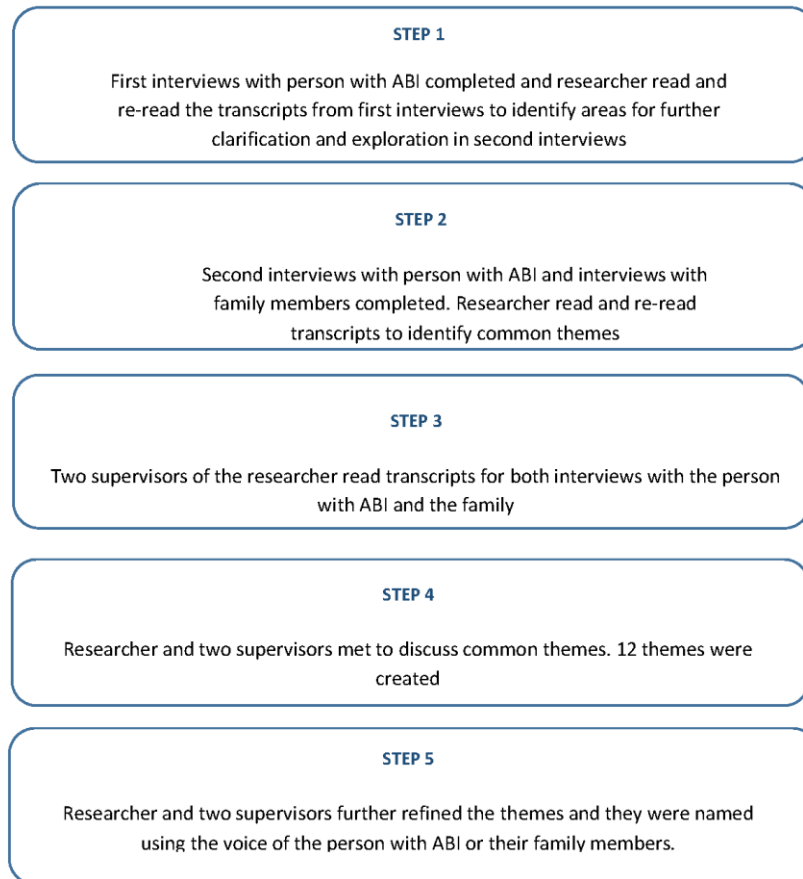


Figure 3.2. Data analysis process for identifying themes

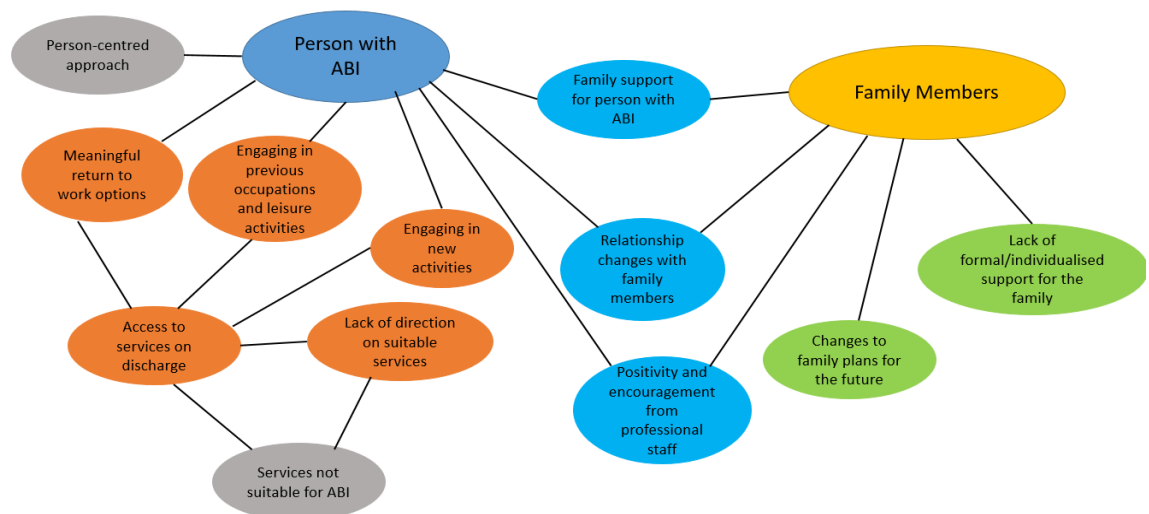


Figure 3.3. Initial thematic analysis showing 12 grouped themes

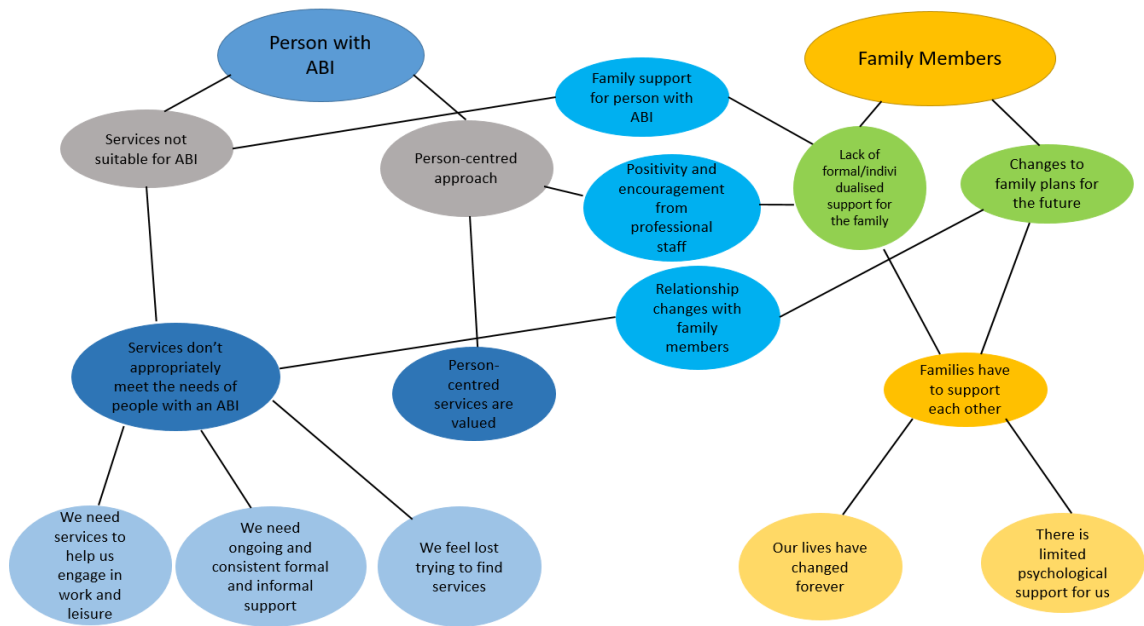


Figure 3.4. Final thematic analysis with the relationships between the themes

3.3 Results

3.3.1 Participants

Six males and four females with ABI aged between 22 and 65 years participated in the study. Participants had experienced their injury in the previous eight months to 20 years. Each participant nominated at least one family member to participate. Table 3.1 summarises the demographics of the participants. Pseudonyms replaced the participants' names to protect their privacy.

Table 3.1. Description of participants with ABI and family members

Participant	Age (y)	Type of Injury	Time since injury	Family Member Interviewed
Mary	23	Stroke	7 years	Mother and boyfriend
John	65	Stroke	7 years	Wife
Sarah	60	Stroke	3 years	Son
Adam	41	Stroke	3 years	Wife
Gerald	61	Multiple strokes	9 years	Wife
Philippa	38	Aneurysm	Most recent 6 months before first interview, first at 2.5 years old	Father and mother
Peter	40	Vasculitis	1.5 years	Niece, mother, and sister
Dion	38	Traumatic injury, MVA	3 years	Mother
Michael	42	MVA	20 years	Sister
Eamon	22	MVA	8 months	Mother

MVA - Motor vehicle accident

3.3.2 Themes – Barriers and enablers for the person with ABI

Two main themes were developed from data obtained from the people with ABI. The first theme was 'Services don't appropriately meet the needs of people with an ABI', and contained three sub-themes; (i) *We need services to help us engage in work and leisure*, (ii) *We need ongoing and consistent informal and formal support*, (iii) *We feel lost trying to find services*. The second theme was 'Person-centred services are valued'.

One main theme was developed from data obtained from the family members. This was 'Families have to support each other' and contained two sub-themes; (i) *Our lives have changed forever*; (ii) *There is limited psychological support for us*. The themes have been named using the language of the participants and their families to ensure the data are presented from the perspectives and 'voices' of each person with ABI and their families.

Theme One: Services don't appropriately meet the needs of people with an ABI

All participants reported that acquiring a brain injury was a life-changing experience. Physical and cognitive impairments caused changes to each person's daily functioning that resulted in the person and their family members needing to learn new ways to manage. Acute and post-acute rehabilitation services helped participants and their families to develop the skills to manage and adapt with the changes in function. For some participants such as Sarah, the acute and post-acute rehabilitation services were enablers to her recovery, 'just brilliant, everyone was brilliant there, like all the carers, the nursing staff, the doctors'. For other participants, services often presented a barrier as they did not meet their needs across a broad range of areas including socialisation and providing age-appropriate treatment. For example, the rehabilitation provided to 23 year old Mary by the acute rehabilitation service in the six months prior to her moving to post-acute rehabilitation service was in 'an older person's place and they weren't equipped for a young person'. Mary was placed on the stroke ward after her stroke, where the youngest patients were aged in their 40s. Mary felt she would have benefited from more opportunities to socialise and participate in therapy groups with people her own age who were on the head injury unit, instead of being with older people on the stroke ward. Mary and her mother felt that throughout Mary's journey there was a gap in the available services for young people who had experienced stroke, because stroke tends to occur in older people and the stroke services were not adequately suited to the needs of a young person.

Some participants had to travel considerable distances to access the available rehabilitation services after discharge from the post-acute rehabilitation service, which proved a barrier to their access to these services. For example, following discharge from the post-acute rehabilitation physiotherapy service John and his wife travelled at least 60 minutes every Monday to Friday for 18 months to attend private physiotherapy appointments. John's wife stated, 'honest to God you were sick of hospitals' as she described travelling after visiting every day during John's admission and then accompanying him to the post-acute rehabilitation service every day for physiotherapy. John reported that

the daily travel to and from services became very tiring and that having services available closer to home or that could come to his home would have been beneficial after his discharge from the post-acute rehabilitation service.

We need services to help us engage in work and leisure

Two participants were able to return to their previous employment with assistance or through adaptation of tasks, and three participants transferred the skills they had developed in previous work to identify and engage in new jobs. Barriers to work or study included the lack of suitable vocational support services and work options. Some participants commenced tertiary and further education (TAFE) courses designed specifically for people with disabilities, but it was difficult to achieve higher than a base level non-tertiary qualification because of memory and concentration difficulties, and because there were no suitable support services to assist the person with ABI to develop study skills or advocate for the person when needed.

Participants' experiences in the workforce were varied. An enabler for Adam was being able to return to work on a voluntary basis in a different role with his original employer, and this eventually led to paid work in the same organisation. Adam found his co-workers were very supportive of his return to work and he enjoyed the social aspects of going back to work, which he felt also helped build his communication skills. Peter, who was unable to obtain work at the time of the interviews, missed the social side of work, 'I miss working, I miss the "crack" that I used to have with the lads'. Many of Peter's friends were from his workplace and he reported that he missed going out with them. Peter was unable to catch up with 'the crew' and play golf because of his poor coordination and inability to drive a vehicle. Peter's options for volunteer or paid work were limited because of his coordination difficulties, vision impairment, and not being able to drive or use public transport. Support to assist him to complete volunteer work and provide transport to the workplace would have been useful for Peter.

Many participants used job support agencies for people with disabilities; however, often the services were a barrier to finding work as they were unable to find appropriate work opportunities or the support they provided was inadequate. Michael was able to obtain work at a local pet store with help from a job support agency; however, he found the work to be 'mind numbing' and would have preferred a job that was more challenging. Michael was in this job for many years and Michael's sister explained, 'after cleaning out

cages and sweeping for 10 or 12 years, they said he was getting lazy' and he eventually was fired. Mary was keen to do any type of work and was receiving assistance from a job support agency at the time of both interviews. Following her injury, she obtained employment that she enjoyed in a charity shop, but the store closed down and she lost her job. At the time of the interviews, Mary had been unable to find a new job despite assistance from the support agency.

Some participants completed voluntary work that they found enjoyable. Philippa was unable to continue volunteering when she moved to residential rehabilitation because of the distance she would have to travel and had not found other volunteer work. Philippa's father reported that a lack of stimulation and productive activity in her days was a barrier to her recovery and he felt this was linked to a decline in her progress. Another participant, Dion, had paid work as a trade assistant for a mechanic and volunteered to cook for the homeless, and enjoyed both jobs. Dion did not use a job support agency and was able to obtain his employment and volunteer work through family connections. In reference to his paid work, Dion said, 'I wouldn't say it is the best thing....it's pretty filthy [work]', but he liked working with tools and 'doing stuff that matters' and planned to continue with the work until 'I win lotto'.

Many participants reported difficulty in resuming or taking up new leisure activities. Adjusting to changes in their abilities was a barrier to involvement in leisure activities, but the main barrier was the lack of suitable services and programs for people with ABI. Many participants enjoyed a variety of leisure activities prior to their injury but did not feel comfortable returning to these activities because of their changed abilities. However, they did not enjoy joining in modified leisure activities because they were organised for people with an intellectual or physical disability, and participants did not feel they had the same needs. For example, Mary enjoyed playing competitive basketball prior to her injury, but her mother reported:

The sports weren't stimulating enough for her, yet to go into normal mainstreams for them, mainstream things it's just that little bit too much. She has more fun playing sport with her (support worker) than she was with other disability [sic] people.

John decided to learn lawn bowls after his injury, but finding a suitable club was difficult because 'the clubs are not geared for it and they won't let you on the green with a

stick.... we're looking to find one a little bit more disabled orientated, if you know what I mean'. Dion had many interests including hang gliding, cycling, and camping prior to his injury and reported he wanted to return to cycling. He had his bike ready but was unsure as to why he no longer engaged in this activity, 'I don't really know why I don't'.

We need ongoing and consistent formal and informal support

Participants reported the barriers they faced in finding ongoing support through specialist services with a good understanding of brain injuries upon discharge from post-acute residential rehabilitation. Michael's sister reported the struggle to find appropriate support services to assist him with activities of daily living and provide social support as his needs changed, 'I wanted someone to come over and reassess him, he has had a disability, you know, for 20 years. They said "we don't have him on our books"'. Michael's sister commented that although he no longer required regular rehabilitation, his needs were changing as he aged, specifically in completing regular household tasks such as cooking and cleaning. It was challenging to find a service to assist him because he was still too young for aged care services. As there were no appropriate services to meet his needs, Michael's sister and other family members were 'filling the gap'. Michael's sister reported that 'It is an ongoing process, it doesn't fix, it's never fixed and they're always going to need something or someone'. Michael's sister felt that it was not appropriate to discharge a person without any specialised support to complete daily tasks or provide social support on an 'as required' basis for the person in the long term. Sarah reported her discharge from post-acute rehabilitation was very stressful due to the lack of ongoing support available to her on her return home. Sarah had experienced significant emotional stressors during her time at the residential rehabilitation service and wanted to live independently in her own home. She continued to receive home support from the rehabilitation service during a six month transition period but there were very limited ongoing services available after that time. Sarah trialed multiple options including using a university gym for exercise sessions but a suitable 'fit for her needs' was not available. This experience made her uncertain about her ability to live independently in the community.

All participants had a significant amount of family support on their return home to fill the gaps that services were unable to provide. The supports provided by families included finding and organising care services, providing transport for appointments, financial assistance, and assistance in completing activities of daily living. Many family members also had to provide emotional support throughout the journey, particularly when

the person's mood and motivation were low. Whilst family support was appreciated and an important enabler in the person's rehabilitation journey, having services that provide ongoing support would better meet the needs of the person with ABI and alleviate the pressure placed on families to provide support. This in turn would lessen some of the stress experienced by families.

We feel lost trying to find services.

Participants reported feeling lost and lacking direction about which services to contact or receive support from on their return home. John and his wife tried everything they could to find a service that would meet his needs, 'It is like we need a manual we can refer to... I can't think of all the things we've done.....always looking'. Knowing where to find services that would be appropriate was something Peter also reported as a challenge. He was on a waitlist for services for nine months following his discharge from hospital. He reported not having any therapy services at all during this time and getting very bored. Eventually, he was offered social support services to take him to do his weekly grocery shopping; however, Peter did not want or need to shop because he lived with his sister and niece who did the shopping. Peter finally accessed a more appropriate service, but his family reported, 'we finally got on to the intensive rehab...but it seems like he hardly ever goes...so that was a bit disappointing'.

Sarah felt a lack of direction in 'where to now' when thinking about her life goals and which services could help her achieve these goals after being discharged from the post-acute rehabilitation service. At the time of the interview, Sarah was trialing services such as cleaning support from a home help organisation and going to a community gym to maintain her physical skills with assistance from the post-acute rehabilitation service. Sarah hoped that 'through telling my story, other people don't have to go through this experience'. Michael described the need for a 'mind map type thing to help navigate through the services'. His sister described 'yelling and crying on the phone, I was so angry....it was very frustrating...not knowing where to go or who to call or who to speak to'. Gerald and his wife showed the interviewer their large folder of paperwork that highlighted the number of services they had contacted or tried to engage with during his rehabilitation journey. Gerald, aged in his 60s, had found a local day centre, which he enjoyed attending regularly for leisure and social activities. While this was an appropriate outcome Gerald, this was an aged care service that would not have been suitable for the younger participants in this study. The participants felt that a formal service to assist with planning support services for

the future after discharge from the post-acute rehabilitation service would assist them during their rehabilitation journey.

Theme Two: Person-centred services are valued

All participants appreciated and valued the person-centred care they received from the post-acute rehabilitation service at Brightwater Oats Street and this was considered to be an enabler during their rehabilitation journey. Participants were able to identify and work towards their own goals, and therapists regarded no goal as being too big to work towards. Eamon who was told he might never be able to walk again by the Doctors in the acute care service, set himself a goal of running 12km in a fun run because he wanted to prove he could do 'normal things'. Eamon worked hard with the physiotherapist in the post-acute rehabilitation service towards his goals and was successful in completing the 12 km fun run. Even though the goal might have seemed unachievable to others it was important for Eamon's recovery that he could work towards a goal that he had chosen. As he reported, 'People think they know what it feels like and therefore tell you what you should and shouldn't be doing. Having staff who listen and support you to do what you want to do was very important'.

A similar approach to goal setting and the delivery of services was considered beneficial for Mary's progress. Mary wanted to obtain her driver's licence and Mary's mother reported, 'We worked very hard to get a licence. It took us probably two years and I think probably about \$5000 worth of lessons... It was one huge hurdle that was a wonderful independence thing for her'. The support given to Mary by the post-acute rehabilitation service to get her learner's permit and organise lessons in combination with encouragement and financial support from her family to achieve this goal was vital to her recovery and she now can drive to TAFE classes, meet her boyfriend or participate in leisure activities with her support worker.

Sarah enjoyed her time at the post-acute rehabilitation service and she felt the close relationship she developed with staff was extremely important enabler to her recovery. 'If it wasn't for the psych [psychologist] at Brightwater, I don't know what I would have done'. Sarah described the support of the staff at the service, 'All the staff are great, you know, they're always happy and smiling and encouraging' and she felt they cared for her own individual needs. Sarah's goal was to return to her own home and live alone, which was all the more challenging because she had not previously lived alone. She appreciated

that staff assisted her to work towards this goal and did not dismiss it as being unachievable. Sarah stated, 'We've been on a really rewarding journey in ways. The staff, the people that we've met along the way have been absolutely extraordinary'. Sarah did achieve the goal of living at home independently and had been living at home for more than six months at the time of the second interview.

3.3.3 Themes- Barriers and enablers for family members

Theme One: Families have to support each other

All family members of the participants with ABI identified a lack of suitable supports as a barrier to assisting them through the journey. Participants reported that the focus was on the person with the ABI throughout the rehabilitation process and although family members were able to speak to staff about the situation, there was a lack of formalised support to meet the needs of the family. Family members reported that most of the support they received came from other families of people with ABI who they met in hospital or at the rehabilitation service. Dion's mother reported that her family received no professional help, but there was 'a nun who came and sat with us for a while'. Dion's mother stated 'everything was focused on Dion so it was left to the families to support each other basically'. She reported that their family and the other families 'sort of became our own little community and we became very supportive of each other because we were all dealing with the same issues'. She felt it would have been useful to have been linked with other families who had been through this experience and who could provide some support, 'as someone who could say "look, this is happening now, don't panic too much"...you just need those words of encouragement from someone who's gone through it before'. Michael's sister stated that they 'had no idea how to deal with it all' and that support services would be beneficial for family members taking on the person's care, because it was 'all so overwhelming'.

Our lives have changed forever

Eamon's mother said, 'the day their [Eamon's] life changes, everyone's life changes' and that she had found a book written by a person who had experienced a stroke the most helpful support to her during this journey. When asked about other assistance she had received, Eamon's mother said, 'this is my therapy, it is good just to have someone to talk to' referring to the interview with this researcher. Gerald's wife reported a similar experience with the interviews; that she found it 'good to talk to someone as I haven't had

a chance to talk to someone'. Some families created photo albums of the person with ABI as they progressed from acute care along the rehabilitation journey as their own form of therapy to enable them to process their experience. The families used these albums to not only motivate the person with ABI but also to reflect on the situation and what they had accomplished together as a family. The families openly shared these albums with the researcher as they discussed how they had progressed through this journey.

The changes to some families' lives included abandoning their own life plans and goals in order to care for their injured family member. Peter's sister left her job to care for him when another family member could no longer provide the level of support needed. John's wife left her job to care for him, and Adam's wife had to decrease her work hours. Eamon's parents' plan to retire to the country was now 'totally off the cards' because 'we've got a requirement that we're here for Eamon in case we are needed and it's turned out that we're needed here'. Dion's family moved from the country to the city so they could provide him with the support he needed during his recovery.

There is limited psychological support for us.

Relationships within families changed following the injury and these changes proved to be both a barrier and an enabler in the rehabilitation journey. Dion's mother reported that Dion used to be very close to his brother but this had changed, 'the accident hit him [the brother] really big and they are not pally anymore'. She was saddened by this change in the siblings' relationship. Sarah's son reported that her marriage broke down a few weeks after her admission to post-acute rehabilitation; something that he believed was due to 'Dad finding it hard not to have his old wife again'. He shared that Sarah's relationship with her daughter had also become strained, and that his own marriage was being affected because his mother needed more emotional and physical support from him and wanted to see him more often. Michael's sister reported that his nieces and nephews did not know how to interact with him and found some of his behaviours hard to manage. Philippa's relationship with her younger brother changed from being his 'role model' to being referred to as 'poor Philippa'. Adam said he was 'having to relearn to bond' with his 4-year old son following the injury and that he received psychological support that was very helpful in learning how to rebuild his relationship with his young children.

Eamon's mother reported that she had 'dark days and dark weeks every few weeks'. Dion's mother reported similar experiences, 'we were both at breaking point a few

times with it all but there was just no support. I'd hit rock bottom that day and there was no one there and I felt that was really, really hard'. Gerald's and John's respective wives became tearful when talking about their husband's injuries and their unique experiences.

Family members were unhappy with the type of support provided by official support groups that were supposed to enable them to manage the changes to their lives but instead were often barriers to helping them cope. John's wife found the carers' support group she attended unhelpful because 'most people just want to talk about sickness and illness and that is what you're trying to get away from'. Dion's mother had a similar experience and she found the group 'more of a social group'. Mary and her mother were offered a stroke support group; however, found they 'didn't really click'. Family members requested more formalised psychological supports such as family counselling or group therapy sessions.

3.4 Discussion

This study aimed to gain an in-depth understanding of the barriers and enablers experienced by people with an ABI and their families during the journey through rehabilitation. It sought to identify ways to further support people living with ABI and their families, and identify opportunities for future research.

Unavailability of appropriate services

All participants reported that the post-acute rehabilitation service provided quality care and they were happy with the care they received, but that there is a current gap in the provision of long-term support to people with brain injuries after the post-acute rehabilitation stage. Health professionals need to advocate for the development of appropriate long-term services for people with brain injuries and their families. Support and assistance from services in work and leisure activities following discharge assist in building the person's confidence and self-worth, which is important to the continued success of their rehabilitation journey (Sveen, Sjøberg, & Østensjø, 2016). The participants with ABI and their families described feeling 'lost' as to what services were available and where to find them. Participants with ABI did not feel the available services were targeted specifically at their needs or understood the unique needs of people with brain injury. People with ABI would benefit from specialised long-term supports to obtain and maintain meaningful employment and engage in leisure activities that were not specifically for people with lifelong disabilities because their needs were not the same. Participants and their families

reported that engaging in mainstream activities without support made them feel uncomfortable, anxious, and reduced their confidence, but they did not feel that they fitted in disability-based activities designed for people with intellectual and severe physical disabilities. The finding from the current study that people with ABI experience boredom at work, lack of involvement in work that was meaningful to them, and were not happy with their current leisure occupations confirm those of a previous study that found 50% of people with ABI were not satisfied with their participation in leisure occupations and only 40% were engaged in work occupations to their desired levels (Johansson, Hogbery, & Bernspang, 2007) The current study has shown that specialised long-term support services are needed to provide people with ABI better opportunities to find and maintain engagement in leisure activities and volunteer or paid employment as they attempt to re-integrate into community life.

The participants in the current study reported that the difficulties in returning to or starting work and leisure occupations could result in reduced rehabilitation outcomes. Encouraging engagement in pre-injury and new occupations is beneficial to improving rehabilitation outcomes, given that integrating skills and experiences from past occupations to engage with current and future occupations is considered vital in restoring the person's self-worth and identity (Sveen et al., 2016) it would seem important to encourage and support people with ABI to return to their previous occupations. The current study has shown the importance of identifying previous occupations and using existing skills to assist the person to re-resume or identify new occupations.

Person-centred care

Person-centred care requires health professionals to consider each person's "unique nature and provide the necessary support and intervention to deliver dignified care to individuals" (Perez-Merino, 2014, p. 41). The current study has confirmed the value of person-centred care for people with brain injuries. Providing person-centred care can be complex and challenging. Although it can be challenging, people with brain injuries and their families appreciate and benefit when provided with person-centred care (Perez-Merino, 2014). Participants and their families in the current study reported a lack of satisfaction and progress with services that did not focus on their unique nature and/or include families in the rehabilitation. The health professionals should place the person with ABI at the centre of the rehabilitation process and use their strengths and aspirations to guide the process. The findings of the current study support Foster et al. (2012) in that the

family should be included and provided with support throughout the rehabilitation journey to ensure better outcomes for the person with ABI. Participants with ABI in the current study felt motivated when given the ability to choose and work towards their own rehabilitation goals, no matter how “unrealistic” they seemed. As reported by Turner et al. (2009) it is important that therapists validate the person’s chosen occupational outcomes and incorporate them in their therapy to promote a successful recovery

The responses of participants in the current study showed that the success of their rehabilitation was improved by being allowed to focus on what was important to them and having positive and encouraging relationships with the health professionals. Several other studies noted the importance of health professionals engaging with the person as a ‘human being’ in the person-therapist relationship, making the person feel valued and providing them with opportunities to take risks in order to achieve their rehabilitation goals (Corring, 1999; D’Cruz, Howie, & Lentin, 2016; Lefebvre et al., 2005). However, the participants with ABI in the current study reported that the health professionals involved in post-acute rehabilitation need to appreciate the challenges people with ABI are facing and be a source of motivation, especially when they are having ‘bad days’.

The need and desire for age-specific services for people with ABI throughout the rehabilitation journey was a key finding of this study. Services should consider age-specific rehabilitation options because existing services for older people who have experienced a stroke are not necessarily suitable for younger people who have had a stroke. Funding specific programs for younger people who have had a stroke may not be feasible due to the small number of young people experiencing strokes (currently 18% of all strokes in Australia) and the cost of developing a new program (Phillips et al., 2011), but making services for all people with ABI irrespective of cause should be considered by policy makers, funders, and service providers.

Support for families

The current study identified that because there was little formal support available for families, they had to seek informal support from other families to cope with challenging periods in the rehabilitation journey. Sanders et al. (2012) agreed the focus during rehabilitation was only on the person with ABI and suggested there needs to be a stronger focus on supporting the family because when families are supported, person outcomes are better (Sanders et al., 2012) . The need for a change in the type and amount of support

provided to families during post-acute rehabilitation and beyond was highlighted by families in the current study.

Available carer support groups were usually through informal support groups with other families and these did not meet families' needs for structure and the coping skills they required. The family members felt formal services such as family-based therapy helped them process information about the injury, the impact it was having on their lives, and develop coping skills would have been beneficial. Family members suggested that the opportunity to "just talk" individually or as a family with a professional about the situation would be helpful. The families felt that formal family therapy including the person with ABI would have helped them manage the changes the person with ABI experienced and the impact on the relationships with their significant family members. Future interventions in family support can be guided by Foster et al. (2012) that recommended support provided to the family should be explicitly structured and include eight areas: early engagement, meeting cultural needs, keeping families together, actively listening, active involvement, education, skills training, and support for community integration. The current study has shown that the family believe formalised services with a specific focus on assisting families to process the experience and developing coping strategies would be useful. This was similar to the findings of Dillahunt-Aspillaga et al. (2013) that the needs of the family changed depending on the stage of rehabilitation and that the person with ABI received better care from their family when their family was well-supported. The findings of the current study confirm the need for services to support the family throughout the journey; however, the level and type of support may change depending on the stage of the person's recovery. A structured support service facilitated by families who have been through the experience would be beneficial.

Limitations and Future Research

One methodological limitation of this study was the recruitment of participants from one service provider that was the only residential post-acute rehabilitation service in Western Australia. Although the study sample included people living with ABI who were in various stages of rehabilitation so as to obtain a range of lived experiences, expanding the study to include participants from other post-acute rehabilitation services across Australia would broaden the representativeness of the sample across different health and disability services jurisdictions.

Prolonged engagement in the field and interviewing participants twice, six months apart, gave opportunity to show that people with ABI can maintain involvement throughout the duration of the project, a factor that is important to success in consumer-orientated research (McKenzie & Hanley, 2007). Future studies on people with ABI should include them not just as participants but also in the development of the research questions, methodologies and dissemination of findings. Being involved in research projects has the potential to improve the motivation and independence of people living with ABI and warrants further investigation.

Future research should build on the findings of this study and follow the participants for more than 12 months to better understand their experiences in the long-term journey through rehabilitation. Research involving people with ABI who are more than 10 years post-injury would be also be valuable, as this study has identified that the needs of people with brain injuries continued to change over time. This time of research would create the much needed evidence about the long-term supports required for a people with ABI and their families.

3.5 Conclusion

An acquired brain injury causes enduring disabilities to a person and changes their lives and those of their families. The study aimed to document the journey through rehabilitation for people with an ABI and their family from their perspectives, in order to identify enablers and barriers to the rehabilitation journey. Throughout the journey, people with ABI found disability services did not appropriately meet their needs and they valued person-centred care that acknowledged and focused on their priorities. Family members identified a lack of suitable support available for them. Health professionals should provide person-centred care to people with ABI and include families in the treatment process to ensure a successful journey through rehabilitation. Opportunities exist for brain injury-specific services to be developed to support the ongoing long-term needs of people with brain injuries and to provide advocacy and support to nurture engagement in leisure and work occupations in the community. Families of people with ABI would benefit from formalised support throughout the journey, which may need to adapt and change according to families' needs at various stages.

3.6 References

- Australian Bureau of Statistics. (2009). Survey of disability, ageing and carers: 2009, people with a disability with requested conditions. Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4446.02009?OpenDocument>
- Australian Institute of Health and Welfare. (2007). *Disability in Australia: Acquired brain injury*. Canberra: AIHW. Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453666>.
- Corring, D., & Cook, J. (1999). Client-centred care means that I am valued human being. *Canadian Journal of Occupational Therapy*, 66, 71-82. Retrieved from <http://journals.sagepub.com>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Los Angeles: SAGE.
- D'Cruz, K., Howie, L., & Lentin, P. (2016). Client-centred practice: Perspectives of persons with a traumatic brain injury. *Scandinavian Journal of Occupational Therapy*, 23(1), 30-38. doi:10.3109/11038128.2015.1057521
- Dillahunt-Aspillaga, C., Jorgensen-Smith, T., Ehlke, S., Sosinski, M., Monroe, D., & Thor, J. (2013). Traumatic brain injury: Unmet support needs of caregivers and families in Florida. *PLOS ONE*, 8(12), e82896. doi:10.1371/journal.pone.0082896
- De Koning, M. E., Spikman, J. M., Coers, A., Schonherr, M. C., & Van Der Naalt, J. (2015). Pathways of care the first year after moderate and severe traumatic brain injury- Discharge destinations and outpatient follow-up. *Brain Injury*, 29(4), 423-429. doi:10.3109/02699052.2014.982188
- Foster, A. M., Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., . . . McPherson, K. M. (2012). Encouraging family engagement in the rehabilitation process: A rehabilitation provider's development of support strategies for family members of people with traumatic brain injury. *Disability and Rehabilitation*, 34(22), 1855-1862. doi:10.3109/09638288.2012.67002
- Head West Brain Injury Association of Western Australia. (2014). Mild traumatic brain injury/concussion report Retrieved from

http://webadmin.communitycreative.com.au/uploads/headwest/HW_Concussion_Worksafes_2014_v5.pdf

- Johansson, U., & Tham, K. (2006). The meaning of work after acquired brain injury. *American Journal of Occupational Therapy, 60*(1), 60-69. doi:10.5014/ajot.60.1.60
- Kat, L., Schipper, K., Knibbe, J., & Abma, T. A. (2010). A patient's journey: Acquired brain injury. *British Medical Journal, 340*, c808. doi:10.1136/bmj.c808
- Kreutzer, J. S., Kolakowsky-Hayner, S. S., Ripley, D., Cifu, D. X., Rosenthal, M. I., Bushnik, T., . . . High, W. (2001). Changes and lengths of stay for acute and inpatient rehabilitation treatment of TBI 1990-1996. *Brain Injury, 15*(9), 763-774. doi:10.1080/026990501118637
- Lefebvre, H., Pelchat, D., Swaine, B., Gélinas, I., & Levert, M. J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury, 19*(8), 585-597. doi:10.1080/02699050400025026
- Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). Australia: Oxford University Press.
- McKenzie, A. E., & Hanley, B. (2007). *Consumer and community participation in health and medical research : A practical guide for health and medical research organisations*. Perth Western Australia: University of Western Australia.
- Parish, L., & Oddy, M. (2007). Efficacy of rehabilitation for functional skills more than 10 years after extremely severe brain injury. *Neuropsychological Rehabilitation, 17*(2), 230-243. doi:10.1080/09602010600750675
- Perez-Merino, R. (2014). Strategies for enhancing the delivery of person-centred care. *Nursing Standard, 28*(39), 37-41. doi:10.7748/ns.28.39.37.e8193
- Phillips, M. C. L., Leyden, J. M., Chong, W. K., Kleinig, T., Czupran, P., Lee, A., . . . Jannes, J. (2011). Ischaemic stroke among young people aged 15 to 50 years in Adelaide, South Australia. *Medical Journal Australia, 195*(10), 610-614. doi:10.5694/mja11.10558

- Richards, L., & Morse, J.M. (2007). *User's guide to qualitative methods* (2nd ed.), United States of America: Sage Publications.
- Sander, A. M., Maestas, K. L., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2012). Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: A multicenter investigation. *Archives of Physical Medicine and Rehabilitation, 93*(5), 842-848. doi:10.1016/j.apmr.2011.11.031
- Saunders, C., Crossing, S., Girgis, A., Butow, P., & Penman, A. (2007). Operationalising a model framework for consumer and community participation in health and medical research. *Australia and New Zealand Health Policy, 4*(1), 1-6. doi:10.1186/1743-8462-4-13
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*, United States of America: SAGE Publications.
- Sveen, U., Sjøberg, H. L., & Østensjø, S. (2016). Biographical disruption, adjustment and reconstruction of everyday occupations and work participation after mild traumatic brain injury. A focus group study. *Disability and Rehabilitation, 38*(23), 2296-2304. doi:10.3109/09638288.2015.1129445
- Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., . . . Chenoweth, L. (2007). A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury, 21*(11), 1119-1130. doi:10.1080/02699050701651678
- Wills, J.W. (2007). *Foundations of qualitative research: Interpretative and critical approaches*, United States of America: SAGE Publications.
- Wittstatt, A. W.-L., & Valadka, A. B. (2017). Acute management of moderate-severe traumatic brain injury. *Physical Medical Rehabilitation, 28*, 227-243. doi:10.1016/j.pmr.2016.12.002

CHAPTER 4

4.0 The journey from the perspective of the health professionals working with the person with Acquired Brain Injury

4.1 Introduction

People with ABI experience physical and cognitive impairments that affect their concentration, memory, motor function, and communication skills (Kat et al., 2010). Approximately, one in 45 people living with ABI experience limitations in their ability to participate in occupations as a result of their injury (Australian Institute of Health and Welfare, 2007). Rehabilitation following ABI is complex and requires a coordinated team approach involving a range of health professionals including, but not limited to, doctors, nurses, psychologists, speech pathologists, occupational therapists, and physiotherapists (Glenn, 2012; Ponsford, 2012). Rehabilitation begins in an acute care setting within four weeks of the injury and continues as post-acute rehabilitation following discharge from hospital (Glenn, 2012). Previous studies have shown improved outcomes in the levels of independence in activities of daily living, behavioural functioning, and vocational status for people with ABI who engage in post-acute rehabilitation (Turner-Stokes, 2008).

Post-acute rehabilitation programs following discharge from acute care services are vital to the person with ABI returning home, developing independence, and participating in community activities (Kim & Colantonio, 2010), and especially when initiated within the first year after sustaining an ABI (Griesbach et al., 2015; Agrawal & Joshi, 2014). Multi-disciplinary interventions during this post-acute period lead to positive outcomes, particularly when delivered in a home-based or community setting (Goranson, Graves, Allison, & Freniere, 2003; Powell, Heslin, & Greenwood, 2002). There are limited numbers of post-acute residential and community-based rehabilitation options available in Australia, and many of those that are available have been described as poorly coordinated, disempowering, and confusing for the person with ABI and their family to navigate access to therapy and medical treatment (Ta'eed, Skilbeck, & Slatyer, 2015; Muenchberger, Kendall, & Collings, 2010). A further complication for people with ABI and their families accessing appropriate services is the lack of similarity in the structure and delivery of ABI rehabilitation services across Australian states and territories, and inequalities in services available to people living in rural and remote areas (Khan, Baguley, & Cameron, 2003; Mitsch, Curtin, & Badge, 2014).

4.2 Context of this study

In Western Australia, people with ABI can receive post-acute rehabilitation at the Brightwater Oats Street residential service. Residents live at the service for approximately two years where they work towards achieving their own goals through rehabilitation that provides a flexible, individualised, person-centred and experiential learning experience (Brightwater Care Group, 2016). The program has an important focus aimed at encouraging the person to participate in purposeful and sustainable activities by developing skills in self-management and interpersonal relationships. For example, rather than just relearning how to walk and talk, the person focuses on achieving goals such as cooking their meals, doing their shopping, and interacting in the community (ACIL Tasman, 2010). The program supports the person “to move beyond independence in physical areas such as mobility and self-care to achieve an independent, community based lifestyle” (ACIL Tasman, 2010, p. 7) and provides assistance to help the person transition from the residential rehabilitation facility to their home and return to community life. The rehabilitation occurs under the guidance of health professionals in therapy sessions and with assistance from support workers who facilitate the person’s participation in activities of daily living in their residence and community (Brightwater Care Group, 2016). Throughout the rehabilitation journey, staff from Brightwater Oats Street work closely with multiple government agencies such as the Department of Health, community support groups and private health providers to ensure people with ABI have the resources required to achieve their goals (ACIL Tasman, 2010).

Understanding the rehabilitation experiences of people with ABI and their families from the perspectives of the health professionals will improve understanding of how they perceive the needs of people with ABI and their families; the current interventions used in rehabilitation; and identify improvements for future program delivery. It is important to gain the perspectives of health professionals from the variety of disciplines who work closely with people with ABI and their families because their views about the person’s level of functioning and health may differ from that of the person and their family, but there might also different perspectives between disciplines (Stucki, Ewert, & Cieza, 2002). The health professionals’ perspectives may also add to our understanding of the person’s rehabilitation journey from a more objective position than that of the person or family member.

In the study about the lived experiences of people with ABI and their families reported in Chapter 3, the participants spoke about the importance of person-centred services; the frequent failure of community-based services to meet their needs, especially after discharge from post-acute rehabilitation services; and the need for more formalised supports for families. Therefore, the aim of this study was to explore the perspectives of the health professionals providing the post-acute rehabilitation on the service's ability to meet the needs of people with ABI and their families, and their recommendations to improve future practice.

4.3 Method

Qualitative research aims to make sense of a phenomena and the meaning it brings to the person (Greenhalgh, 2014). A qualitative approach using inductive reasoning thematic analysis by Braun & Clarke (2006) was undertaken to assist in understanding the phenomenon of having an ABI from the perspectives of the health professional. Braun and Clarke (2006) methodology is an inductive research approach that is not linked to a specific theoretical approach but offers a flexible and rigorous approach to thematic analysis of qualitative data. The six stages of this approach which are familiarising yourself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report were followed to ensure the methodological rigour and trustworthiness of the findings (refer to figure 4.2). Inductive reasoning was used due to the existing knowledge of the researcher from interviews completed with people with ABI and their families in the previous study (refer to Chapter 3) (Hayes, Heit, & Swendsen, 2010). Individual in-depth interviews were conducted with health professionals who provided post-acute rehabilitation to people with ABI. Semi-structured interviews were used to provide an opportunity for the perspectives of the health professionals to be captured and explored in depth (Liamputtong, 2009). The health professionals' thoughts, feelings, and experiences were discussed and explored to obtain their perspectives on the needs of the people with ABI who they had treated and their families, to better understand the phenomenon of having an ABI.

4.3.1 Participants

A purposive sample was obtained from health professionals working in a 43 bed post-acute rehabilitation service providing 24/7 rehabilitation for people with ABI to regain daily life skills and community participation. To be eligible for inclusion, participants must

have worked with at least one person with ABI who had been previously interviewed for the study reported in Chapter 3. The program manager and 11 health professionals responded to an email invitation. Participants were all female and the duration of their work experience in brain injury rehabilitation ranged from one to 30 years (mean = 9 years). A description of the participants' professional disciplines and work experience in the field of ABI is provided in Table 4.1. All the health professionals worked across the residential and community rehabilitation services provided by Brightwater Oats Street, except for the enrolled nurse who was a team leader in the residential service, and one of the therapy assistants who was a community integration coordinator. Pseudonyms are used when reporting the data to maintain confidentiality of the participant's responses.

Table 4.1. Description of health professionals

Pseudonym	Role	Professional discipline	Experience in ABI rehabilitation (y.)
Caris	Program manager	Business	1.5
Barbara	Clinical manager	Nursing	30
Dianne	Nurse	Nursing	12
Tina	Team leader	Enrolled nursing	8
Beth	Therapist	Occupational therapy	1
Anna	Therapist	Occupational therapy	3.5
Lucy	Therapist	Physiotherapy	4
Sarah	Therapist	Speech pathology	4.5
Rachel	Therapist	Speech pathology	21
Stephanie	Clinical specialist	Social work	7
Patricia	Therapy assistant	Care work	6
Lana	Community integration coordinator	Care work	22

This study was approved by the Curtin University Human Research Ethics Committee (Approval: HR 144/2012) and participants provided written informed consent prior to data collection.

4.3.2 Procedure

All participants were interviewed separately by the researcher and were audio-recorded with participants' consent. The interviews were transcribed verbatim for later analysis. Duration of interviews ranged between 30 minutes and 85 minutes and all

interviews were conducted at Brightwater Oats Street facility at a time suitable to each participant. Semi-structured interviews commenced with demographic questions about the participant's current role in the service, their qualifications or training, and their level of experience in working with people with ABI. Participants were then asked to describe their role in the rehabilitation journey of a person with ABI, and their perspectives on the nature of the services the person and their family received at the facility.

In the qualitative study reported in Chapter 3, participants with ABI identified what they believed were barriers to their rehabilitation journey. These included a lack of appropriate services to assist the person to engage in work and leisure activities, a lack of ongoing support for the person with ABI, and a lack of support services for the families. The families identified that the support they received throughout the rehabilitation journey was not appropriate to meet their needs. The health professionals interviewed in this study were asked to provide their perspectives on these prior findings. A sample of the interview schedule is given in Figure 4.1.

1. Ask each participant to introduce themselves, their current role in the workplace and level of experience and qualification
2. What do you see as your role in the rehabilitation journey of someone with ABI?
3. During the interviews with people with ABI and their families they spoke about a lack of direction on appropriate services when they return home from Oats St, from your experience would you say there is a lack of direction for services when they return home? And how could this be managed more effectively?
4. How do you think relationships of people with ABI change with their friends from before their injury? How could we improve/help maintain these relationships?
5. What would be the best way to assist with helping people with ABI and their families understand each profession's specific role?
6. People with ABI report that they find it beneficial to have services tailored to meet their individual needs, is this something that has been reported to you? And how do you meet the individual needs of your clients with differences in what everyone needs as well as the constraints in time and resources that you experience as a clinician?
7. What do you believe would be appropriate services for people with ABI once they leave Oats St?
8. What sort of supports do you feel would be suitable for family members of people with ABI?

9. Something that has really stood out during the interviews with people with ABI and their family members is how motivated they are to achieve their rehabilitation goals, what do you think drives this motivation? (extrinsic/intrinsic)
10. In your experience, do you find different cultures manage a brain injury in their family differently? And if so how?
11. What do you think is currently working well in rehabilitation of people with ABI?
12. What do you think could be improved in the rehabilitation of people with ABI?

Figure 4.1. Sample interview schedule for health professionals

4.3.3 Data Analysis

Data were analysed using a six stage approach to thematic analysis as described by Braun & Clarke (2006) and outlined in Figure 4.2.



Figure 4.2: Process of thematic analysis (Braun & Clarke, 2006)

All transcripts were read and re-read by the researcher in order to become familiar with the data. Pseudonyms assigned to participants, and their professions and roles classified as per Table 4.1 were noted throughout the data analysis process to provide context and meaning to their data. Annotations and notes were made for initial recognition of codes. The transcripts were manually coded and driven by the content of the data set. Codes were then categorised using a card sort process that identified 22 common categories. A selection of transcripts were reviewed by a second researcher (research supervisor) and common categories were discussed. The 22 categories were refined into 12 main themes. Following subsequent discussion with the second researcher, the themes were further refined into five core themes. These final themes were discussed, defined, named, and presented to the participating health professionals for comment on their validity.

4.4 Results

Five identified themes were developed in the process of analysis: *Person factors*; *Relationships with others*; *Employment opportunities*; *Community awareness*; and *Creating the best environment for rehabilitation*.

4.4.1 Person factors

The health professionals reported person factors (for the person with ABI) such as motivation, current level of insight, and changes in personality that occurred post-injury, as either the barriers or enablers to the person's ability to achieve their rehabilitation goals. They reported also that the more insight and acceptance of the changes to the person with ABI that the person and their family had, the more satisfied they were with the outcomes of rehabilitation. Most of the health professionals held the belief that many people with ABI often felt they were no different to before their injury and that they could still do everything they previously did. The health professionals reported that often people with ABI expected to still enjoy their previous activities and were unaware or unprepared if they found that engaging in these activities was different than before their injury. As clinical manager, Barbara, reported, "a lot of people are very regimented in their thoughts and what they believe, and a lot of them don't have insight into their level of disability". Upon

realising the changes in their capacities, people with ABI often withdrew from rehabilitation activities and meaningful occupations. Speech pathologist, Sarah explained:

So there was one person who got involved in a dramatic society and the group was recommended by a student who'd been in the group. The group was welcoming...but because of his fatigue levels he was too tired to do all the rehearsals, all the performances and then have a big party afterwards... he said "Nup, I'm just too tired" and he stopped attending.

The health professionals also reported that it is important for the person with ABI to have a desire and the motivation to get better or to improve in order to progress throughout their rehabilitation journey; as clinical specialist social worker, Stephanie, stated, "some clients are (motivated) but most clients struggle with the motivation themselves, they need the proper encouragement, the celebration of achievements, and then they move on to another level".

The health professionals identified that while having insight was helpful in setting realistic goals, insight also created ongoing psychological impacts for the person with ABI and their family. With insight came grief, as highlighted by speech pathologist, Sarah, "...grief follows the person every step of the way". Ongoing grief was believed to be a barrier to the person and the family remaining motivated throughout the journey. The health professionals felt that they, along with the families, played a significant role in motivating the person with ABI to continue working towards their rehabilitation goals; particularly when they were frustrated or feeling low. Some health professionals believed that some people with ABI were motivated to achieve their goals for the sake of their families, while others were "go-getters" who set their goals and would do anything to achieve them. Therapy assistant, Patricia, reported, "their families are a big part of motivation, not for all clients, but for some". The health professionals highlighted the importance of being able to adapt to their clients' different levels of motivation. Celebrating the small achievements during rehabilitation was useful in maintaining motivation among people with ABI and the health professionals reported their concerns that this external validation of progress towards goals was often missing once the person was discharged from the post acute rehabilitation service.

Services

The health professionals reported that people with ABI wanted to leave the residential rehabilitation service, and at first they were excited about returning home, but when the time came to return home they were worried about how they would cope. Significant gaps in appropriate post-discharge services were noted by the health professionals who highlighted there was insufficient choice of available services. For example, clinical specialist social worker, Stephanie shared the story of a family who contacted her many years after the person with ABI had been discharged from the service:

You [sic] get a phone call and it was about a client who was here probably nine years ago....the family member who phoned had some concerns about the person's ability to manage finances and they didn't know who to contact about what to do.

All health professionals reported that current community-based services were either too segregated from the community or did not have an adequate understanding of how to work with people living with ABI. Health professionals involved in the discharge of people with ABI to these community-based services reported that there were "bureaucratic hurdles" to overcome and that the services often lacked the flexibility required for working with a person with ABI. Consequently, some community-based services inappropriately discharged the people with ABI from their programs; as physiotherapist, Lucy, described, "the service discharged the person because they were always late and therefore felt the person didn't need the service". Program manager and business administrator, Caris, added that another complicating factor was that people with ABI did not engage well with new services because of their perception that "nothing is ever as good as Brightwater". Therapy assistant, Patricia, agreed with this dilemma, "We can't find anywhere to discharge people to". Decreased funding available for people with ABI when they are discharged from post-acute rehabilitation to home was reported by many of the health professionals as extremely disappointing and frustrating. Nurse Dianne explained, "When they don't get the funding, slowly they start to decline, it is like they're stuck".

4.4.2 Relationships with others

The health professionals believed that the support the person with ABI received from family and friends was a crucial enabler to the success of the rehabilitation journey; as

speech pathologist, Sarah, reported, “Lots of clients who are very successful here have the family support and the whole structure..... It’s very important”. The importance of friendship and the difficulties that people with ABI have in establishing and maintaining friendships was a major concern reported by all health professionals in the study. They felt there should be a stronger focus during post-acute rehabilitation on managing relationships and developing the person’s social skills to maintain old and new relationships. Health professionals reported that past friendships were at risk because a person’s social skills were often affected by the head injury, and often their pre-injury friends found it difficult to remain connected to that person. This was illustrated in a comment by speech pathologist, Rachel, “His friends, they did stop....obviously the group of friends that he was with were all athletes, active, and he couldn’t really keep up with all of them anymore”. The health professionals reported that new friendships were often created with other people living with ABI; however, creating lasting friendships and starting romantic relationships was difficult and varied due to the nature of the head injury. Speech pathologist, Rachel explained:

He made new friends here. There was another client that he had a relationship with, that gave him confidence. Everyone was kind of against it but, in reality, it gave him the confidence to go “Someone still finds me attractive”.

The health professionals reported seeing many relationships break down following the person’s acquired brain injury. Clinical specialist social worker, Stephanie, stated, “Lots of marriages break up...because the person is not the [same] person anymore and that’s the sad reality”. Children, particularly teenagers, of people with ABI reportedly found the relationship with their parent challenging and often confronting. They found it hard to adapt to the changes in their relationship with their parent who was “different” to their parent before the injury. Older people with ABI were considered better able to maintain their friendships and relationships, perhaps because of having many more shared life experiences with family and friends.

Family support was recognised as being an important enabler for successful rehabilitation, and those who had regular contact and strong relationships with family, particularly families with realistic expectations, had the best outcomes. However, many family members reportedly experienced high stress, exhaustion, grief, and anger about the ABI and the slowness of recovery. The health professionals reported that families

sometimes acted out their negative emotions towards the health professionals and other facility staff, especially when the person with ABI was not making the progress that the family had expected. As one occupational therapist, Beth, reported, "It can take families many years to realise that the person will not be the same". This was confirmed by therapy assistant, Patricia:

People are desperate for hope, and whilst we always keep hope there, we try to keep it as a realistic hope, not a miracle or everything's going to be fine, when clearly it's not. Life is now going to be difficult in regards of how you look at it. So it's a fine line to walk down.

The health professionals also reported that frustrations could work the other way, with the person with ABI becoming very frustrated with the pressure their family placed on them:

I have my sessions - parents or other family members come into the session and then I'm giving certain instructions for them to do certain things and the family is giving them extra instructions and non-stop.....you can see the client being quite frustrated with their family as well. It's like "It's alright, you just sit there, we will do this and then I'll ask you your feedback later". (Physiotherapist, Lucy)

Some health professionals felt families needed continual education about the impact of the injury on the person and what to expect during rehabilitation and beyond, and that providing information only once to families was not enough. Giving pamphlets was not seen as a sufficient form of communication with families because the families "take the pamphlets, say yes, yes, and don't do it" (Clinical specialist social worker, Stephanie). Therapy assistant, Patricia spoke about some of the challenges in providing family education:

Over the years we've tried a number of things, and they'll work with a small number of people for a finite period of time. At various times we've run education sessions for families. Unfortunately we end with quite small numbers, which is not to negate the importance of it for those people.

Support groups had varying degrees of success, with some health professionals reporting that support groups can become negative when not facilitated well. Occupational therapist, Anna commented:

I don't think we understand the needs for caregivers very well. You know, our service is very limited to the client. In terms of, you know, a lot of our clients, the place that they live, all of those things impact on the care-giver.

The availability of dedicated case management specifically for families to monitor and provide support to families was identified by the health professionals as a useful strategy, particularly because it would allow for tailored education and psychological support to be provided to children of people with ABI. This would also provide an opportunity for the health professionals to develop rapport with families and help them to travel with and support the person with ABI and their families as they experience the many highs and lows throughout the journey.

4.4.3 Employment opportunities

The health professionals acknowledged the benefits of employment participation for people with ABI as being an enabler to their recovery, but they reported there were few options available other than sheltered workshops. The health professionals identified inadequate success in facilitating employment opportunities and providing support in the workplace for people with ABI. Speech pathologist, Rachel pointed out, “[people with ABI] need someone that is going to be supportive and that can intervene or advocate for [them], because you're going to have issues with other staff members”. The health professionals believed that current mainstream employment services often did not meet the unique needs of people with ABI and often employment came from family connections:

We used to have a lot of clients go to [service provider] because they worked well with people with an ABI but then it changed and we had to have people go to this other agency. And they don't seem to have a lot of open employment; it's all in like sheltered workshops, which is not appropriate. (Speech pathologist, Rachel)

The health professionals felt that employment goals were better achieved when the person had good social skills and the employer had a good understanding of ABI. Program manager and business administrator, Caris summed up the employment difficulties facing people with ABI:

I would say employment's probably one of the hardest areas, I think probably one of the least successful areas that I've ever encountered is obviously vocational and workshop type of support. Because naturally it's difficult for anyone to maintain a job and also have a health balance of being rewarded, being paid and, you know, it's difficult for someone without a disability, so when you have a disability on top of that, and people don't understand brain injury.

4.4.4 Community awareness

A lack of awareness and understanding of ABI in the community was noted by the health professionals as a barrier to recovery. Some health professionals believed there was inadequate knowledge in the community about brain injury, more so than some other disabilities, due to the "invisibility" of the disability:

If people know what a brain injury is and kinds of common things like behavioural issues, cognitive difficulties, perhaps physical things and, you know, people then become more accepting of them. Everyone knows what a heart attack is, everyone knows what cancer is, and there's not as many connotations because people understand that it could be them....And brain injury doesn't have that status attached to it. (Program manager, Caris)

Some health professionals described misguided community support, with people "going out of their way" to help the person, describing them as special, and unintentionally demeaning them by talking to the carer and not to the person. The health professionals felt it was their role to model appropriate behaviours when interacting with a person with ABI in the community and to provide community education:

The other Friday we went to the city and I noticed the transport guy who checks the tickets, [he] saw me with a girl in a wheelchair and three other clients and a volunteer behind and he saw us and we went to get our tickets to show him and he

saw she was in a wheelchair and he said, “Oh no, no. It’s fine. You go through” and the girl in the wheelchair said “I hate that, that I’m singled out because I’m in a wheelchair” and I thought it was really unfair, he should check her ticket and our tickets just the same as you check anybody else’s tickets, not go, “Oh, you’re in a wheelchair. Oh you’re helping her. Oh, you guys are special. That’s okay. You go through”. I thought it was quite yuk actually. I didn’t like that. (Speech pathologist, Sarah)

4.4.5 Creating the best rehabilitation environment

Being supported to take “safe risks” during rehabilitation was identified as an essential enabler for recovery. The health professionals reported that it was often family who raised concerns about the person with ABI taking “safe risks”, such as catching a train by themselves with the health professional waiting at the station for them after providing appropriate training. However, the health professionals reported benefits such as improved confidence and motivation for the person with ABI opportunities to take these risks were provided. The health professionals felt it was important for people with ABI to take these “safe risks” to achieve their rehabilitation goals. As Program manager, Caris, stated, “You know they’re wrong (the person with ABI) and they’re going to suffer. But you’re there to guide them”. The health professionals reported that rapport between the health professional, and the person with ABI and their family was an important enabler to the person achieving their rehabilitation goals, and that rapport had to be developed so that safe risks could be taken as part of their rehabilitation program. Clinical specialist social worker, Stephanie explained:

If you have good rapport with families then it is so positive and, you know, I like that role (getting to know families). The person should not be treated as someone with an ABI but an individual person with efforts made to make the person feel important.

The health professionals advocated for a 24/7 rehabilitation approach with the viewpoint that every minute was a “rehabilitation minute” and rehabilitation goals could be worked on during all tasks. The health professionals explained they had to adapt their

approach with each person with ABI until they found something that worked. As nurse, Dianne, noted, “Each person should be seen as an individual and we shouldn’t fit them to a mould, we fit the mould to the person”. The health professionals worked very hard to create opportunities for the person to achieve their goals, and surrounding the person with positive and motivating people was seen as a crucial enabler to the success of rehabilitation:

I know with [person with ABI], one of his main goals was to get a girlfriend. Like, well, how do you make a rehab program that supports that, when you don’t have that outlet?...We tried having very informal kind of support workers that act as friends, so they’re kind of like the wing man situation. And [person with ABI] has a girlfriend now, which is great. (Occupational therapist, Beth)

Interprofessional Team

The value of working as an interprofessional team was noted to enable the health professionals to all being committed to working together on the same goals for each person with ABI, and supported them to understand their respective roles in the process. For example, Physiotherapist, Lucy combined a running session with the occupational therapist’s transport training session. Good communication, creativity, and respect for each other’s roles whilst maintaining a sense of autonomy, created a positive dynamic in the team that proved to be positive for the health professionals, the person with ABI, and their families:

We work so closely together, for example, I’m a speech pathologist but I will be working very closely with an occupational therapist and the community integration coordinator; you know, we just – it’s a unique workplace, it’s a very unique workplace. And I think that clients also feel that. We put our heads together and help the clients achieve goals that were maybe a little bit outside of the box. That works well. (Speech pathologist, Sarah)

All the health professionals spoke about the valued role of the residential rehabilitation support workers who cared for the people with ABI and worked on their rehabilitation goals outside of the therapy sessions. The health professionals worked

alongside the support workers to show them how to incorporate rehabilitation skills into the daily activities of people with ABI; however, funding restrictions severely limited opportunities for more education for the support workers:

The more skilled support workers that we have to deliver rehabilitation, the better. But it's, you know, finding the right people in terms of, you know, disability support workers, and developing the right culture, the right mindset..., there needs to be someone who actually will facilitate the rehabilitation, you know, they're not your typical carer. We're trying to instill in them that you're actually paid to challenge our clients. (Occupational therapist, Anna)

4.5 Discussion

The findings of this study have provided us with an understanding of factors that present as barriers and enablers to the rehabilitation journey for people with ABI, from the perspectives of health professionals involved in providing post-acute rehabilitation care. Internal and external motivation was identified as an important factor in the rehabilitation journey. The health professionals in this study believed that internal motivation was often lacking, particularly when the person had sufficient insight and was aware of the differences between their current and past being and research in managing the psychological impacts of ABI including developing strategies on how to effectively motivate people with insight so they will continue to work well on their rehabilitation goals. These findings concur with a prior study (Wilson, 2010) that reported people with ABI need to be internally and externally motivated to achieve their rehabilitation goals.

Family support was identified as a key motivator and factor in the person with ABI achieving their goals. Previous studies have shown that family involvement in rehabilitation was essential to the person's recovery (Sander et al., 2012; Foster et al., 2012). Families who supported and encouraged the person even as they made small achievements, assisted the person to be more positive about their rehabilitation. Importantly, the current study has highlighted that this was not the only important relationship, because the dynamics between the person, their family, and the health professionals are also very important and is consistent with the findings of Laroie (2003). The health professionals believed that the degree of rapport achieved with families impacted on the type and

degree of difficulty of tasks that could be completed during rehabilitation, and so had an overall influence on rehabilitation outcomes.

A more individualised response is needed with the necessary time and resources to work through issues with families who placed unrealistic expectations on the person with ABI and who placed considerable emphasis on the health professional and their role in helping the person, rather than on the person with ABI. The findings of this study draw attention to the need for regular and consistent communication with families by providing ongoing education about the brain injury and expected recovery outcomes as essential, which are consistent with the recommendations of Gagnon, Lin and Stergiou-Kita (2016).

An interesting finding of the current study was that the transition from a residential post-acute rehabilitation service to home could be as challenging for the health professional as it was for the person with ABI and their family. This was sometimes due to difficulties in meeting families' expectations of support and community resources and also because of the lack of flexibility and limited understanding among the available community services of the needs of people with ABI. This highlights the need for physical and emotional support for families to cope with the changes in people with ABI when discharged from post-acute rehabilitation to home. This includes coping with changes to the level of physical assistance and emotional support the person with ABI requires from their family to complete everyday tasks in and out of the home environment. The findings of this study highlight that community-based services need to focus on ensuring the unique needs of people with ABI are met including their physical and emotional supports. This will assist in lessening the burden on the families after the person with ABI has been discharged from post-acute rehabilitation. Community services could also provide psychological supports either through group or individual services to help the families process the experience and learn to manage their lives now they have changed.

Another finding of this study that provided insight into the gaps in existing community services was the health professionals' views that individual need must be recognised by community services and more individualised funding models are needed. The National Disability Insurance Scheme (NDIS) introduced by the Australian Government in 2013 uses a lifetime approach to provide individualised supports and funding to assist people with permanent disabilities to achieve their goals (Commonwealth of Australia, 2013). If a person with a brain injury meets the access criteria for this scheme, they are eligible to receive individualised funding, but alternative funding models are needed to

meet the requirements of people who may not be eligible under one scheme. The Catastrophic Injuries Scheme (Insurance Commission of Western Australia, 2017) was introduced in Western Australia in 2016 to provide financial support for the medical treatment, rehabilitation, and care required by people catastrophically injured in motor vehicles crashes over the course of their lives. In the first 12 months of the scheme in 2016/17, there were 48 total catastrophic injuries and 69% of these were acquired brain injuries, highlighting the importance of research and evidence-based practice to meet individual needs of people receiving care under this scheme (Insurance Commission of Western Australia, 2017).

Employment is important for improving self-esteem, quality of life and inclusion in the community (Evans & Repper, 2000). Work options for people with ABI were very limited and the health professionals in the current study confirmed there is a lack of understanding among employers and co-workers about the needs of people with ABI. These findings highlight that work options need to be more meaningful to the person with ABI and a full assessment of their work interests and skill levels should be completed to ensure a good fit with potential jobs. This was also noted by Johnstone (2003) who recommended that guidance should be given to the person with ABI to ensure that realistic workplace goals were developed and on-the-job training was provided. Cocks, Thoresen, & Lee (2015) identified the benefits for people with disabilities associated with returning to the workforce or completing training and reported increased ability to contribute to the community and better quality of life. The findings of the current study have shown that future research is needed to determine if more opportunities for work or associated workplace training to assist with the integration of people with ABI into the workforce can be achieved through better advocacy for people with ABI, and educating workplaces about ABI and how to support and work with someone with ABI. Health professionals have an opportunity to advocate, educate, and promote ABI in the community, particularly in workplaces. This could be through the development of a specific role within community-based services to provide information on ABI. Working together with families to increase community awareness of ABI, in particular with future employers or training providers, may improve employment outcomes for the people with ABI upon discharge from post-acute rehabilitation.

The findings of the current study acknowledge the value in increasing the person's social networks within the community to assist in developing friendships and in developing

the communication and social skills, which may have been impacted by the brain injury. The loss of friends and social supports is identified as a common cause of psychological distress for people with ABI (Callaway, Sloan, & Winkler, 2005). Developing friendships can be difficult and anxiety-provoking (Shorland & Douglas, 2010), but if they are developed through shared activities and daily occupations, these friendships could assist in building the person's self-efficacy and support their integration back into the community. Improved community awareness and knowledge about ABI may provide a greater understanding of the person's behaviours but also their personal strengths. Specific social support programs connecting people with and without ABI is an option that can be considered to provide opportunities for people with ABI to develop their communication and social skills, and find friendship. Befriend is a not-for-profit organisation located in Perth, Western Australia that provides opportunities for people to create friendships by breaking down barriers and social rules (Befriend Inc, 2017) . Befriend is one community-based option for people with ABI to develop friendships; however, more community-based social opportunities of this type would be beneficial.

There is growing evidence that interprofessional healthcare teams provide better-health services to patients and the community (World Health Organization, 2010). The health professionals in the current study supported the use of an interprofessional team approach to work with people with ABI. The health professionals enjoyed working with other disciplines to achieve the person's common goals and valued incorporating discipline-specific goals into shared intervention sessions. The current study has confirmed that interprofessional teams can work well in post-acute rehabilitation settings, and identified the specific characteristics for success: (i) being creative in working together to develop interventions that help the person to achieve their goals; (ii) maintaining autonomy with their discipline-specific roles; and (iii) having respect for other disciplines and prioritising good communication and rapport among all team members. This is consistent with the findings of Bethea, Holland, & Reddick (2014) who reported that having a clear goal, and respect and appreciation of each team member's contribution was important to the success of an interprofessional team.

The health professionals in this study reported they believed that a 24/7 rehabilitation approach, where support workers supported the person with ABI to work towards their therapy goals outside of formal therapy sessions, helped achieve positive rehabilitation outcomes; however, there were some challenges to using this approach. In

Australia, the majority of disability support workers hold vocational-level qualifications and there is a high turnover rate among support workers that are often due to poor employment conditions, such as low pay rates and irregular hours; 84% of disability support workers in Australia are employed either part-time (43%) or casually (41%) (National Disability Services, 2017). The instability in the workforce and low education levels have proved to be a barrier to the success of support workers embedding therapeutic activities in a 24/7 rehabilitation approach. The current study found that the role of the disability support worker in the interprofessional team was valued and appreciated by other team members; but that more specific education and professional development of support workers is needed to ensure they work effectively with the interprofessional team, the person with ABI, and the family to achieve the rehabilitation goals. The disability workforce is ageing and with increasing difficulties in filling vacancies (National Disability Services, 2017), the current study recommends that more incentives such as better pay, more permanent positions, improved education and training, and better recognition of the role of disability support workers is given to encourage more people to consider this as a career option. Using well trained disability support workers to not only provide 'care' to the people with ABI but to assist the person to work towards their rehabilitation goals on a 24/7 basis should be considered as a rehabilitation approach for use in other ABI services.

Limitations

The main limitation of this study was that health professionals interviewed were recruited from only one post-acute rehabilitation service in one location in Australia. Including health professionals working under different service delivery models with people with ABI in different stages of their post-acute rehabilitation journey would have offered broader insights from the perspectives of the health professionals who provide care to this population.

4.6 Conclusion

Acquired brain injuries are complex impairments that usually result in activity limitations and participation restrictions. Post-acute rehabilitation services provided by an interprofessional team through a 24/7 rehabilitation approach can be effective to develop the physical and cognitive skills of people with ABI and support their family. This study sought the perspectives of health professionals working with people with ABI and their families to better understand the needs of the person with ABI on the rehabilitation

journey and identify factors that were enablers and barriers to that journey.

Encouragement and recognition of the person's achievements by the health professionals and families were important sources of motivation for the person with ABI to achieve their rehabilitation goals. The lack of suitable community-based services available on discharge from post-acute rehabilitation and the absence of personalised supports provided to the family throughout the journey were concerns for the health professionals. The health professionals enjoyed working in interprofessional teams and perceived benefits for the health professionals and the people with ABI and their families. Health professionals supported a 24/7 rehabilitation approach to embed therapeutic activities into the everyday activities and routines of people with ABI to address their rehabilitation goals, but they believed that more specific education on this approach is needed for the disability support workers.

4.7 References

- ACIL Tasman. (2010). *Oats Street facility redevelopment: a social cost-benefit analysis*. Victoria: ACIL Tasman Pty Ltd.
- Agrawal, M., & Joshi, M. (2014). Impact of rehabilitation on functional outcome during the first year of moderate and severe traumatic brain injury. *Brain Injury, 28*(3), 292-297. doi:10.3109/02699052.2013.865266
- Australian Institute of Health and Welfare. (2007). *Disability in Australia: Acquired brain injury*. Canberra: AIHW Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453666>.
- Befriend Inc. (2017). Befriend Home. Retrieved from <http://befriend.org.au/>
- Bethea, D. P., Holland, C. A., Jr., & Reddick, B. K. (2014). Storming the gates of interprofessional collaboration. *Nursing Management, 45*(9), 40-45. doi:10.1097/01.numa.0000453272.11253.01
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Brightwater CareGroup. (2016). *Brightwater care group-disability care and support-productivity*. Retrieved from www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0398.rtf.
- Callaway, L., Sloan, S., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal, 52*(3), 257-260. doi:10.1111/j.1440-1630.2005.00492.x
- Cocks, E., Thoresen, S. H., & Lee, E. A. L. (2015). Pathways to employment and quality of life for apprenticeship and traineeship graduates with disabilities. *International Journal of Disability, Development and Education, 62*(4), 422-437. doi:10.1080/1034912X.2015.1025714
- Commonwealth of Australia. (2013). National disability insurance scheme: Operational guidelines. Retrieved from <https://www.ndis.gov.au/operational-guideline/overview-sitemap.html>

- Cope, D. N. (1995). The effectiveness of traumatic brain injury rehabilitation: A review. *Brain Injury, 9*(7), 649-670. doi:10.3109/02699059509008224
- Evans, J., & Repper, J. (2000). Employment, social inclusion and mental health *Journal of Psychiatric and Mental Health Nursing, 7*, 15-24. doi:10.1046/j.1365-2850.200.00259.x
- Foster, A. M., Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., . . . McPherson, K. M. (2012). Encouraging family engagement in the rehabilitation process: A rehabilitation provider's development of support strategies for family members of people with traumatic brain injury. *Disability and Rehabilitation, 34*(22), 1855-1862. doi:10.3109/09638288.2012.670028
- Gagnon, A., Lin, J., & Stergiou-Kita, M. (2016). Family members facilitating community re-integration and return to productivity following traumatic brain injury - motivations, roles and challenges. *Disability Rehabilitation, 38*(5), 433-441. doi:10.3109/09638288.2015.1044035
- Glenn, M. (2012). Rehabilitation following traumatic brain injury. . In J. W. Tsao. (Ed.), *Traumatic brain injury: A clinician's guide to diagnosis, management and rehabilitation*. New York: Springer
- Goranson, T. E., Graves, R. E., Allison, D., & Freniere, R. L. (2003). Community integration following multidisciplinary rehabilitation for traumatic brain injury. *Brain Injury, 17*(9), 759-774. doi:10.1080/0269905031000088513
- Greenhalgh, T. (2014). *How to read a paper: The basics of evidence-based medicine* (5th ed.). United Kingdom: Wiley Blackwell
- Griesbach, G. S., Kreber, L. A., Harrington, D., & Ashley, M. J. (2015). Post-acute traumatic brain injury rehabilitation: Effects on outcome measures and life care costs. *J Neurotrauma, 32*(10), 704-711. doi:10.1089/neu.2014.3754
- Hayes, B.K., Heit, E., & Swendsen, H. (2010). Inductive reasoning, *Advanced Review, 1*, 278-292. doi: 10.1002/wcs.44
- Insurance Commission of Western Australia (2017). 2017 Catastrophic Injuries Statistics. Retrieved from https://www.icwa.wa.gov.au/__data/assets/pdf_file/0020/13772/ICWA-Media-

Release-Insuranceies-Support-presents-Catastrophic-Injuries-Support-scheme-one-year-on-Fact-Sheet.pdf

- Johnstone, B., Vessell, R., Buonds, T., Hoskins, S. & Sherman, A. . (2003). Predictors of success for state vocational rehabilitation clients with traumatic brain injury,. *Archives of Physical Medicine Rehabilitation, 84*, 161-167
doi:10.1053/apmr.2003.50098
- Kat, L., Schipper, K., Knibbe, J., & Abma, T. A. (2010). A patients journey: Acquired brain injury. *British Medical Journal, 340*,c808. doi:10.1136/bmj.c808
- Khan, F., Baguley, I. J., & Cameron, I. D. (2003). Rehabilitation after traumatic brain injury. *Medical Journal Australia, 178*(6), 290-295. Retrieved from <https://www.mja.com.au>
- Kim, H., & Colantonio, A. (2010). Effectiveness of rehabilitation in enhancing community integration after acute traumatic brain injury: A systematic review. *American Journal of Occupational Therapy, 64*(5), 709-719. doi:10.5014/ajot.2010.09188
- Laroi, F. (2003). The family systems approach to treating families of persons with brain injury: a potential collaboration between family therapist and brain injury professional. *Brain Injury, 17*(2), 175-187. doi:10.1080/0269905021000010140
- Liamputtong, P. (2009). *Qualitative research methods* (3rd ed.). Melbourne, Australia: Oxford University Press.
- Mitsch, V., Curtin, M., & Badge, H. (2014). The provision of brain injury rehabilitation services for people living in rural and remote New South Wales, Australia. *Brain Injury, 28*(12), 1504-1513. doi:10.3109/02699052.2014.938120
- Muenchberger, H., Kendall, E., & Collings, C. (2010). Beyond Crisis Care in Brain Injury Rehabilitation in Australia. *Journal of Primary Care & Community Health, 2*(1), 60-64. doi:10.1177/2150131910383578
- National Disability Services. (2017). *Australian Disability Workforce Report*. Retrieved from Sydney New South Wales Retrieved from <https://www.nds.org.au/news/australian-disability-workforce-report-first-edition-released>

- Ponsford, J. (2012). Mechanism, recovery and sequelae of traumatic brain injury: A foundation for the REAL approach. In J. Ponsford, S. Sloan & P. Snow (Eds.), *Traumatic brain injury: Rehabilitation for everyday adaptive living* (2nd ed., pp. 1-33). New York: Psychology Press.
- Powell, J., Heslin, J., & Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry*, *72*(2), 193-202. doi:10.1136/jnnp.72.2.193
- Sander, A. M., Maestas, K. L., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2012). Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: A multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, *93*(5), 842-848. doi:10.1016/j.apmr.2011.11.031
- Shorland, J., & Douglas, J. M. (2010). Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. *Brain Injury*, *24*(4), 569-580. doi:10.3109/02699051003610441
- Stucki, G., Ewert, T., & Cieza, A. (2002). Value and application of the ICF in rehabilitation medicine. *Disability and Rehabilitation*, *24*(17), 932-938. doi:10.1080/09638280210148594
- Ta'eed, G., Skilbeck, C., & Slatyer, M. (2015). Service utilisation in a public post-acute rehabilitation unit following traumatic brain injury. *Neuropsychological Rehabilitation*, *25*(6), 841-863. doi:10.1080/09602011.2014.990043
- Turner-Stokes, L. (2008). Evidence for the effectiveness of multi-disciplinary rehabilitation following acquired brain injury: A synthesis of two systematic approaches. *Journal of Rehabilitation Medicine*, *40*(9), 691-701. doi:10.2340/16501977-0265
- Wilson, B. A. (2010). Brain injury: recovery and rehabilitation. *Wiley Interdisciplinary Reviews: Cognitive Science*, *1*(1), 108-118. doi:10.1002/wcs.15
- World Health Organization. (2010). Framework for action on interprofessional education and collaborative practice. Retrieved from http://apps.who.int/iris/bitstream/10665/70185/1/WHO_HRH_HPN_10.3_eng.pdf?ua=1

CHAPTER 5

5.0 Discussion and Conclusion

5.1 Summary of studies and findings

This thesis aimed to explore the perspectives of people with ABI, their families, and health professionals about their rehabilitation journey to address four research objectives: (i) identify gaps in our current knowledge about the experiences of people with ABI from their perspective; (ii) describe the journey through rehabilitation for people with ABI in Western Australia; (iii) identify the barriers and enablers experienced by people with ABI and their families during the journey; and (iv) identify the current needs of people with ABI and their families to inform future services.

The study in Phase 1 was a scoping review that identified gaps in evidence for interventions to assist persons with ABI to maintain relationships with their family and friends. The scoping review highlighted the need for more research about the impact of ABI on a person's existing friendships; the development of new friendships; changes to relationships with family members; and the social contexts in which the person engages. The importance of engaging people with ABI in community activities such as paid or unpaid work was highlighted. This review identified the lack of research that considered the perspectives of people with ABI, their families, and health professionals who provided their care. The review showed there is a need for more research that gives people with ABI an opportunity to share their experiences on the rehabilitation journey.

The study in Phase 2 explored the perceptions of people living with ABI and their families on the rehabilitation journey and identified that community-based support services available upon discharge from post-acute rehabilitation were not meeting the needs of people with ABI. Specifically, community services did not understand how to work with people with ABI or how to provide services that meet their individual needs. In particular, the study found that employment services were not adequately placing people with ABI in work or study activities, nor were they providing suitable supports if the person was employed or studying. The study found that the person's family or friends were more successful in identifying and creating employment and study options than formal services. The study also found that people with ABI and their families experienced a lack of direction in seeking appropriate community-based services to provide the support they required. People with ABI reported they valued person-centred services and being able to work towards their own goals no matter how unachievable they may have seemed.

Families of people with ABI reported that having a family member with ABI does not only change the life of the person with ABI but it also changes the family's lives forever. The families reported the type and amount of psychological support services provided to them were not adequate in meeting their needs, and the support they received from other families of people with ABI was often more beneficial. The families identified that more structured psychological support services, facilitated by family members of people with ABI, would be a better option for them.

The study in Phase 3 found that health professionals involved in delivering post-acute rehabilitation services agreed that there was a lack of direction in finding suitable community-based support services after discharge from post-acute rehabilitation, and that these support services did not adequately meet the needs of people with ABI and their families. Health professionals reported experiences where a lack of community awareness about ABI resulted in people with ABI experiencing barriers towards achieving their goals within the community; specifically, they agreed that engaging people with ABI in work or study is an area that is poorly addressed. The health professionals found that families' expectations for the person with ABI and the health professionals can often be a barrier to the person achieving their goals, and that more appropriate family supports are needed. The health professionals reported they had tried many options for family support but finding the right solution to providing support to families is difficult.

The health professionals enjoyed working in their interprofessional teams and believed the interprofessional team combined with a 24/7 rehabilitation approach is successful for the person with ABI and for their families. However, in order for the effectiveness of this approach further training of support workers is required.

When a person sustains an ABI they begin a life-long rehabilitation journey of working towards their rehabilitation goals. During this journey, the person is accompanied by their family and health professionals who are there to provide emotional and physical support and assist them to achieve their goals. The families and health professionals who accompany that person on the journey may have similar or different perspectives of the same journey than the person and to each other, but regardless, they need to be on the same path, heading in the same direction, and working towards the person's chosen goals. Along the way the person may encounter organisational, social, legislative, physical, and economic barriers to achieving their goals, such as inadequate funding to access needed services, lack of suitable support services when they are discharged from post-acute

rehabilitation, difficulties with finding appropriate services, and a lack of community awareness of ABI. As such, the person may require the support of the family, health professionals, or other members in the community to overcome these barriers and enable them to continue on their journey.

The findings of this thesis have implications for people with ABI, their families, and health professionals, and can be used to inform and improve post-acute rehabilitation services and community-based support services for people with ABI and their families. Through acknowledging the barriers and enablers to their rehabilitation journey, people with ABI and their families have identified potentially new areas for intervention such as specialised psychological supports, flexible employment support services, and services to assist people with ABI to develop and maintain social relationships. The value of having people with ABI and their families involved in consumer-orientated research, the importance of person-centred care, and the contribution of an interprofessional team were also highlighted in the findings of this study, and are explored in more detail.

5.2 Implications for people with acquired brain injuries and their families

This research has identified new areas for future intervention and supports for people with ABI and their families and ways to expand current rehabilitation and support services to improve the rehabilitation journey experience. A significant moment for the person with ABI during the rehabilitation journey is the time at which they develop insight into the impact of their injuries on their life. Motivation and feelings of self-worth vital to the success of rehabilitation (Alkhed & Olsson, 2013) are affected during this stage, which can hinder their progress towards their rehabilitation goals. The findings of Phase 2 show that psychological support from health professionals and other people who have experienced ABI is a priority need for people with ABI and their families at this time. Access to psychological supports can help maintain motivation and improve self-worth during a time when the person with ABI is most vulnerable.

Family members of people with ABI require education about ABI and what outcomes to expect from rehabilitation. All the families of people with ABI in Phase 2 wanted better education to improve their understanding of the injury to help them develop realistic expectations of the person's recovery, but the timing of this education was dependent on the specific needs and capacities of each family. Some families required education early in the process; others needed it later; and some families required

education multiple times throughout the journey. The health professionals in Phase 3 aimed to provide families with relevant information and education, but providing the education only at pre-determined times; for example, on entry to the post-acute rehabilitation services and on discharge to the community, may not meet the needs of all families. Health professionals need to be flexible as to when and how education about ABI pathology and medical expectations for the person's recovery are shared with families. Health professionals need to ensure they do not contribute to families' unrealistic expectations for the person's recovery when providing families with support, provide education and information about the nature and level of support provided by future services the person may receive.

This research has shown that in addition to flexible timing of education, families needed more psychological support options throughout the rehabilitation journey than they currently received, and these supports also need to be flexible in their delivery. A variety of support options are needed, ranging from formal individual or group services through to opportunities to access informal supports. Effective support may assist families to better understand the person and their injury, and in doing so, not only improve the families' psychological well-being, but also allow families to provide more appropriate informal support to the person with ABI throughout their journey (Foster et al., 2012).

An unfortunate outcome of ABI is the breakdown of relationships with family and friends (Jumisko et al., 2007). Studies in phases 2 and 3 highlighted that many people with ABI experience changes to their relationships; for example, the relationship between one participant with ABI and his children had changed because he was no longer able to participate in many activities with them. Specialised psychological supports that focus on managing the relationships between the person with ABI and their family and friends are needed to help everyone adapt to life following the injury and maintain or strengthen existing relationships. These targeted supports would allow the person with ABI and their family members to feel equally valued (Bay, Blow, & Yan, 2011). A particularly important finding of the current research project was the gap in the levels of support given to children of people with ABI. Specialised case management would be beneficial to help the children better understand and adapt to the changes they now see in their parent.

Young people with ABI who participated in this research project experienced social isolation due to the loss of many pre-injury friendships and a lack of opportunities to socialise within their community post-injury. This social isolation occurred at a time in their

lives when relationships with peers have a positive influence on young people's access to community-based activities and employment (Stewart, Staveness, King, Antle, & Law, 2006). Opportunities for a person with ABI to participate in community activities with a peer support worker (i.e. another person with ABI who has progressed further through their journey) can provide physical and psychological support to assist in creating new friendships and fostering existing, pre-injury friendships (Wobma, Nijand, Ket, & Kwakkel, 2016). Community services and organisations that use peer support workers provide an opportunity for the person with ABI to learn from and engage with a peer with ABI to assist them in maintaining or developing friendships, and has the potential to benefit not only the person with ABI, but also their friends and the wider community as it will assist in developing community awareness of brain injury and how it affects the person (both positively and negatively). This research project identified the need for improved opportunities to assist young people with ABI to maintain existing friendships and develop new friendships with people outside the "disability" community. Organisations such as Befriend Social Network, a Perth-based not-for-profit social organisation "sparking an inclusive, connected world" that helps connect people with others, regardless of ability or circumstance (Befriend, 2017), can be a useful resource for people with ABI, but more of this type of social network are needed.

The people with ABI in this research project valued opportunities to return to their previous employment, or if that was not possible, to return to some form of meaningful work or vocational activity. This finding is consistent with other qualitative research that identified high motivation to return to work after brain injury because of a belief that life would return to normal when this was achieved (Materne, Lundqvist, & Strandberg, 2016). Existing community-based employment services that find work for people with disabilities did not meet the unique needs of people with ABI. The work options were often "boring and repetitive" and on-the-job support was not adequate to help the person with ABI maintain their employment. Employment services require a better understanding of ABI and the impact of injury on the person's capacities, and education on better ways to assess their specific needs for the workplace. There should be a focus on the person's strengths, previous employment, and activities of interest when placing the person in employment, work trials, or vocational training. The participants in this research project highlighted that it is not sufficient for employment services to just find a job or training course and then discharge the person with ABI. Instead, employment services need to provide ongoing support on an as-needed basis to help the person maintain employment or finish their

training. Employment services are in the unique position to provide relevant education and information to the person's co-workers and supervisors to improve their understanding of ABI and the person's abilities and support needs, and foster acceptance of the person with ABI at the workplace. ABI is a complex condition and many people with ABI experience fatigue, weakened vision or sensitivity to bright lights, impaired memory, and executive dysfunction affecting their concentration, organisation, and problem solving. Difficulties handling stress and coping with changes in the work environment also impact on their ability to manage the demands of the workplace (Headway United Kingdom, 2017). Therefore, tailoring employment services to each person's individual needs, modifying the work environment when required, and providing regular follow up, rather than a generic approach may lead to better employment outcomes for the person with ABI and the employer (Matérne et al. 2016; Ponsford, 2012).

5.3 Clinical Implications

5.3.1 Recommendations for health professionals

This research project has highlighted the value of consumer participation in research. People with ABI are keen to share their experiences and have a strong desire to improve the services they utilise. The people with ABI and their families in Study 2 identified what was currently working in services, but also had many ideas for service improvements. The involvement of people with ABI in more research projects would be beneficial for improving service delivery to better meet their needs, and it also may assist in helping the person with ABI to process their experience and improve their motivation and self-worth (Saunders et al., 2007).

The findings of this research project provide evidentiary support for creating ABI services that are based on principles of person-centred care. Participants with ABI described how person-centred care had improved their experiences in the rehabilitation journey by making them feel respected and valued. The use of a person-centred care approach by staff at Brightwater Oats Street also created strong working relationships among the people with ABI, their families, and the health professionals who participated in this research project. Person-centred care requires health professionals to consider the unique nature of the person and their situation when providing necessary supports and interventions, delivering dignified care to the individuals (Perez-Merino, 2014). Current and future health professionals in the post-acute rehabilitation field should be encouraged and

supported to provide care through a person-centred lens because this approach provides opportunities for people with ABI to positively reframe their sense of self as being valued and capable (D’Cruz, Howie & Lentin, 2016).

Motivation had a strong impact on progress through rehabilitation for the people with ABI in this research project. Specific factors that impact on a person’s motivation are still not clearly understood; however, this research project has identified that health professionals can help motivate the person with ABI by developing person-centred goals that focus on not only the person’s impairments, but also their strengths and their personal goals and aspirations. For example, Eamon wanted to run 12km; a goal that was considered very challenging. Using a person-centred approach, the post-acute rehabilitation team at Brightwater Oats Street helped him work towards this goal, which led to his ultimate success. This excellent outcome was because the health professionals listened to Eamon’s needs and put steps in place to help him achieve a goal that could have otherwise been seen unachievable. This research has confirmed that an interprofessional team approach where health professionals working together in creative ways to work on the person’s chosen goals can improve the person’s motivation and potentially improve the rehabilitation outcomes.

Families have a significant role in providing physical and emotional support and encouragement of the person with ABI throughout the rehabilitation journey. This research project highlighted that health professionals should encourage families to provide support to the person with ABI throughout their rehabilitation journey, and that families should be included as part of the team in providing care to the person. Health professionals need to provide ongoing education to families on ways to provide appropriate support to the person with ABI and what to expect from their rehabilitation. Without this education, the families may develop unrealistic expectations of rehabilitation that when not met, can cause them to become despondent and not challenge the person with ABI to achieve more, or to push the person too hard. Both approaches can hinder progress in the rehabilitation journey.

Health professionals in Phase 3 enjoyed working within their interprofessional teams. They worked closely with other professionals from other disciplines to assist the person with ABI to achieve their rehabilitation goals and found this beneficial for the rehabilitation outcomes for the person and family, and for their own professional development and sense of well-being in their work. Good communication among all

disciplines, respect for each other's roles, and creativity when working together were reportedly important for the interprofessional team to be effective. It is recommended that all health professionals and care staff working with people with ABI have training in interprofessional team work to develop skills in communication and conflict resolution.

5.3.2 Contribution to service delivery

People with ABI should not be given an 'end date' for the support services they require. As shown by this research project, people with ABI have needs that are ongoing and change over time. Services should be accessible over the person's lifetime and information should be easily available to the person with ABI and their families over time. A significant barrier to the rehabilitation journey for the person with ABI and their families was not knowing which services are available; not understanding differences in how services operate; the lack of long-term community based services; and the lack of understanding by services in how to support people with ABI. These barriers caused frustration for the person and their families and delayed progress through rehabilitation. A website or hotline the person and their families can access at any stage and feel comfortable accessing where they can ask questions about their current situation and what services would be useful will help alleviate the stress and frustration experienced by the person and their families.

The National Disability Insurance Scheme (NDIS) could benefit Australians with ABI and their families by providing more control and flexibility in the services and supports they receive (Reddihough, Meehan, Stott, & Delacy, 2016). Reddihough et al. (2016, p. 69) states that support given "will be focused on the individual, their family, ... As a result, there will be more opportunity for independence and greater participation in the community"; and that plans will be based on the person's goals with family input when needed. The findings of the current research project suggest that this person-centred approach will be valued by all stakeholders. While it will be important for people with ABI to have the ability to set their own goals, and have control and flexibility in choosing their own services, it is important that an adequate assessment of their needs is made.

This research project has confirmed that ABI is a complex condition that affects people with ABI and their families differently. This research highlighted the gap in the provision of services for young people who have a stroke, a type of acquired brain injury that has a higher prevalence in people aged over 65 years (Australian Institute of Health

and Welfare, 2016). Prior research has defined a young stroke survivor as being aged 18-65 years (Morris, 2011); however, the values, interests, important occupations, and pending milestones in the life of an 18 year old are likely to differ vastly from those of a 65 year old. (A decision needs to be made to either develop a new service for young people who experience stroke to ensure their needs are met, or to treat them using existing brain injury services that are not stroke specific but which service a younger population. The current practice in Western Australia of having young stroke survivors treated in units that are predominately for older people affects their motivation during rehabilitation, especially when the therapeutic activities used in rehabilitation are not age appropriate.

The impact of brain injury on family members' psychological well-being and their unmet support needs has been previously documented in the literature (Coco, Tossavainen, Jaaskelainen, & Turunen, 2011; Dillahunt-Aspillaga et al., 2013). All families in Study 2 wanted access to flexible psychological support services to meet the individual needs of people with ABI and their families. Specifically, access to support groups facilitated by family members but within a structured framework to ensure their appropriateness and benefit to families. The families acknowledged the benefit of having the opportunity to tell their story to the researcher, regardless of their stage in the rehabilitation journey. Family members, including children, should be given access to individual psychological support as part of the rehabilitation package for the person with ABI, to assist families to process the impact of the injury on the family unit.

Previous studies have proposed the potential benefits of interventions occurring in natural learning environments, such as improved service efficiency (Shelden & Rush, 2001). The 24/7 rehabilitation approach used at Brightwater Oats St involves embedding rehabilitation interventions into a residential learning environment and uses a holistic approach to service delivery. This approach was recognised by participants in the current research project as beneficial to maintaining the person's progress through rehabilitation. This 24/7 approach also ensured the person with ABI was working towards his or her goals by participating in meaningful and functional activities embedded throughout their daily routine. The important role of the residential support workers who assisted the people with ABI to engage in these activities was highlighted in this research. The support workers continued rehabilitation activities outside of therapy sessions by encouraging and assisting the person to participate in their meaningful everyday tasks, such as self-care activities, food preparation and eating, and community mobility to attend vocational and leisure

activities. Most support workers hold vocational-level qualifications and the workforce experiences a high turnover rate due to poor employment conditions including low pay rates and irregular hours (National Disability Services, 2017), which did impact on the capacities of support workers to implement the 24/7 rehabilitation approach. It was noted by the health professionals in Phase 3 that when support workers tried to be overly helpful to the person, they hindered the rehabilitation process. They believed that the support workers sometimes provided too much assistance because of their lack of understanding of ABI and the role and purpose of rehabilitation in helping the person to become more independent. Therefore better education and training for support workers is urgently needed to help them understand the purpose and role of the therapy provided by each discipline on the rehabilitation team, and how and why therapy principles are embedded 24/7 in the person's naturalistic environments.

People with ABI and their families reported a lack of awareness in the wider community about ABI and the impact on the person's capacities. This lack of understanding hindered community engagement because there were limited community activities, including vocational and leisure pursuits, which were accessible and met the unique needs of the people with ABI in this research project. The health professionals in Phase 3 believed promoting awareness in the community, led by the person, their families and health professionals may help improve community engagement. Funding to allow people with ABI to participate in community activities with support from possibly a peer support worker may be more beneficial to the person and the community than creating more activities solely for people with disabilities and expecting people with ABI to participate in them. Through engaging people with ABI in community activities, initially with an allocated peer support worker who is either a family member or health professional, may allow them to participate in meaningful activities in the wider community.

5.4 Recommendations for Further Research

Many opportunities for further research have been identified from the findings of this research project. An opportunity exists to identify the characteristics of a successful interprofessional team in acquired brain injury rehabilitation. Formal evaluation of the 24/7 rehabilitation approach used at Brightwater Oats Street is needed to provide empirical evidence of its effectiveness in ABI rehabilitation. More long-term studies tracking the progress of people with ABI following their discharge from post-acute rehabilitation would be beneficial. Only seven out of 20 studies included in the scoping review (Phase 1)

followed people with ABI over time. One study completed follow up interviews with people with ABI up to 24 years post-injury (Colantonio et al., 2004); however, the researchers did not track people periodically over time to determine outcomes at different points in the rehabilitation journey, nor did the researchers seek to gain the perspectives of the people with ABI regarding their rehabilitation journey. A recommendation for future research is to recruit people at the time of discharge from post-acute rehabilitation and follow them over a 10 year period to identify how their needs change over time and track their post-discharge engagement with community-based services; specifically, their involvement in employment and community leisure activities. Likewise, an evaluation is needed of community-based support services regarding the services they provide to people with ABI, their understanding of ABI, and what they believe needs to be done to meet the needs of people with ABI will improve these services. More in-depth investigation of the support services accessed by families of people with ABI and what they would like to receive from these support services is needed. Findings from this type of research may inform support services on how to better meet the needs of families who also experience an important period of adjustment and change following the acquired brain injury.

5.5 Strengths and limitations

Strengths

The main strength of this research project is that the perspectives of 10 people with ABI, 14 family members, and 12 health professionals who provided post-acute rehabilitation care were obtained via in-depth interviews. This research provided people with ABI and their families the opportunity to have their voice heard through telling their stories from their perspective to help identify barriers and enablers in the journey they have experienced. Interviewing the person with ABI twice over a six month period allowed the researcher to capture information about any changes that may have occurred during the journey to be discussed and ensure that the data collected could be clarified and explored in more detail in the second interview. The research also allowed for health professionals to comment on the findings of the person with ABI and their families to gain the perspectives of the professionals involved in providing their care. This triangulation of data from multiple sources helped improve the credibility and dependability of the research findings.

Limitations

The main methodological limitation to this research was that study participants were recruited from only one post-acute rehabilitation service. Currently, Brightwater Oats Street is the only post-acute residential rehabilitation service available in Western Australia. However, the researcher made the decision to engage Brightwater Oats St as the partner in this research because of the lack of alternative service providers, the established working relationship between the university where this research was undertaken and Brightwater Care Group, and the enthusiasm of the Program manager and health professionals at Brightwater Oats Street to engage with the researcher. Future studies would benefit from involving other services across Australia as there may be differences in the experiences of people with ABI, their families, and health professionals across Australia who are involved in post-acute rehabilitation.

The existing professional relationship between Brightwater Oats Street and the university, particularly in relation to occupational therapy student clinical fieldwork placements, may have contributed to some biases in the responses from the participating health professionals. Furthermore, most health professionals interviewed knew or had worked with the people with ABI and their families who participated in the study and were aware of their specific needs. In-depth interviews with all participants and triangulation of data sources during data analysis were done to take these potential biases into consideration.

5.6 Conclusions

An acquired brain injury is a complex condition that affects the lives of people with ABI and their families. The journey through rehabilitation is a shared experience with the person with ABI, their family, and health professionals all working together to help the person achieve their rehabilitation goals. This research project has shown it is important to hear and acknowledge the perspectives of people with ABI, their families, and health professionals to help improve the rehabilitation experience for everyone involved in the journey. This study has shown that the people with ABI valued person-centred services and involvement in meaningful activities; however, the lack of flexibility by community-based services, particularly after discharge from post-acute rehabilitation is a barrier to their progress.

The lives of the families of the people with ABI will never be the same again. The families in this study identified that the available psychological supports to assist them to come to terms with their experiences of ABI were not adequate in meeting their needs. Rather, the support they received from other families was considered more beneficial.

The 24/7 rehabilitation approach was identified by the research participants as being beneficial to progress in the rehabilitation journey; but the health professionals identified that further education and training of support workers about ABI and their role in the rehabilitation journey was required to improve support they provided outside of formal therapy sessions to people with ABI in order to achieve their rehabilitation goals. The health professionals in this research project agreed with the participants with ABI and their families that community-based employment services were not effective in returning people with ABI to work or study activities. This research has highlighted that when all parties worked together as a team to overcome barriers and took advantage of enabling factors, this was beneficial to the progress of the person with ABI on their rehabilitation journey.

5.7 References

- Australian Institute of Health and Welfare. (2016). *Australia's health 2016: Australia's health series no. 15* (Cat No. AUS 199). Retrieved from http://www.aihw.gov.au/Work_Area/DownloadAsset.aspx?id=60129555788
- Bay, E.H., Blow, A.J., & Yan, X. (2011). Interpersonal relatedness and psychological functioning following traumatic brain injury: Implications for marital and family therapists, *Journal of Marital and Family Therapy*, 38(3), 556-567. doi: 10.1111/j.1752-0606.2011.00231.x
- Befriend Inc. (2017). Befriend Home. Retrieved from <http://befriend.org.au/>
- Coco, K., Tossavainen, K., Jääskeläinen, J.E., & Turunen, H. (2011). Support for traumatic brain injury patients' family members in neurosurgical nursing: A systematic review. *Journal of Neuroscience Nursing*, 46(6), 337-348. doi: 10.1097/JNN.0b013e318234ea0b.
- Colantonio, A., Ratcliff, G., Chase, S., Kelsey, S., Escobar, M., & Vernich, L. (2004). Long term outcomes after moderate to severe traumatic brain injury, *Disability and Rehabilitation*, 26 (5), 253-261. doi: 10.1080/09638280310001639722
- D'Cruz, K., Howie, L., & Lentin, P. (2016). Client-centred practice: Perspectives of persons with a traumatic brain injury. *Scandinavian Journal of Occupational Therapy*, 23(1), 30-38. doi:10.3109/11038128.2015.1057521
- Dillahunt-Aspillaga, C., Jorgensen-Smith, T., Ehlke, S., Sosinski, M., Monroe, D., & Thor, J. (2013). Traumatic brain injury: Unmet support needs of caregivers and families in Florida. *PLOS ONE*, 8(12), e82896. doi:10.1371/journal.pone.0082896
- Foster, A.M., Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., ... McPherson, K.M. (2012). Encouraging family engagement in the rehabilitation process: A rehabilitation provider's development of support strategies for family members of people with traumatic brain injury, *Disability and Rehabilitation*, 34(22), 1855-1862, doi: 10.3109/09638288.2012.670028
- Headway United Kingdom. (2017). Brain injury: A guide for employers. Retrieved from <https://www.headway.org.uk/media/4123/brain-injury-a-guide-for-employers.pdf>

- Jumisko, E., Lexell, J., & Söderberg, S. (2007). The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives. *Disability and Rehabilitation*, 29(19), 1535-1543. doi:10.1080/09638280601055816
- Marterne, M., Lundqvist, L. O., & Strandberg, T. (2016). Opportunities and barriers for successful return to work after acquired brain injury: A patient perspective. *Work*, 56(1), 125-134. doi:10.3233/WOR-162468
- Morris, R. (2011). The psychology of stroke in young adults: The roles of service provision and return to work, *Stroke Research and Treatment*, 2011, 534812. doi: 10.4061/2011/534812.
- National Disability Services. (2017). *Australian Disability Workforce Report*. Retrieved from Sydney New South Wales Retrieved from <https://www.nds.org.au/news/australian-disability-workforce-report-first-edition-released>
- Ponsford, J. (2012). Mechanism, recovery and sequelae of traumatic brain injury: A foundation for the REAL approach. In J. Ponsford, S. Sloan & P. Snow (Eds.), *Traumatic brain injury: Rehabilitation for everyday adaptive living* (2nd ed., pp. 1-33). New York: Psychology Press.
- Reddihough, D.S., Meehan, E., Stott, N.S., & Delacy, M. (2016). The national disability scheme: A time for real change in Australia, *Developmental Medicine and Child Neurology*, 58, (Supp. 2), 66-70. doi: 0.1111/dmcn.13007
- Saunders, C., Crossing, S., Girgis, A., Butow, P., & Penman, A. (2007). Operationalising a model framework for consumer and community participation in health and medical research. *Australia and New Zealand Health Policy*, 4(1), 1-6. doi:10.1186/1743-8462-4-13
- Shelden, M., & Rush, D. (2001). The ten myths about providing early intervention services in natural environments. *Infants & Young Children: An Interdisciplinary Journal of Special Care Practices*, 14, 1-13. Retrieved from https://www.researchgate.net/publication/232173280_The_Ten_Myths_about_Providing_Early_Intervention_Services_in_Natural_Environments

Wobma, R., Nijand, R.H.M., Ket, J.C.F. & Kwakkel, G. (2016). Evidence for peer support for individuals with acquired brain injury: A systematic review, *Journal of Rehabilitation Medicine*, 48, 837-840. doi: 10.2340/16501977-2160

CHAPTER 6

6.0 Bibliography

- ACIL Tasman. (2010). *Oats Street facility redevelopment: a social cost-benefit analysis*.
Victoria: ACIL Tasman Pty Ltd.
- Agrawal, M., & Joshi, M. (2014). Impact of rehabilitation on functional outcome during the first year of moderate and severe traumatic brain injury. *Brain Injury, 28*(3), 292-297. doi:10.3109/02699052.2013.865266
- Andelic, N., Sigurdardottir, S., Schanke, A.K., Dandvik, L., Sveen, U. & Roe, C. (2010). Disability, physical health and mental health one year after traumatic brain injury. *Disability and Rehabilitation, 32*(13), 1122-1131. Retrieved from doi:10.3109/09638280903410722
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32. Retrieved from doi:10.1080/1364557032000119616
- Australian Bureau of Statistics. (2009). Survey of disability, ageing and carers: 2009, people with a disability with requested conditions. Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4446.02009?OpenDocument>
- Australian Institute of Health and Welfare. (2016). *Australia's health 2016: Australia's health series no. 15* (Cat No. AUS 199). Retrieved from http://www.aihw.gov.au/Work_Area/DownloadAsset.aspx?id=60129555788
- Australian Institute of Health and Welfare. (2007). *Disability in Australia: Acquired brain injury*. Canberra: AIHW Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453666>.
- Bay, E.H., Blow, A.J., & Yan, X. (2011). Interpersonal relatedness and psychological functioning following traumatic brain injury: Implications for marital and family therapists, *Journal of Marital and Family Therapy, 38*(3), 556-567, doi: 10.1111/j.1752-0606.2011.00231.x
- Befriend Inc. (2017). Befriend Home. Retrieved from <http://befriend.org.au/>

- Bergquist, T. F., Micklewright, J. L., Yutsis, M., Smigielski, J. S., Gehl, C., & Brown, A. W. (2012). Achievement of client-centred goals by persons with acquired brain injury in comprehensive day treatment is associated with improved functional outcomes. *Brain Injury, 26*(11), 1307-1314. doi:10.3109/02699052.2012.706355
- Bethea, D. P., Holland, C. A., Jr., & Reddick, B. K. (2014). Storming the gates of interprofessional collaboration. *Nursing Management, 45*(9), 40-45. doi:10.1097/01.numa.0000453272.11253.01
- Braunling-McMorrow, D., Dollinger, S. J., Gould, M., Neumann, T., & Heiligenthal, R. (2010). Outcomes of post-acute rehabilitation for person with brain injury, *Brain Injury, 24* (7-8), 928-938, <http://dx.doi.org/10.3109/02699052.2010.490518>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Brightwater Care Group. (2017). *Brightwater oats street*. Retrieved from <https://www.brightwatergroup.com/disability/oats-street>
- Brightwater Care Group. (2016). *Brightwater care group-disability care and support-productivity*. Retrieved from www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0398.rtf.
- Bryan-Hancock, C., & Harrison, J. (2010). The global burden of disease project 2005: Methods utilised by the injury expert group for estimating world-wide incidence and prevalence rates. *Injury Prevention, 16*(Suppl 1), A99-A99. doi:10.1136/ip.2010.029215.356
- Callaway, L., Sloan, S., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal, 52*(3), 257-260. doi:10.1111/j.1440-1630.2005.00492.x
- Chamberlain, D. J. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing, 54*(4), 407-417. doi:10.1111/j.1365-2648.2006.03840.x
- Cocks, E., Thoresen, S. H., & Lee, E. A. L. (2015). Pathways to employment and quality of life for apprenticeship and traineeship graduates with disabilities. *International Journal*

of Disability, Development and Education, 62(4), 422-437.
doi:10.1080/1034912X.2015.1025714

Coco, K., Tossavainen, K., Jääskeläinen, J.E., & Turunen, H. (2011). Support for traumatic brain injury patients' family members in neurosurgical nursing: A systematic review. *Journal of Neuroscience Nursing*, 46(6), 337-348. doi: 10.1097/JNN.0b013e318234ea0b.

Colantonio, A., Ratcliff, G., Chase, S., Kelsey, S., Escobar, M., & Vernich, L. (2004).

Long term outcomes after moderate to severe traumatic brain injury, *Disability and Rehabilitation*, 26 (5), 253-261, doi: 10.1080/09638280310001639722

Commonwealth of Australia. (2013). National disability insurance scheme: Operational guidelines. Retrieved from <https://www.ndis.gov.au/operational-guideline/overview-sitemap.html>

Conneeley, A. L. (2003). Quality of life and traumatic brain injury: A one-year longitudinal qualitative study. *British Journal of Occupational Therapy*, 66(10), 440-446. doi:10.1177/030802260306601002

Cope, D. N. (1995). The effectiveness of traumatic brain injury rehabilitation: A review. *Brain Injury*, 9(7), 649-670. doi:10.3109/02699059509008224

Corring, D., & Cook, J. (1999). Client-centred care means that I am valued human being. *Canadian Journal of Occupational Therapy*, 66, 71-82. Retrieved from <http://journals.sagepub.com>

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Los Angeles: SAGE.

Crisp, R. (1993). Personal responses to traumatic brain injury: A qualitative study. *Disability, Handicap & Society*, 8(4), 393-404. doi:10.1080/02674649366780371

D'Cruz, K., Howie, L., & Lentin, P. (2016). Client-centred practice: Perspectives of persons with a traumatic brain injury. *Scandinavian Journal of Occupational Therapy*, 23(1), 30-38. doi:10.3109/11038128.2015.1057521

- Davis, K., Drey, N., & Gould, D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies*, 46(10), 1386-1400.
doi:10.1016/j.ijnurstu.2009.02.010
- De Koning, M. E., Spikman, J. M., Coers, A., Schonherr, M. C., & Van Der Naalt, J. (2015). Pathways of care the first year after moderate and severe traumatic brain injury- Discharge destinations and outpatient follow-up,. *Brain Injury*, 29(4), 423-429.
doi:10.3109/02699052.2014.982188
- Department of Health Western Australia. (2017). Rehabilitation. Retrieved from http://healthywa.wa.gov.au/Articles/N_R/Rehabilitation
- Dillahunt-Aspillaga, C., Jorgensen-Smith, T., Ehlke, S., Sosinski, M., Monroe, D., & Thor, J. (2013). Traumatic brain injury: Unmet support needs of caregivers and families in Florida. *PLOS ONE*, 8(12), e82896. doi:10.1371/journal.pone.0082896
- Dimancescu, M. D. (2007). Neurosurgery and acquired brain injury: An educational primer. In J. Elbaum & D. Benson (Eds.), *Acquired brain injury: An integrative neuro-rehabilitation approach* (pp. 4-17). New York: Springer.
- Doig, E., Fleming, J., Cornwell, P. L., & Kuipers, P. (2009). Qualitative exploration of a client-centered, goal-directed approach to community-based occupational therapy for adults with traumatic brain injury. *American Journal of Occupational Therapy*, 63(5), 559-568. doi:10.5014/ajot.63.5.559
- Doig, E., Fleming, J., Kuipers, P., & Cornwell, P. L. (2010). Comparison of rehabilitation outcomes in day hospital and home settings for people with acquired brain injury - a systematic review. *Disability and Rehabilitation*, 32(25), 2061-2077.
doi:10.3109/09638281003797356
- Evans, J., & Repper, J. (2000). Employment, social inclusion and mental health *Journal of Psychiatric and Mental Health Nursing*, 7, 15-24. doi:10.1046/j.1365-2850.200.00259.x
- Fortune, N., & Wen, X. (1999). *The definition, incidence and prevalence of acquired brain injury in Australia*. Canberra: AIHW Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442467114>.

- Foster, A. M., Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., . . . McPherson, K. M. (2012). Encouraging family engagement in the rehabilitation process: A rehabilitation provider's development of support strategies for family members of people with traumatic brain injury. *Disability and Rehabilitation, 34*(22), 1855-1862. doi:10.3109/09638288.2012.670028
- Gagnon, A., Lin, J., & Stergiou-Kita, M. (2016). Family members facilitating community re-integration and return to productivity following traumatic brain injury - motivations, roles and challenges. *Disability and Rehabilitation, 38*(5), 433-441. doi:10.3109/09638288.2015.1044035
- Gill, I. J., Wall, G., & Simpson, J. (2012). Clients' perspectives of rehabilitation in one acquired brain injury residential rehabilitation unit: A thematic analysis. *Brain Injury, 26*(7-8), 909-920. doi:10.3109/02699052.2012.661118
- Glenn, M. (2012). Rehabilitation following traumatic brain injury. In J. W. Tsao. (Ed.), *Traumatic brain injury: A clinician's guide to diagnosis, management and rehabilitation*. New York: Springer
- Goranson, T. E., Graves, R. E., Allison, D., & Freniere, R. L. (2003). Community integration following multidisciplinary rehabilitation for traumatic brain injury. *Brain Injury, 17*(9), 759-774. doi:10.1080/0269905031000088513
- Granacher, R. P. (2003). *Traumatic brain injury: Methods for clinical and neuropsychiatric assessment*. London: CRC Press.
- Griesbach, G. S., Kreber, L. A., Harrington, D., & Ashley, M. J. (2015). Post-acute traumatic brain injury rehabilitation: Effects on outcome measures and life care costs. *Journal of Neurotrauma, 32*(10), 704-711. doi:10.1089/neu.2014.3754
- Greenhalgh, T. (2014). *How to read a paper: The basics of evidence-based medicine* (5th ed.). United Kingdom: Wiley Blackwell
- Haggstrom, A., & Lund, M. L. (2008). The complexity of participation in daily life: A qualitative study of the experiences of persons with acquired brain injury. *Journal of Rehabilitation Medicine, 40*(2), 89-95. doi:10.2340/16501977-0138
- Hayes, B.K., Heit, E., & Swendsen, H. (2010). Inductive reasoning, *Advanced Review, 1*, 278-292. doi: 10.1002/wcs.44

- Head West Brain Injury Association of Western Australia. (2014). *Mild traumatic brain injury/concussion report* Retrieved from http://webadmin.communitycreative.com.au/uploads/headwest/HW_Concussion_Worksafe_2014_v5.pdf
- Headway. (2012). *The silent epidemic of acquired brain injury*. Retrieved from <http://www.headway.ie/information/abi/the-silent-epidemic-of-acquired-brain-injury/>
- Headway United Kingdom. (2017). Brain injury: A guide for employers. Retrieved from <https://www.headway.org.uk/media/4123/brain-injury-a-guide-for-employers.pdf>
- Hirshon, J.M., Risko, N., Calvello, E.J.B., Stewart de Ramirez, S., Narayan, M., Theodosios, C. & O'Neill, J. (2013) Perspectives: Health systems and services: the role of acute care, *Bulletin World Health Organization*, 91, 386-388, doi:10.2471/BLT.12.112664
- Hoffman, S.J., Rosenfield, D., Gilbert, J.H.V., & Oandasan, I.F. (2008). Student leadership in interprofessional education: Benefits, challenges and implications for educators, researchers and policymakers. *Medical Education*, 42, 654-661, doi:10.1111/j.1365-2923.2008.03042.x
- Holm, S., Schonberger, M., Poulsen, I., & Caetano, C. (2009). Patients' and relatives' experience of difficulties following severe traumatic brain injury: the sub-acute stage. *Neuropsychol Rehabil*, 19(3), 444-460. doi:10.1080/09602010802296402
- Hoofien, D., Gilboa, A., Vakil, E., & Donovan, P. J. (2001). Traumatic brain injury (TBI) 10-20 years later: A comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury*, 15(3), 189-209. doi:10.1080/026990501300005659
- Howes, H., Benton, D., & Edwards, S. (2005). Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology & Health*, 20(1), 129-142. doi:10.1080/0887044042000272903
- Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007). The impact of traumatic brain injuries: A global perspective. *NeuroRehabilitation*, 22(5), 341-353. Retrieved from <https://search.ebscohost.com>

- Insurance Commission of Western Australia. (2017). *2017 Catastrophic Injuries Statistics*.
https://www.icwa.wa.gov.au/__data/assets/pdf_file/0020/13772/ICWA-Media-Release-Insuranceies-Support-presents-Catastrophic-Injuries-Support-scheme-one-year-on-Fact-Sheet.pdf
- Johansson, U., & Tham, K. (2006). The meaning of work after acquired brain injury.
American Journal of Occupational Therapy, 60(1), 60-69. doi:10.5014/ajot.60.1.60
- Johnston, M. V., Goverover, Y., & Dijkers, M. Community activities and individuals 2019; satisfaction with them: Quality of life in the first year after traumatic brain injury.
Archives of Physical Medicine Rehabilitation, 86(4), 735-745.
doi:10.1016/j.apmr.2004.10.031
- Johnstone, B., Vessell, R., Buonds, T., Hoskins, S. & Sherman, A. . (2003). Predictors of success for state vocational rehabilitation clients with traumatic brain injury.
Archives of Physical Medicine Rehabilitation, 84, 161-167
doi:10.1053/apmr.2003.50098
- Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: A perspective based on personal experience. *Disability and Rehabilitation, 30*(7), 507-516.
doi:10.1080/09638280701355561
- Jumisko, E., Lexell, J., & Söderberg, S. (2007). The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives. *Disability and Rehabilitation, 29*(19), 1535-1543.
doi:10.1080/09638280601055816
- Kat, L., Schipper, K., Knibbe, J., & Abma, T. A. (2010). A patients journey: Acquired brain injury. *British Medical Journal, 340*,c808. doi:10.1136/bmj.c808
- Katz, D., Cohen, S, Alexander, M. (2015). Mild Traumatic Brain Injury. *Handbook Clinical Neurology, 127*, 131-156. doi:10.1016/B978-D-444-52892-6.00009-X
- Keightley, M. L., Ratnayake, R., Minore, B., Katt, M., Cameron, A., White, R., . . . Colantonio, A. (2009). Rehabilitation challenges for Aboriginal clients recovering from brain injury: A qualitative study engaging health care practitioners. *Brain Injury, 23*(3), 250-261. doi:10.1080/02699050902748331

- Khan, F., Baguley, I. J., & Cameron, I. D. (2003). Rehabilitation after traumatic brain injury. *Medical Journal Australia*, 178(6), 290-295. Retrieved from <https://www.mja.com.au>
- Kim, H., & Colantonio, A. (2010). Effectiveness of rehabilitation in enhancing community integration after acute traumatic brain injury: A systematic review. *American Journal of Occupational Therapy*, 64(5), 709-719. Retrieved from <http://search.proquest.com/>
- King, D., & Curtin, M. (2014). Occupational therapists' use of advocacy in brain injury rehabilitation settings. *Australian Occupational Therapy Journal*, 61(6), 446-457. doi:10.1111/1440-1630.12149
- Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science*, 12(1), 9-16. doi:10.1080/14427591.2005.9686543
- Kreutzer, J. S., Kolakowsky-Hayner, S. S., Ripley, D., Cifu, D. X., Rosenthal, M. I., Bushnik, T., . . . High, W. (2001). Changes and lengths of stay for acute and inpatient rehabilitation treatment of TBI 1990-1996. *Brain Injury*, 15(9), 763-774. doi:10.1080/02699050118637
- Kwan, J. (2007). Care pathways for acute stroke care and stroke rehabilitation: From theory to evidence. *Journal of Clinical Neuroscience*, 14, 189-200. doi:10.1016/j.jocn.2006.01.026.
- Laroi, F. (2003). The family systems approach to treating families of persons with brain injury: a potential collaboration between family therapist and brain injury professional. *Brain Injury*, 17(2), 175-187. doi:10.1080/0269905021000010140
- Lefebvre, H., Pelchat, D., Swaine, B., Gélinas, I., & Levert, M. J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury*, 19(8), 585-597. doi:10.1080/02699050400025026
- Lewinter, M., & Mikkelsen, S. (1995). Patients' experience of rehabilitation after stroke. *Disability and Rehabilitation*, 17(1), 3-9. doi:10.3109/09638289509166621

- Lexell, E. M., Alkhed, A.-K., & Olsson, K. (2013). The group rehabilitation helped me adjust to a new life: Experiences shared by persons with an acquired brain injury. *Brain Injury*, 27(5), 529-537. doi:10.3109/02699052.2013.765598
- Liamputtong, P. (2009). *Qualitative research methods* (3rd ed.). Melbourne, Australia: Oxford University Press.
- Liamputtong, P. (2013). *Qualitative reseach methods* (4th ed.). Australia: Oxford University Press.
- Linden, M. A., Hanna, D., & Redpath, S. J. (2007). The influence of aetiology and blame on prejudice towards survivors of brain injury. *Archives of Clinical Neuropsychology* 22(5), 665-673. doi:10.1016/j.acn.2007.04.009
- Mahar, C., Fraser, K. . (2001). Strategies to facilitate successful community reintegration following acquired brain injury. *International Journal of Disability Management Research*, 6(1), 68. doi:10.375/jmr.6.1.68
- Marterne, M., Lundqvist, L. O., & Strandberg, T. (2016). Opportunitites and barriers for successful return to work after acquired brain injury: A patient perspective. *Work*, 56(1), 125-134. doi:10.3233/WOR-162468
- McColl, M. A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The definition of community integration: Perspectives of people with brain injuries. *Brain Injury*, 12(1), 15-30. doi:10.1080/026990598122827
- McGlynn, C. (2005). The triple whammy of acquired brain injury and concurrent disorders. . *Cross Currents*, 9(1), 8-9. Retrieved from <http://search.proquest.com>
- McKenzie, A. E., & Hanley, B. (2007). *Consumer and community participation in health and medical research : A practical guide for health and medical research organisations*. Perth Western Australia: University of Western Australia.
- McLellan, T., Bishop, A., & McKinlay, A. (2010). Community attitudes toward individuals with traumatic brain injury. *Journal of International Neuropsychological Society*, 16(4), 705-710. doi:10.1017/s1355617710000524

- Mitsch, V., Curtin, M., & Badge, H. (2014). The provision of brain injury rehabilitation services for people living in rural and remote New South Wales, Australia. *Brain Injury, 28*(12), 1504-1513. doi:10.3109/02699052.2014.938120
- Moorin, R., Miller, T. R., & Hendrie, D. (2014). Population-based incidence and 5-year survival for hospital-admitted traumatic brain and spinal cord injury, Western Australia, 2003-2008. *Journal of Neurology, 261*(9), 1726-1734. doi:10.1007/s00415-014-7411-y
- Morris, R. (2011). The psychology of stroke in young adults: The roles of service provision and return to work. *Stroke Research and Treatment, 2011*, 534812. doi: 10.4061/2011/534812.
- Muenchberger, H., Kendall, E., & Collings, C. (2010). Beyond Crisis Care in Brain Injury Rehabilitation in Australia. *Journal of Primary Care & Community Health, 2*(1), 60-64. doi:10.1177/2150131910383578
- Murray, C. D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretative phenomenological analysis. *Disability and Rehabilitation, 26*(13), 808-816. doi:10.1080/09638280410001696746
- Murray, H. M., Maslany, G. W., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury, 20*(6), 575-585. doi:10.1080/02699050600664590
- National Disability Services. (2017). *Australian Disability Workforce Report*. Retrieved from Sydney New South Wales Retrieved from <https://www.nds.org.au/news/australian-disability-workforce-report-first-edition-released>
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine, 46*(7), 869-878. doi: 10.1016/S0277-9536(97)00211-6
- O'Callaghan, C., Powell, T., & Oyebode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychology Rehabilitation, 16*(5), 579-593. doi:10.1080/09602010500368834

- Parish, L., & Oddy, M. (2007). Efficacy of rehabilitation for functional skills more than 10 years after extremely severe brain injury. *Neuropsychological Rehabilitation*, 17(2), 230-243. doi:10.1080/09602010600750675
- Parsons, L., & Stanley, M. (2008). The lived experience of occupational adaptation following acquired brain injury for people living in a rural area. *Australian Occupational Therapy Journal*, 55(4), 231-238. doi:10.1111/j.1440-1630.2008.00753.x
- Parvaneh, S., & Cocks, E. (2012). Framework for describing community integration for people with acquired brain injury. *Australian Occupational Therapy Journal*, 59(2), 131-137. doi:10.1111/j.1440-1630.2012.01001.x
- Payne, J. M., D'Antoine, H. A., France, K. E., McKenzie, A. E., Henley, N., Bartu, A. E., . . . Bower, C. (2011). Collaborating with consumer and community representatives in health and medical research in Australia: Results from an evaluation. *Health Research Policy and Systems*, 9(1), 1-14. doi:10.1186/1478-4505-9-18
- Perez-Merino, R. (2014). Strategies for enhancing the delivery of person-centred care. *Nursing Standard*, 28(39), 37-41. doi:10.7748/ns.28.39.37.e8193
- Phillips, M. C. L., Leyden, J. M., Chong, W. K., Kleinig, T., Czapran, P., Lee, A., . . . Jannes, J. (2011). Ischaemic stroke among young people aged 15 to 50 years in Adelaide, South Australia. *Medical Journal Australia*, 195(10), 610-614. doi:10.5694/mja11.10558
- Ponsford, J. (2012). Mechanism, recovery and sequelae of traumatic brain injury: A foundation for the REAL approach. In J. Ponsford, S. Sloan & P. Snow (Eds.), *Traumatic brain injury: Rehabilitation for everyday adaptive living* (2nd ed., pp. 1-33). New York: Psychology Press.
- Powell, J., Heslin, J., & Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry*, 72(2), 193-202. doi:10.1136/jnnp.72.2.193
- Reddihough, D.S., Meehan, E., Stott, N.S., & Delacy, M. (2016). The national disability scheme: A time for real change in Australia, *Developmental Medicine and Child Neurology*, 58, (Supp. 2), 66-70. doi: 0.1111/dmnc.13007

- Richards, L., & Morse, J. M. (2007). *User's guide to qualitative methods* (2nd ed.), United States of America: Sage Publications.
- Roozenbeek, B., Maas, A. I. R., & Menon, D. K. (2013). Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*, *9*(4), 231-236. doi:10.1038/nrneurol.2013.22
- Rosenthal, M., Christensen, B. K., & Ross, T. P. (1998). Depression following traumatic brain injury. *Archives of Physical Medicine Rehabilitation*, *79*(1), 90-103. doi:10.1016/S0003-9993(98)90215-5
- Rumrill, P. D., Fitzgerald, S. M., & Merchant, W. R. (2010). Using scoping literature reviews as a means of understanding and interpreting existing literature. *Work*, *35*(3), 399-404. doi:10.3233/wor-2010-0998
- Sander, A. M., Maestas, K. L., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2012). Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: A multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, *93*(5), 842-848. doi:10.1016/j.apmr.2011.11.031
- Saunders, C., Crossing, S., Girgis, A., Butow, P., & Penman, A. (2007). Operationalising a model framework for consumer and community participation in health and medical research. *Australia and New Zealand Health Policy*, *4*(1), 1-6. doi:10.1186/1743-8462-4-13
- Shelden, M., & Rush, D. (2001). The ten myths about providing early intervention services in natural environments. *Infants & Young Children: An Interdisciplinary Journal of Special Care Practices*, *14*, 1-13 Retrieved from https://www.researchgate.net/publication/232173280_The_Ten_Myths_about_Providing_Early_Intervention_Services_in_Natural_Environments
- Shorland, J., & Douglas, J. M. (2010). Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. *Brain Injury*, *24*(4), 569-580. doi:10.3109/02699051003610441

- Shotton, L., Simpson, J., & Smith, M. (2007). The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: A qualitative investigation. *Brain Injury, 21*(8), 857-869. doi:10.1080/02699050701481621
- Stalder-Luthy, F., Messerli-Burgy, N., Hofer, H., Frischknecht, E., Znoj, H., & Barth, J. (2013). Effect of psychological interventions on depressive symptoms in long-term rehabilitation after an acquired brain injury: a systematic review and meta-analysis. *Archives of Physical Medicine & Rehabilitation, 94*(7), 1386-1397. doi:10.1016/j.apmr.2013.02.013
- Stergiou-Kita, M., Yantzi, A., & Wan, J. (2010). The personal and workplace factors relevant to work readiness evaluation following acquired brain injury: occupational therapists' perceptions. *Brain Injury, 24*(7-8), 948-958. doi:10.3109/02699052.2010.491495
- Strandberg, T. (2009). Adults with acquired traumatic brain injury: Experiences of a changeover process and consequences in everyday life. *Social Work in Health Care, 48*(3), 276-297. doi:10.1080/00981380802599240
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*, United States of America: SAGE Publications.
- Stucki, G., Ewert, T., & Cieza, A. (2002). Value and application of the ICF in rehabilitation medicine. *Disability and Rehabilitation, 24*(17), 932-938. doi:10.1080/09638280210148594
- Sveen, U., Sjøberg, H. L., & Østensjø, S. (2016). Biographical disruption, adjustment and reconstruction of everyday occupations and work participation after mild traumatic brain injury. A focus group study. *Disability and Rehabilitation, 38*(23), 2296-2304. doi:10.3109/09638288.2015.1129445
- Ta'eed, G., Skilbeck, C., & Slatyer, M. (2015). Service utilisation in a public post-acute rehabilitation unit following traumatic brain injury. *Neuropsychological Rehabilitation, 25*(6), 841-863. doi:10.1080/09602011.2014.990043
- Turner-Stokes, L. (2008). Evidence for the effectiveness of multi-disciplinary rehabilitation following acquired brain injury: A synthesis of two systematic approaches. *Journal of Rehabilitation Medicine, 40*(9), 691-701. doi:10.2340/16501977-0265

- Turner-Stokes, L., Pick, A., Nair, A., Disler, P., & Wade, D. (2015). Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. *Cochrane Database of Systematic Reviews*, 12(Art. No.: CD004170), 691-701.
doi:10.1002/14651858.CD004170.pub3
- Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., . . . Chenoweth, L. (2007). A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury*, 21(11), 1119-1130. doi:10.1080/02699050701651678
- Wills, J.W. (2007). *Foundations of qualitative research: Interpretative and critical approaches*, United States of America: SAGE Publications
- Wilson, B. A. (2010). Brain injury: recovery and rehabilitation. *Wiley Interdisciplinary Reviews: Cognitive Science*, 1(1), 108-118. doi:10.1002/wcs.15
- Wittstatt, A. W.-L., & Valadka, A. B. (2017). Acute management of moderate-severe traumatic brain injury. *Physical Medical Rehabilitation*, 28, 227-243.
doi:http://dx.doi.org/10.1016/j.pmr.2016.12.002
- Wobma, R., Nijand, R.H.M., Ket, J.C.F. & Kwakkel, G. (2016). Evidence for peer support for individuals with acquired brain injury: A systematic review, *Journal of Rehabilitation Medicine*, 48, 837-840, doi: 10.2340/16501977-2160
- World Health Organization. (2010). *Framework for action on interprofessional education and collaborative practice*. Retrieved from
http://apps.who.int/iris/bitstream/10665/70185/1/WHO_HRH_HPN_10.3_eng.pdf?ua=1
- Yates, P. J. (2003). Psychological adjustment, social enablement and community integration following acquired brain injury. *Neuropsychological Rehabilitation*, 13(1-2), 291-306. doi:10.1080/09602010244000408

“Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.”

APPENDICES

APPENDIX A: Interview Guide-Person with ABI

Interview Guide-People with ABI

Interview 1

-Introduce self and obtain demographic details, discuss the study and obtain written informed consent

- If participant is comfortable to proceed, ask participant to introduce themselves

-Tell me about yourself?

-*Prompts:* previous employment, previous activities you enjoyed, current work situation current social activities, leisure interests

-What is your relationship like with your family?

-*Prompts:* who are you close to? How would you describe your relationship with your family members? How often do you see your family? What activities do you do when you see your family?

-Tell me about how you acquired a brain injury?

-What have been some significant events or experiences you have had during your rehabilitation>

-Introduce further discussion around topics: previous work roles, family life, accommodation, socialization, leisure activities

Interview 2

-Remind the person about the study and obtain written informed consent

-Recap what was discussed during previous interview 'Last time we were talking about....'

-What is happening for you with your rehabilitation at the moment?

-Ask about the future, where do you see yourself in six months? 12 months? 5-10 years?

-What have been the main challenges you have experienced throughout your rehabilitation journey?

-What has helped you throughout the journey?

-Ask about any areas of the participant's journey that may require clarification or further information

Interview Guide-Family Members

-Introduce self and ask participant to introduce themselves, establish the nature of their relationship to the participant, discuss the study and obtain written informed consent

-If comfortable, encourage participant to share what happened to their family member in regard to the ABI

-How would you describe the experience through rehabilitation for.... (person with ABI)?
What has been helpful? What has been challenging?

-How has your life changed since the ABI?

-Thinking about the future, what are your plans? What would you like to see happen?

-What changes would you like to see occur in the rehabilitation of people with an ABI?

Interview Guide-Health Professionals

- Introduce myself, current role and relevant experience, discuss study and obtain written informed consent

-Ask each participant to introduce themselves, their current role in the workplace and level of experience and qualification

-What do you see as your role in the rehabilitation journey of someone with an ABI?

-During the interviews with people with ABI and their families, they spoke about a lack of direction on appropriate services when they return home from Oats St, from your

experience would you say there is a lack of direction for services when they return home?
And how could this be managed more effectively?

-How do you think relationships of people with ABI change with their friends from before their injury? How could we improve/help maintain these relationships?

-What would be the best way to assist with helping people with ABI and their families understand each profession's specific role?

-People with ABI report that they find it beneficial to have services tailored to meet their individual needs, is this something that has been reported to you? And how do you meet the individual needs of your clients with difference in what everyone needs as well as the constraints in time and resources that you experience as a clinician?

-What do you believe would be appropriate services for people with ABI once they leave Oats St?

-What sort of supports do you feel would be suitable for family members of people with ABI?

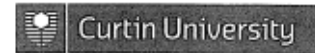
-Something that has really stood out during the interviews with people with ABI and their family members is how motivated they are to achieve their rehabilitation goals, what do you think drives this motivation? (extrinsic/intrinsic)

-In your experience, do you find different cultures manage a brain injury in their family differently? And if so how?

-What do you think is currently working well in rehabilitation of people with ABI?

-What do you think could be improved in the rehabilitation of people with ABI?

APPENDIX B: Curtin University Ethics Approval



Memorandum

To	Professor Beverley McNamara, School of Occupational Therapy and Social Work, Occupational Therapy
From	Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval HR 144/2012
Date	6 December 2012
Copy	Mrs Annalise Marie O'Callaghan, School of Occupational Therapy and Social Work Professor Errol Cocks, School of Occupational Therapy and Social Work

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784

FACSIMILE 9266 3793

EMAIL hrec@curtin.edu.au

Thank you for your application (4382) submitted to the Human Research Ethics Committee (HREC) for the project titled "*The journey through rehabilitation: a study of people with an Acquired Brain Injury in Western Australia.*". Your application has been reviewed by the HREC and is **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 144/2012**. Please quote this number in any future correspondence.
- Approval of this project is for a period of twelve months **04-12-2012** to **04-12-2013**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **04-12-2013**.
- It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- if at any time during the twelve months changes/amendments occur, or
- if a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Yours sincerely



Professor Stephan Millett
Chair Human Research Ethics Committee

APPENDIX C: Information Sheet-Person with ABI and family members

The journey through rehabilitation: A study of people with acquired brain injury in Western Australia

This project aims to document the rehabilitation journeys of people with an acquired brain injury living in Western Australia. People with an acquired brain injury, their family member/primary carer and health professionals involved in the care of people with acquired brain injuries are invited to take part in the study. The study aims to describe the barriers and enablers for people with ABI and their family member/primary carer in the journey, as well as identify the role of health professionals in supporting them. The findings will be used to identify new areas for intervention and provide directions for future areas of research. You will be interviewed by the researcher on two occasions about your experiences since onset of the acquired brain injury as either (1) a person with an acquired brain injury or (2) a family member/primary carer of a person with an acquired brain injury. You will be asked to answer some questions about your age, place of residence, and provide some information on the nature of the acquired brain injury and the services you received. Each interview will last for approximately one hour, and the details of the date, time and venue will be arranged at a time that is convenient for you.

What are the benefits and risks of taking part in this study?

It is hoped that the findings of this study will assist in identifying:

- The barriers experienced on the journey through rehabilitation for people with an acquired brain injury and their family members/primary carers
- The enablers on the journey through rehabilitation for people with an acquired brain injury and their family members/primary carers
- The role of the health professional throughout the journey

If there are any questions which you are unable or unwilling to discuss you can choose not to answer them, and you can also decide to stop the interview at any time. If you become upset and would like to talk to somebody about it, please contact your case manager at Brightwater. Information from the project will be published and distributed to interested people.

People involved in the project include:

- Annalise O'Callaghan (Masters student), School of Occupational Therapy and Social Work, Curtin University –contact 9266 2339, annalise.ocallaghan@curtin.edu.au
- Professor Bev McNamara (Supervisor), School of Occupational Therapy and Social Work , Curtin University-contact bev.mcnamara@curtin.edu.au

-Professor Errol Cocks (Associate Supervisor), Director, Centre for Research into Disability and Society, School of Occupational Therapy and Social Work, Curtin University-contact e.cocks@curtin.edu.au

This study has been approved by the Curtin University Human Research Ethics Committee (approval number HR 144/2012). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth 6845; or by telephoning 9266 2787; or by emailing hrec@curtin.edu.au

APPENDIX D: Information Sheet-Health Professionals

The journey through rehabilitation: a study of people with acquired brain injury in Western Australia

This project aims to document the rehabilitation journeys of people with an acquired brain injury living in Western Australia. People with an acquired brain injury, their family member/primary carers and health professionals involved in the care of people with acquired brain injuries are invited to take part in the study. The study aims to describe the barriers and enablers for people with ABI and their family member/primary carers in the journey, as well as identify the role of health professionals in supporting them. The findings will be used to provide services of new areas for intervention and provide directions for future areas of research. You will be participating in an interview facilitated by the researcher on one occasion about your experiences working with people with an acquired brain injury. You will be asked to answer some questions about your discipline, experience working with people with acquired brain injuries and provide some information on the nature of the work you complete. The group will last for approximately one hours, and the date, time and venue will be arrange at a time that is convenient to all involved.

What are the benefits and risks of taking part in this study?

It is hoped that the findings of this study will assist in identifying:

- The barriers experienced on the journey to recovery for people with acquired brain injury and their family member/primary carers
- The enablers on the journey to recovery for people with acquired brain injury and their family member/primary carers
- The role of the health professional throughout the journey

If there are any questions which you are unable or unwilling to discuss you can choose not to answer them, and you can choose to withdraw from the group. If you become upset and would like to talk to somebody about it, please contact the researcher, Annalise O'Callaghan. Information from the project will be published and distributed to interested people.

People involved in the project include:

-Annalise O'Callaghan (Masters Student), School of Occupational Therapy and Social Work, Curtin University –contact 9266 2339, annalise.ocallaghan@curtin.edu.au

-Professor Bev McNamara (Supervisor), School of Occupational Therapy and Social Work , Curtin University-contact bev.mcnamara@curtin.edu.au

-Professor Errol Cocks (Associate Supervisor), Director, Centre for Research into Disability and Society, School of Occupational Therapy and Social Work, Curtin University-contact e.cocks@curtin.edu.au

This study has been approved by the Curtin University Human Research Ethics Committee (approval number HR 144/2012). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth 6845; or by telephoning 9266 2787; or by emailing hrec@curtin.edu.au

APPENDIX E: Consent Forms

The journey through rehabilitation: A study of people with acquired brain injury in Western Australia

Consent Form (for the person with acquired brain injury OR their family member/primary carer)

I, (print full name) _____,
have read the enclosed information and agree to participate in the project.

I understand that my participation is voluntary and I can withdraw from the project at any time without consequences.

I am consenting to:

- Meet with one or more of the researchers involved in the project, who will visit me (or my relatives) and discuss my (or my relatives) previous and current experiences and living arrangements.
- The discussion will be audio recorded
- One or more of the researchers talking to other people who are important to my care (relative's care) including people who provide support and services.

I know that any personal information will be kept confidential

I know the findings of the study will be shared in presentations and publications, however all information will not include any identifying features.

My contact details are:

PHONE NUMBER: _____

EMAIL ADDRESS: _____

SIGNATURE: _____

DATE: _____

This study has been approved by the Curtin University Human Research Ethics Committee (approval number HR 144/2012). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth 6845; or by telephoning 9266 2787; or by emailing hrec@curtin.edu.au

The journey through rehabilitation: A study of people with acquired brain injury in Western Australia

Consent Form (for the health professionals)

I, (print full name) _____,

have read the enclosed information and agree to participate in the project.

I understand that my participation is voluntary and I can withdraw from the project at any time without consequences.

I am consenting to:

- Be involved in an interview facilitated by one of the researchers involved in the project
- The group will be audio recorded

I know that any personal information will be kept confidential

I know the findings of the study will be shared in presentations and publications, however all information will not include any identifying features.

My contact details are:

PHONE NUMBER: _____

EMAIL ADDRESS: _____

SIGNATURE: _____

DATE: _____

This study has been approved by the Curtin University Human Research Ethics Committee (approval number HR 144/2012). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth 6845; or by telephoning 9266 2787; or by emailing hrec@curtin.edu.